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**THÈSE** présentée par :

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**Les conséquences et le soutien psychologique après  
une perte périnatale.**

Etude longitudinale mixte de dix-huit mois menée auprès  
de vingt-neuf parents endeuillés.

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*To my family*

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## Résumé en français

Ce qui suit est un résumé de la thèse en français. Il contient les principaux aspects et réflexions exprimés au cours de l'étude.

Vous trouverez ci-dessous les principaux points, comme :

- L'introduction ;
- La revue de la littérature ;
- Les hypothèses générales ;
- La méthodologie ;
- La procédure de recherche ;
- Les entretiens semi-directifs et outils utilisés (les deux questionnaires administrés, Alceste et l'Interpretative Phenomenological Analysis) ;
- Les participants ;
- Les critères de participation ;
- Les enfants décédés ;
- Les résultats qualitatifs et quantitatifs ;
- L'analyse des résultats ;
- La discussion et les conclusions.

## **Introduction**

Le projet consiste en une étude sur les conséquences de la perte périnatale chez les parents. L'objectif est d'intégrer les études théoriques et l'évaluation empirique du deuil périnatal -en rencontrant des parents endeuillés pendant les mois qui suivent la perte d'un enfant-, pour comprendre les conséquences du deuil et évaluer les effets du soutien psychologique, en particulier la participation à des groupes de parole de parents en deuil.

La thèse est divisée en cinq parties (théorique, clinique, résultats, discussions et conclusions) pour un total de quatorze chapitres.

Le but de la première partie est de présenter un cadre théorique général de la perte périnatale.

Les recherches bibliographiques aident à connaître, identifier et comprendre les principales caractéristiques de cette perte, sur les plans psychologique, physiologique, relationnel et social.

Après une perte périnatale, les implications psychologiques peuvent être graves et durables. Pour cette raison, les soutiens psychothérapeutique et sociaux sont essentiels.

Cette perte ne concerne pas seulement le parent qui la vit, mais également le couple parental, les frères et sœurs, les grands-parents et les enfants suivants.

La formation et la sensibilisation des professionnels font donc partie des aspects sur lesquels la recherche s'engage à accompagner la personne endeuillée.

Les sept premiers chapitres et les recherches bibliographiques ont pour objectif de mieux présenter le sujet de la recherche et les principales hypothèses sur lesquelles repose l'étude.

La partie clinique de cette recherche concerne une étude longitudinale menée pendant 18 mois grâce à la participation active et constante de 29 parents français ayant perdu leur enfant au cours de la période périnatale.

## Revue de la littérature

Le deuil périnatal est un thème qui n'est pas suffisamment traité dans le monde culturel et social. Il représente encore un tabou et en même temps qu'une contradiction car le nombre de décès périnataux reste élevé, malgré les nouvelles technologies et les découvertes médicales.

Des études ont révélé qu'environ trois millions de décès étaient survenus chaque année dans le monde au cours du premier mois de la vie d'un enfant et 2,6 millions au cours du troisième trimestre de la grossesse (Ezechi & Odberg-Petterson, 2012; Lawn et al., 2016).

Selon les données de l'INSEE, en France, le taux de mortalité infantile pour 1000 naissances en 2018 était de 3,8 ("Espérance de vie - Mortalité – Tableaux de l'économie française | Insee," n.d.).

En général, la perte périnatale correspond au décès d'un enfant après la 22e semaine d'aménorrhée ou d'un enfant pesant au minimum de 500 g (tel que recommandé par l'Organisation Mondiale de la Santé) jusqu'au premier mois de vie de l'enfant (World Health Organization, 2016).

Dans cette étude, le terme perte périnatale sera utilisé de manière plus large. En conséquence, les mortinaissances, les interruptions de grossesse tardives et les pertes survenant après la naissance au cours des premiers mois de la vie sont toutes comprises dans l'expression "pertes périnatales".

Selon les chercheurs, les distinctions et les critères bureaucratiques ne correspondent pas aux critères sociaux et psychiques. Nous nous référons en particulier au fait que la perte périnatale n'inclut pas exclusivement le décès survenu au cours et jusqu'à la fin du premier mois de la vie de l'enfant. Cette restriction est trop rigide. Pour cette raison, nous avons également considéré les parents qui ont perdu leur enfant au-delà du premier mois de la vie.

Les parents endeuillés présentent un risque plus élevé d'hospitalisations psychiatriques, en particulier les mères, des symptômes dépressifs majeurs, d'état de bien-être diminué et de problèmes majeurs de santé, en particulier au niveau cardiovasculaire, des niveaux plus élevés d'anxiété (Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008) et un risque accru de troubles anxio-dépressifs au cours de la prochaine grossesse (Blackmore et al., 2011).

Leur risque de mortalité est plus élevé comparativement à la même population de mères dont l'enfant reste en bonne santé, même 35 ans après la mort de l'enfant (Harper & Thompson, 2011).

En particulier, le principal intérêt de cette thèse consiste à rechercher le trouble du deuil compliqué chez les parents, défini par Prigerson pour la première fois en 1995 (Prigerson et al., 2009; Prigerson, Maciejewski, et al., 1995; Prigerson & Jacobs, 2001; Prigerson & Maciejewski, 2005).

Sa symptomatologie comprend: un sentiment d'incrédulité face à la mort; de la colère; des émotions récurrentes douloureuses, un désir ardent de retrouver le défunt; des préoccupations pour la personne aimée incluant souvent des pensées intrusives pénibles liées au décès (Shear et al., 2005).

Le deuil compliqué est également associé à une vie sociale, professionnelle et familiale inadaptée, à des troubles du sommeil, à des idées suicidaires et à une consommation accrue d'alcool et de tabac (Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008; Prigerson et al., 1997; Shear et al., 2011).

Le trouble du deuil compliqué partage des similitudes avec la dépression et le trouble de stress post-traumatique (TSPT). En cas de syndrome de stress post-traumatique et de trouble du deuil compliqué, les patients ont tendance à manifester de la tristesse, de la culpabilité, un repli sur soi, des troubles du sommeil, ainsi que des pensées suicidaires associées à la dépression, à un sentiment d'incrédulité, à des images intrusives, à des difficultés de concentration et à l'évitement du SSPT (Horowitz et al., 1997; Prigerson, Frank, et al., 1995; Prigerson, Shear, & Jacobs, 2000; Shear et al., 2005).

Il peut aussi y avoir des formes d'auto hyper-implication dans le deuil, comme penser et parler de la personne décédée en permanence, aller constamment au cimetière, ne pas ranger les objets ou les vêtements du défunt ou éviter des situations qui rappellent la perte (Lombardo et al., 2014).

En plus, malgré des troubles psychologiques ou des liens moins prolongés qu'avec la mère, les pères présentent aussi de graves souffrances à la suite d'un deuil périnatal. Leur douleur est en fait souvent sous-estimée et ignorée, encore aujourd'hui.

Alors que les femmes ont des troubles psychologiques plus durables et évidents, ainsi qu'un besoin plus important d'aide et de soutien social, elles se concentrent souvent sur le lien exclusif avec leur enfant. Les hommes s'adaptent différemment par le biais de l'agressivité, le déni de la douleur et la consommation d'alcool. Ils expriment leurs émotions moins ouvertement et perçoivent comme imposé socialement leur rôle d'homme fort, source de soutien pour la femme « fragile » (Klier et al., 2002; Neria et al., 2004; Stroebe et al., 2001; Ware et al., 2007; Wijngaards-de Meij et al., 2008; Wing et al., 2001).

Prises ensemble, ces différences peuvent se traduire par des difficultés de communication et de soutien au sein du couple, générant une insatisfaction conjugale. Cette insatisfaction est perceptible également sur le plan sexuel – ce qui dans certains cas peut conduire à la séparation (Büchi et al., 2009; Cacciatore, 2013; Schwab, 1998).

Plusieurs hypothèses identifient les causes de ces différences de genre entre mères et pères. Nous avons donc dû considérer le rôle des différents liens ou attachements avec l'enfant pendant le développement, les différentes réactions au stress et les stratégies d'adaptation, les différents rôles sociaux imposés par la communauté, qui influenceraient également la socialisation, l'expressivité émotionnelle et les modèles d'identité (Wing et al., 2001).

Au niveau interpersonnel, divers aspects déterminent le progrès et la résolution du travail du deuil, en parvenant ainsi à son acceptation. Le style d'attachement du parent, le sexe, la modalité du décès



et le soutien du partenaire et des amis peuvent influencer le pronostic du deuil et ses conséquences, souvent multiples et durables.

En outre, si les risques et les conséquences sont différents et de durée variable, ils n'affectent pas que les parents, mais tous les membres de la famille (Aho, Inki, & Kaunonen, 2018; Avelin, Erlandsson, Hildingsson, & Rådestad, 2011; Blackmore et al., 2011; Harper & Thompson, 2011). La mort d'un enfant peut avoir des conséquences chez les frères et sœurs précédents et suivants. En outre, la perte d'un petit-enfant peut également présenter des risques pour les grands-parents, qui vivent un deuil souvent oublié et négligé.

Dans notre société, la perte d'un enfant mort-né ou d'un jeune enfant est souvent sous-estimée. Cette étude longitudinale vise à fournir une évaluation complète des conséquences du deuil périnatal, en tenant également compte des effets de la participation à des groupes de parole. Suivre les parents pendant dix-huit mois au total fournit une description détaillée de l'évolution psychologique, y compris d'éventuelles « réactions anniversaires ».

Dans l'environnement scientifique et social, cette recherche peut apporter une contribution importante à l'étude du deuil périnatal et aux méthodes de soutien les plus efficaces.

## **Hypothèses générales**

Les conséquences pour les parents ayant perdu un enfant pendant la période périnatale peuvent être très graves et durables.

Les parents suivis pendant dix-huit mois ont fourni une description détaillée de leur évolution psychologique. Ce cadre temporel a été choisi afin de permettre une évaluation approfondie et complète des progrès, du travail du deuil et des réactions possibles d'anniversaire. En particulier, nous voulions confirmer le risque de deuil compliqué après la perte d'un enfant en période périnatale et examiner les effets possibles d'une psychothérapie individuelle et de groupe.

Rencontrer des personnes qui ont vécu le même drame au sein de groupes de parole, percevoir une totale liberté d'expression, disposer d'un emploi du temps et d'un lieu défini où parler et se souvenir de l'enfant grâce à l'accompagnement de professionnels, apportent un soutien psychologique efficace au travail du deuil du parent.

Dans le cadre du projet de recherche, un troisième élément a également été considéré: le soutien et l'effet apportés par la participation à des groupes présents sur Internet, en particulier vis-à-vis de groupes spécifiques dédiés à la perte périnatale sur des réseaux sociaux (tels que Facebook, des blogs, des forums, etc.).

Selon les discussions avec les participants, les parents confondent ces groupes en ligne avec des groupes thérapeutiques de parole. Il est donc important de déterminer si la participation à ces groupes est utile pour le travail du deuil en confirmant la perception des participants à l'égard de ces groupes en ligne.

Les groupes en ligne en question sont généralement des groupes fermés composés d'utilisateurs qui ressentent le besoin de rencontrer et de reconforter d'autres parents qui traversent une expérience similaire, même si les membres du groupe restent anonymes. Souvent, pour faire partie de ces groupes, la personne doit s'inscrire et expliquer sa motivation à vouloir s'inscrire.

La caractéristique essentielle de ces groupes est leur participation active, qui se déroule quotidiennement au travers de commentaires fréquents sur des posts, de débats, de partage d'histoires et de photos, ainsi que de correspondances privées avec les autres membres du groupe.

Dans le contexte de notre société contemporaine, il est impossible d'ignorer le rôle et l'importance qu'Internet prend dans nos vies. Il est donc important de souligner son effet sur le chagrin des parents afin d'en examiner l'utilisation et les risques.

Dans un contexte scientifique et social, ce projet de recherche apportera une contribution importante à l'étude de la perte périnatale et des méthodes d'appui les plus efficaces.

La recherche peut être utile pour les futurs parents, pour lutter contre leur sentiment d'isolement, pour réaliser que leur processus de deuil n'est pas unique et prendre conscience des effets possibles liés à l'emploi de différents réseaux sociaux.

En outre, cette étude contribuera à sensibiliser les professionnels travaillant sur ce sujet (psychologues, médecins, sages-femmes, etc.) et les contextes micro et macro-sociaux entourant les parents endeuillés.

## **La méthodologie**

Afin de répondre aux questions de recherche, une méthodologie mixte a été utilisée, basée sur des entretiens semi-directifs et deux questionnaires (le Inventory of Complicated Grief et le General Health Questionnaire - 28).

Les deux questionnaires ont été choisis parce qu'ils sont considérés comme le plus approprié pour évaluer le deuil compliqué et les conséquences psychopathologiques qui pourraient survenir après la perte d'un enfant.

Les entretiens ont été analysés par l'Interpretative Phenomenological Analysis et par le programme français de statistique qualitative Alceste.

La comparaison entre les données quantitatives et qualitatives semblait le choix le plus approprié pour obtenir une validité et une robustesse de la recherche et pour évaluer les résultats.

Pour cette raison, afin d'utiliser les deux méthodes, nous avons fixé le nombre de participants à 30, considérant cette quantité comme un compromis entre le nombre élevé classique de recherches quantitatives et le nombre plus petit des études qualitatives.

De plus, l'échantillon de base requis pour une analyse quantitative est de 30 participants (Field, Miles et Field, 2012).

Au début du projet, 31 participants étaient disposés à collaborer, mais avec le temps, deux personnes ont arrêté leur participation et le nombre de parents en deuil est tombé à 29.

Ayant déjà commencé l'étude et compte tenu du calendrier de la recherche, les chercheurs ont décidé de ne pas recruter d'autres participants.

Le nombre est donc resté inchangé après la troisième réunion (T3), car il a été jugé suffisant pour les objectifs prédéfinis.

## Procédure

29 parents français endeuillés (21 femmes et 8 hommes, dont 8 couples) ont été rencontrés pour un total de cinq réunions réparties sur dix-huit mois. Après la réunion initiale, les participants ont été rencontrés trois mois, six mois, un an et dix-huit mois :

- T1 (première réunion);
- T2 (deuxième réunion, après 3 mois);
- T3 (troisième réunion après six mois);
- T4 (douze mois plus tard);
- T5 (dernière réunion, dix-huit mois après le début de l'étude).

Pour 7 participants basés en Alsace, les réunions se déroulaient toujours en personne. Ceux qui n'habitent pas en Alsace ont été interviewés via Skype, Messenger, WhatsApp ou par téléphone. Les réunions se sont tenues en fonction de la disponibilité des participants et généralement pendant la soirée. Chaque participant a signé un formulaire de consentement dans lequel les objectifs de la recherche, de l'utilisation et de la conservation des données sensibles ont été clarifiés.

L'étude a également été soumise et a été approuvée par le comité d'éthique de l'Université de Strasbourg.

La participation était totalement gratuite et les parents recevaient une fiche d'information et signaient un formulaire de consentement sur lequel était précisé qu'ils pouvaient se retirer de l'étude à tout moment, en fonction des difficultés ou des besoins rencontrés.

Chaque réunion était caractérisée par un entretien semi-directif et par l'administration des deux questionnaires : l'Inventory of Complicated Grief (ICG) et le General Health Questionnaire – 28 (GHQ-28).

Outre les deux questionnaires, qui correspondent à la méthodologie quantitative du travail, à un niveau qualitatif pour l'estimation des entretiens et pour compléter l'étude préétablie, ont été utilisés l'Interpretative Phenomenological Analysis et le programme statistique français Alceste (Smith, 1996).

Toutes les entrevues ont été enregistrées après avoir obtenu le consentement oral de chaque participant.

Les questionnaires ont été administrés en personne ou par le biais du programme Qualtrics. Dans ce cas, les participants pouvaient seulement accéder au questionnaire une fois après avoir reçu un lien envoyé par mail.

Pour les couples, les entretiens ont été menés sans la présence du partenaire, afin de permettre à chacun des participants de s'exprimer librement.

Les réunions se tenaient tous les trois ou six mois, en essayant de respecter les mêmes dates pour chaque réunion.

Les rencontres avec les parents ont commencé en juin 2017. Les premières interviews ont donc été menées de juin à décembre 2017.

## Entretiens semi-directifs

Chaque rencontre avec les participants a été caractérisée par un entretien semi-directif mené individuellement, en personne ou via Skype, Messenger, etc.

Les entretiens ont toujours été enregistrés après avoir obtenu le consentement oral des participants. Le choix de l'entretien semi-directif nous a semblé le plus approprié pour pouvoir commencer par des questions prédéfinies mais aussi pour pouvoir développer d'autres sujets spontanés, utiles pour une meilleure compréhension du participant.

Chaque entretien a été caractérisé par des explications préliminaires dans lesquelles la chercheuse a rappelé à tous les participants que l'entretien pouvait être interrompu à tout moment et qu'ils étaient libres de demander une pause en fonction de leurs souhaits et de leurs besoins.

À la suite de questions principales, à savoir la collecte de l'anamnèse des participants (nom, prénom, âge, emploi, situation de famille), la chercheuse a posé des questions préétablies. L'objectif était d'obtenir une représentation explicative et complète de la situation psychologique et sociale de la personne. Les principales thématiques des questions concernaient les objectifs de l'étude : les conséquences psychologiques et le soutien thérapeutique.

1. L'état psychique du parent: "Pouvez-vous me dire ce qui vous est arrivé?", "Que ressentez-vous à propos de ce qui vous est arrivé?", "Récemment, c'était l'anniversaire de la mort de votre fils/fille, comment vous sentez-vous ?" "La dernière fois, vous m'avez dit que vous ressentiez ces difficultés, comment ça va maintenant?", "La dernière fois que nous nous sommes rencontrés était il y a six mois, comment allez-vous maintenant ?", "En ce qui concerne vos difficultés, vous avez dit qu'elles s'améliorent, comment avez-vous réussi à les surmonter ou à les limiter?".

Ces questions ont été posées dans le but d'encourager les parents à s'exprimer et à lancer des réflexions utiles.

2. Soutien psychologique : "Êtes-vous suivi par un professionnel?", "Avez-vous déjà été suivi par un professionnel?", "Participez-vous à des groupes de parole?", "Souhaitez-vous participer à des groupes de parole?", "Continuez-vous à participer à des groupes en ligne? "

Ces questions ont été posées pour comprendre le soutien psychologique des parents, ainsi que leurs besoins et leurs résistances. La question sur les groupes en ligne a été ajoutée plus tard, en raison de la confusion des parents qui considéraient les groupes de parole thérapeutique comme équivalents aux groupes en ligne.

À partir de ces questions prédéfinies, l'évolution des entretiens a suivi un enchaînement spontané et linéaire. Lorsque le participant a discuté ou cité des concepts intéressants, la chercheuse a demandé et encouragé ses explications.

Comme la recherche était longitudinale, certaines questions ont été posées sur les thématiques de l'entretien précédent et sur des cas individuels (comme des questions sur la nouvelle grossesse, « À quel mois êtes-vous ? Comment vous sentez-vous ? »).

Pour les parents qui avaient plus de difficulté à verbaliser leur expérience, en particulier les hommes, la chercheuse devait répéter la question plusieurs fois, en essayant de ne pas être envahissant ou autoritaire.

De plus, les durées moyennes des entretiens étaient très variables. Au fil du temps, les entrevues se sont allongées et ont duré jusqu'à 150 minutes (avec une moyenne de 25, 31, 43, 61 et 52 minutes pour chaque réunion). Les femmes ont eu tendance à prolonger l'entretien davantage que les hommes, dont la participation a été caractérisée par des entretiens plus courts.

Cette différence de réponse démontrée entre les sexes peut s'expliquer par le rôle social assumé par les hommes et par la difficulté à exprimer des sentiments et des émotions plutôt que par des différences individuelles et de caractère (Dyregrov & Matthiesen, 1987).

L'augmentation générale de la durée des entretiens peut également indiquer comment les participants ont commencé à baisser leurs défenses et à se sentir plus à l'aise avec la chercheuse, en s'ouvrant et en partageant plus de détails et de nuances sur leur chagrin.



## **Instruments**

Pour avoir une vision complète et définie des conséquences du deuil périnatal, l'étude utilise deux types de méthodologie : une quantitative et une qualitative.

Au niveau quantitatif, deux questionnaires ont été utilisés : l'Inventory of Complicated Grief (ICG) et le General Health Questionnaire – 28 (GHQ-28).

Les variables quantitatives issues de l'analyse des données ont été mesurées et analysées à l'aide du logiciel d'analyse Jamovi.

De plus, considérant que les interactions avec les parents comprenaient non seulement l'administration des tests mais également un entretien de recherche semi-directive, l'Interpretative Phenomenological Analysis et Alceste, un programme statistique français d'analyse qualitative, ont été utilisés pour analyser les entretiens au niveau qualitatif.

### **Inventory of Complicated Grief**

L'Inventory of Complicated grief est un questionnaire conçu par Prigerson et ses collaborateurs en 1995 et utilisé pour mettre en évidence le risque de trouble du deuil compliqué (Prigerson et al., 1995). Prigerson est donc la même personne qui a nommé le trouble et inventé le questionnaire (ICG) nécessaire à son diagnostic.

Le questionnaire comprend 19 items. C'est très simple et il faut environ 5 minutes pour le remplir. Chaque item est caractérisé par quatre scores (de 0 à 4) sur le modèle de Likert, en fonction de la fréquence à laquelle le patient a ressenti la condition décrite (0 = jamais ; 1 = rarement ; 2 = plusieurs fois ; 3 = souvent ; 4 = toujours).

Prigerson et ses collaborateurs ont analysé et validé le questionnaire grâce à des recherches menées auprès de 97 aînés victimes de deuil conjugal.

Le score total montrait une association élevée avec le Beck Depression Inventory (BDI), le Texas Revised Inventory of Grief (TRIG) et le Grief Measurement Scale (GMS), utilisés pour vérifier la validité de l'instrument par rapport au deuil et à d'autres maladies.

Le questionnaire a donc révélé une cohérence interne élevée des 19 items ( $\alpha$  de Cronbach de 0,94) et une fiabilité test-retest de 0,80 (Prigerson et al., 1995).

De plus, Prigerson et al. ont constaté qu'avec un score ICG > 25, le risque de fonctionnement psychique négatif était plus élevé, définissant ainsi cette mesure comme la limite permettant de définir le tableau clinique.

La version française qui a été utilisée pour les participants est la version traduite de Zech (2006), avec un Cronbach de  $\alpha$  de 0,93, qui a été ensuite légèrement modifié afin de mieux adapter les questions à la situation (Zech, 2006). En particulier, le terme générique « décédé » a été modifié en lui ajoutant le mot « enfant » pour éliminer toute neutralité ou imprécision, sans affecter la validité et la construction du questionnaire. Cette modification a été validée par l'auteur Prigerson, qui a été contactée afin de confirmer l'efficacité de cette adaptation.

### **General Health Questionnaire – 28**

Le General Health Questionnaire – 28 (GHQ-28) est un questionnaire d'auto-évaluation pour les troubles psychopathologiques. Il a été conçu par Goldberg en 1978 et traduit en 38 langues différentes. C'est l'un des tests les plus fiables pour détecter les troubles et les comorbidités possibles, avec une sensibilité de 94%, une spécificité de 87% et un coefficient de corrélation ( $r$ ) de 0,77 (Goldberg & Hillier, 1979; Goldberg, 1972; Goldberg, 1978; Sterling, 2011).

Le premier General Health Questionnaire – 28 remonte à 1972, suivi de quatre autres versions : GHQ-60 ; GHQ-30 ; GHQ- 28 et GHQ-12 (Sterling, 2011).

Le GHQ-28, comme on peut le déduire de son nom, se compose de 28 items, répartis en quatre sous-échelles de 7 items chaque un. Le questionnaire est caractérisé et conçu pour définir : les symptômes somatiques (items de 1 à 7) ; anxiété et insomnie (items de 8 à 14) ; dysfonctionnement social (de 15 à 21) et dépression sévère (items de 22 à 28) (Goldberg, 1978).

Chaque élément donne quatre réponses possibles (Likert) qui permettent au patient de définir et de décrire la fréquence d'une sensation ou d'une pensée.

Le questionnaire est simple et rapide à remplir et nécessite au maximum dix minutes.

Il existe deux méthodes possibles pour collecter les résultats. Il est possible de noter chaque réponse avec une note de 0 à 3, avec un total de 23/24, ou alternativement en utilisant une méthode binaire dans laquelle les réponses « Pas du tout » et « Pas plus que d'habitude » valent 0 et « Plutôt plus que d'habitude » et « Beaucoup plus que d'habitude » comme 1. Ce dernier a été utilisé dans cette étude. Le seuil utilisé pour identifier une éventuelle présence de détresse est de 4 (Goldberg, 1986; Sterling, 2011).

La version utilisée dans l'étude a été traduite en française en 1992 par Pariente (Pariente et al., 1992). Le questionnaire a été administré à 158 patients psychiatriques et a montré une cohérence interne avec le coefficient  $\alpha$  de 0,91, et une sensibilité et une spécificité de 59% et 87%, confirmant ainsi la validité de la traduction ainsi que son utilité et sa pertinence.

## Alceste

Alceste (*Analyse lexicale par Contexte d'un Ensemble de Segments de Texte*) est un logiciel statistique français qui effectue une analyse qualitative de différents textes comme ceux d'interviews, d'articles de revues, d'œuvres littéraires, etc. (Delavigne, 2003). Il a été conçu en 1980 par Max Reinert et développé et commercialisé depuis 1986 par la société IMAGE sous licence du CNRS de l'Université de Toulouse (Image Ltd., Toulouse, France).

Une grande partie de la recherche scientifique menée sur Alceste a confirmé son efficacité. Ces études ont été menées dans les domaines de la psychologie sociale et de la sociologie (Geka & Dargentas, 2010; Gonin, 2008; Kalampalikis, 2005; Lahlou, 1998; Scharnitzky & Kalampalikis, 2007; Temple & Denoux, 2008; Viaud et al., 2007), sciences sociales, pédagogiques et psychologie clinique (Aubert-Lotarski & Capdevielle-Mougnibas, 2002; Metz et al., 2019; Truc, 2011), etc.

Le logiciel tente de mettre en évidence l'utilisation des mots et leurs relations en fonction de leurs apparitions et de leurs positions dans un texte (Bart, 2011). La méthode utilisée est la « classification hiérarchique de haut en bas ». À partir du corps central du texte, le programme subdivise le texte et extrapole des classes de mots plus représentatifs sur le plan de leur fréquence (Delavigne, 2003). Les classes ne sont donc pas basées sur le sens des mots mais sur une analyse statistique distributive (Delavigne, 2003).

Alceste fournit une sorte de profil détaillé pour chaque classe. Cela signifie que l'analyste a accès à la liste des mots les plus significatifs de chaque classe, de chaque unité et à leur cooccurrence (c'est-à-dire la position des mots et leur utilisation conjointe). Au niveau statistique, le Khi2 met en évidence et classe le degré d'appartenance (fort ou faible) d'un mot à une classe et les termes les plus significatifs (Delavigne, 2003).

Plus précisément, l'analyse est caractérisée par quatre étapes. Dans le premier cas, Alceste reconnaît les unités de contexte initiales (*u.c.i.*) ou les segments composant le corps du texte (dans notre cas, par exemple, les *u.c.i.* sont les différents entretiens des participants).

De plus, le logiciel sélectionne et distingue les « mots nécessaires » utiles à la construction syntaxique (tels que les articles, les conjonctions, les prépositions, etc.) des mots « complets » (noms, verbes, adjectifs, adverbes), qui sont les seuls à être analysés (Bart, 2011).

Par la suite, le corps du texte est divisé en unités de contexte élémentaire (*u.c.e.*), autrement dit une ou plusieurs lignes de texte consécutives, et est classé en fonction de la répartition et du lien statistique entre les formes (suffixes des mots) et les classes créées.

Les deux dernières étapes consistent en la présentation des premiers résultats, fournissant les profils et caractéristiques des différentes classes (mots analysés, mots ignorés, fréquence des mots, etc.), et la génération de calculs complémentaires, tels que : croisement d'une partie du texte avec une variable

ou un mot particulier (deux *types de tris croisés*) ; et l'Analyse Factorielle des Correspondances (AFC). Cela permet à l'enquêteur d'expliquer toute relation d'attraction ou de distance entre les classes et les formes. Il peut ainsi créer une classification hiérarchique ascendante qui montre la proximité entre les mots (Bart, 2011; Delavigne, 2003).

De manière générale, l'analyse d'Alceste concerne :

- le lexique, à travers la somme des mots et la cooccurrence de formes ;
- le contenu, donné par la segmentation du texte ;
- et les données quantitatives, par classification textuelle ascendante et descendante.

En outre, à la fin de l'analyse, il est possible d'afficher le degré de pertinence du traitement (faible, moyen, élevé ou très élevé). La pertinence du traitement est basée sur le pourcentage de l'unité de texte que le programme a réussi à classer. Pour cette raison, il est conseillé d'obtenir un degré de pertinence élevé ou très élevé.

Après avoir inséré le corps du texte dans le programme, le chercheur est en mesure de modifier les paramètres d'analyse qui déterminent le degré de pertinence. Les paramètres comprennent notamment le type de classification, le nombre minimum de classes, etc.

Dans notre cas, le degré élevé de pertinence a été atteint sans que des modifications aient été apportées, mais par le biais des critères standard et prédéfinis du programme.

Cela signifie que la sélection du UCE (Unité Contexte Élémentaire) est automatique (ETAPE A).

De plus, les unités du contexte sont analysées selon une double classification décroissante et avec un nombre déterminé de mots normalisés par les deux classifications (Valeur *DONN.1* et *2*). Selon les critères prédéfinis d'Alceste, le nombre de classes pour chaque classement décroissant est au maximum de huit et une unité de contenu doit être présente au moins quatre fois (Fréquence *minimale d'une forme analysée*).

De plus, la taille minimale d'une classe par rapport au nombre d'unités est automatique, allant d'une valeur comprise entre 1 et 3000 (ETAPE C).

Enfin, l'étape D (ETAPE D) correspond à des calculs complémentaires, à savoir comment effectuer la classification hiérarchique ascendante, le nombre d'unités textuelles affichées dans les résultats d'analyse (dans ce cas 100), etc.

Après qu'Alceste a terminé l'analyse, la première fenêtre qui apparaît est un résumé de toutes les données obtenues : la classification des classes, les pourcentages du traitement, le dictionnaire, la liste des termes de la double une classification ascendante, etc.

Outre cette première fenêtre, d'autres fonctions sont également disponibles, telles que : l'affichage de classes et de co-occurrences des mots dans un motif en spirale ou une analyse mot à mot, etc.

Les classes numérotées et colorées apparaissent par ordre d'apparition. Leur nombre dépend de l'homogénéité des mots, tandis que le pourcentage dépend de la présence des mots de la classe dans le texte.

Pour chaque classe, les coefficients khi2 sont également indiqués, ce qui est un coefficient d'association qui mesure la relation entre un mot et sa classe : plus le coefficient est élevé, plus la connexion est solide.

De plus, les classes d'Alceste sont appelés « mondes lexicaux » du sujet, qui permettent d'une interprétation sémantique des mots qui les composent.

Une fois que le programme a effectué son analyse, il appartient au chercheur de comprendre et d'interpréter les résultats.

Notre évaluation a porté spécifiquement sur l'étude des classifications descendantes et sur le rapport détaillé fourni par Alceste. La première correspond aux résultats indiqués dans la fenêtre principale qui apparaît après la fin de l'analyse, tandis que le second inclut le résumé de toutes les informations et des analyses réalisées, y compris des fragments de phrases par rapport aux mots sélectionnés.

Dans le cadre de notre recherche, Alceste a été utilisé pour une analyse qualitative des entretiens semi-directifs réalisés avec les participants.

En particulier, deux types d'analyses différentes ont été créés pour valider nos hypothèses de départ. La première analyse a porté sur les conséquences psychologiques consécutives à la perte périnatale, et plus particulièrement sur le syndrome de deuil compliqué et les changements du discours au fil du temps.

Le délai maximal entre la date du décès de l'enfant et la première réunion était d'environ dix mois (soit neuf mois et vingt-sept jours), le minimum étant de vingt-deux jours.

Les 29 participants ont été divisés en trois groupes différents, en fonction du temps écoulé de la perte: moins de six mois, de six mois à un an, plus de 12 mois.

En outre, la deuxième analyse concerne l'évaluation de l'efficacité de la psychothérapie.

Les participants ont été divisés en trois autres groupes : ceux qui n'ont suivi aucune thérapie ; ceux qui ont été suivis par un psychothérapeute et / ou ont participé à des groupes de parole ; et ceux qui ont participé aux groupes sur les réseaux sociaux.

Le critère temporel fixé pour les soins psychologiques était de 10 séances. Les participants ont été inclus dans le deuxième groupe (ceux qui ont suivi une psychothérapie), s'ils ont assisté à au moins 10 séances avant ou pendant la participation à la recherche. Ces données ont été extrapolées à l'aide de questions spécifiques lors des entretiens.

Après avoir sélectionné les participants en fonction de ces variables (temps après la perte et le soutien psychologique), toutes les interviews de chaque participant ont été incluses dans un seul texte du groupe de référence.

L'objectif était donc de vérifier si chaque groupe avait un type de langage / discours différent et quels étaient les thèmes principaux dans chaque groupe.

### **Interpretative Phenomenological Analysis**

L'Interpretative Phenomenological Analysis (IPA) est une méthodologie qualitative qui vise à comprendre l'interprétation que le sujet donne de son expérience.

Conçu en 1996 par Smith, l'IPA est basée sur trois concepts fondamentaux : la phénoménologie, l'herméneutique et l'approche idiographique (Smith, 1996 ; Smith & Larkin, 2009).

La phénoménologie, une méthode philosophique d'investigation basée sur la pensée d'Edmund Husserl, implique l'étude des phénomènes uniques et discernable des autres. La phénoménologie met en évidence la manière dont les événements apparaissent à la conscience et prennent un sens universel et logique. Cependant, cette méthode est loin des idées préconçues conventionnelles et connues.

L'herméneutique de Heidegger (terme issu du grec ancien « interpréter », « clarifier ») guide l'analyse des résultats et étudie le sens et l'interprétation du phénomène par l'individu en tant qu'être pensant.

Enfin, l'approche idiographique consiste à prendre une seule étude de cas et à l'utiliser pour produire une catégorisation générale et prédéfinie (Pietkiewicz & Smith, 2014, Smith & Osborn, 2015). L'IPA est donc un processus inductif d'analyse de la signification que l'individu attribue à ses propres expériences intimes.

Outre les principaux concepts de base exprimés ci-dessus, il est également important de considérer le rôle de l'expérimentateur dans ce que l'on pourrait définir comme une « double herméneutique » : un processus dynamique actif dans lequel le chercheur tentera de donner un sens à la vision du monde des sujets contactés à travers ses conceptions personnelles (Pietkiewicz & Smith, 2014; Smith & Osborn, 2008) .

Les données sont recueillies par la transcription d'entretiens semi-structurés, méthode la plus recommandée (Smith, 2004). Au cours des entretiens, les participants sont encouragés à décrire leur expérience en profondeur.

Ce qui motive l'IPA, ce sont des problèmes prédéfinis, dans le but d'évaluer les hypothèses de l'étude. La procédure d'analyse commence par une relecture répétée du texte et, à côté des phrases individuelles, par quelques notes et mots-clés, pour souligner le concept identifié.

A partir de ces synthèses, l'enquêteur va commencer une analyse « bottom up » : à partir des annotations et des synthèses, il commencera un processus de codage des significations (« codes », marqué ligne par ligne), en essayant de créer des catégories d'arguments plus généraux ou « superordonnés », y compris des sous-catégories (Larkin & Thompson, 2011; Reid et al., 2005; Smith, 2004).

Les annotations peuvent être écrites aux marges et, avec l'intensification de l'étude, l'expérimentateur commencera à se concentrer exclusivement sur les synthèses, et éventuellement sur les catégories.

La littérature suggère d'utiliser cette analyse pour un nombre homogène et limité de participants (Collins & Nicolson, 2002; Eatought & Smith, 2017; Smith, 2004; Smith & Osborn, 2003).

Par conséquent, dans notre recherche, après avoir effectué une première analyse avec les 3 premières interviews conduites avec 29 parents, pour une IPA plus approfondie, nous n'avons sélectionné que 4 participants.

L'analyse finale a donc été consacrée à 20 entretiens seulement (c'est-à-dire aux cinq entretiens de 4 parents, 2 femmes et 2 hommes).

Après une analyse générale initiale, ces quatre participants ont été considérés comme les plus représentatifs des catégories de l'IPA issues de l'analyse préliminaire et comme des études de cas utiles en ce qui concerne les conséquences du deuil.

Nos recherches ont été effectuées exclusivement par une seule personne (la chercheuse de la thèse), qui a tenté d'être la plus lucide possible dans l'identification des catégories et problématiques au cours des recherches à long terme.

Suivant les instructions de l'auteur principal (Smith, 1996), la chercheuse a commencé l'analyse par une lecture attentive de chaque entretien. Après avoir lu les interviews à deux reprises, seulement après trois fois la chercheuse a noté des synthèses du concept / phrase au bord de la page.

Pour tenter de mettre en évidence les concepts de manière lucide, la chercheuse a laissé quelques jours s'écouler entre chaque lecture.

Après avoir coché et vérifié plusieurs fois les premières synthèses, un processus de codification et de catégorisation a eu lieu. Au fil du temps, la chercheuse s'est concentré exclusivement sur les annotations, puis a tenté de donner un titre à chaque concept émergé. À partir de cette phase préliminaire, la chercheuse a tenté de mettre en relation chaque code identifié pour trouver des catégories générales et des sous-catégories.

L'objectif était de résumer par ces noms les aspects spécifiques apparus au cours des entretiens de manière générale et exhaustive.

Le travail de codage a nécessité environ trois processus pour pouvoir trouver les codes pertinents et inclure les thématiques dans le moins de catégories possible.

En conclusion, l'IPA a été choisi car il fournit une comparaison entre les participants et met en évidence les fonctionnalités de la personne. Il permet d'évaluer le phénomène de la perte et la façon dont il a été vécu par les parents, ainsi que de prendre en compte leur perception et leur compréhension du phénomène.



## Participants

Vingt-neuf parents endeuillés ont participé à l'étude, 21 femmes (72%) et 8 hommes (28%). 8 femmes et 8 hommes inclus dans les 29 participants constituaient 8 couples.

Les femmes contactées étaient initialement les participantes. Après leur accord à collaborer à l'étude, elles ont également demandé à leur partenaire s'il était prêt à y participer. Comme nous l'avons vu, seuls 8 hommes ont accepté.

Compte tenu du sexe des participantes, la majorité des femmes est remarquable.

Il est important de toujours considérer que le nombre d'hommes n'est ni exhaustif ni représentatif car ils sont minoritaires, mais leurs résultats et leurs comparaisons pourraient être utiles en tant que valeur indicative pour des hypothèses et des considérations.

En outre, au début de l'étude les participants étaient 31, correspondent à 23 femmes et 8 hommes.

Trois mois après le premier entretien, une mère a décidé de quitter l'étude, ce qui a porté à 30 le nombre de parents, dont 22 femmes (70,9%) et 8 hommes (25,8%).

Trois mois plus tard, alors que devait se tenir la troisième réunion (T3), une autre femme a décidé de mettre fin à sa participation à l'étude. Cela signifiait que le nombre final de participants était de 29 parents (8 hommes et 21 femmes).

Les deux femmes qui ont cessé de participer n'ont pas expliqué la raison de leur choix, devenant simplement inaccessibles, par courrier et par téléphone. Il est seulement possible de formuler des hypothèses sur leur décision. Peut-être répondre aux questions semblait trop pénible. Leur décision pourrait également être due à une défense psychologique, dans une tentative d'éviter les situations qui se réfèrent à la mort de l'enfant.

Les participants avaient un âge entre 26 à 41 ans, en particulier entre 26 et 30 ans (45%), et avec un âge moyen de 31,4 ans.

7 personnes (4 femmes et 3 hommes) vivent en Alsace, 21 dans d'autres régions métropolitaines et une mère en Guadeloupe (France non métropolitaine).

La majorité des participants sont *pacés* (34,5%). Le *pacte civil de solidarité* (PACS) est la forme contractuelle française d'union civile entre deux adultes de même sexe ou de sexe différent.

Depuis 1999, année de son institutionnalisation, le pourcentage de couples qui optent pour le PACS a considérablement augmenté chaque année. Comme les données le confirment, il est devenu l'un des principaux choix parmi les différents types d'union, en particulier chez les couples les plus jeunes (de 24 à 35 ans) (Ferret, 2018).

Un même pourcentage des parents (34,5%) vivent avec leur partenaire mais ne sont ni *pacés* ni mariés. Les autres participants sont mariés (28%) ou célibataires (3%).

La plupart des participants ont un emploi (86%) et ont obtenu un diplôme professionnel (41%), suivis d'un master (24%), d'un diplôme d'études secondaires (17%), d'un baccalauréat (14%) et d'un brevet (3%).

Les emplois exercés par les participants sont très hétérogènes : infirmiers, enseignants, employés de magasin, femmes au foyer, etc. Ils sont très différents et difficiles à classer.

Sur 29 participants, 4 ne travaillent pas ou sont officiellement au chômage à la recherche d'un emploi (3 femmes) ou ne perçoivent aucun salaire (1 femme est femme au foyer).

Même si, pour la plupart des participants, leur carrière professionnelle a débuté tôt et avec, probablement, l'indépendance économique, il n'y a pas de différence significative entre le niveau de formation du parent, son âge et le nombre d'enfants nés avant la perte présents dans la famille (7 au total). Dans la plupart des cas, l'enfant décédé était le premier enfant (82,8%) et seulement 17% des participants étaient déjà devenus parents, sur un maximum de deux enfants.

### **Critères de participation**

En France, les critères d'étude des taux de mortalité infantile et périnatale sont fondés sur les recommandations de l'OMS : en ce qui concerne la mort spontanée d'un enfant ou d'une Interruption Médicale de Grossesse (IMG) survenue à partir de la 22ème semaine d'aménorrhée ou de 500 g de poids de l'enfant (Ministère du travail, de la santé et du secrétariat d'État à la santé, 2011). Ces indications ont donc déterminé les critères de sélection en fonction du moment du décès de l'enfant.

En raison de la maîtrise de la langue, il était également nécessaire que les participants soient de langue maternelle française. Sur 29 participants, 2 sont belges, résidant en France.

Dans un premier temps, nous avons cherché à recruter des personnes ayant perdu un enfant le plus récemment possible. Compte tenu des difficultés rencontrées pour trouver des parents disponibles pour participer à la recherche, il était nécessaire d'étendre le critère temporel entre le décès de l'enfant et le premier entretien. Enfin, ont été inclus les parents qui ont perdu leur enfant dans les dix mois précédant le premier entretien. Cet intervalle de temps n'a pas été jugé trop éloigné mais suffisamment utile pour recruter des parents disposés à participer. Cela signifie que le temps écoulé entre la perte de l'enfant et le début de la recherche n'est pas le même pour tous les participants.

Deux méthodes ont été les plus utiles pour recruter des parents désireux de participer : la publication d'annonces de recrutement sur les réseaux sociaux et la collaboration avec des associations françaises de parents endeuillés.

## **Les enfants perdus**

Sur les 32 enfants décédés, 21 étaient des filles (67%) et 11 des garçons (34%). Trois participants ont perdu des jumeaux.

Le délai maximal entre la date du décès de l'enfant et la première réunion était d'environ dix mois (soit neuf mois et vingt-sept jours), le minimum étant de vingt-deux jours.

Le décès des enfants est survenu entre novembre 2016 et novembre 2017.

50% des pertes ont eu lieu pour des complications médicales (problèmes respiratoires, cardiaques et des malformations générale, maladies génétiques, accouchement prématuré, etc.).

En raison de malformations et de maladies (par exemple, la trisomie 21), 34% des parents ont décidé de procéder à une Interruption Médicale de Grossesse (IMG).

Par rapport à l'anamnèse collectée sur les enfants, seuls 22% des enfants ont nées vivants. Un bébé a vécu quelques minutes (3%), un quelques heures (3%), quatre bébés (12,5%) pendant quelques jours (maximum deux semaines) et 6% d'enfants pour trois mois (jusqu'à un maximum de 96 jours). 75% sont décédés pendant la grossesse à partir de la vingt-deuxième semaine d'aménorrhée.

La plupart des enfants (75%) ont été crématisés. En outre, 53% des enfants, crématisés ou non, ont été célébrés par une stèle. Dans les 47% restants, les cendres ont été dispersées ou les parents ont décidé d'en donner l'entière responsabilité à l'hôpital.

## Résultats quantitatifs

Au fil des mois, les moyennes générales des deux questionnaires (l'Inventory of Complicated Grief et le General Health Questionnaire – 28) se sont nettement améliorées. Ces résultats ont montré une diminution progressive du risque de développer des troubles psychopathologiques, tels que le trouble de deuil compliqué (évalué grâce au questionnaire ICG), les troubles anxieux, somatiques, sociaux et la dépression (c'est-à-dire les sous-échelles de GHQ-28).

En particulier, les parents n'ont atteint le seuil de deuil « normal » ou non compliqué que 18 mois après le début de l'étude (et une majorité fréquente de valeurs inférieures au seuil 21 mois après la perte). Par rapport au GHQ-28, les résultats de toutes les sous-échelles ont montré des valeurs inférieures au seuil de référence à partir de la deuxième réunion (T2).

En général, les différences entre les valeurs des femmes et des hommes n'ont pas été mises en évidence.

De plus, en ce qui concerne les causes de décès, les résultats de ceux qui ont perdu l'enfant pour des causes inconnues ont montré un risque de deuil compliqué uniquement en T1.

Ceux qui ont effectué une IMG ont constamment montré des moyennes générales et une fréquence plus élevée de résultats au-dessus du seuil de référence.

D'autre part, compte tenu du moment de la mort, les parents qui ont perdu l'enfant pendant la grossesse ont connu un risque plus faible de développer un deuil compliqué tandis que ceux qui ont perdu un enfant après quelques mois ont obtenu les moyennes générales les plus élevées en T5 et des résultats constamment supérieurs à la valeur de référence.

De plus, le *d* de Cohen dans T4 et les effect sizes ont confirmé que ceux qui ont perdu le bébé pendant la grossesse ont un risque plus faible de développer des troubles anxieux et d'insomnie.

Par rapport à ceux qui étaient déjà devenus parents avant le décès (17%), ceux qui avaient déjà un enfant ont montré un plus grand risque d'anxiété et des troubles somatiques et sociaux en T4. This latter one was also confirmed by the frequencies of the results above and below the cut-off: those who had already had a living child recorded a value above 4 in the Social dysfunction subscale in T1, T4, and T5.

Après la perte, au cours des dix-huit mois de l'étude, 38% des parents ont eu un nouvel enfant, sans montrer de différence significative, ils ont enregistré une fréquence de valeurs plus élevée que la seuil de référence de l'ICG jusqu'à T4.

Par rapport au soutien psychologique, au début, environ 64% des parents étaient suivis par un psychologue (17 femmes et 4 hommes), atteignant le pourcentage d'environ 28% (8 femmes) à la fin de l'étude. La seule différence significative concerne les résultats obtenus dans T5. Ceux qui avaient demandé l'aide d'un professionnel présentaient un risque accru de développer des symptômes

d'anxiété. Au niveau de la fréquence de la seuil, en T5, seul un parent sur 8 qui avait demandé un soutien thérapeutique avait enregistré une valeur supérieure à 4. Bien que non significative, cette population a également systématiquement montré un niveau supérieur à 25 par rapport à l'ICG.

De plus, la participation aux groupes de parole a été un facteur de soutien en T1, en particulier en ce qui concerne le développement du deuil compliqué. Le pourcentage de participation à ces groupes étaient de 24% au départ, puis atteignait 17% en T5. Cette participation a été un facteur de soutien en T1, notamment en ce qui concerne le développement du deuil compliqué, données confirmées également par les fréquences: les 22 parents qui n'ont pas participé ont enregistré une valeur supérieure au seuil de référence de l'ICG, alors que seuls 4 participants sur 7 ont obtenu un score supérieur à 25. De plus, les non-participants ont également montré une majorité totale de résultats supérieurs à 4 dans les sous-échelles Anxiété et insomnie, et Dysfonctionnement social, toujours en T1.

Une participation active et prolongée à des groupes en ligne a montré un risque plus élevé de deuil compliqué, de dépression, d'anxiété et de troubles somatiques par rapport aux résultats obtenus en T4 et T5. En T5, sur 5 femmes, 3 présentaient une valeur supérieure à 25 respect avec l'ICG, par rapport à celles qui n'y ont pas participé: 16 personnes sur 24 ont obtenu un résultat inférieur au seuil.

En T1, environ 59% des parents ont participé à ces groupes (femmes uniquement), atteignant 17% en T5.

Au niveau du soutien émotionnel, ceux qui percevaient le soutien du partenaire présentaient un risque moins élevé d'anxiété (en T3, T4 et T5), de deuil compliqué et de troubles somatiques (en T4) et de dépression (en T4 et T5). Nous avons vu une grande effect size des sous-échelles de dysfonctionnement social et de dépression sévère en T2, résultats également confirmés par les fréquences des résultats au-dessus ou au-dessous du seuil, et en ce qui concerne les symptômes somatiques, l'anxiété et l'insomnie, et sévère sous-échelle de dépression dans T3. De plus, il y avait une différence significative de T4 par rapport à l'ICG et à la sous-échelle des symptômes somatiques, toujours confirmée par les fréquences du seuil.

Percevoir le soutien de la famille constituait un facteur de protection contre le risque de développer un deuil compliqué (T4), des troubles somatiques, anxieux, un dysfonctionnement social et une dépression (T5). Ceux qui percevaient plutôt un soutien émotionnel de la part de leurs amis présentaient un risque moins élevé de dépression en T1 et de deuil compliqué en T3.

Ces données ont également été confirmées par la fréquence des résultats au-dessus et en dessous du seuil: pour la sous-échelle de la dépression en T1, 7 des 11 parents qui ne percevaient pas un tel soutien ont enregistré une valeur supérieure à 4 et de ceux qui se sentaient soutenus, 15 des 18 parents

ont obtenu une valeur inférieure à la valeur seuil; en considérant l'ICG dans T3, 9 parents sur 10 qui ne se sentaient pas soutenus ont obtenu un résultat supérieur à 25.

Les parents qui prenaient des médicaments (environ 6%) présentaient un risque de développer un deuil compliqué, des symptômes somatiques et troubles anxieux (en T2, T4 et T5), du dysfonctionnement social (en T2 et T5) et de la dépression sévère en T2.

Enfin, 34% des parents qui ont déménagé après la perte ont présenté un risque accru de dépression par rapport aux résultats de T4.

En plus des données quantitatives, la recherche a été également composée d'une analyse qualitative, dont les résultats seront présentés ci - dessous.

Une méthodologie mixte s'est donc révélée appropriée et pertinente pour les objectifs prédéfinis.

Les deux méthodologies ont été utiles pour valider les principales hypothèses de l'étude, ainsi que pour trouver une comparaison correcte et pour confirmer les résultats de chaque analyse.

## Les résultats qualitatifs

L'analyse qualitative comprend deux outils différents : Alceste, un programme statistique qualitatif et l'Interpretative Phenomenological Analysis (IPA).

Deux analyses différentes ont été effectuées concernant Alceste.

La première consistait à suivre l'évolution du discours du participant, en essayant également d'identifier les aspects liés au trouble de deuil compliqué.

Pour cette raison, trois groupes différents ont été créés en fonction du moment de la perte.

Le délai minimum entre le décès et la première réunion était de 22 jours et le maximum d'environ 10 mois.

Le groupe I (<6) (composé de 19 participants, dont 14 femmes et 5 hommes, et 30 entretiens) était composé de ceux qui avaient perdu leur enfant depuis moins de 6 mois.

Les parents du groupe II (6-11) (composé du nombre total de participants, soit 29 parents, dont 21 femmes et 8 hommes, avec un total de 41 entretiens) avaient perdu l'enfant de 6 à 11 mois.

Le troisième et dernier groupe (de 29 participants et 74 entretiens) a perdu le bébé pendant plus d'un an.

Le nombre total de classes était de 5: 4 pour le groupe I (<6), 3 pour le groupe II (6-11) et 5 classes pour le groupe III (> 12).

Les catégories qui ont émergé concernaient : les causes du décès, la description de l'événement, les objets liés à l'enfant, la maison, le soutien émotionnel et psychologique (psychothérapie, groupes de parole et groupes en ligne des réseaux sociaux), les rites, les dates considérées comme plus difficiles (comme les anniversaires) et la bureaucratie.

Selon les résultats, un changement dans les sujets de discussion a été mis en évidence. Les catégories pour chaque groupe étaient presque toujours les mêmes mais apparaissaient dans des classes différentes.

Ce résultat montre comment le discours des parents a changé au fil des mois.

En outre, exclusivement dans le groupe III (6-11) était présente la catégorie de la psychothérapie, tandis que dans le groupe III (> 12) celles des dates et de la bureaucratie.

Enfin, il est possible de constater qu'il n'y a pas de changements brusques dans la position des catégories des trois groupes. Cette comparaison a mis en évidence le changement linéaire et progressif du discours et des besoins des parents, indiqué par un besoin initial de maintenir le lien avec l'enfant (première classe du Groupe I) pour finir avec l'importance de sa reconnaissance sociale (dernière classe du Groupe III).

La deuxième analyse d'Alceste concernait le soutien thérapeutique. Les participants étaient en fait divisés en trois groupes : ceux qui ne demandaient aucun soutien (groupe A - NO) ; ceux qui ont été

suivis par un professionnel et / ou ont participé à des groupes de parole (groupe B - psychothérapie) pendant au moins dix séances ; et ceux qui ont participé à des groupes en ligne dédiés au deuil périnatal sur les réseaux sociaux pendant un minimum de six mois (groupe C - groupes IT).

Le premier groupe (groupe A) était composé de 15 parents (9 femmes et 6 hommes), le deuxième (groupe B) de 14 (12 femmes et 2 hommes) et le troisième (groupe C) de 9 femmes.

Au total, les classes étaient de 6 : 5 pour le groupe A (NO), 6 pour le groupe B (psychothérapie) et 4 pour le groupe C (groupes IT).

Plus précisément, nous avons constaté une similarité de classes entre le groupe A (NO) et le groupe C (groupes IT).

En outre, dans le groupe A (NO), les catégories « partenaire », « famille », « religion » et « bureaucratie » n'étaient présentes que dans ce groupe, tandis que la catégorie de l'enfant suivant était absente.

La catégorie de psychothérapie personnelle n'était présente que dans le groupe B (psychothérapie).

En général, les groupes A et C présentaient moins de références aux aspects émotionnels du deuil et du soutien psychologique et social que le groupe B (psychothérapie).

Enfin, en ce qui concerne la comparaison entre les deux analyses d'Alceste, elles présentent presque toujours les mêmes catégories, mais avec quelques différences. Dans la première analyse, il n'y avait aucune référence aux catégories spécifiques du couple, de la famille, de la religion et de l'enfant subséquent. Alors que dans la deuxième analyse, la catégorie des dates considérées comme difficiles manquait.

La deuxième analyse qualitative concerne l'Interpretative Phenomenological Analysis (IPA).

L'IPA est un processus de compréhension de l'interprétation de l'événement par le sujet, à travers le rôle actif du chercheur qui doit essayer de donner un sens à la vision du monde de l'autre personne.

Pour obtenir les meilleurs résultats possibles, l'IPA a été utilisée pour analyser les cinq entretiens de quatre participants, deux hommes et deux femmes. La chercheuse a sélectionné ces participants en tant que représentants des catégories issues d'une première analyse générale avec tous les participants.

Les quatre parents sont : Cindy, Susan, Tim et Thomas.

Cindy a décidé d'interrompre sa grossesse à la 26<sup>e</sup> semaine de grossesse, à la suite du diagnostic d'une malformation cérébrale et motrice grave. L'enfant est né vivant et a survécu trois minutes. Elle a été suivie par un thérapeute et a participé à des groupes en ligne.

Susan a décidé de faire une IMG au huitième mois de grossesse après un diagnostic de malformation cardiaque. Elle a été suivie par une thérapeute et elle a participé à des groupes de parole et à des groupes en ligne.



Tim et son compagne ont réalisés une IMG à la 36ème semaine de grossesse pour le diagnostic d'une malformation cérébrale. Il a été suivi par un thérapeute.

Enfin, Thomas a perdu son enfant au neuvième mois de sa grossesse. Environ six mois plus tard, lui et sa femme ont découvert la raison de la mort : un défaut du placenta. Il n'avait pas demandé de soutien psychologique.

Au cours des dix-huit mois qui ont caractérisé l'étude, Cindy, Susan et Tim ont eu un nouveau bébé alors que Thomas a repris un programme de procréation médicalement assistée.

L'IPA a mis en évidence cinq catégories différentes : description des événements ; lien continu ; soutien social, enfant suivant et soutien psychologique. Bien qu'elles soient identiques à celles d'Alceste, les catégories IPA sont subdivisées en sous-catégories qui couvrent des sujets plus spécifiques.

- Dans la catégorie “description de l'événement”, il y a : émotions et sentiments, expériences avec l'enfant et cause de la perte.
- Dans celle de la “continuité du lien” : objets de liaison, représentations symboliques et religieuses et bureaucratie.
- En “soutien social” : partenaire, famille, amis et hôpital.
- Dans “l'enfant suivant” : désir, grossesse et enfant suivant.
- En “soutien psychologique” : psychothérapie, groupes de parole et groupes IT.

L'IPA a été utile pour mieux comprendre l'expérience du parent et les conséquences psychologiques possibles. Des questions intéressantes ont été soulignées, ainsi qu'une distinction claire entre les mécanismes d'expression et de défense mis en œuvre chez les femmes et les hommes.

## **Analyse des résultats**

Au niveau quantitatif et qualitatif, à la fin des dix-huit mois qui ont caractérisé l'étude, le risque de développer des troubles psychopathologiques était moindre.

Ce n'est qu'après la cinquième interview que les parents atteignent le seuil du deuil non compliqué comparé aux valeurs de l'ICG (et après 21 mois suivant la perte, selon les valeurs de fréquence du seuil). Ces données ont été confirmées en ce qui concerne les analyses qualitatives, également mises en évidence en ce qui concerne la première analyse d'Alceste, dans laquelle les parents ont présenté différentes classes en fonction du moment de la perte.

En outre, si au niveau quantitatif il n'y a pas de différence entre les valeurs des hommes et des femmes, les différentes expressions du chagrin émergent au niveau qualitatif. En particulier, différents mécanismes de défense ont été mis en évidence, influençant la relation et la perception du soutien du partenaire.

Par rapport à la cause du décès, au niveau quantitatif, les seules différences ont été enregistrées dans T1, groupe dans lequel ceux qui ne connaissaient pas la raison de la perte présentaient un risque plus élevé de développer un deuil compliqué. Sur le plan qualitatif, toutefois, des sentiments de culpabilité et une plus grande difficulté à accepter la perte sont apparus chez les parents qui ont décidé d'effectuer une IMG (données confirmées par la fréquence des résultats supérieurs et inférieurs au seuil de référence et les valeurs de la moyenne générale).

En outre, par rapport à ceux qui ont perdu un bébé vivant, les personnes ayant perdu leur bébé pendant la grossesse ont présenté un risque moins élevé de développer des troubles psychopathologiques (trouble de deuil compliqué, anxiété et insomnie, dysfonctionnement social et dépression).

Ceux qui sont déjà devenus parents d'un enfant ne montrent pas de différence significative alors qu'au contraire, sur le plan qualitatif, la présence d'enfants vivants est perçue comme fondamentale. Par contre, il n'y avait pas de différence par rapport à ceux qui avaient (55%) ou n'avaient pas eu d'enfant ultérieur mais ces derniers ont montré une fréquence de valeurs supérieure au seuil de l'ICG jusqu'à T4. D'après l'analyse des entretiens, les aspects obsessionnels possibles ont été mis en évidence pour ceux qui ne pouvaient pas avoir d'enfant en raison de problèmes de fécondité.

Pour les deux méthodes, le soutien émotionnel perçu par le partenaire, la famille et les amis a été confirmés comme facteur de soutien.

Par rapport au soutien psychologique, les personnes suivies par un thérapeute présentaient un risque plus élevé de troubles anxieux lors de la T5. Ceux qui ont demandé une aide professionnelle ont radicalement diminué avec le temps, passant de 72% à 28% (de T1 à T5). De plus, ceux qui ont participé à des groupes de parole ont enregistré un risque de deuil compliqué plus faible en T1. Même pour ceux qui ont participé à ces groupes, la participation a diminué de 24% à 17%.

De plus, les mères qui ont continué à participer assidûment aux groupes en ligne ont montré un risque de deuil compliqué (en T4 et T5), de troubles somatiques, d'anxiété et de dépression (en T5).

De nombreuses mères ont cessé de participer au fil des mois (passant de 59% à 17%), affirmant que ces groupes en ligne ont rendu la progression et l'acceptation de la perte encore plus difficile.

De plus, au niveau quantitatif, il est apparu que les personnes qui prenaient des médicaments (environ 7%) avaient un risque plus élevé de deuil compliqué (T2, T4 et T5), d'anxiété (T4 et T5) et de troubles somatiques (T2 et T4).

Enfin, certaines catégories n'ont émergé qu'au niveau qualitatif.

Ce sont les catégories de la « continuité du lien » (qui comprend les objets, les représentations symboliques de l'enfant et de la bureaucratie) et le soutien reçu à l'hôpital (présent dans la catégorie du soutien social).

Après la présentation de l'analyse des résultats, il est important de souligner comment l'utilisation d'une méthodologie mixte a été confirmée comme la plus utile et la mieux adaptée à l'étude des expériences et des conséquences de la perte périnatale.

La décision d'utiliser Alceste s'est avérée efficace et conforme aux objectifs de la recherche. Les catégories issues de l'analyse qualitative statistique étaient également les mêmes que celles mises en évidence par l'IPA.

## Discussion

Le deuil équivaut non seulement à la perte d'un être cher, mais également à la perte de son rôle, de son identité. Surmonter cette douleur signifie être capable de mener à bien un processus mental complexe conduisant à l'acceptation et à la transformation d'images mentales de soi et de l'objet perdu. Pour réussir à surmonter la perte, il est fondamental que la personne ait réalisé une structuration psychique complète et surmonté l'angoisse de séparation (inhérente au processus du développement), en tant qu'instrument intrapsychique de base pour le travail du deuil.

Les caractéristiques de la perte périnatale ne peuvent cependant pas être incluses dans un discours général, c'est une forme unique de chagrin.

Les parents qui ont perdu un enfant pendant la grossesse ou au cours de ses premiers mois de vie n'ont pas eu la possibilité de créer suffisamment de souvenirs et d'imprimer son souvenir au sein de la communauté (Alexandre & Gaugue, 2016).

En général, la perte d'un jeune enfant, en particulier pendant la grossesse, est souvent minimisée et, après un certain temps, socialement oubliée, contrairement à ce qui se passe chez le parent (Cacciatore, 2013; Sani et al., 2019).

Outre la perte de l'enfant lui-même et de l'objet d'amour, cela correspond également à une perte symbolique. La perte de l'enfant est la non réalisation de la meilleure partie de soi-même, une blessure narcissique infligée à son rôle et à l'identification des processus vécus pendant la grossesse (vis-à-vis de ses propres parents et avec soi-même dans son enfance) (Leon, 1986).

La perte périnatale est un événement traumatique (*deuil traumatogène*) dans lequel se mêlent de nombreux éléments : la menace de mort pour un être cher, la menace de mort pour soi-même (pour la femme qui porte l'enfant) et la séparation de l'objet d'amour (Bacqué, 2003).

La coïncidence de la mort avec la naissance est un lien impossible à concevoir. Ces événements sont les représentants de deux pôles opposés, deux événements indépendants qui nécessitent une réorganisation psychique au sein de la dimension diachronique (Ugo, 2012).

Selon Freud (1915/1976), l'individu nie le concept de mort : "*Personne au fond ne croit à sa propre mort ou, ce qui revient au même, dans l'inconscient chacun de nous est convaincu de son immortalité*" (Freud, 1976). Le sentiment de toute puissance et de contrôle est blessé après la perte périnatale, qui est considérée comme illogique et contre-nature.

La naissance rappelle des expériences et la pensée magique de pouvoir créer quelque chose à partir de rien. La mort, par contre, correspond à la dissolution de quelque chose qui a vécu, mais comment pouvons-nous alors intégrer la perte d'une personne qui n'a pas eu le temps nécessaire pour « exister » ? (Ugo, 2012).

Contrairement aux attentes sociales, qui tendent à sous-estimer la perte périnatale, ne reconnaissant souvent pas l'existence de l'enfant et la douleur du parent, ce décès peut déterminer une détresse psychologique.

Le travail de deuil que doit accomplir le parent est un processus psychique lent et progressif.

Un aspect important à considérer est le risque de pathologiser et de stigmatiser les réactions des parents suite à cette perte. Il est essentiel de se rappeler que tout le monde éprouve le deuil et le détachement d'une personne chère de manière totalement personnelle et avec des aspects et des réactions liés à la culture d'appartenance et aux variables contextuelles (Frances et al, 2010; Wakefield, 2013).

L'introduction d'une éventuelle maladie liée au deuil au sein du DSM 5 a donc conduit à un double effet: à une reconnaissance et plus grande attention et prise de conscience des enjeux liés à la perte et, d'autre part, à une généralisation et médicalisation de l'un des plus personnels aspects qui distinguent la personne.

Cela signifie que le risque est celui de mal diagnostiquer les réactions normales de deuil, entraînant des fréquences élevées de faux positifs et un traitement psychiatrique inapproprié (Lacasse et Cacciatore, 2014; Wakefield, 2013).

Nos études confirment les résultats de plusieurs études qui ont montré que les parents endeuillés ont des valeurs plus élevées que les autres populations (Thieleman & Cacciatore, 2014). En utilisant les résultats quantitatifs comme lignes directrices et comme matière à réflexion, il est donc important de se rappeler l'impossibilité de généraliser et d'étiqueter le processus de deuil des parents et leur besoin de maintenir un lien avec l'enfant comme pathologique.

La recherche longitudinale nous a permis de suivre l'évolution des parents au cours de ce processus. Particulièrement soulignée grâce à l'analyse qualitative, il a été possible d'observer les réactions des participants, qui ont expérimenté le fort désir d'être réunis avec l'enfant, le sentiment de culpabilité, la colère, la difficulté à accepter la mort et un sentiment d'apathie, tous caractéristiques typiquement d'un deuil compliqué, dont l'intensité a progressivement diminué, retrouvant un état mental fonctionnel et sans complications après plus de dix-huit mois suivant le décès de l'enfant.

La douleur, la colère et la culpabilité, ainsi que l'identification à l'enfant, peuvent donc agir comme une forme de protection, maintenant un lien avec l'enfant selon les besoins de l'ego du parent (Soubieux, 2013).

Bien qu'à un stade avancé du travail de deuil, au niveau quantitatif, le risque de développer des pathologies telles que le trouble de deuil compliqué subsistait plusieurs mois après la perte de l'enfant (T4).

Les résultats de l'ICG dans T5 ont montré que les parents avaient atteint le seuil de deuil sans complications exclusivement après plus d'un an et demi après la perte.

L'amélioration était également évidente pour le questionnaire GHQ-28, dont les sous-échelles (symptômes somatiques, anxiété et insomnie, dysfonctionnement social et dépression grave) correspondaient à d'autres troubles possibles que les parents en deuil pourraient développer (Christiansen et al., 2013; Prigerson et al., 1996).

De plus, contrairement à ce qui est exprimé dans la littérature (Bornstein & Clayton, 1972; Musaph, 1990), certaines réactions anniversaires n'ont pas été mises en évidence dans notre étude.

L'un des principaux objectifs de l'étude longitudinale de 18 mois était de déterminer si les difficultés et les symptômes des parents s'aggravaient vers le douzième mois du deuil. Les parents ont perçu plusieurs dates spécifiques comme plus compliquées, telles que les anniversaires mensuels, les anniversaires, les fêtes, etc. Au fil du temps, toutefois, ces difficultés ont également diminué. Les parents ont essayé de donner un sens et un but à ces dates considérées comme plus difficiles, en se rappelant et en commémorant l'enfant et en percevant non seulement la colère et la souffrance, mais également la sérénité et la gratitude.

Surmonter la perte d'un enfant nécessite donc un ensemble de tâches et d'aides fondamentales spécifiques, notamment un soutien social et professionnel.

La sidération psychique du parent peut être réduite grâce au travail thérapeutique, notamment en ce qui concerne la participation à des groupes de parole.

Comme démontré par nos recherches et la confirmation de la littérature (Bacqué & Merg, 2015; Cacciatore, 2007; Côté-Arsenault & Freije, 2004; Dyregrov et al., 2013; Stirtzinger & Robinson, 1989; Umphrey & Cacciatore, 2011), la participation et le partage de leurs expériences et la perception de la reconnaissance émotionnelle de la douleur des parents produisent des effets positifs sur l'acceptation de la perte et sur les conséquences psychologiques, en particulier au début.

Les parents considèrent que les groupes de parole sont essentiels. Malheureusement, il existe très peu de villes françaises où il existe des associations offrant ce service, ce qui confirme que les pertes périnatales sont encore trop peu reconnues et validées au niveau culturel et social.

En outre, entre 12 et 25% des pères ont participé à des groupes de parole, confirmant ainsi la littérature selon laquelle leur participation à des groupes de parole a augmenté pendant ces vingt dernières années (Bacqué & Merg, 2015).

Il est important de souligner que lorsque la chercheuse leur a demandé si elles souhaitaient participer à des groupes de parole, de nombreuses mères ont répondu par la déclaration suivante : « *Pas en personne, mais à celles de Facebook, oui* ». Les groupes sur les réseaux sociaux étaient donc associés et confondus avec les groupes thérapeutiques.

Beaucoup de femmes décrivent les groupes Facebook et divers forums comme des outils très avantageux, préférables aux groupes de parole : ceux sur Internet sont disponibles à toute heure, sans horaires ni espaces physiques empêchant la participation, accessibles sans obstacles.

Ils sont considérés comme un lieu où chacun peut communiquer, échanger des informations et partager ses expériences. Dans ces groupes il n'y a pas de jugements ou du sens de la pitié qui empêchent les participants de partager leur chagrin, même avec les plus proches. De plus, ces groupes garantissent l'anonymat, autre facteur que les parents considèrent comme fondamental.

Un autre élément en faveur du groupe de parole est le sens de l'altruisme qui se dégage du sentiment d'aider d'autres parents (Cacciatore, 2007). Cela a également été perçu en ce qui concerne les groupes disponibles sur les réseaux sociaux (comme pour Cindy et Susan), soulignant ainsi une autre association possible entre les groupes thérapeutiques et numériques.

L'un des processus clés dans le développement du chagrin est la capacité de mentalisation, un processus qui se développe et se maintient depuis l'enfance à travers les relations interpersonnelles. Il est donc possible que dans notre société, de plus en plus régies par la technologie, il existe un fantasme selon lequel les réseaux sociaux sont une forme d'aide, de communication et de relation permettant de mentaliser la situation difficile, en remplacement possible de l'introspection (Bortolotti, 2017).

Le phénomène de partage impulsif est souvent une réaction liée aux sentiments d'anxiété et de confusion perçus après la perte, mais il est essentiel de se rappeler qu'il n'y a pas de connaissance, de contrôle et de soutien professionnel derrière la communication en ligne. Notre étude a confirmé qu'une participation constante à ces sites Web pouvait influencer sur l'apparition de troubles psychopathologiques tels que l'anxiété et les maladies somatiques, la dépression et le deuil compliqué, favorisés par la rumination et l'isolement.

On peut en déduire qu'avec le temps, l'effet du partage social d'émotions en ligne peut ne pas être positif, mais néfaste pour la personne endeuillée.

Ainsi, alors que les groupes de parole ont montré un effet bénéfique initial, la possibilité de partager et de parler de la mort de l'enfant à tout moment, de l'anonymat et du manque de perception physique de l'autre ne sont que quelques-uns des nombreux aspects pouvant compromettre l'évolution psychologique (les seuls utilisateurs).

Selon la littérature, les personnes qui participent activement à ces groupes sont les femmes caucasiennes, les adultes de moins de 50 ans, ayant un niveau d'éducation élevé, un revenu décent et une connaissance minimale de l'utilisation d'Internet (Gold et al., 2016; Swartwood et al., 2011). Notre recherche a donc confirmé que ce sont principalement les femmes qui en font partie, mais de classes sociales différentes. Contrairement à une idée qui peut surgir spontanément, ce ne sont pas

seulement les femmes au chômage et celles qui ont plus de temps pour participer à ces groupes : la tranche d'âge, le statut, l'emploi et l'éducation sont très variés.

Une interprétation possible, confirmée par nos résultats, est que ceux/celles qui utilisent et cherchent le confort sur Internet ne perçoivent pas un soutien émotionnel adéquat dans leur monde "réel". Outre le manque d'aide professionnelle (comme la difficulté d'adhérer à des associations de thérapie de groupe), certaines mères perçoivent également un soutien social insatisfaisant, même à l'égard des personnes les plus proches (partenaires, amis, membres de la famille, etc.).

Il est donc essentiel de considérer l'isolement comme l'un des principaux problèmes de perte.

La reconnaissance sociale du chagrin, de la douleur et de l'existence de l'enfant, accompagnée d'un soutien constant dans le temps (donc présente non seulement dans les premiers jours ou mois suivant la perte) sont des aspects centraux et essentiels du travail du deuil.

Comparé à la psychothérapie, il est considéré comme fondamental par les parents qui ont demandé et ont continué à recevoir un tel soutien.

Les recherches suggèrent que seules les personnes à risque des complications psychiques peuvent réellement bénéficier d'un soutien professionnel et que toutes les personnes endeuillées n'ont pas besoin d'aide spécialisée (Endo et al., 2015; Gold et al., 2016; Schut & Stroebe, 2005; Steiner, 2006). Néanmoins, ceux qui déclarent ne pas avoir besoin de contacter un professionnel (en particulier les pères) pourraient mettre en place une résistance afin d'éviter leur propre douleur et les contenus inconscients de leur appareil psychique, confirmant ainsi les données quantitatives et qualitatives.

Le travail psychothérapeutique aide la personne à accéder à des souvenirs, à des expériences et à des sentiments refoulés ou supprimés, provoquant ainsi une anxiété fonctionnelle pour la personne (Marty, 2017). Selon Lecours (2005), « *Le travail de la thérapie porte alors essentiellement sur la recherche de contenus cachés : compléter les lacunes de la mémoire, défaire le travail de déguisement effectué par la censure, étoffer les scénarios préconscients par la traduction des manifestations de l'inconscient, agrandir le domaine du moi* » (Lecours, 2005).

Le soutien thérapeutique est donc confirmé comme essentiel pour accompagner les parents dans leur travail de deuil, compte tenu de la nécessité d'être suivi à la fois par un professionnel dans l'établissement d'une thérapie personnelle et par une thérapie de groupe.

De plus, compte-tenu spécifiquement des résultats obtenus en matière de soutien social, la perception du soutien de l'entourage primaire est une priorité, en particulier par rapport aux personnes considérées comme plus intimes (partenaires et membres de la famille).

Dix-huit mois après le début de notre étude, l'appui du partenaire et de la famille s'est révélé être un facteur de protection important des éventuels troubles pathologiques (anxiété, somatisation, dépression et dysfonctionnement social).



En outre, les parents déclarent que le soutien le plus important est celui du partenaire, la seule personne capable de comprendre la douleur et la souffrance liées à la perte de l'enfant.

De nombreux parents (surtout les mères) ont toutefois du mal à percevoir leur partenaire comme un soutien.

En ce qui concerne la distinction entre les mères et les pères, le sexe semble jouer un rôle fondamental dans l'expérience du deuil. Alors que l'identité est quelque chose que l'on possède (en raison de la corrélation entre représentations et expérience de soi), les rôles de genre se développent et dépendent également des relations interpersonnelles, des attentes sociales et du contexte historico-culturel. Cela correspond à la relation syntonique entre le style de comportement et l'identité biologique et sexuelle (Attorre, 2016).

La recherche scientifique montre que les femmes sont plus disponibles que les hommes pour demander un soutien psychologique et pour montrer un plus grand besoin de partage (Ware & Raval, 2007; Wijngaards-de Meij et al., 2008; Wing et al., 2001). En outre, selon Vance et ses collaborateurs, les mères ont tendance à exprimer leur détresse émotionnelle environ deux ou trois ans après la perte, contre huit mois pour les pères (Vance et al., 2002).

Ces données ont été également confirmées dans notre étude. Tout d'abord, plus de femmes que d'hommes ont consenti à participer à cette recherche. En outre, même si leur nombre est plus petit et non représentatif, parmi les 8 hommes, quelques-uns d'entre eux ont "essayé" de consulter un psychologue, principalement parce qu'ils y avaient été poussés par leur partenaire, arrivant à une participation masculine égale à 0 en T5.

En outre, comme le confirme la littérature (Ware & Raval, 2007), les hommes ressentent la pression sociale de devoir être forts et de respecter le stéréotype pour lequel leur chagrin est secondaire. Ils nient, projettent et « masquent » leur douleur pour soutenir et reconforter la mère considérée comme ayant davantage besoin d'attention et en difficulté.

De plus, les hommes peuvent utiliser les relations sexuelles comme un moyen de réconfort et d'intimité, alors que dans certains cas, les femmes ne sont pas encore prêtes à considérer le sexe comme un acte agréable ou intime, mais comme une trahison de l'enfant (Hunter et al., 2017).

Malgré l'influence remarquable du rôle imposé par les conventions sociales et les différents mécanismes de défense entre hommes et femmes, qui régulent et influencent l'expression du deuil et probablement la relation du couple, les résultats quantitatifs confirment que les deux parents en deuil ont les mêmes niveaux et risques de complications consécutives à la perte de l'enfant. Nous pouvons donc affirmer que l'attachement à l'enfant et les conséquences de sa perte sont les mêmes chez l'homme et chez la femme.

De plus, nos recherches ont montré que la perte d'un enfant ne détermine pas mécaniquement la séparation du couple. Sur les 29 couples, un seul s'est séparé après le décès de l'enfant. De nombreux participants ont déclaré craindre le divorce ou la séparation, mais aussi que l'acceptation progressive de la perte favorisait la compréhension de l'expression de douleur du partenaire et la perception d'un couple encore plus uni et solide.

En plus, outre le souvenir partagée avec le partenaire et les proches, il est important que le parent ait la possibilité de reconnaître l'enfant au niveau bureaucratique et de l'inscrire officiellement dans l'arbre généalogique.

Dans une société où la reconnaissance de l'enfant est déterminée par les impératifs liés à la médecine, ce sont les aspects biologiques et physiologiques de l'enfant à la naissance ou au décès qui conditionnent la perception sociale du deuil.

Dans cette perspective, le rôle et les besoins du rite apparaissent avec énergie, confirmant la spécificité et le caractère unique de la perte périnatale.

Tout d'abord, il est important de rappeler que, lors de la crémation de bébés mort-nés ou de fœtus, il est impossible d'obtenir les cendres car le calcium des os des enfants de moins d'un an n'est pas encore suffisamment consolidé. Dans les cimetières, il existe généralement un lieu commun où tous les enfants se souviennent et certains crématoriums fournissent un symbole, tel qu'un médaillon (Rocle, 2012).

C'est probablement pour ces raisons que le parent endeuillé ne semble pas reconnaître le cimetière comme lieu de repos de l'enfant et perçoit la nécessité de procéder à des pratiques commémoratives à l'intérieur de la maison.

La maison du parent est l'endroit où il n'y a pas de tabou et où les objets symboliques de l'enfant sont rassemblés et affichés dans un coin spécifique, comme une sorte de petit autel, où le parent peut se souvenir de l'enfant et effectuer des pratiques habituellement limitées à des cimetières ou des lieux de culte (comme allumer une bougie ou offrir des fleurs, des cadeaux, etc.).

Le parent perçoit le besoin de se souvenir de l'enfant au moins à la maison, par des actions et des éléments symboliques et, dans certains cas, d'éluder et de supprimer ce tabou en affirmant l'existence de l'enfant en publiant des photos, des vidéos et des commentaires sur les réseaux sociaux (comme les vidéos postées sur YouTube), ce qui réduit le sentiment d'aliénation (Sani et al, 2019).

En plus de confirmer la littérature, les participants présentent une plus grande sensibilité liée aux aspects spirituels (comme le contact avec la nature, la musique, etc.) et une relation conflictuelle initiale avec la foi (pour les croyants), qui parviennent à reconnaître leur croyance comme un soutien (Arnold & Buschman Gemma, 2008; Greeff et al., 2011; Nuzum et al., 2017).

Il est également intéressant de noter que, dans un État typiquement laïc comme la France, certains aspects liés à la religion ont pris une connotation culturelle plutôt que religieuse, tels que l'association de l'enfant à la figure de l'ange, du paradis et dans certains cas, demander un baptême civil pour un enfant décédé (non reconnu et autorisé sur le plan juridique et social).

En général, tous les formes de soutien - professionnel, social et religieux - sont essentielles pour accompagner le parent. Après des situations difficiles telles que la perte d'un enfant, la prise de décision est en effet l'une des tâches les plus compliquées.

Les parents sont confrontés à la réalisation des fantasmes et se demandent si, à un niveau inconscient, l'ambivalence présente pendant la grossesse a prévalu et a induit de véritables forces destructrices.

Le parent perçoit un sentiment de culpabilité et d'échec face à l'impossibilité de sauver l'enfant et de finaliser l'acte reproductif, destiné à être biologique, mécanique et naturel, déterminant l'image d'un soi destructeur et non fonctionnel (notamment chez la mère). Cela est particulièrement vrai si c'était le premier enfant.

Dans les cas les plus difficiles, le parent qui a des difficultés à concevoir peut développer des pensées obsessionnelles, percevant le besoin viscéral d'avoir un nouvel enfant, qui peut assumer la fonction de réparation de la blessure narcissique infligée après la perte.

De plus, l'enfant suivant est à la fois source de joie et de frustration, projetant inconsciemment les fantasmes et les expériences du précédent sur la nouvelle grossesse.

L'événement traumatisant amène le parent à vivre dans un état d'anxiété anticipée et dans la nécessité de passer les dates du diagnostic et de la mort, et de rencontrer l'enfant, apaisant ses peurs uniquement par des tests de réalité, touchant un enfant en bonne santé.

Les inquiétudes et les fantasmes de revivre une nouvelle perte pourraient influencer le manque d'investissement émotionnel du parent vers le nouvel enfant. Dans de nombreux cas, ce manque d'investissement est une forme claire de déni, une défense d'un Moi trop faible pour faire face à un autre événement douloureux.

Dans les cas les plus graves, le parent peut développer le syndrome de l'enfant de remplacement ou de l'enfant vulnérable, caractérisé par une hyper protection (Burden et al., 2016; Cacciatore, 2013; Franche & Bulow, 1999; Gaudet, et al., 2010; Hunter et al., 2017; O'Leary, 2004). En outre, avoir un bébé de moins d'un an impliquerait un niveau plus élevé d'anxiété, de dépression et d'TSPT, ainsi que le prolongement des symptômes jusqu'à la première année de la vie d'un bébé en bonne santé (Hughes et al., 1999; Hunter et al., 2017; Rousseau, 1999; Turton et al., 2001; Zeanah, 1989) .

Contrairement à ces observations, les résultats de notre étude ont plutôt montré que la grossesse suivante n'affectait pas les risques psychopathologiques possibles du parent ou par rapport à l'enfant

suivant (y compris le syndrome du remplacement et de l'enfant vulnérable), malgré une conception à partir du six mois après la perte.

Par rapport aux causes de décès, au fil du temps il y a eu une nette progression même pour ceux qui ne connaissaient pas ses raisons (soit 15,6% selon le tableau 37). Cela signifie que, contrairement à la littérature, connaître les causes du décès n'affectait pas de manière significative un risque mineur de développer un trouble du deuil compliqué (Keese et al., 2008; Lichtenthal et al., 2013; Song et al., 2010).

D'autres facteurs, psychiques et externes, ont probablement influencé la diminution des valeurs et le travail du deuil des parents, leur permettant ainsi de donner un sens à la perte.

De nombreux participants ont décidé de pratiquer une interruption médicale de grossesse (IMG), une sorte d'euthanasie fœtale qui amène le parent à considérer sa douleur comme secondaire. Paradoxalement, le parent choisit de protéger l'enfant en le privant de la vie. Pour beaucoup de parents, en particulier pour les mères, le sentiment de culpabilité et le regret sont déchirants.

Il est également intéressant de noter que le choix du parent d'effectuer une IMG influence la décision du prénom. De nombreux participants ont attribué au prénom de l'enfant une autre connotation symbolique liée à son destin. Les prénoms ont été choisis sur la base de leur signification, en tant qu'image de force, de courage ou liée à l'image spirituelle de l'enfant au paradis.

En outre, en comparant les personnes ayant perdu un enfant pendant la grossesse à celles ayant perdu un enfant en vie, notre étude confirme la théorie selon laquelle les conséquences des parents qui ont connu l'enfant (même si elles sont minoritaires) sont plus profondes (telles que le trouble de deuil compliqués et de dépression) (Wijngaards-de Meij et al., 2005).

La grossesse correspond à une période au cours de laquelle l'investissement affectif du parent et la création de l'enfant imaginaire sont activés. Sa mort (qu'il s'agisse d'un avortement ou d'une IMG) est donc une véritable perte d'un objet investi avec des attentes et des identifications parentales d'une manière fantasmatique et symbolique.

Le moment de la naissance est plutôt une interruption de cet investissement et l'introduction dans la sphère réelle. Les fantasmes et représentations nourris pendant la grossesse sont modifiés, activés par la rencontre avec l'enfant réel, dont le parent commence à mémoriser les caractéristiques, les mouvements, l'odeur, etc.

La mort d'un enfant qui a vécu détermine donc non seulement la perte de l'objet imaginaire, mais aussi de l'objet réel. De plus, l'aspect de la vie quotidienne entre également en ligne de compte : la mère prend soin de l'enfant tous les jours, en répondant à ses besoins (selon la préoccupation maternelle principale de Winnicott) et en augmentant le degré d'investissement, d'expériences et de souvenirs réels avec lui.

Après un décès survenu trop tôt, dans lequel les souvenirs sont gravés dans la mémoire des parents, l'objet symbolique prend une connotation encore plus profonde que les autres décès. C'est le témoignage de l'existence de l'enfant.

Outre les photos et les objets ayant appartenu à l'enfant ou imaginés pour lui, de nombreux parents ont décidé de se faire tatouer l'empreinte, la date de naissance et de décès, etc.

Cela correspond à une nouvelle pratique commémorative très fréquente dans notre société et également mise en évidence lors de notre étude.

Dans un contexte culturel dans lequel le tatouage est de plus en plus accepté et lié à des raisons esthétiques, le tatouage pour un enfant est un retour ancestral, une métaphore corporelle et éternelle, dont le symbole réside dans le sens et l'emplacement, imprimé sur le corps du parent.

Enfin, le rôle et la fonction prioritaires des professionnels de l'hôpital sont confirmés. Le rôle paternel, perçu comme faisant autorité, et le rôle maternel, perçu comme accueillant, sont projetés sur la structure de l'hôpital.

Les parents ont besoin de soutien constant afin de les accompagner émotionnellement, de fournir toutes les informations et explications détaillées médicales et bureaucratiques. Les mécanismes de défense mis en place par les professionnels sont souvent perçus comme des attitudes lointaines et dévalorisantes à l'égard des demandes des parents. Cependant, aucune critique n'a été émise quant à la manière dont les professionnels ont géré la décision des parents de voir ou de ne pas voir l'enfant. Compte-tenu également de la possibilité de prendre des photos et d'obtenir la boîte des souvenirs, il est clair que les hôpitaux français sont sensibilisés à la perte périnatale, une prise de conscience qui a commencé mais qui n'est toujours pas suffisante.

## **Conclusions et perspectives futures**

Notre étude a voulu mettre en évidence les conséquences psychologiques possibles du parent endeuillé et l'efficacité du soutien thérapeutique.

Notre étude était une recherche longitudinale. 29 parents français, 21 femmes et 8 hommes ont été réunis cinq fois au total, répartis sur dix-huit mois.

Le temps écoulé entre la perte et la première réunion n'est pas le même pour tout le monde. La durée minimale était de 22 jours, tandis que la durée maximale était d'environ dix mois.

En particulier, notre objectif était d'étudier le risque de développer un trouble de deuil compliqué après la perte d'un enfant pendant la période périnatale.

En tant que thérapeute, nous voulions analyser l'efficacité possible donnée par la thérapie personnelle et la participation à des groupes de parole. Une troisième variable ajoutée au cours de la recherche était le rôle des groupes en ligne dédiés à la perte périnatale.

Nous avons choisi d'analyser cette participation après avoir compris la confusion au sujet de l'association des parents : ils croyaient que ces groupes avaient la même fonction que les groupes thérapeutiques.

Notre méthodologie était mixte. Chaque réunion a été marquée par un entretien semi-directif et l'administration de l'Inventory of Complicated Grief (Prigerson et al, 1995) et du General Health Questionnaire-28 (Goldberg, 1978). Au niveau qualitatif, les entretiens ont été analysés par le programme statistique français Alceste et l'Interpretative Phenomenological Analysis (Smith, 1996). Grâce à nos recherches, nous avons pu confirmer que la perte d'un enfant pendant la période périnatale est un événement difficile et risqué.

Comme indiqué par Leon (1996) dans son modèle multidimensionnel, à la suite d'une perte périnatale, les axes de développement, pulsionnels, relationnels et narcissiques du parent sont touchés et, dans certains cas, endommagés (Leon, 1996; Shulz et al., 2015). La perte de l'enfant réel et imaginaire, le rôle de parent et la blessure narcissique du moi ont donc invalidé le soi de ce dernier. Le travail de deuil périnatal a donc pris plusieurs mois pour se réaliser pleinement.

Seulement un an et demi après la perte, les parents ont atteint ce que l'on appelle le seuil de deuil normal ou non compliqué, résultat confirmé par les analyses qualitatives et quantitatives.

Nos données ont confirmé les difficultés prolongées des parents et la détresse psychologique présentes dans les mois suivants après la perte. Dans le même temps, l'analyse qualitative a souligné l'évolution et le fonctionnement psychique du travail de deuil.

En outre, bien que ce ne soit pas le trouble principal sur lequel nous voulions enquêter, aucun élément n'a permis de diagnostiquer un trouble de stress post-traumatique.

De plus, même si elles ne sont pas soulignées en termes quantitatifs mais uniquement en ce qui concerne les valeurs qualitatives, des réactions de deuil et des difficultés peuvent réapparaître à des occasions spéciales, telles que l'anniversaire de naissance ou de décès, les vacances, etc.

La douleur des parents, des mères et des pères est un aspect important à souligner. Nous ne pouvons évidemment pas quantifier le chagrin, mais il est possible de souligner comment les aspects affectif sont les mêmes (Bennett et al., 2005; Schaap et al., 1997; Turton et al., 2006). Ce qui est différent sont leurs manifestations. En fait, le rôle social et les consignes culturelles du genre influent sur l'expression du deuil : les hommes ont tendance à ne pas verbaliser leur tristesse et leurs besoins, les niant et les projetant sur les femmes (Stroebe et al., 2013) ; les femmes ont probablement un besoin plus grand, mais aussi moins de résistance, à verbaliser leur tristesse et leur souffrance, cherchant plus fréquemment une aide professionnelle et sociale (Cacciatore, 2013; Schaap et al., 1997; Zeanah, 1989) .

Sans surprise, 65% des participants sont des mères, les mêmes qui se sont rendues disponibles pour participer à l'étude après avoir lu l'avis de recrutement publié sur les groupes de réseaux sociaux, auxquels les femmes participent plus assidûment et plus activement.

Ces groupes sont une réponse au manque de reconnaissance sociale de la perte périnatale. Les parents se sentent souvent abandonnés et isolés, à la fois émotionnellement et concrètement (par exemple, en ce qui concerne les informations médicales et / ou bureaucratiques et juridiques).

Par conséquent, si ces groupes jouent le rôle classique des réseaux sociaux, basés sur l'échange d'informations et de contacts, ils ne correspondent pas en même temps à un soutien affectif et ne doivent pas être confondus avec une aide professionnelle.

Notre étude a montré que penser que les groupes en ligne et les groupes thérapeutiques sont équivalents est une illusion, un risque de développer des maladies liées au deuil, telles que le deuil compliqué, la dépression, l'anxiété et les troubles somatiques. De plus, ce résultat confirme que le fait de parler et d'exprimer ses sentiments ne signifie pas seulement faciliter l'expérience du deuil (Stroebe et al., 2005), surtout dans un contexte incontrôlé qui risque de nourrir la rumination et de maintenir le parent dans la phase aiguë du deuil.

En ce qui concerne le soutien psychologique, la possibilité de participer à des groupes de parole semblerait donc utile. Rencontrer et comparer des parents endeuillés dans un cadre professionnel et thérapeutique est très important, en particulier au début.

Par rapport à la thérapie personnelle, ce n'est que par rapport à la dernière réunion et donc 18 mois après le début de la recherche que des données significatives ont émergé, mettant en lumière le travail psychique et le manque de déni de ceux qui ont demandé ce soutien.

Les résultats pourraient donc confirmer que la psychothérapie ne peut réellement être utile que pour ceux qui en ressentent le besoin. Compte tenu également des expériences exprimées par les parents lors des entretiens, la singularité qui caractérise chaque chagrin doit être très claire pour les thérapeutes.

Ils doivent accompagner les parents en tenant compte des besoins, des difficultés spécifiques et des motivations qui conduisent la personne à demander le soutien et le respect de leurs choix et leur culture (Zech et al., 2010).

En ce qui concerne le soutien émotionnel, la proximité et l'aide du partenaire et de la famille sont très importantes. Se souvenir et commémorer l'enfant malgré le temps qui passe et les grossesses ultérieures est fondamental.

Il est évident que cette reconnaissance ne concerne pas seulement l'entourage le plus intime mais aussi le plus étendu. Les parents doivent en effet avoir la possibilité d'exprimer leur chagrin et d'obtenir des informations sur tous les aspects de la perte.

Il est donc nécessaire de souligner la nécessité de sensibiliser la société à cette question, en commençant par l'administration et tous les professionnels traitant des pertes périnatales (médecins, sages-femmes et infirmières, y compris des psychologues).

Il serait utile de mener une formation professionnelle spécifique sur ce sujet, afin de comprendre l'expérience des parents, les risques, leurs besoins et comment les soutenir.

Nous avons vu que les groupes de parole sont fondamentaux. Malheureusement, les associations professionnelles offrant cette opportunité ne sont pas toujours présentes. Il pourrait donc être utile de concentrer les énergies et les ressources pour essayer de créer ou d'étendre ces associations sur tout le territoire et pas seulement dans les grandes villes.

De plus, en ce qui concerne notre méthodologie, nous pouvons également conclure que l'utilisation d'une méthodologie mixte a été utile pour atteindre nos objectifs et mettre pleinement en évidence le fonctionnement psychique du parent endeuillé.

Nos résultats ont également confirmé la validité de l'utilisation d'Alceste associée à l'Interpretative Phenomenological Analysis. Alceste a donc démontré sa validité en ce qui concerne l'étude des entretiens semi-directs sur la perte périnatale.



## **Limites**

Cette recherche a également montré certaines limites. Notre concentration a surtout porté sur certains troubles, tels que le deuil compliqué. Des recherches éventuelles pourraient donc également envisager d'autres problèmes pouvant survenir après une perte périnatale, tels que le syndrome de stress post-traumatique.

Une autre limitation à souligner est le rôle d'une seule chercheuse dans cette étude. Pour les travaux ultérieurs, il serait utile d'avoir la possibilité d'avoir un co-chercheur pour obtenir une plus grande validité à côté des résultats qualitatifs.

De plus, il n'a pas été possible de créer un groupe homogène permettant une comparaison réelle, en particulier par rapport au sexe des participants (dont un tiers environ sont des femmes), au moment du décès de l'enfant (que ce soit pendant la grossesse ou après la naissance) et à ceux qui ont demandé un soutien thérapeutique.

Ces limitations étaient dues à la difficulté initiale de pouvoir recruter le nombre de participants sur une période limitée.

Il est important de souligner que la plupart des participants ont été recrutés dans des groupes de réseaux sociaux sur la perte périnatale. Comme le montrent également nos données, la plupart des utilisateurs sont des femmes et des parents qui ont perdu un enfant pendant leur grossesse (ou ce sont eux qui ont montré une plus grande disponibilité). Il est donc possible d'interpréter ces limitations comme un besoin plus grand pour ceux qui présentent ces caractéristiques en voulant exprimer leur douleur et rechercher un soutien.

## **Perspectives**

Il est important de continuer à mener des études sur la perte périnatale pour pouvoir connaître les conséquences psychologiques chez les parents et comment les soutenir.

En particulier, des recherches longitudinales pourraient être suggérées pour mettre en évidence comorbidités spécifiques et possibles suite à une perte traumatique, telles que le trouble de stress post-traumatique.

En outre, les conséquences éventuelles pourraient être évaluées pour les enfants vivants, les grands-parents et l'enfant suivant.

Il est également important de continuer à analyser le rôle d'Internet dans une telle perte et les conséquences possibles qu'il peut déterminer.

De plus, la pratique de séances de psychothérapie avec Skype se répand actuellement. Celles-ci ont commencé à être modélisées en fonction des besoins et des restrictions des patients, par exemple pour

ceux qui vivent à l'étranger ou ne peuvent pas se déplacer pour des raisons médicales, ou pour ceux qui souffrent d'agoraphobie, etc. (Bouchard et al., 2004; Cipolletta, 2015; Edirippulige et al., 2013; Freeman et al., 2013). Suivant cet exemple, certaines associations ont commencé à promouvoir les réunions de groupes de parole via Skype (ecoute-psy.com, 2016; «Groupes de soutien en ligne - Conscient NI», 2019 ).

Leur efficacité n'a pas encore été démontrée, mais cela pourrait constituer un sujet intéressant pour les recherches futures. Il est nécessaire de trouver une solution pour les personnes ayant des limitations géographiques et leur permettre de rejoindre l'association de groupes de parole s'ils en ressentent le besoin.

En outre, comme indiqué précédemment, nos recherches ont démontré la validité et l'efficacité de la comparaison entre les catégories issues de l'IPA et du programme statistique français Alceste.

Il pourrait donc être utile, à des fins méthodologiques, de continuer à analyser cette association et, éventuellement, d'utiliser Alceste également pour des études internationales.

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## List of acronyms and abbreviations

### **Acronyms and abbreviations**

ART

CG

GHQ-28

ICG

IMG

IPA

IT Groups

LTP

PMA

PTSD

T1

T2

T3

T4

T5

### **Full definitions**

Assisted Reproductive Technology

Complicated Grief disorder

General Health Questionnaire - 28

Inventory Complicated Grief, questionnaire

Interruption Medical de Grossesse

Interpretative Phenomenological Analysis

Online groups

Late Termination of Pregnancy

Procréation Médicalement Assistée

Post-Traumatic Stress Disorder

First interview

Second interview, three months after the first meeting

Third interview, six months after the first meeting

Fourth interview, twelve months after the first meeting

Fifth interview, eighteen months after the first meeting

## **Introduction**

What I am going to present to you is the result of my three-year doctoral project.

This study concerns the perinatal loss, that is the decease of a child during pregnancy up to the first period of life (Chan, 2011; Verdon et al., 2009).

In our society, perinatal loss is still a taboo and at the same time a contradiction, because the number of perinatal deaths remains high despite new technologies and medical discoveries (Ezechi & Odberg-Petterson, 2012; Lawn et al., 2016).

Furthermore, the psychological consequences can be serious and lasting. Although rare, parents can develop depression, anxiety, complicated grief and Post-Traumatic Stress Disorder (Bennett et al., 2008; Hazzard et al., 1992; Murphy et al., 2014; Scheidt et al., 2012).

They may have a lower state of well-being and major health problems, particularly at cardiovascular level (Lannen et al., 2008) and an increased risk of anxio-depressive disorders during the next pregnancy (Blackmore et al., 2011).

In particular, women are at greater risk of psychiatric diseases and hospitalizations, even thirty-five years after the loss (Harper & Thompson, 2011).

Therefore, our study aims to evaluate the risk of complicated grief disorder and the contribution of psychological support (professional, or personal and group, and online).

Besides thus focusing on these objectives, the innovation of the following study is the use of a mixed method, qualitative and quantitative, as well as longitudinal.

29 bereaved French parents (21 women and 8 men, including 8 couples) were met for a total of five meetings distributed over one year and half after loss. After the initial meeting the participants were met after three months, six months, one year and eighteen months (including anniversary reactions). Each meeting, which took place in person or on Skype, was characterized by the semi-directive interview and subsequent administration of two questionnaires: The Inventory of Complicated Grief (ICG) and the General Health Questionnaire-28 (GHQ-28).

The two questionnaires were analyzed through the statistical program Jamovi, while the interviews were evaluated through the Interpretative Phenomenological Analysis and the French qualitative statistical program Alceste.

The objective was therefore to illustrate the difficulties of bereaved parents, how they are perceived by the participants, and to show how the two approaches can be associated with each other.

The path that led me to this topic was not entirely linear.

After studying Clinical Psychology at the Sapienza University in Rome, I subsequently became interested in Post-Traumatic Stress Disorder (PTSD).

After completing my studies, I obtained a second level master's degree in Emergency Psychology and Psychotraumatology at the Lumsa University, Rome.

Over the years, in addition to having fueled my clinical interest in PTSD, I also started getting more and more interested in the world of research. For this reason, I subsequently moved to Amsterdam, where I worked for almost one year as a research assistant at the Vrije University, collaborating on various projects always focused on PTSD.

Once this period was over, I was sure of my deep interest in scientific research. In particular, during those months, I had already approached and focused on the issue of grief, reading and informing myself on the most current research, and then going on to the theme of infantile and perinatal loss. A subject that was new for me, which I had never met during my academic studies, but which had aroused in me a deep curiosity and interest.

For this reason, I got in touch with the one who would later become my supervisor, Prof. Marie-Frédérique Bacqué, Professor and Director of the SuLiSom Research Unit of the University of Strasbourg and expert in psychotraumatology and thanatology.

After writing to Prof. Bacqué and introducing myself along with my interest in starting a collaboration, she contacted me a few months later saying that a vacancy was available at the University of Strasbourg. A selection for a student to carry out a doctoral project on perinatal loss was in progress. The object of interest, purpose and methodology of the research were already defined and funded by a grant.

Since the beginning, I was honored to have had the opportunity to follow this project.

This was hard, yet very satisfying work.

We hope this research can make an important contribution to the study of perinatal loss and the most effective methods of support.

The study can be useful for future parents, for their feeling of isolation, to realize that their process of grief is not unique and to become aware of the possible effects that can be generated by different supports.

In addition, this project can help sensitize professionals working on this theme (psychology, medicine, midwifery, etc.) and the micro and macro social contexts surrounding bereaved parents about the long-term consequences that may result from this loss.

Furthermore, it is important to remind parents that their feelings and reactions are completely normal: there is no right or wrong way to live through grief and pain, they are not alone and should not be.



The whole of the work that will be presented below is divided and composed of five different parts:

- Part A: the first part concerns the presentation of the theoretical framework of grief and in particular of perinatal loss, emphasizing the possible psychopathological diagnosis of parents, risk and protection factors and reactions of family members (including grandparents, children born before and after loss).
- Part B: From part B the clinical study will be presented in detail. It defines the objectives and the research methodology, as well as the general data of the participants.
- Part C: in this section, the quantitative and qualitative results collected are presented.
- Part D: this corresponds to the examinations of results, where qualitative and quantitative data are discussed and compared.
- Part E: the last part concerns the conclusions. The results are discussed with respect to the initial objectives and hypotheses, as well as a clarification of the limitations and possible prospects for future research.

## **PART A. THEORETICAL PART**

Life is a dynamic combination of situations and relationships that condition our existence, our being.

In this continuous movement we find loss, which accompanies and influences our life since birth.

According to Stroebe and collaborators (2001), grief is defined as "a primarily affective reaction due to the loss of a loved one through death which incorporates a diverse set of psychological and physical manifestations" (Bacchetta, 2014; Stroebe et al., 2001).

Everyone lives the grief and pain caused by loss in an individual and personal way. The duration and intensity of symptoms and the consequences are neither determined nor predefined. Grief is influenced by a wide range of personal, relational and social reactions and situations.

Every loss, every separation is unique and different. Starting from a general introduction on grief, the goal of this theoretical part is to summarize the main concepts and research that surround the central theme of this study.

The seven chapters start from more general aspects of grief, to then present the various characteristics of perinatal loss: definitions, diagnostic criteria, the various risks and characteristics of family members, the social and legal, historical and modern recognition of a such traumatic event.

The death of a child in the perinatal period is in fact an important loss and in some cases a risk to the health of the parent.

More and more research in recent years is taking an interest in this issue, as a response to a parental need that has long been ignored, but of which many gaps still have to be filled.

It is therefore hoped that growing research will succeed in making professionals better understand the mechanisms that derive from this loss and be able to accompany parents in the evolution of their mourning, still too little recognized.

## Chapter 1: Presentation of mourning

This first chapter aims to introduce the general concept of grief, tracing a theoretical and bibliographical framework.

Through an initial description of the etymological meaning of the term "grief", and its expressions and nuances in English, French and Italian, we proceed to the presentation of "historical" theories about the subject.

Starting from Freud, the theories about the grief are introduced and summarized, following a chronology of the first main models that then determined and influenced future analyses.

### 1.1 Etymological introduction

As expressed previously, grief is a present and determining component of human life.

The term has ancient origins, deriving from Old French (from *grever*, 'to burden'), and understood as an "intense sorrow, especially caused by someone's death" (Oxford, 2013).

In English there are also several words that take on different nuances, such as: *grieve*, which indicates to "feel intense sorrow" (from latin, *gravare*, *gravis*, 'heavy, grave') and the term *grave*, which has the same root and which means both the tomb, the sepulcher, and premature death (*premature grave*). The term *bereavement* refers to "the action or condition of being bereaved", while *mourning* is "the expression of sorrow for someone's death" and the "black clothes worn as an expression of sorrow when someone dies" (Oxford, 2013).

It is interesting to note the quantity, variety and nuances of the terms that exist to indicate the grief and feelings around death. In Italian, for example, the word "lutto" derives from the latin (*lūctus -us*, *lugere*, to cry, to be in mourning), and is understood as the consequence of "cordoglio" (*cordolium*, to feel pain). It represents the feeling of profound sorrow felt for the death of a loved one, the set of customs that are observed, for a more or less definite period, and every external sign with which grief is manifested, such as the way of dressing (the linguistic equivalent of *portare il lutto*, "bring the grief"): the black clothes; the black band around the arm; the black button in the buttonhole, etc. (*Treccani 2014 dizionario della lingua italiana*, 2013).

In French the word "deuil" is used, which comes from the latin (*dolus*, "douleur") and from the ancient French (*duel*, "douleur", "affliction due to the death of someone").

The meaning between the two roman words *deuil* and *lutto* is not so distant. Even the French term refers to the loss of a person, and to the pain, the ways and timing with which this is externalized (Ray-Debove & Rey, 2000).

Different from the Italian, the *deuil* refers to the funeral procession that accompanies the deceased's body and his burial. In addition, in French there is a verb used to express grief: *endeuiller*, that is, "to plunge oneself into mourning, to be full of pain" (Ray-Debove & Rey, 2000). From this, its past participle *endeuillé* is used as an adjective to express bereaved people, a term that can be translated as the English word "bereavement," but for which has no equivalent or possible literal translation in Italian.

By the presentation of the terms and its etymological origins, it is clear how grief assumes an individual and social meaning. The different linguistic nuances of grief of the three languages presented here (Italian as mother tongue and French and English as secondary and adoptive languages) thus underline the different cultural needs.

It seems that the French (even with less vocabulary options) and the English present more connotations to express grief. In Italian the terms and their meaning are more limited, specifically describing the social impositions and the approximate emotional implications. Three different cultures compared that reflect their identity through the linguistic use of the words used. Three different societies, for which pain and feelings experienced after a loss assume a specific connotation, community or privacy.

In all three languages, different words are used to express the circumstances of grief and, in particular, the subjective and cultural implications that follow the loss, thus satisfying the linguistic needs of communication, emotional and social expression (Lombardo et al., 2014).

The culture of each country is reflected in its language, determining linguistic meanings and social interpretations, delimiting conventions and attitudes in the face of loss.

## 1.2 Thanatological approach

Since the early years of the last century, psychology and psychoanalysis began to establish and distinguish themselves from other disciplines, to analyze and theorize the main psychical aspects of the individual, including grief.

The cited authors reflect a chronological path where their main analyses about loss are evoked and summarized. The theories presented have as their main theme the recognition of the work of mourning, understood as the psychic work of the individual following a loss. This process triggers a wide range of reactions and consequences that can determine pathological outcomes.

Their ideas and reflections of these authors are the archetypes and basic pillars of grief theories, from which research and future studies have emerged and developed.

Therefore, presenting a complete theoretical and bibliographic framework is fundamental to subsequently introduce the central subject of my research, namely the perinatal loss.

### 1.2.1. Sigmund Freud

At the historical and literary level, it was around 1915 that Sigmund Freud began his psychological studies on mourning, determining and defining the key concepts regarding the loss of a loved one, of love's object and of ego's involvement.

For the conception of such reflections, the private and personal experiences that he lived in that period were probably influential. Two of his sons left for the front, and isolated and far from some of his greatest friends (like Abraham and Ferenczi) and living serious economic hardship, Freud focused on the composition of books and essays of the *Metapsychology* collection. In this state of mind, probably restless and worried, in just eleven days Freud completed the essay "Mourning and melancholia" which for logistical reasons, also linked to the war, was then published two years later, in 1917 (Fidanza, 1990; Freud, 1917).

In it Freud deals with the theme of mourning, of loss, not only of the beloved person, but of everything to which the person feels emotionally linked and connected, defining mourning as "the reaction to the loss of a loved person, or to the loss of some abstraction which has taken the place of one, such as one's country, liberty, an ideal, and so on" (Freud, 1917).

The decisive and basic concept of the work is the contrast between mourning and melancholy. Freud introduced and developed the idea of identification with the lost object of love, articulating the narcissistic traits and ambivalent relationship of the bereaved person.

In his analysis, he explicitly links to the essay by his colleague and friend Karl Abraham, "Notes on the psycho-analytical investigation and treatment of manic-depressive insanity and allied conditions" of 1911. After reading a copy of his essay, Freud and Abraham also begin a series of epistolary exchanges: Abraham asserts a parallelism between the anal libidinal phase, typical of the obsessive neurosis, and the oral one, typical of melancholy; Freud, agreeing with his reflections, "goes on to caution Abraham not to foreground sadism and anal eroticism in explaining melancholia, but to focus instead on the dynamic, topological, and economic dimensions which alone illuminate the mechanism that engenders and explains the affection" (Rickels, 1988).

According to Freud, "mourning has a quite specific physical task to perform: its function is to detach the survivors' memories and hopes from the dead ". It activates what he defines as the "trauerarbeit" (work of mourning), that is: the withdrawal of the whole libido from "what is connected with the

object of love", the painful task that the person in mourning must perform (Freud, 1917; Freud, 1990; Stroebe & Schut, 1999).

This is a process that requires time and acceptance of the examination of reality, thus being aware of the loss suffered, whether it is a person or any emotional and affective bond (Bonanno & Kaltman, 1999).

It is therefore an essential process of mourning, in which the person activates an intrarelatational and dynamic connection between the ego and the external world. After searching and remembering the lost object and all the aspects connected to it and having felt anger, sadness and guilt, the libido is in fact ready to separate from the object of love and return to itself (introjection) (Frost & Condon, 1996; Lombardo et al., 2014; Wayment & Vierthaler, 2002).

Subsequently, "once the work of mourning has been completed, the ego becomes free and uninhibited again". The last stage corresponds in fact to the completion of the work of mourning and therefore to the presence of an ego ready to detach and to address to a new object, reshaping the previous emotional bond with the deceased (Freud, 1917; O'Leary, 2004; Rando, 1983).

The purpose of the author is to compare and differentiate normal mourning from pathological or melancholic grief, or what we might define today with the term depression. Both present discomfort, disinterest in the outside world, inability to love, inhibition in carrying out any activity, feeling disdain and lack of self-esteem. What characterizes and distinguishes melancholy from normal mourning is the narcissistic relationship with the object, the total impoverishment of the ego, the refusal to feed, insomnia and total repulsion to life (Freud, 1917).

In melancholy, the libido has not managed to reinvest itself and it is brought back into the ego, thus establishing identification with the object and simultaneously losing not only the object but "a part of itself". If "in mourning is the world which has become poor and empty, in melancholy is the ego itself", to which his contempt, aggression, responsibility and guilt are addressed (Freud, 1917; Lombardo et al., 2014; Wayment & Vierthaler, 2002).

The pathological mourning is unconscious, unaware: the person knows he has lost something but he is not able to decipher what he has lost. Unable to integrate the loss of the object and the libido, the bereaved person incorporates and identifies himself with the lost object, making the ego part of the object itself. The same self-criticism and self-defense destined to the outside, to the object, are - through the identification process - addressed to himself, thus activating a vortex of disdain, anger, poverty and emotional immobility typical of the melancholic one.

Freud and Abraham were therefore the firsts to consider mourning in a psychoanalytic perspective and in particular to try to grasp and theorize its dysfunctional aspect, distinguishing it from normal or uncomplicated mourning (Bacchetta, 2014).

Freud's innovation was to succeed in describing and deciphering in a clear and linear way the reaction that follows the mourning. For him, the bereaved person should indeed keep to oneself, think about the lost person and the shared moments, and then gather strength and reopen oneself to the world, according to a subjective timing.

The analyses and critiques of this essential work have led numerous authors to investigate all the main and secondary aspects of grief, developing their theories, concepts and circumscribing the possible consequences and timing.

### 1.2.2 Helen Deutsch

Helen Deutsch, an Austrian psychoanalyst and student of Freud, concentrated most of her studies on the psychoanalytic aspects related to women and to female psychosexual development.

In a marginal but brilliant way, she presented in some articles the theme of grief (Deutsch, 2005; Deutsch, 2007).

Starting from the reflections on childhood reactions and the presentation of clinical cases, the author departed from the analysis on mourning and neurotic reactions expressed by contemporary psychoanalytic doctrines.

Through her theories, Deutsch has hypothesized and explained the possible temporal and causal connotations of grief in the course of life, from infancy to adulthood, and its consequences and psychopathological manifestations (Bacchetta, 2014).

In fact, she believed that the lack of emotional and sentimental expression that could emerge in children and adults following the death of a loved one is the result of childish anguish, which is the child's reaction to the separation from the caregiver.

In childhood this anguish emerges when the child's ego is not sufficiently developed or is not able to withstand the tension of loss, thus determining the activation of self-protective defenses, such as lack of affection.

Defences' strength and the intensity of fulfillment depend on the relationship with the deceased (as in the case of a conflictual relationship), on the degree of ego development and on other special circumstances, such as: an investment on another object, another narcissistically satisfying situation or a previous pain.

The grief defined as repressed or denied grief is always able to find a mode of expression, a "realization effect" (Deutsch, 2005).

Deutsch compares the latent manifestations of unresolved grief to the guilt of criminals expressed by Freud. According to him, such individuals commit a crime to be able to rationalize and contextualize a frustrating and illogical feeling of previous guilt (Deutsch, 2007).

Psychic energy, even if weak at the moment of loss, always manages to identify its source of discharge. The manifestations of affective impulses are not certain or established, they differ in each individual and they influence their personality. For example, the author identifies in adults depression that emerges without a clear reason the possible unconscious expression and realization of the repressed grief, determined by the child anguish and by the defense mechanisms associated with it (Deutsch, 2007; Deutsch, 2005; Parat, 2005).

As stated, although limited to women's psyche studies, the author's contributions to grief were fundamental. The association of the child's development and experience with regard to loss has also made a further contribution to the study of this issue. Specifically, the contribution from Deutsch has been a useful starting point for the analysis of perinatal loss, the central subject of this research.

### 1.2.3 Daniel Lagache

Daniel Lagache, French psychiatrist and psychoanalyst, refers to mourning as "the obligations that society imposes for a more or less long period".

In the article "Le travail de deuil", the author presents his analysis of mourning through a detailed theoretical and analogical framework between individual psychological content and primitive societies, reporting studies and examples of clinical cases (Lagache, 1977). The analyses of Lagache include and evoke the psychological, sociological and anthropological aspects of the work of mourning.

The bereaved person, even as a component of the society in which he is immersed and lives, is a single entity, living the experience of mourning in an intimate, personal and individual way. The loss activates the awareness of the relationship with the deceased and of the new reality, determining a transposition of mourning and death from a purely physical and biological level to a human and psychological one.

In normal forms, the work of mourning, understood as the effort of the "intrinsic forms of defense and adaptation", is an unconscious act. It is activated and acts in an uncontrolled and instinctive manner, determining the overcoming and acceptance of the loss ("killing death"). It therefore represents an overcoming of death and its defeat, restoring the psychic balance and separation from the deceased (Lagache, 1977, 1982).



For the author, the crucial element of mourning would in fact reside in the process of identification and distinction with the deceased and therefore in the internal conflict between the Id's life punctuation and Super Ego's guilt for surviving (Zublena, 20002).

Following death, the rites help determine the duration of grief and guilt. Through them, sadness, identification and aggression directed at death and the deceased - a sign of abandonment - have a fixed time (Bacqué & Hanus, 2016).

The examples shown by the author concern in particular the studies and research of Robert Hertz on the Dayaks population of Borneo, according to which mourning would assume a purely social connotation. Rites and ceremonies have the function of expressing, through an explicit and clear demonstration, the feelings experienced by the survivor - and by the community - toward the deceased. They define the final farewell, the fulfillment of mourning and the connection of the deceased with the world of the living.

The aggressiveness freed from death, the process of identification and the clear and conscious separation between life and death take extreme connotations in the forms of pathological grief. In the melancholy form, the narcissistic aspect and the oral fixation are predominant, as a sort of psychic cannibalism, dictated by the projection, by the dependence on the other and, at the same time, by a strong aggressive component. The idealization of the deceased thus redirects the aggressiveness previously liberated towards the self. This leads the Super-ego to activate a mechanism of self-reproach, self-accusation and self-punishment.

While in melancholy mourning the self can't free itself and is destined to succumb, in maniacal grief, which initially presents the same deviant traits, "the instinct of self-preservation is able to prevail and be free".

The analysis and study of analogies thus leads the author to exclude a regression of the patient "to a form of archaic psyche or to the presence of a collective unconscious" (Lagache, 1977). Rather, he supposes the presence of a primitive and unconscious necessity of the interhuman reality in situations of loss. The mourning is therefore considered as an internal struggle of the survivor, the fulfillment of balance and of the aggressive and erotic drives' restoration that death had previously modified and damaged.

#### 1.2.4. Melanie Klein

As we said, a fundamental concept of the work of mourning coined by Freud is the examination of reality. It helps the ego to free itself from memories and identification with the object / loved person, and then be ready to evolve and reopen itself to the world. Freud defines this act of acceptance of reality as a compromise, probably meaning this process as a kind of interaction, a point of contact and exchange between the inner world (the psychic functions) and the external world (life without the beloved person) (Klein, 1940).

An initial and interesting distinction between Freudian and Kleinian thought concerns the concept of reality. For both the examination and adaptation to reality are fundamental aspects. Freud described the examination of reality as an essential process of the work of mourning, which however can only be completed with an adequate development of the intrapsychic faculties. Contrary to Freud, for Melanie Klein psychic development is precocious and occurs from the first months of life, in which the child goes through the so-called psychic anxieties, characterized by two positions: the maniacal and the depressive one. It is therefore in the early childhood that the examination of reality is carried out with the aim of trying to help the child to overcome the precocious and pre-established sense of mourning typical of the depressive position (Klein, 1950).

The capacity of the principle of reality during the first months of life thus defines a premature psychic development of the elaborate intra and inter-relational functions of the child with the internal and external world. From an early age, the child experiences a kind of internal struggle. Initially he divides the good objects from the bad ones (good breast and bad breast), trying desperately to control and keep alive the object of love. He defends himself and attempts to annihilate with his aggression and greed the wicked part of the object, full of hatred and murderous instincts towards him (the schizo-paranoid position). Subsequently, the child understands the uniqueness and the totality of love's object and from that moment, love and hate, good and bad objects merge. The object does not correspond exclusively to the good breast but to the mother as a whole. He understands that he does not possess it and with his aggression he fears to destroy not only the bad but also to the good part, now inseparable from the other one. While the persecutory anxiety decreases, the emotional climax of anxiety and depression increases and with it also the destructive fantasies towards the object, the sense of guilt and the subsequent reparatory forms used to protect and reassemble the wounded love object (depressive position) (Klein, 1950).

For Klein, in this vortex of emotional and psychic development, typical of early childhood, after believing that he had annihilated the object of love with his own destructive fantasies, the child experiences for the first time the feeling of grief. The loss of the object of love, its annihilation and the understanding of its uniqueness and autonomy from the will of the child, corresponds to the

profound sorrow of mourning. This feeling will reappear with the death of a loved one in the following years.

The suffering and the work of mourning in old age is a return, a reliving of that archetypal childhood experience (Bacqué & Hanus, 2016; Moretti, 2011).

In normal grief, feelings of triumph can also re-emerge, delaying the work of mourning or increasing the pain of loss.

The sense of triumph comes from the maniacal position: the child and, in old age, the adult, after having succeeded in defeating the dangers, therefore feel a sense of victory from the death of the loved one (and from the internal representation of the reference figures that it represents). This sense of triumph also determines an upheaval in the process of idealization which is a fundamental step in the mental development of the child (Klein, 1940). As in early childhood, the depressive position is overcome and modified by infantile neurosis, even the grieving adult manages to overtake the reactivated depressive phase.

On the contrary, what characterizes the difficulty to complete the work of mourning is the lack of ability to have overcome the depressive position during childhood, and therefore to never have integrated good objects and a sense of inner security (Klein, 1940).

Subsequently, in normal grief, as at the end of the depressive position, the individual (as an adult and child) manages to restore a sense of internal security, the ability to survive, to adapt and trust in the future.

#### 1.2.5. Erich Lindemann

In 1944, Lindemann published the first empirical study about grief.

One hundred and one participants in his research were psychoneurotic patients who lost a relative during the study, relatives of patients who died in hospitals, in the armed forces, and victims of the Coconut Grove Fire (a big fire at a night club in Boston happened on November 28, 1942 in which four hundred and ninety-two people lost their lives) (Lindemann, 1944).

They were thus all people encountering grief and different types of traumatic events (death at work, disaster, natural death, etc.).

In addition to the experimental study, Lindemann pioneered an archetypal nosographic distinction between normal, delayed and anticipatory grief (Parkes, 2002).

Starting from his work, empirical studies on the consequences of loss were conducted and deepened. The range of symptoms listed by Lindemann have in fact initiated and determined the criteria for future diagnosis during the assessment phase (Moretti, 2011). He defines the five characteristics of

normal or uncomplicated grief: Somatic symptoms, such as breathing and muscular problems, lack of energy, throat and digestive disorders; Intense preoccupation with the image of the deceased, accompanied by a slight sense of unreality and emotional distance from people; Sense of guilt and self-accusation of negligence; Hostile and aggressive behavior towards others; Change in habitual behavior and activities, as well as a sense of restlessness and difficulty in starting and completing appointments.

According to Lindemann, assuming the characteristic traits of the deceased (such as the way of walking) could also be considered a sixth aspect of grief (Bacqué & Hanus, 2016; Lindemann, 1944; Wing et al., 2001).

As previously stated, the duration of the work of mourning is subjective. It depends on the time that the bereaved person employs to emancipate himself, to adapt to the surrounding environment of the loss, and therefore to start new relationships. The obstacle to this process is the difficulty of beginning the work of mourning, tending to avoid the intense pain and suffering that it entails (Davies, 2004; Lindemann, 1944).

In addition to normal grief, the author has also identified another reaction, the most "impressive and frequent", that is delayed grief.

It corresponds to a sort of freezing, remaining unperturbed to the death of the loved one. Probably triggered by a mechanism of denial, it can last for weeks, re-emerging in the form of exaggerated, chronic grief or, months or years after the event, in the form of absent grief, a rare form of pathological grief (Lin & Lasker, 1996).

In the lapse between death and the emergence of delayed grieving reactions, in the subject a kind of alteration of habitual behavior may develop, such as: an overactive attitude made by a sense of well-being and enthusiasm (i.e. carrying out adventurous activities); a sort of identification and assuming the illness's symptoms of the deceased; medical problems (i.e. ulcerative colitis, rheumatoid arthritis and asthma); alterations in relationships with friends and relatives, with a irritability, isolation and hostility against specific persons; hiding the hostility, the bereaved could become formal and wooden, resembling schizophrenic forms and losing some patterns of social interaction; ruining the own social and economic belongings; depression disease (Lindemann, 1944).

The other form of grief identified and defined by Lindemann is anticipatory grief: bereavement reactions are triggered not by the person's death but in the period preceding death or separation, such as when the loved one is ill or in war.

Grief is in fact a reaction caused by separation, not exclusively from the person's death. Death is obviously a type of definitive and irreversible detachment, but the feeling of grief can also be triggered by other types of separation, physical and / or emotional ones (Lindemann, 1944).

### 1.2.6 John Bowlby and the attachment theory

Since the second half of the last century, John Bowlby has introduced and theorized the attachment theory, defining fundamental analyses and concepts in the study of the observation of behavior, relationships and development of the child.

One of the key concepts is the "secure base", the role assumed by the child's attachment figure or caregiver (Bowlby, 1988; Parkes, 2002). Generally, a child can have more than one attachment figure at the same time. The relationship installed with them is based on empirical experiences repeated over time which have determined in the child a code of behavior and predefined expectations. The relationship with the caregiver cannot therefore be modified or poisoned by a single event, but rather by repeated behaviors, which therefore lead the child to review this relationship and the attitude towards it. The type of relationship between the caregiver and the child is fundamental for the development of the latter, on a behavioral, emotional and cognitive level. The mental representations of this link are at the base of the different attachment styles and therefore of behavior's models and patterns that will be repeated by the subject also in future relationships (Bowlby, 1983; Shear & Shair, 2005).

In his work "Attachment and Loss", published in three volumes in 1969, 1973 and 1980, Bowlby extended the theorization of behavior patterns of the different attachment styles developed during childhood to the reactions experienced after a loss in adulthood (Bowlby, 1980; O'Leary, 2004; Parkes, 2002; Rando, 1993).

Like the child, the adult experiences different phases: the numbness (later inserted, in 1970, following the collaboration with Parkes); the protest given by the lack, seeking to restore contact with the person through tears and despair; feelings of anguish and anger; nostalgia; despair, with irritability and isolation; reorganization and detachment, in other words a recovery, resolution and processing of grief (Bowlby, 1983, 1998; Bowlby & Parkes, 1970; Moretti, 2011).

This latter process is characterized by a reorganization of the self-representations and by a reinvestment towards the outside world, without deteriorating the attachment and the affection toward the deceased person (Bowlby, 1980; Moretti, 2011). Following death, the subject risks developing two types of disordered grief: the unresolved chronic one or, to the opposite excess, the absent and total lack of grief (Bowlby, 1980; Carmassi et al., 2016; Zeanah, 1989). In both cases, the subject believes that the passing is reversible and the return and reunification with the deceased is possible (Zeanah, 1989). According to Bowlby, following the loss and the same reactions experienced during childhood (research, desire, anger, etc.), the functional coping strategies employed by the subjects with a style of secure attachment would result in a subsequent acceptance of the person's death (Bowlby, 1980; Moretti, 2011; Wayment & Vierthaler, 2002).

On the contrary, adults with an anxious-ambivalent style would develop chronic grief, a severe suffering that would not be reduced over time (Bowlby, 1980; Main & Goldwyn, 1984). They are individuals whose attachment figures were inconsistently present, and who have therefore developed a strong sense of insecurity, a search for attention and a difficulty in accepting and understanding the person's definitive loss (Field & Sundin, 2001).

According to their attachment pattern, characterized by the lack of responsiveness to childhood needs, avoiding adults would show complete disinterest and emotional distance (Bowlby, 1980; Field & Sundin, 2001).

Later studies and research have reported how people with a secure attachment have a lower risk of developing anxiety and depression disorders following loss, as opposed to anxious-avoidant individuals. Furthermore, people with an avoidant model would report a greater risk of somatic disorders in response to exhausting control of avoiding defenses compared to sadness, depression, anxiety, etc. (Bonanno & Kaltman, 1999; Moretti, 2011; Wayment & Vierthaler, 2002).

### 1.2.7 The stages' model of Elisabeth Kubler Ross

In 1969, the year of her book's publication "On Death and Dying", the Swiss psychiatrist Elisabeth Kubler-Ross proposed for the first time a theory on the different emotional and psychological phases facing terminal patients.

Her studies were focused on cancer patients, when four students of theology at the University of Chicago asked for her help for a study about the "crisis in human life" (Kübler-Ross, 1996). Subsequently, the answers expressed by people who are dying and who are confronted with the idea of death have been associated with the reactions of grief, with the loss of a loved one. Following her observations and meetings with patients, the five stages proposed by Kubler-Ross have now become an integral part of the general culture.

The author emphasizes how her definitions have evolved and, in some cases, altered in their main meanings and purposes. According to her thinking, respect for mourning is intact: every grief is personal, like the relationship with the deceased. The goal of proposing these stages is to explain and identify the tools and feelings that can emerge following a loss (Kubler-Ross & Kessler, 2011).

The first reaction is that of denial. Following an initial shock, the defense system implemented by a person is an anxious rejection. The denial of the situation, of the illness and of a loved one's loss ("not true", "not to me") is a determined reaction that over time will be replaced by other feelings.

However, this does not characterize only the first stage but, like all the other reactions that tend to follow each other, it may recur later (Kübler-Ross, 1996).

In the survivor, the sense of disbelief is driven by the inability to accept their own fear of dying. In the bereaved person, the refusal is not directed to deny the reality of death but to the impossibility of imagining a life without the deceased. The shock emerges in the form of anesthesia, numbness and paralysis. It is a defense mechanism that blocks the most dangerous, overwhelming feelings that the psyche is not able to face yet. Denial is part of a linear path whose aim is to temporarily contend the pain, helping the person gradually accept reality and react to mourning (Kubler-Ross & Kessler, 2011).

Then, the stage of despair comes ("Why me?") and a vortex of negative feelings and anger begins. This resentment is expressed and addressed without a precise direction, it is generalized and not selective, it can be directed towards the deceased, themselves, doctors, God, etc. Anger is proportionate to the emotions felt for the missing person and it is a fundamental process, a feeling that emerges when the bereaved person begins to be able to cope with loss. It is a temporary reaction but it can come back later, helping every time to deal more deeply with grief (Idem).

The third stage is that of bargaining. It is a short stage that leads the person to ask some "discounts". It corresponds to a search for life's control, to manage events, even if in a totally illusory way. The person generally tends to seek bargaining with God, with the Church, etc. (promising, for example, that if the request is achieved he will dedicate his life to prayer). This bargain is often associated with guilt for not having done everything possible for the deceased (Kübler-Ross, 1996).

The author states that following the refusal, the anger and the attempted negotiation, the stage of depression comes. Depression is like a sense of disorientation and numbness. The subject is slowly but brutally coming into contact with reality and with what happened. He can live two types of depression: one of reaction and another one of preparation for what the person is about to lose (Idem). In grief, this feeling of devastating emptiness is the "appropriate response to a great loss".

Depression experienced following the death of a loved one is a painful but adaptive reaction. It should not be stifled by medication or minimization, as instead happens regularly, but be respected and considered distinct from clinical diseases (Kubler-Ross & Kessler, 2011).

The last stage, following the other reactions previously listed and described, is that of acceptance. The subject therefore accepts his destiny, his illness or the death of the deceased. There are no more feelings of anger or rejection but resignation and awareness (Kübler-Ross, 1996). It corresponds to admitting that continuing one's life without the deceased is a permanent and definitive situation. It is the acceptance of having to adapt, reorganize one's own existence, own objectives and roles, and establishing a new relationship with the deceased (Kubler-Ross & Kessler, 2011).

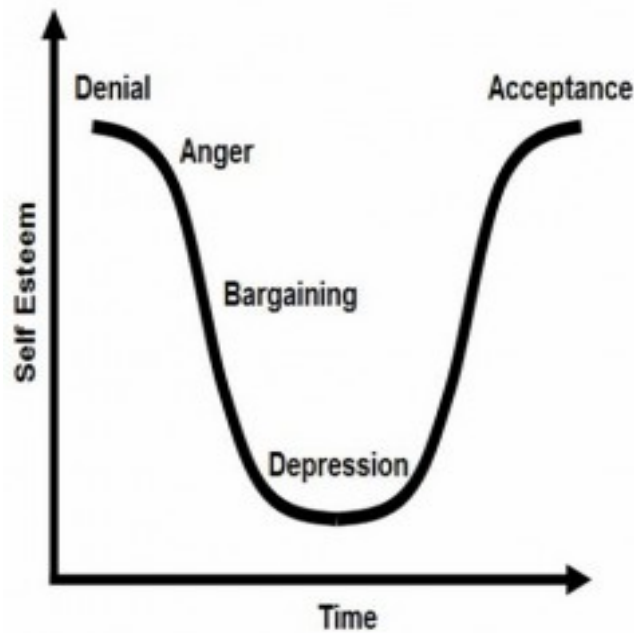


Figure 1 Curve of the five stages proposed by Kubler-Ross (1969)

The five stages introduced and specified by the author are the reactions and defense mechanisms that could follow the loss of a loved one. They are transition phases that emerge and that are activated for a certain period with the possibility of coming back later.

What is often highlighted is the uniqueness of grief: every grief is different and there are no prefixed norms, both with respect to the reactions and intensity and duration. It depends on various factors, including the relationship and connection with the deceased, the attitude and personal characteristics of the bereaved person (Kübler-Ross, 1996; Prigerson & Maciejewski, 2008).

Furthermore, as a result of the shock, the activated mechanisms assume a protective and defensive connotation: the reactions that allow the psyche to adapt to the loss emerge, stifling the most harmful and destructive ones that would require a greater commitment, impossible to tolerate at that precise moment (Kubler-Ross & Kessler, 2011).

One of the fundamental contributions of Kubler-Ross's work, besides a clear, linear and detailed classification of the possible consequences of a loss, has been its scientific vulgarization. They have undergone universal dissemination, which has also led to criticisms.

What is in fact reproached is that the stages are too general, simplistic and not entirely exhaustive (Prigerson & Maciejewski, 2008). Furthermore, it is believed that they can determine and negatively affect some reactions, creating expectations in sick or in bereaved people (Friedman & James, 2008). Such diffusion of the possible implications may have in any case influenced a sort of "normalization" of mourning, disclosing the possible reactions that may emerge in such situations. This mechanism



may therefore have led the person towards the acceptance of his own feelings and the recognition of their normative and non-pathological nature.

#### 1.2.8 The Dual Process Model

Margaret Stroebe and Henk Schut conceptualized their coping model for grief situations for the first time in 1999. This model is called the Dual Process Model of Coping with Bereavement. Stroebe defined mourning as a "cognitive process of confronting a loss, of going over the events before and at the time of death, of focusing on memories and working toward detachment from the deceased. It requires an active, ongoing, effortful attempt to come to terms with loss. Fundamental to current conceptions is the view that one needs to bring the reality of loss into one's awareness as much as possible and that suppression is a pathological phenomenon" (Stroebe, 1993).

Starting from contemporary models and research, they felt the need to understand and analyze in a more meticulous way the strategies and modalities of grief's coping (which can be adaptive or maladaptive) and how to reduce possible situations at risk and clinical, physical and mental complications (Stroebe & Schut, 1999, 2010).

The fundamental contribution to the construction of this model was the attachment theory of John Bowlby (1980). According to Bowlby, the main task of mourning is to be able to reorganize the bond with the missing person, modeling and positioning oneself and the deceased in a reality marked by his physical absence, a mechanism that the author indicates with the term "reorganization".

Stroebe and Schut believe that the preeminent gaps in the study and in the analysis of the consequences of grief concern in particular: the absence of definitions and of stressors' specifications that are activated after death; the lack of a clear psychological process of grief and the change of the bereaved person's reality; considerations too focused on intrapersonal aspects, while interpersonal aspects are totally ignored; a lack of universal application of models, considering gender and cultural differences.

Some of the contemporary theories at the time of Dual Process Model (DPM) theorization have been assessed as useful but at the same time not fully satisfying for the objectives set by the two authors.

For example, they consider the cognitive stress theory (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984), which defines stress and its mechanisms as not applicable to grief.

For Stroebe and Schut, it is impossible to distinguish between problem-focused and emotion-focused coping processes, as argued by the cognitive stress theory.

While the authors focus on the effects of the event, Horowitz (1986) focuses exclusively on the causes that led to the trauma and its antithetical reactions of intrusion (a compulsive event's re-experience)

and avoidance (a process of denial), reactions that if extreme are considered pathological (Horowitz, 2001).

Further interesting suggestions were provided by: Two-Track Model of Bereavement by Rubin and Malkinson (1981), who identified and distinguished two reactions to the stressor of grief, that is Binary I, which refers to the outcome of the event and describes the biopsychosocial reactions, and the Binary II, about the relational bond with the deceased (Rubin, 1981); and the Model of Incremental Grief by Cook and Oltjenbrun which highlights how a loss can often trigger a second one, that is the consequences and changes in the life of the subject after the bereavement (for example, the separation of a couple after the own child's death) (Cook & Oltjenbruns, 1998).

Starting from the definition of the objectives and the study of the most important clinical models provided by the literature, the two authors theorized their own model based on two main strategies: loss and restoration oriented. It has been developed starting from the analysis of the reactions activated following the death of the spouse but it's applicable to all grieving situations.

The loss-oriented coping modalities focus on the loss of the person and on the bond with him, on the lives spent together and on the circumstances of death. The bereaved person alternates between negative and nostalgic feelings (such as looking at old photos) and, especially after the first period, more positive emotions (Stroebe & Schut, 1999, 2010).

The restoration-oriented strategies are instead oriented to secondary factors, reorganization and investment toward the outside and to the additional sources of stress and anxiety that follow the event. This modality does not therefore principally concern the reactions to the passing of the beloved but to the problems that derive indirectly from it. They include, for example, reorganizing one's life and tasks (managing finances, selling the house, etc.) and changing one's role and identity (such as, from being a wife to a widow). In the case of a child's death, it is important to consider gender differences and how men and women grieve differently, risking leading to a lack of understanding, of communication and, therefore, to a further source of anguish.

Generally, women tend to use a more loss-oriented strategy, to express their feelings and anxieties, while men would use more a restoration-oriented coping strategy, with less expressive and more practical manners (Stroebe & Schut, 1999, 2010; Wijngaards-de Meij et al., 2008).

Fundamental to the coping strategies is "oscillation", a dynamic process that occurs between loss and restoration-orientation. This cognitive process is a regulator mechanism between confrontation and avoidance of different stressors associated with grief. This alternation influences the grief's processes and resolution and the adaptive coping, assuming an important role in respect to the physical and mental conditions of a bereaved person (Figure 2) (Parkes, 2002; Stroebe & Schut, 1999).

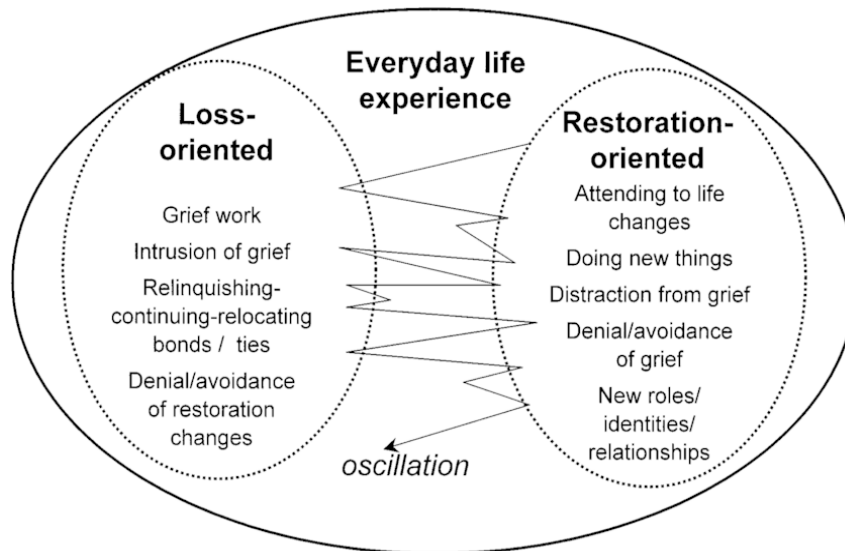


Figure 2 The Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999).

Years later, compared to cognitive processing and primary coping strategies, the authors started further analyses and introduced into the oscillation process, both in loss-oriented and restoration-oriented coping, positive and negative reconstruction feelings (Figure 3). This internal oscillation makes it possible to deal adequately with grief: the negative feeling places the person in front of a strong pain; the positive one supports the effort of coping. Their possible crystallization, in positive or negative feelings, is equivalent to an omission and minimization of grief, underlining the processes of confrontation and avoidance as central and fundamental (Stroebe et al., 2001; Stroebe & Schut, 2010).

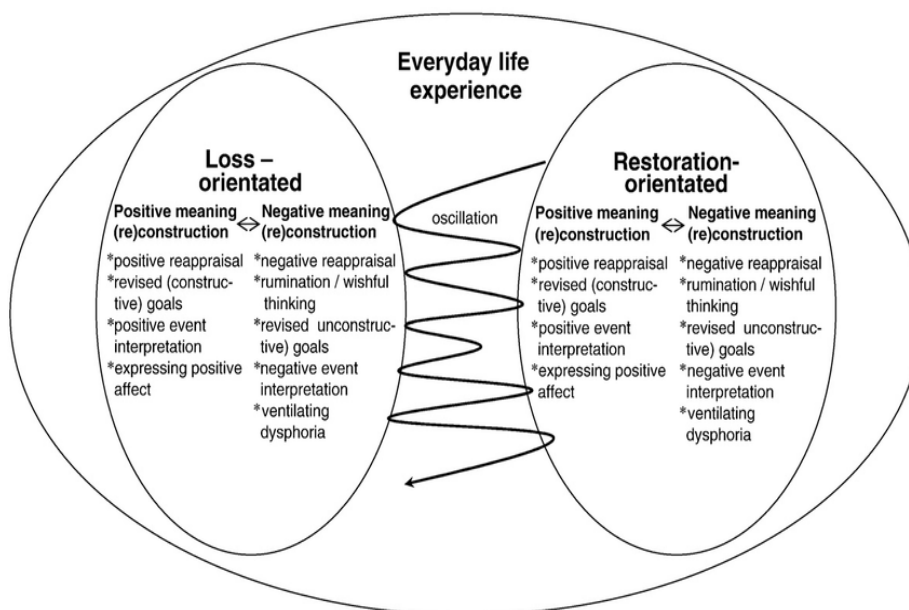


Figure 3 Appraisal process in the Dual Process Model (Stroebe & Schut, 2001).

Over the years, this model has provided numerous contributions to various psychological theories. The extreme reactions expressed previously have been associated, for example, with different forms of complicated grief. Focusing on the loss has been likened to a chronic grief, a permanent restoration-oriented coping to an absent grief, while a traumatic grief could manifest extreme intrusion and avoidance symptoms (Parkes, 2002). In all forms of complicated grief there is not any oscillation, the fundamental and dynamic process of adaptive strategies which characterize a non-pathological grief (Stroebe & Schut, 2010).

Over time, the increasing attention paid to restoration strategies determines the gradual reduction of loss-oriented activities, leading to the resolution of mourning (Idem).

Furthermore, it is important to consider the presence of additional stressors to the physical and mental health of the bereaved person. This stress can be defined as "the bereaved person's perception of having more than s/he feels able to deal with— too much or too many activities, events, experiences and other stimuli" (Stroebe & Schut, 2016). In fact, there may be events or stressful situations that make the person's oscillation even more difficult. This overload can also be determined by other events or disturbances, such as burnout. It is therefore essential to be able to control external and internal stressors, with the aim of reducing the risk of any serious consequences (Stroebe & Schut, 2016).

On the other hand, the Dual Process Model can be subject to various criticisms. Based on a properly cognitive structure and architecture, it leaves no space for subjectivity and emotionality, that govern grief instead. In fact, this theory underlines a mechanism or a rigid system which underlies the processing of loss.

Another fundamental element is the interpersonal aspect that can determine the course and adaptation to bereaved person's difficulties.

It is difficult to be able to circumscribe the grief and the work of mourning exclusively according to a rational viewpoint. They are determined by different factors and contexts, intrapsychic and relational, typical of the emotional and affective sphere.

## Chapter 2: Pathological grief

Since the first studies about grief, authors have tried to describe a clear distinction between the reactions that can be considered "normal", and therefore acceptable, and those that are considered risky and debilitating to the individual, that is the "pathological" ones. The following chapter will outline the clinical differences that have led psychology and mental health studies to identify such nuances over the last few years.

Starting from a presentation of grief defined as "uncomplicated", we will explore the understanding of the pathological reactions and consequences that the loss of a loved one can cause in a person.

We must always consider the need not to generalize these criteria, both with respect to individual manifestations and to different cultures and societies, which have unique characteristics and demands.

### 2.1 Uncomplicated grief

Grief is the reaction that arises following a loss (Lombardo et al., 2014). The resulting reactions and consequences depend on a set of psychic and interpersonal factors, in addition to the degree of relationship and attachment with the deceased, the situation of death, age, and the social and cultural context.

According to Hanus, grief should not be generalized but we should use this word in a plural sense ("griefs"), considering individual and circumscribed experiences to the situation (Hanus, 2006). It is not possible to categorize the path that follows a loss : this is totally personal in its expression and timing.

The suffering follows a process of "waves", of "ups and downs". Feelings of sadness, of anger and of disbelief envelop the bereaved person, influencing his actions, thoughts and worldview. The person can feel a sense of loss, due to the disappearance of the deceased and to the emotional and behavioral reactions (unusual for his temperament), causing the appearance of unknown aspects of the Self (Lombardo, 2014).

The process of acceptance and completion of mourning's work is generally characterized by two phases that define the first months of condolences. Initially there is "acute grief", the period following the news of death, characterized by a deep state of anguish, shock, dysphoria, difficulty in concentration, concern for the deceased, anger, isolation, etc. (Worden, 1991).

These feelings take root in the defenseless and suffering person, at first as a constant flow, then as overwhelming waves. Feelings of relief and joy alternate - with a possible sense of guilt towards the deceased. This process evolves until the second phase, the 'integrated grief', in which the memory of the deceased emerges only through specific stimuli and with greater serenity.

The bereaved person resumes his daily activities and relationships, without forgetting the deceased, but simply integrating the loss to the new existence (Bacqué, 1990). In a normal or uncomplicated grief, resolution is gradual, with a decreasing intensity and a progressive adaptation to reality (Bogensperger & Lueger-Schuster, 2014).

Uncomplicated grief has a course of about a year. Moments of deep sadness and despair can come back even after months, such as close to anniversaries and important dates.

The time that the person takes for grief's resolution must be respected, not diminished or medicated. It is good that the person comes into contact with his negative feelings to bring out its coping styles and resilience (Lombardo, 2014).

Literature has also been interested in that form of coping defined as rumination, namely: the predisposition of thoughts and behaviors focused mainly on negative emotions (Nolen-Hoeksema et al., 1999). People with a ruminative style think repetitively about their suffering and the circumstances that led them to this situation. Ruminative coping is therefore inversely related to problem solving. Moreover, the cognitive and social mechanisms used by the ruminating subject are associated with a greater predisposition to depression and pathologies and they include, for example: continuous negative thoughts and memories; a near-absence of problem solving; the reduction of useful behaviors and the progressive distancing from one's primary social group and interpersonal conflicts.

These subjects say that through the rumination they try to fix the problem and reach possible solutions. On the contrary, it is shown that this strategy leads them to arrive at worse outcomes (Onofri & La Rosa, 2016; Zech et al., 2010). Bereaved people may be unwilling to stop ruminating, considered a last link with the deceased (Onofri & La Rosa, 2016).

Furthermore, uncomplicated grief can differentiate from complicated grief. According to the model of Stroebe and Schut (1999), the "normal" grief would be characterized by a balanced alternation between the two main coping processes: the loss-oriented and restoration-oriented.

According to Parkes, there are four main groups that include risk and protection factors: characteristics of the bereaved; the quality of the deceased's relationship; the mode of death and the quality of the social support system of the bereaved (Parkes, 1990).

For example, in the case of perinatal loss, attachment is one of the key concepts that explains the suffering, pain and parent's consequences (Scheidt et al., 2012).

For Bowlby, uncomplicated grief is associated with a secure attachment style, in which the person gradually becomes detached from the obsession to the deceased, approaching the complete acceptance of loss. In contrast, the anxious and avoidant attachment styles are associated with deviant responses, such as chronic and disordered grief, respectively (Field & Sundin, 2001).

## 2.2 Complicated Grief

The studies described above have therefore led to a distinction between what has been called uncomplicated and pathological grief. This difference is considered clinically fundamental but also very variable, on a purely practical level. The reactions and psychological timing of grief depend on numerous factors, inter and intra personal ones, which are often too difficult to categorize and circumscribe. Furthermore, expressions of grief depend on the person and on the culture and society of belonging.

In the wide range of clinical spectra that characterize complicated grief, it is considered a temporal deviation, with a more intense and debilitating symptomatology of the "normal" one (Bacchetta, 2014).

On a global scale, complicated grief (CG) afflicts about 2-3% of the population and about 30% of bereaved parents, compared to perinatal loss (Kersting et al., 2011; Meert et al., 2012).

Complicated grief is characterized by a lack of acceptance of loss and by a crystallization of the "acute" phase, without being able to reach the integrated grief and its resolution (Prigerson et al., 1996). This means that the symptoms and the state of suffering that generally determine the first period following a loss are extreme and permanent. They pervade every aspect of the person's life: personal, social, work and family.

Complicated grief also includes a series of subtypes that have been highlighted in the literature and which are part of what is generally referred to as "pathological" grief. These include: "chronic" and "prolonged" grief (Bowlby, 1980), whose symptoms and inability to accept death have an extended and persistent duration; "inhibited" and "delayed" grief (Parkes & Prigerson, 2009), with an absent or soft symptomatology, a late onset and unconventional timing; and "absent" grief (Bowlby, 1980), with symptoms that may occur later or remain stifled, as expression of the incapacity of the subject to cope with his own experience (Bacchetta, 2014).

Chronic grief has two forms of expression: a melancholic one, characterized by depression's symptoms with irrational self-accusations; and a sub-depressed grief, with interminable tears due to the uncertainty of the death (as in the case of disappearances, body not found, etc.) (Bacqué & Hanus, 2016). In this, the reactions that characterize an uncomplicated grief are prolonged and very intense and they may persist beyond the first year after loss (Lin & Lasker, 1996).

In its inhibited version, grief is denied and the avoidance of reality emerges as depression or psychosomatic disorders. Compared to delayed grief, results indicate that it is present mainly in men and in those who have suffered an early loss (Bacqué & Hanus, 2016; Lasker & Toedter, 1991).

Furthermore, according to the personality of the bereaved person, the psychopathologies could be circumscribed in:

- hysterical grief, in which unconscious sexual energy is converted into significant diseases (such as paralysis), self-injurious behavior and suicide attempts;
- obsessive grief, defined by a sense of guilt and in which the work of mourning is avoided by a whirlwind of thoughts that revolve around the desire for death and deceased's images, trying to gather rational solutions;
- maniacal grief, in which intense feelings of exaltation and sadness alternate rapidly and in which denial (characterized by megalomania, absence of suffering and therefore triumph over death) leads to aggressive behavior and a sense of guilt;
- and melancholy grief, well described by Freud and Abraham as a form of depression, with a sense of guilt, self-denigration and the complete absence of any kind of positive narcissistic element, often reaching suicide (Bacqué & Hanus, 2016).

Symptoms that mark the complicated grief (CG), present for at least six months after death, can be divided into two main clusters: sadness, pain and concern for the deceased (linked to the separation distress); intrusive thoughts, avoidance of places and situations related to the deceased, dissociation, inability to accept loss and anger (associated with post-traumatic distress) (Prigerson & Jacobs, 2001). Furthermore, a strong sense of guilt is associated with the CG. It is commonly experienced in perinatal loss, especially if there is a feeling of ambivalence towards pregnancy or the thought of having done something wrong, such as too much sport or smoking (Kersting & Wagner, 2012; Li et al., Stroebe, 2018).

In CG the life of a bereaved person is entirely dedicated to the deceased: thoughts and actions are projected towards the memory of the missing person, considering the current life useless and meaningless without their loved one (Lombardo, 2014).

Among the symptoms that distinguish the pathology there is also depersonalization, derealization, dissociation, difficulty in concentration and hyper involvement in activities and situations related to the deceased, for example: going to the cemetery every day; keeping the house or the room of the deceased intact; handling and continuously reorganizing objects or clothes belonging to the deceased or, on the contrary, carefully avoiding situations and places related to loss.

Moreover, remaining stuck in this phase can be considered by the bereaved person as a sort of confirmation of attachment to the deceased and therefore a comfort, as the resolution or feeling happy and satisfied again can be perceived as a betrayal, thus generating an intense sense of frustration and guilt (Lombardo, 2014).

In some cases, the bereaved person may develop hallucinatory symptoms (visual, auditory and olfactory hallucinations that lead the subject to see, hear and smell the deceased) and a pathological identification with him, perceiving the same symptoms (Carmassi, 2016). Moreover, the attachment



styles may be risk factors for a CG, such as anxious attachment, which is more associated with chronic grief (Bonanno & Kaltman, 1999; Neria & Litz, 2004; Parkes & Weiss, 1983).

Complicated grief is associated with numerous mental and physiological risks: social isolation; sleep disorders; substance abuse; panic attacks; suicidal ideations; a greater probability of oncological and cardiac diseases; anxiety disorders (Shear, 2015).

At the neuropsychological level, alterations were found in autobiographical memory, neural systems involved in emotional regulation and neurocognitive functioning (Shear, 2015).

Furthermore, this disorder may be indicative of a risk of a reduced quality of life and psychiatric comorbidity (Boelen & Prigerson, 2007). Depression, post-traumatic stress disorder and separation anxiety are the main comorbidities that distinguish the clinical frame (Gesi et al., 2017; Shear, 2015).

In situations of illness, and therefore of expected deaths, the young age of the bereaved person, the female gender, and a scarce preparation for the death are considered the main risk factors to predict a diagnosis of major depression associated with complicated grief (Nielsen et al., 2017).

Depression is the most frequent comorbidity (between 52% and 70%) but it is important to note that they are different from each other in fundamental ways, even if with a partial symptomatological overlap (Aoyama et al., 2018; Carmassi et al., 2016; Prigerson et al., 1996; Simon et al., 2007).

Emotional inhibition - typical of depression - can lead the person to a continuous negative rumination, that is to a vortex of obsessive thoughts about the meaning of life without the deceased. This attitude risks generating further social isolation and limiting interpersonal relationships, which are instead one of the main supportive aspects to reach a full resolution of grief (Carmassi et al., 2016; Lannen et al., 2008; Shear, 2012). In depression, dysphoria, feelings of guilt, negative and self-critical ruminations are generalized and constant. In grief, however, dysphoria occurs in waves and negative and obsessive thoughts and memories are centered mainly on the deceased. They would end if only the missing person could return (Shear, 2012).

With respect to suicidal thoughts, the bereaved person thinks of suicide as a possible means of reuniting with the missing person, not to put an end to his existence as it happens in depression (Carmassi, 2016).

The fundamental aspect of the differential diagnosis concerns the psychomotor inhibition – that is absent in CG- and a minor impairment of basic cognitive functions (such as concentration and attention), which are instead compromised in cases of major depression (Carmassi, 2016).

Furthermore, the distinction between the two disorders is confirmed at the neurobiological level. Research shows that REM sleep disorders are present in particular in depressed subjects and that pharmacological treatments for depression are completely ineffective in cases of CG (Carmassi et al., 2016; Simon et al., 2007; Wittouck et al., 2011).

Furthermore, an activation of the nucleus accumbens in CG has been observed. The nucleus accumbens is a region of the basal forebrain rostral which assumes a fundamental function in the processes of aversion, reward, reinforcement and motivation (“Nucleus accumbens,” 2018). In CG, this activation underlines the expectation of reward, the burning desire to see the deceased - almost as much as an addiction - and the attachment to the latter (O’Connor et al., 2008).

In CG, but not in depression, an activation of dopaminergic circuits is also observed, which plays a major role in the regulation of pleasure, in memory, in the regulation of sleep, in reward, attention and learning (Carmassi et al., 2016; McDermott et al., 1997).

In cases of sudden, violent and traumatic death, the differential analysis concerns Post-Traumatic Stress Disorder (PTSD) (Dell’Osso et al., 2012).

In both clinical settings, the subjects present avoidance, intrusive thoughts, and disturbances in sleep and concentration. Conceptually, the CG could be considered more similar to PTSD than depression, because both are the answers to a traumatic and specific event, but there are fundamental differences. PTSD develops following a traumatic event that can be considered as a threat to the life of the individual, directly or indirectly, causing fear and hypervigilance (Gemigani, 2013).

A further differential diagnosis of CG involves adjustment disorder. According to the DSM-V (2013), it is characterized by: "a psychological response to one or more identifiable stressful factors that lead to the development of clinically significant emotional or behavioral symptoms", which may indeed be revealed in CG. Therefore, the symptoms of adjustment disorder are unclear and not as specific as those of CG. Finally, at a temporal level, adjustment disorder must show itself within a month from the stressful event, while the diagnosis of CG requires at least 6 months from death (American Psychiatric Association, 2013; Carmassi et al., 2016).

Research has shown that there are several predictors of CG. For example, losing a young child can be a risk factor, compounded by factors including social status, education level, having experienced more losses, an ambivalent relationship to the fetus during pregnancy and a lack of social and partner’s support (Murphy et al., 2014; Scheidt et al., 2012).

Furthermore, alexithymia, an outward-oriented thinking (concrete thinking) and other relevant aspects to the personality and structure of the Self can be risk factors for CG.

Lower levels of self-esteem, a poor concept of self, constant negative rumination, the inability to cope with unexpected events, emotional distress resulting from loss and the tendency to maintain an exclusive bond with the deceased can determine and influence the prolonging of grief and delay its processing (Lombardo, 2014).

### 2.3 Post-Traumatic Grief

Post-traumatic grief is a further pathological reaction that risks developing after a double trauma: a threat to the safety of oneself and the death of a loved one (Romano et al., 2006).

This threatening and risky event can involve the bereaved person directly or in a totally indirect way (such as, having decided to stop by chance five minutes before the collapse of the bridge) or for a mechanism of empathy and projection (Bacqué, 2006).

Post-traumatic grief, conceptualized by Bacqué, is “a psychological state of a person escaped from a dramatic, brutal, unforeseen situation, a collective death or numerous death threats” (Bacqué, 2003a). According to Freudian thought, grief is the death of a part of ourselves and a narcissistic wound inflicted. The work of mourning therefore includes a rewriting of reality, an integration of the loss in ourselves and a re-investment of the relationship and affection felt for the deceased (Bacqué, 2006). Through a process of idealization and mentalization, the bereaved person is able to confront his own psychic and external reality, finding confirmation and recognition of grief on a social level, thus arriving, in a painful and discontinuous manner, to full acceptance (Freud, 1917).

In post-traumatic grief, the work of mourning is static. The trauma determines the negation for the death and prevents the loss's resolution.

In uncomplicated grief the bereaved may look or recall to lost souvenirs with pleasure. In post-traumatic grief the bereaved prefers to avoid the memories because they are linked to the traumatic scene. This could signal a pathognomonic difference between these different types of grief.

In post-traumatic grief, the bereaved person is at the center of a psychic struggle, a vortex made up of opposite but equally present elements: trauma and grief.

The trauma is a "rupture", a fracture that undermines the sense of security of the individual, which pervades his existence and generates discontinuity (Onofri & La Rosa, 2016).

In trauma the person struggles with all his strength but without succeeding. He finds himself catapulted into a traumatic space-time dimension: through dreams, intrusive thoughts and flashbacks, against his will, he finds himself living and sensually perceiving the traumatic event. The trauma bursts into the flow of consciousness, forcing the person to remember (Onofri & La Rosa, 2016).

The extreme and uncontrollable event implies a psychic break that leads the subject to the avoidance of situations and memories unmanageable at the meta-cognitive level linked, in this case, to loss. Dissociation is the lack of organizational and integrative functions of consciousness. It manifests itself in a fragmented memory at the temporal (keeping the person in mourning motionless at the time of the trauma) and at the physiological level. The person can no longer find a balance between his orthosympathetic system (which involves the activation of escape and attack) and parasympathetic (of

meditation and tranquility), living in a constant state of alertness and nervousness (Bacqué, 2003b; Onofri & La Rosa, 2016).

At the same time, it is not only the traumatic aspect that exists, that invades the psyche and defines the consequences of loss. Simultaneously with the symptoms associated with post-traumatic stress grief, including the strong sense of guilt of being survivors, there are also elements of grief. This implies a strong, almost morbid attachment to the deceased, to his memory and to the search for projective symbols (Bacqué, 2006).

If in trauma the person tries in every way to get away as the event invades his existence, in grief it is the loss that must be integrated with the new reality.

Post-traumatic grief therefore has a different duration from other types of grief because the trauma determines the reactivation of post-traumatic symptoms (Bacqué, 2006).

The traumatized person tries to give meaning to the chaos he is experiencing, attempting to integrate his ego to the new situation.

The ability to talk about what happened is one of the ways in which the work of mourning can be carried out. In trauma, verbalization promotes the integration and cognitive restructuring of loss, of self-exploration, of emotions' self-regulation and bodily sensations (Bonanno & Kaltman, 1999).

In addition to repetition, anguish and neurovegetative reactions, the grief reaction is also characterized by social isolation or self-exclusion leading to victimization and rumination (Bacqué, 2006).

Post-traumatic grief presents an unfavorable prognosis that can last over time, risking - if not diagnosed and treated- affecting future generations on an intergenerational level (Idem).

## 2.4 From Complicated to Prolonged Grief Disorder

Freud, Lindermann, Bowlby, Parkes, Rando, Raphael and Martinek, Horowitz and Prigerson are some of the most important scholars who have observed and analyzed pathological grief, with the aim of defining its characteristics in as detailed a way as possible (Bowlby, 1980; Freud, 1917; Horowitz et al., 1997; Lindemann, 1944; Parkes, 1972; Prigerson et al., 1999; Rando, 1993; Raphael & Martinek, 1997). Particularly since the 90s, research focused on identifying a clear symptomatology and a nosographic classification.

It is essential, however, to remember that a general classification is impossible to obtain, both with respect to the variety of populations (age, situations, gender, etc.), and the different cultures and ways of expressing grief. In a society in which the symptomatological standardization is considered

advantageous and necessary, we have arrived - after doubts, debates and insecurities – at having “prolonged grief disorder” (PGD) included within the DSM-V and the ICD-11.

The PGD can be considered the result and the compromise of teamwork between the two most important working groups on complicated grief: Horowitz et al. and Prigerson et al. Building from the studies on pathological grief and the analysis of its characteristics carried out by pioneers like Freud, Lindermann, Bolwby, etc., in 1997 Horowitz theorized and defined for the first time what is now officially referred to as "complicated grief", in line with stress-response syndromes, as a reaction to a stressful life event (Horowitz et al., 1997; Killikelly & Maercker, 2017). From a study conducted on 70 widows, they identified a series of common disorders (intrusive thoughts, moments of strong emotion, stress, loneliness, loss of interest, etc.) which then led to the first classification of the following symptoms:

<i>A. Event criterion/prolonged response criterion</i>
Bereavement (loss of a spouse, other relative, or intimate partner) at least 14 months ago (12 months is avoided because of possible intense turbulence from an anniversary reaction)
<i>B. Signs and symptoms criteria</i>
In the last month, any three of the following seven symptoms with a severity that interferes with daily functioning
Intrusive symptoms
1. Unbidden memories or intrusive fantasies related to the lost relationship
2. Strong spells or pangs of severe emotion related to the lost relationship
3. Distressingly strong yearnings or wishes that the deceased were there
Signs of avoidance and failure to adapt
4. Feelings of being alone far too much or personally empty
5. Excessive avoidance of people, places, or activities that remind the subject of the deceased
6. Unusual levels of sleep interference
7. Loss of interest in work, social, caretaking, or recreational activities to a maladaptive degree.

Table 1 Criteria defined by Horowitz et al. (1997)

Subsequently, Prigerson identified the symptoms of pathological grief (distinct from depression and anxiety disorders) by unifying them in what she decided to call "traumatic grief", that is a traumatic suffering caused by loss (Prigerson et al., 1995; Prigerson et al., 1996; Prigerson & Jacobs, 2001). The author considered the term "complicated" as too vague and non-specific, while terms such as "pathological", "distort" and "abnormal" were too dispiriting. This name lasted until 2001; after the events of 9/11 they resumed calling it "complicated" to avoid confusion with PTSD (Lichtenthal et al., 2004; Wagner & Maercker, 2010).

Traumatic grief in particular concerns borderline personalities and an ambivalent anxious attachment style. The bereaved person (anxious, insecure, angry and with a strong sense of guilt) has not reached the psychic development necessary to adequately internalize the loss, translating this suffering into depression and into somatic and behavioral symptoms (Bacqué & Hanus, 2016).

As previously described, the clusters of criteria defined by Prigerson et al. (1995) were subdivided into two main categories of symptoms, namely: (1) separation distress-- the sense of loneliness, preoccupation, craving and searching for the deceased, etc.; and (2) traumatic distress-- disbelief about the death, avoiding reminders of the deceased, sense of anger, shock and futility about the future and emptiness, a fragmented sense of trust, security and control (Prigerson & Jacobs, 2001; Wagner & Maercker, 2010) .

Initially the temporal criterion considered only two months from the development of the symptoms, but they were subsequently replaced by a period of six months to be able to distinguish the symptoms of a pathological disorder from those of a normal or uncomplicated grief (Latham & Prigerson, 2004; Prigerson & Maciejewski, 2005; Wagner & Maercker, 2010).

Unlike uncomplicated grief, in the traumatic version, the psychological defenses fail to manage and control the reactions after the loss, generating an anguish that is psychic- influenced and linked to archetypal attachment, to the dependence on the object and to the fickleness of the subject's narcissism (Bacqué & Hanus, 2016).

The criteria highlighted by Prigerson et al. in 2001 were the following:

<i>Criterion A</i>
1. Person has experienced the death of a significant other
2. Response involves 3 of 4 symptoms below experienced at least sometimes :
2a. intrusive thoughts about the deceased
2b. yearning for deceased
2c. loneliness as a result of the death
<i>Criterion B – In response to the death, 4 of the 8 following symptoms experienced as mostly true :</i>
1. Purposelessness or feelings of futility about the future
2. Subjective sense of numbness, detachment, or absence of emotional responsiveness
3. Difficulty acknowledging the death (e.g. disbelief)
4. Feeling that life is empty or meaningless
5. Feeling that part of oneself has died
6. Shattered world view (e.g. lost sense of security, trust, control)
7. Assumes symptoms or harmful behaviors of, or related to, the deceased person
8. Excessive irritability, bitterness, or anger related to the death
<i>Criterion C</i>
Duration of disturbance (symptoms listed) is at least two months
<i>Criterion D</i>
The disturbance causes clinically significant impairment in social, occupational, or other important areas.

Table 2 Criteria defined by Prigerson et al. (2001).

Both groups, Prigerson and Jacobs (2001) and Horowitz (1997) have highlighted how the symptoms of grief compromise the person's functioning. However, some important differences are registered, above all with respect to the duration of grief and the symptoms of avoidance, sleep disorders, and functional disturbances.

Prigerson and Jacobson (2001) did not include in their criteria avoidance -due to low specificity- contrary to what is expressed in numerous research, suggesting that avoidance behavior is characteristic of grief reactions (Boelen et al., 2003; Langner & Maercker, 2005; Schut et al., 1991). Boelen, van den Bout and de Keijser (2003) have in fact pointed out that avoidance is significantly related to CG and depression. Therefore, this is one of the symptoms that has been reinstated in the

subsequent classification of the prolonged grief disorder in 2009 (Prigerson et al., 2009; Wagner & Maercker, 2010).

Furthermore, Prigerson and Jacobson (2001) had not included sleep disorders as criteria, based on research that did not show any significant differences (McDermott et al., 1997; Prigerson et al., 1999), which have now been retracted (Forstmeier & Maercker, 2007; Germain et al., 2005; Wagner & Maercker, 2010).

Unlike Prigerson, Horowitz did not consider separation distress as a primary criterion and he did not include: loneliness; emotional detachment; identification with the deceased (that is, a seeking ways to preserve elements of the missing person); and feelings of anger and disbelief (Hanus, 2006; Lombardo et al., 2014).

Comparing timing, for Horowitz it was necessary to spend fourteen months from the loss (to minimize the effects of the anniversary date), whereas at the beginning, Prigerson required only two months (subsequently modified in six months) (Lombardo et al., 2014; Prigerson & Maciejewski, 2005).

The comparison between the two classifications has shown that the criteria proposed by Horowitz et al (1997) are overall more inclusive than those of Prigerson et al (2001), recording prevalence rates significantly higher in the samples of populations analyzed (Forstmeier & Maercker, 2007; Lombardo et al., 2014; Wagner & Maercker, 2008, 2010).

In more recent times the necessity of a phenomenological distinction between the different clinical frames and of an independent grief's nosography has led to the integration of the symptoms previously discussed (given a collaboration between the two research groups) and to the definition of "prolonged grief disorder" (PGD) (Lombardo et al., 2014; Maciejewski & Prigerson, 2017; Nakajima, 2018; Prigerson et al., 2009).

PGD is characterized by intense, severe and functionally compromising pain symptoms for the individual. Symptoms, other than depression and anxiety disorders following death (possibly predictive of reduced quality of life or mental disorders), may persist for a prolonged period of at least six months or more (Boelen & Prigerson, 2007; Prigerson et al., 2009).

The study of 2009 was carried out with the aim of developing algorithms suitable for classifying PGD, and finally managing to include pathological grief within the DSM V and the ICD-11 (American Psychiatric Association, 2013; Prigerson et al., 2009).

The results obtained from a combinatorial analysis of structured interviews administered to 291 mourners at a distance of 0-6, 6-12, 12-24 months from the death, through the Item Response Theory, have therefore conducted a criteria algorithm used for the PGD.

The PGD was then introduced into the DSM-V, within the category of "other specified trauma- and stressor-related disorders", with the denomination of "Persistent Complex Bereavement Disorder"



(PCBD), and in the eleventh edition of the ICG. PCBD can be diagnosed 12 months after loss and PGD at six months but in terms of symptomatology and psychometric properties (reliability and validity), PCBD and PGD are essentially the same (American Psychiatric Association, 2013; Boelen & Smid, 2017; “ICD-11 - Mortality and Morbidity Statistics,” n.d.; Maciejewski et al., 2016).

<b>DSM-5 criteria for persistent complex bereavement disorder</b>	<b>Prolonged grief disorder for Prigerson et al.</b>	<b>Prolonged grief disorder proposed for ICD</b>
<b>Event</b>		
Person experienced the death of someone close at least 12 months previously	Person experienced the death of someone close at least six months previously	Person experienced the death of someone close at least six months previously
<b>Separation distress</b>		
At least one of the following symptoms frequently and to a clinically significant degree	Yearning, longing, or emotional suffering as a result of the desired unfulfilled reunion with the deceased, daily or to a disabling degree	Longing for the deceased or persistent preoccupation
1. Persistent yearning or longing for the deceased		
2. Intense sorrow and emotional pain		
3. Preoccupation with deceased person		
4. Preoccupation with circumstances of the death		
<b>Other symptoms</b>		
At least six of the following symptoms frequently and to a clinically significant degree	At least five of the following symptoms daily or to a disabling degree	Longing or preoccupation is accompanied by intense emotional pain (eg, sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one’s self, an inability to experience positive mood,
1. Difficulty accepting the death	1. Confusion about one’s role and diminished sense of self (eg, feeling that part of	
2. Disbelief or numbness		
3. Difficulty in reminiscing positively about the deceased		

4. Bitterness or anger	self died)	emotional numbness, difficulty
5. Maladaptive self-appraisals associated with the loss (eg, self blame)	2. Difficulty accepting the loss	in engaging with social or other activities)
6. Excessive avoidance of stimuli (places, people, objects) reminding of the loss	3. Avoidance of reminders of the reality of the loss	
7. A desire to die to be with the deceased	4. Inability to trust others	
8. Difficulty trusting other people	5. Bitterness or anger related to the loss	
9. Feeling alone or detached from others	6. Difficulties moving on with life (eg, making new friends, pursuing interests)	
10. Feeling that life is empty or meaningless or that one is unable to function without the deceased	7. Numbness (absence of emotion)	
11. Confusion about one's role and diminished identity (eg, feeling that part of self died)	8. Feeling that life is empty, meaningless, or unfulfilling	
12. Difficulties pursuing interests or making plans for the future (eg, friendships, activities)	9. Feeling stunned, dazed, or shocked	
Impairment		
Substantial impairment in personal, family, social, educational, occupational, or other important areas of functioning as a result of the symptoms	Substantial impairment in personal, family, social, educational, occupational, or other important areas of functioning as a result of the symptoms	Substantial impairment in personal, family, social, educational, occupational, or other important areas of functioning as a result of the symptoms
Additional criteria		

Reactions are out of proportion or inconsistent with cultural or religious norms.	The disturbance is not better accounted for by major depressive disorder, generalised anxiety disorder, or post-traumatic stress disorder	The grief response has persisted for an atypically long period ( $\geq 6$ months) and clearly exceeds norms for the individual's social, cultural, or religious context
Following death in traumatic circumstances (eg, homicide, suicide, disaster, or accident), responses to reminders of the loss include distressing thoughts, images, or feelings related to traumatic features of the death (eg, the deceased suffering, gruesome injury)		

Table 3 The criteria that define the Prolonged Grief Disorder in the DSM-5, in the ICD-11 and by Prigerson et al. (2009). Source of the table: Boelen & Smid, 2017.

As we can see in Table 3, the only substantial differences between the different diagnostic criteria concern the duration of symptoms. For the DSM-5 these must be present at least 12 months after loss; for Prigerson and the ICD for at least 6 months.

In addition, under the heading "other symptoms", in the DSM-5 there must be at least 6 among those listed, while according to the Prigerson criteria only 5 are required.

It is therefore apparent that the DSM-5 inclusion criteria are more selective, including specific references to the difficulties in reminiscing positively about the deceased, to the maladaptive appraisals about self associated with the loss and to the desire to die in order to stay with the deceased. The ICD-11 criteria are very similar to the other two, albeit with less specific criteria and descriptions of the symptoms.

According to the DSM the prevalence of complicated grief is 2.4-4.8%, with a greater incidence in women than men. Furthermore, the disorder can occur at any age (from the first year of life) and different reactions and timing of diagnosis for adults and children are specified (Onofri & La Rosa, 2016).

As specified in Criterion E, the reaction and severity of grief may be related to one's cultural environment, religious affiliation or the development phase of the subject (Carmassi et al., 2016).

Some individuals may present auditory and visual hallucinations of the deceased (which represents a large difference from the criteria included in previous Prigerson studies) and perceive his same physiological disorders and symptoms (Onofri & La Rosa, 2016; Wagner & Maercker, 2010). Among

the correlated risk factors are suicidal intention, an increase in consumption of alcohol and tobacco and the onset of serious medical conditions (such as heart disease, cancer, hypertension and immunological deficits) (Carmassi et al., 2016).

Violent deaths and loss of a child are among the risk factors for the development of PGD. Those who managed to find a coherent meaning in the understanding of a violent death (including that of the child) experienced lower levels of PGD and a favorable prognosis (Currier et al., 2006; Lichtenthal et al., 2013; Meert et al., 2010; Murphy et al., 2003; Wu et al., 2008).

The ICD-11 criteria are more flexible. Its aim is to be able to give greater consideration to the clinical judgment of the doctor. The criteria are always based on the symptoms now considered crucial for the diagnosis of PGD, namely: yearning and longing, persistent preoccupations, symptoms of intense emotional pain, and significant psychosocial impairment, for a minimum of 6 months, considering the social and cultural rules of belonging (Evans et al., 2013; Killikelly & Maercker, 2017).

Research has tested the predictive validity, specificity and sensitivity of the ICD-11's symptoms compared to those of the PCBD and PGD by Prigerson et al. (2009). These symptoms are also considered easy to memorize and readily applicable in various clinical settings worldwide (Killikelly & Maercker, 2017).

It is important to emphasize that numerous studies are trying to validate which of the temporal criteria that characterize these disorders is the best. Research has shown that, compared to the PCBD of DSM-5, according to which the disorder can only be present starting from the 12 months following a loss, the 6-month time criterion recognized by the PGD seems to be the most inclusive and the most appropriate (Boelen & Prigerson, 2012; Bonanno & Malgaroli, 2019; Killikelly & Maercker, 2017; Prigerson et al., 2009; Shear et al., 2011).

### **Chapter 3: Perinatal loss and its consequences**

After having drawn a general theoretical picture of the theme of mourning, it is time to concentrate our analysis on the central subject of this research, namely perinatal loss. The death of a child is a tragic event and too often trivialized on a scientific and social level. It can lead to important and serious consequences in the bereaved parent and in the entire family. The chapter below describes the studies and analyses that have been conducted so far on this topic. In particular, we will see in detail the difficult consequences and risks that the loss of a child can determine, as well as the protective factors and the different experiences and emotional expressions between the parents, the bereaved mothers and fathers.

#### **3.1 Perinatal loss**

Officially, according to the World Health Organization, perinatal loss corresponds to the period of death that occurred during the pregnancy starting from the 28th week of pregnancy until the first 28 days of the child's life. A death occurring before the 28th week of pregnancy is considered an abortion, while after that time is considered a stillbirth (World Health Organization, 2016).

On a societal level, the term “perinatal loss” includes further and different definitions and situations, and the entire emotional and psychological vortex in which parents are overwhelmed (Molinié & Hureaux, 2012; Verdon et al., 2009). It can include the circumstances of miscarriage, stillbirth, neonatal death, voluntary and medical interruption of pregnancy and death due to complications developed in the mother or child during pregnancy or after birth, up to the first months of the child's life (Chan, 2011; Verdon et al., 2009).

Furthermore, the causes of the child's death are varied and they can include: a birth defect; preterm birth and low birth weight; Sudden Infant Death Syndrome; malnutrition and pregnancy complication (such as high blood pressure, gestational diabetes, infections, preeclampsia, altered placenta development, etc.) (“What causes infant mortality?,” n.d.).

Worldwide, annually the number of children who died in the first 4 weeks of life is around 3 million and approximately 2.6 million died during the third trimester of pregnancy, most of them in low and middle income countries (Ezechi & Odberg-Petterson, 2012; Lawn et al., 2016).

In particular, in France, where our research was conducted, according to INSEE, the infant mortality rate per 1,000 births in 2018 was 3,8 (“Taux de mortalité infantile en 2018 | Insee,” 2018).

Although certainly much lower than in the past, despite scientific discoveries and new technologies, these data confirm that child loss is an event that is still very frequent in our society.

An article by Flenady et al. (2011) on the study of causes and percentages of stillbirth in high-income countries has shown that many of the reasons that led to the death of the child are predictable and therefore avoidable. These include: obesity (one of the main risk factors for various diseases and negative health conditions on a global scale); the age of women; primiparity; smoking (active and passive) and the consumption of drugs and alcohol (Flenady et al., 2011). The age of women (> 35) is considered an independent variable associated with stillbirth since advancing age is a general risk to women's health (for example, it can affect obesity, diabetes, infertility, etc.) (Flenady et al., 2011; Woolner & Bhattacharya, 2015).

Furthermore, women living in disadvantaged conditions and poverty have higher birth and mortality rates, probably due to the difficulty of obtaining specialized medical care and assistance.

Guidelines and specific preventive programs for risks of pregestational and gestational medical disorders could be associated with lower rates of stillbirth and a general improvement in women's health in high-income countries (Flenady et al., 2011).

The absent of funds, adequate and accessible structures and the lack of recognition of physical and psychological consequences can be some of the reasons why the prevention of stillbirth is still limited. Even though perinatal loss has accompanied humankind since ancient times, it has only been since the 60s and 70s that the possible consequences on bereaved parents have been studied (Bacqué et al., 2018a; Bacqué et al., 2018b).

This interest has been fostered by various social and cultural factors: a greater school education; increased medical supervision over pregnancies and birth; openness in being able to discuss grief and personal crises; numerous publications; more widespread media attention and the growth of supportive therapeutic groups (Toedter et al., 2001).

Despite the developments in many disciplines (medical, nursing, psychological, sociological, anthropological, etc.), perinatal loss still represents a taboo: the death of a child generates social and cultural banishment. The same research is very often contradictory, testifying how a full knowledge and understanding of this tragic and devastating phenomenon is still difficult and incomplete.

A cloud of uncertainty and ignorance has accompanied perinatal loss since its scientific dawning, such as Deutsch's psychological theories. According to these theories, infertility was due to unconscious unexpressed conflicts and the child's death to an unconscious desire for death, to an expression of repressed aggression, to an ambivalent maternal relationship or to a compulsion to repeat a traumatic spontaneous abortion (Leon, 1996).

Modern medical studies have discredited these theories, attributing the causes of losses and infertility not to psychological disorders, but to medical and physiological reasons. Marginalizing the psychoanalytic theories, thus denying the role of unconscious conflicts and their causal connection,

it is possible to affirm that psychological aspects, such as stress, can influence the physiological systems linked to reproduction, understood as the result of a psychosomatic expression (Idem).

In psychological terms, perinatal loss remains a unique and specific grief. If it occurred during pregnancy, the object of parental love has never lived, and parents have not had time to build experiences and memories with their child (Haussaire-Niquet, 2003). The moment when parents come into contact and know their child is the same in which they have to greet him and say goodbye (Bacqué & Merg, 2013). This loss marks "a discontinuity in the course of personal and family history", directly and indirectly investing each member of the family (Haussaire-Niquet, 2003).

Conception and the project of having a child implies a concept of transmission. The child marks the continuation of life, lineage, and the best parts of the self, thus subtending an unconscious resurrection quest. The child's death, described as an amputation, thus entails the narcissistic loss of the parent and his or her own identity and expectations (Hanus, 2001).

Leon (1996) identifies perinatal loss as a different grief, impossible to compare to the death of a husband or a parent. It is characterized by the interaction between the imaginary and real child and by the acceptance of the latter one (Hanus, 2001).

According to the author, rather than remaining focused on the rigid Freudian model, or on the psychic disinvestment from the object of love and on the narcissistic and conflict effects, we must focus on its uniqueness (Molinié & Hureaux, 2012).

Beginning in the last trimester, perinatal attachment assumes an increasingly strong connection, both in the mother and in the father (Leon, 1996; Uren & Wastell, 2002). The child becomes a separate entity that determines an investment in object relations. Research shows how the fantasies and images that are constructed in the parent's mind during pregnancy determine the parent's vision of the child for the first six months of life (Leon, 1996).

Contrary to what was expressed for example by Deutsch (Deutsch, 1945), according to whom the child could not be the object of love as a fantastic product of the mother's psychic life, current research has highlighted how the suffering that derives from perinatal loss is not less than the grief for a spouse, a parent's death, etc., confirming Leon's theories (Zeanah, 1989). The attachment to the child does not begin at the time of delivery, at which point the mother already has the feeling of knowing her child, but it is modeled from the design of conception, from imagining and assigning a place to the unborn child within the nuclear family (Robinson et al., 1999). The degree of investment and the affection for the child is therefore not determined by the length of the period of pregnancy or by the physical presence after childbirth.

According to several authors, there are nine stages that characterize the phases of a mother's attachment, that is: the planning of pregnancy and the decision to have a child; the confirmation of

being pregnant and of becoming a mother; acceptance of pregnancy; feeling the baby's movements in her uterus; the acceptance of the fetus as a single and separate entity; the birth; seeing the child with her own eyes, knowing him, holding him and taking care of him (Bennett, et al., 2005; Peppers & Knapp, 1980). Furthermore, thanks to new technologies, the modern ultrasound immortalizes the child in a clear and detailed way, preparing and helping the parent to know the child, to associate own fantasies, feelings and kinesthetic sensations to a real person (Leon, 1996; Sani et al., 2019).

In addition to a greater scientific knowledge, recent studies have influenced and fostered more attention to the bereaved parent, visible in the different sectors with which the parent interacts (legal, medical, psychological, etc.). For example, in many hospital institutions professionals are trained to deal with such emergencies, with specific protocols to accompany the parent in an efficient and empathetic attitude. Listening, respect and providing detailed and clear information before and after delivery are some of fundamental qualities required and appreciated by parents in this situation (Cacciatore et al., 2008; Coffey, 2016; Ellis et al., 2016). Some mothers have said that hospital reception is seen as a fundamental support to mitigate suffering for the loss (Cacciatore, 2013; Shakespeare et al., 2018).

In many cases, hospitals work to collect prints, pictures, dresses, locks of hair, stuffed animals, etc. These memories are then gathered in what is called a "memory box", a personalized box for the parent with all the baby's objects inside.

There is sometimes also a collaboration with professional photographers from some associations (such as the Dutch 'Make a memory') who arrive in the ward to immortalize the child, alone or with parents.

Pictures can help the work of mourning, validating the loss and transition of parental identity following death. In fact, they can act as a ritual, accompanying the parent's emotional and cognitive processes and the social recognition of the child's existence, providing a narrative that can be shared with the community. The symbolic representations of the pictures can also weaken the parent's defense mechanisms, through a "more immediate access to important feelings and memories" (Blood & Cacciatore, 2014).

Furthermore, according to protocol, the parent is allowed to see and hold the baby. It is important for the hospital staff to respect the parent's choice and to be aware that their verbal and non-verbal attitude can be understood and perceived by the bereaved parent. When the professional indicates a personal judgment to the desire to see the child, considering it abnormal or 'inconceivable', the parent can feel a sense of isolation, fear and closure (Cacciatore et al., 2008; Molinié & Hureaux, 2012; Zeanah, 1989). Fathers have a greater chance of wanting to hold the baby in their arms based on higher gestational age, shorter time interval between antepartum death and delivery and a mother's



decision (Hennegan et al., 2018). The choices of the woman in the hospital can be influenced by various factors, such as attachment to the child, coping style, available time to make decisions, previous perinatal loss and the quality of hospital care (Bennett et al., 2008).

Giving a name to the child, expressing emotions and memories and organizing a funeral rite can help the bereaved parents to metabolize the loss and get in touch with their feelings (Stirtzinger & Robinson, 1989). The rituals that take place around the body have always assumed a supportive function, "mediating pain and facilitating a symbolic connection with the deceased" (Cacciatore et al., 2008). It is necessary to allow the parents and the whole family to know the child, to memorize and insert him in the family biography, supposing a prenatal attachment with the child, and providing greater attention to the parent's needs (Üstündağ – Budak et al., 2015).

The death of a child is one of the most devastating experiences (Bogensperger & Lueger-Schuster, 2014). As mentioned previously, it is an event considered "against nature", against the cycle of normal life, according to which the elder is to die before the young and not the opposite (Cacciatore, 2013). Within society, the parental role assumes an exclusive and dynamic connotation: a parent has unique functions and responsibilities toward a child, impossible to recognize in any other cultural roles of our community. Following the death of the child, the parent can experience a sense of emptiness, failure and misunderstanding of the world that was previously considered safe and predictable. Anger, despair and total disorientation can also involve the most personal aspects of the individual, such as his/her own values, desires, representations and rules (Braun & Berg, 1994).

According to Schwartzberg, "the primary challenge faced by trauma survivors is how to reinscribe meaning to life and their place in the world" (Schwartzberg, 1993). Following a trauma, such as a loss, the individual's resilience and effectiveness depend on the meaning that the subject attributes to the event. The perception of a lack of control, of inconsistency and uncertainty derives from the mismatch between the interpretation of what has happened and the codification of external reality (Uren & Wastell, 2002). Research shows that people who perceive the world as controllable are at risk of major implications as a result of traumatic events.

In a totally incomprehensible world, the bereaved parent tries to give meaning to the event and re-establish a logic, a process Neimeyer called the "sense making" (Neimeyer et al., 2002; Uren & Wastell, 2002). Sense making corresponds to the reconstruction of meaning, to the cognitive processes that lead the person to understand and conceive of the event, its causes and consequences (Bogensperger & Lueger-Schuster, 2014).

Some parents report that the exhausting search for meaning is an almost unbearable and very difficult task, especially given the total absence of social support perceived in numerous cases (Cacciatore, 2013; Neimeyer et al., 2002; Uren & Wastell, 2002).

Those who succeeded in understanding the significance of the event experienced greater satisfaction in the relationship with their partner, greater contact with the child, better physical health and lower levels of stress and the risk of complicated grief. Parents who claim to have accepted death report having changed their life perspectives, conceptions about the different meanings of events, priorities of life, and sense of altruism and self-confidence (Cacciatore, 2013).

Grief therefore requires a reinterpretation of the event, a recovery and reformulation of reality and its consequences. Being able to give meaning to events is closely related with the person's attachment type. Subjects with a secure attachment style will have a greater and more adaptive resilience (Uren & Wastell, 2002). For Antonovsky, a person's coping depends on the sense of coherence (SOC). The definition of SOC is defined by three simple basic principles, namely: the perception that internal and external stimuli can be explained; the existence of available resources to deal with the requests coming from these stimuli; and the idea that stimuli are simply another challenge that the person has to face. Being able to understand and apply SOC is typical of a secure attachment style. SOC is a protective factor for the individual, which limits the possible onset of psychological disorders (Uren & Wastell, 2002). The safe basis of caregivers helps the child to develop a sense of manageability and understanding of the world, fundamental for growth and future interactions with the environment (Antonovsky, 1993).

What helps the parent to find meaning of the event, of one's own self and of life is the person's perceived level of social support, the activities carried out, their beliefs and values, the connection with the lost child and the keeping alive of his or her memory (Wheeler, 2001).

In perinatal loss it is fundamental for parents to make sense of what has happened and to affirm the existence of the child through testimonies and intimate memories, as a further confirmation of the uniqueness of this kind of loss. The death of a child during pregnancy or after the birth is indeed the only case in which the parent has to "prove" the existence of the child (Uren & Wastell, 2002).

The perception and the way in which the parent experiences perinatal loss therefore depend on a set of fundamental, psychological and circumstantial processes that determine its consequences, risks and possible comorbidities. The set of factors described lead the person to face grieving and to live normative or pathological conditions of different natures and durations.

### 3.2 The health consequences of bereaved parents

Perinatal loss is a critical event and the consequences that parents can develop following such a tragedy can be multiple and durable, such as anxiety disorders, depression, complicated grief, obsessive-compulsive disorder, suicidal ideation and substance abuse (Bennett et al., 2008; Bogensperger & Lueger-Schuster, 2014; Cacciatore, 2013; Fernández-Alcántara & Zech, 2017; Rogers et al., 2008; Zeanah, 1989).

Complicated grief can be diagnosed over the next five years following the loss, particularly in women, as well as anxiety, which can last up to four years after death (Dyregrov & Matthiesen, 1987a; McSpedden et al., 2017).

There are several factors that can contribute to the development of anxiety disorders, such as: age (being more mature is considered a risk); perceiving that the partner is reacting better; and difficulties of communication and support that can emerge within the couple, any of which can cause a further sense of solitude and insecurity (Dyregrov & Matthiesen, 1987a).

In addition, a greater level of anxiety was found in the three years following loss in parents who had to wait 24 hours or more between diagnosis, childbirth and viewing the child (Hughes & Riches, 2003). Anxiety can be divided into psychic and somatic symptoms. Psychic symptoms include feelings of apprehension, fear, and a tendency to worry excessively, while somatic symptoms present palpitations, sweating and feelings of stress (Carter et al., 2007).

In some cases, particularly on the day or around the days of loss, or in a subsequent pregnancy, women may also experience panic attacks, palpitations, difficulty breathing, dizziness and sweating (Idem). The risk of depression may depend on individual and situational factors, such as: sex; religiosity; psychological support; the time of death and, according to some research, the age of the child (Hogue et al., 2015; Wijngaards-de Meij et al., 2008, 2005). An additional support and protection factor for the parent's possible depression is the presence of other living children within the family unit (Jenewein et al., 2008).

According to attachment theory, the consequences of death depend on the style of attachment that determines the disorders and comorbidities, such as complicated grief, anxiety, depression and somatization troubles, typical of anxious-avoidant attachment (Nazali & Yildirim, 2017). In fact, the repression of one's own pain (typical of the latter) can cause physical problems, such as: back problems, nausea, digestive disorders and headaches, even for two years following the child's death (Wayment & Vierthaler, 2002).

Parents experience sadness, guilt, anger, somatic symptoms (on the cardiovascular level, sleep disorders, lack of appetite, headaches and dizziness), dissociation and aggression (Gemma & Gemma,

2008; Fernández-Alcántara & Zech, 2017; Murphy et al., 2014; Rogers et al., 2008; Scheidt et al., 2012).

The human reproductive function fosters a sense of omnipotence, immortality and control. For this reason, the guilt and failure that follow perinatal loss can be considered defense mechanisms to mitigate the harm to one's narcissistic instincts and self-esteem, providing an imaginary comfort of regaining control of the situation (Leon, 1996).

The sense of guilt felt by the parent, particularly after death in utero, is stronger than the loss of an older child or adult. This is because, over time, the awareness of not being able to have total control over the outside world, over situations and over the child intensifies gradually.

In perinatal loss and especially in cases where the reasons for death are unknown, it is common for women to feel responsible for not being able to protect the child, considering her own body as dangerous and injured, causing a crisis of identity and of her role as mother and woman (Bennett et al., 2008; Cacciatore, 2013; Carlson, 1993; Frost & Condon, 1996; Hale, 2007; Leon, 1996).

The dissociation can instead be seen as a way toward defense and adaptation, with the aim of conserving the energies and resilience skills of the parent for when they will eventually be able to face the grief, too painful and psychically risky at the beginning (Murphy et al., 2014).

Furthermore, dissociative symptoms are associated with a disorganized attachment style in which the traumatic event of loss leads to the reactivation of the maladaptive and controlling strategies that characterized the development of the individual (Onofri & La Rosa, 2016).

Aggression, hostility and escape-avoidance patterns (such as sleeping a lot and consumption of alcohol and drugs) can also be considered distracting mechanisms used by the parent to try to manage traumatic memories (Carlson, 1993; Murphy et al., 2014).

Psychiatric and somatic symptoms that develop as a result of the loss may persist for years, particularly in women. Research shows that a high percentage of women (or 25%) are at risk of developing psychological disorders such as depression, anxiety and PTSD (Bennett et al., 2008; Hazzard et al., 1992; Murphy et al., 2014; Scheidt et al., 2012). Moreover 17% of bereaved parents are diagnosed with a PTSD one month after the child's death, an incidence that diminishes to 9% after the next 3-12 months (Christiansen et al., 2013). Women with a PTSD diagnosis may show signs of hyperarousal and the avoidance of places related to the child (such as the hospital where they gave birth or meeting other pregnant women and little kids), which can further damage their social functioning (Carter et al., 2007).

An insecure attachment style, coping strategies focused on maladaptive emotions (such as rumination) and an unsatisfactory perception of social support are considered three important

predictors of PTSD. These three aspects interact and affect the psychological outcome of the bereaved parent (Christiansen et al., 2013; Scheidt et al., 2012).

In addition to PTSD, maladaptive coping strategies are also related to a greater risk of diagnosing depression and anxiety disorders (Bennett et al., 2008).

Furthermore, after a stillbirth, there are several conflicting studies concerning knowing the child. According to some of them, holding the child can favor the development of anxiety, depression and PTSD disorders, especially in the three months following the event (Hennegan et al., 2018; Robinson, 2014) or during the subsequent pregnancy (but only for a transitory period) (Cacciatore et al., 2008; Hughes & Riches, 2003; Molinié & Hureaux, 2012; Sani et al., 2019). According to others, seeing and touching the child, having the possibility to say goodbye (such as the exposure of the body to the house, according to Dutch culture), are protective factors, associated with lower levels of anxiety and depression for the two years following death (Cacciatore et al., 2008; Kingdon et al., 2015; Reynolds, 2004; Wijngaards-de Meij et al., 2008). Contact with the real child can, therefore, mitigate the levels of grief, providing a comfort in the process of recognition and acceptance of death (Sani et al., 2019; Wijngaards-de Meij et al., 2008).

From the stories of mothers' experiences, it has emerged that they have often felt themselves obliged by social pressure to 'move on', to forget and to immediately have another child, perceiving their grief as ridiculed and minimized (Cacciatore, 2013; Sani et al., 2019).

Without any gender difference, both parents have worse health, especially in cases where the child has died in violent circumstances (Song et al., 2010). Parents who have lost a child due to a traumatic death, to an unexpected death and to an illness, show more intense symptoms of grief than stillbirths or neonatal losses (Wijngaards-de Meij et al., 2005). These results could be a confirmation of attachment theory, according to which the development of attachment to the person depends on "learning from mutually satisfying experiences and sharing" (Wijngaards-de Meij et al., 2005). Without diminishing the pain of parents who have lost the baby during pregnancy or in the neonatal period, a hypothesis for the greater intensity of grief's symptoms is that the parental attachment increases with the age of the child, at least in the first childhood. Moreover, those who have lost a child through an unexpected death declare that they are no longer able to perceive a situation of security and trust in the outside world (Idem).

We must not forget that intrauterine death is an emotionally complex situation characterized by a set of risk factors present at the same time, such as: the sense of impotence; the total dependence of the child; the sense of guilt; doubts and torments and an enormous sense of loneliness (Barr & Cacciatore, 2008; Sani et al., 2019; Schaap et al., 1997). Even in cases where the pregnancy is interrupted for medical reasons, the guilt of the parent is a fundamental aspect that characterizes

grief. This sense of guilt and self-accusation matches the concerns and agitations felt by parent during the subsequent pregnancy (Hanus, 2001; Sani et al., 2019).

Furthermore, following a perinatal loss, parents present a higher risk of mortality, even thirty-five years after the child's death, of oncological diagnosis and psychiatric hospitalization, especially in women during the first year after death (Bogensperger & Lueger-Schuster, 2014; Harper et al., 2011; Youngblut et al., 2013).

### 3.3 Risk and protection factors

As seen previously, the risks that may arise following the death of a child are different, with consequences, timing and repercussions that can affect the person, partner, family and friends.

Predictors of uncomplicated and pathogenic grief are: the sex of the parent; the parent's level of education; social support; having experienced a critical event during pregnancy (like a bereavement, a separation, economic problems, etc.); the type of loss; the relationship with the partner; the presence of other children; previous psychiatric diagnoses; having experienced other perinatal losses; the age of the child; the duration of mourning and sense-making (Hughes & Riches, 2003; Keesee, et al., 2008; Mancini & Bonanno, 2009; Rozalski et al., 2017; Wijngaards-de Meij et al., 2005; Zeanah, 1989).

There is contrasting research regarding whether age can be considered a risk factor. Some also include the additional predictive factors of: difficulty in conceiving; the sex of the child; socio-economic status and religious observance (Dyregrov et al., 2003; Hughes & Riches, 2003).

According to attachment theory, the person's attachment style is considered a predictor of the consequences of grief: in secure attachment, the positive representations that the bereaved person retains of the deceased, real or idealized, can help to overcome the pain, while in ambivalent attachment, the subject desires and rejects the object of love, experiencing an enormous difficulty in accepting the permanent separation and risking the development of chronic or prolonged grief (Bonanno & Kaltman, 1999). Those with an insecure preoccupied attachment present a greater risk of developing the disorders of complicated grief, depression, anxiety, PTSD and somatic disorders (Bennett et al., 2008). A secure attachment is a source of resilience, allowing the person to better manage grief and its consequences in a more flexible and less stressful way (Scheidt et al., 2012; Shear & Shair, 2005).

Moreover, the child's death can lead to communication, relational and support difficulties within the parental couple, causing in some cases separation (Carlson, 1993; Murphy & Cacciatore, 2017; Najman et al., 1993).

In addition to the couple level, problems can also arise with respect to wider social contexts, such as friends and family. Bereaved parents can feel the sensation of not being understood and that their pain is not respected or recognized, producing a sense of isolation and social withdrawal (Bennett et al., 2005; Stirtzinger & Robinson, 1989).

There are conflicting results with respect to social status. According to some research, being a single parent or being married does not influence any reactions to loss. Being a couple is therefore not considered a resource or a protective factor for the child's death (Lohan & Murphy, 2007). According to others, however, not being married is instead identified as a risk factor (Campbell-Jackson & Horsch, 2014).

It is essential to identify the protective factors that can help and support the person. An example of a protective factor is giving the mother all the time necessary to spend with the child (Radestad et al., 1996). There are no differences with respect to the length of time spent with the child and the presence of anxiety disorders in the following three years. Anxiety, however, exists in higher levels in mothers who felt the need and wanted more time to spend with their child (Hughes & Riches, 2003). Healthcare personnel must be trained to listen to and respect parental needs. We must not try to impose any ritual but, on the contrary, be flexible towards the person, the situation and the timing (Radestad et al., 1996).

A considered protective factor in perinatal loss is the perception of a partner's support with respect to the risk of developing depressive disorders following death (Song et al., 2010).

Within the nuclear family, commitment to the family, perceiving life and difficulties as challenges can be strengths, aspects of resilience and adaptation of the parent to a new life and condition (Greeff et al., 2011).

The support of friends, family members and psychotherapy are also fundamental. Following the loss, it is important to try to redefine the crisis situation, which that requires a certain commitment and cognitive development -for this reason, the parents must try to support and help the living children in their grief- (Bennett et al., 2008; Greeff et al., 2011).

The support of family and friends is in fact essential for an emotional and sentimental need and at a practical level as well (as for organizing the ceremony or alleviating some of daily life's tasks that become a burden following a loss) (Neria & Litz, 2004; Stroebe & Schut, 2001).

The factors that can influence the resilience are different, such as: the type of attachment; religious beliefs and the presence of positive emotions and memories. These factors can contribute to the way in which the person copes with loss and overcomes and accepts the child's death.

Research shows that spiritual beliefs are a supportive and protective factor in cases of loss. Bereaved people who consider themselves as "believers" and who are able to perceive religious comfort tend

to solve and perform the work of mourning more quickly (Rogers et al., 2008; Thearle et al., 1995; Walsh et al., 2002). Being a religious or spiritual person (i.e. going to church, seeking contact with nature, music, etc.) are therefore considered important coping strategies (Greeff et al., 2011). In some cases, however, perinatal loss also causes an internal spiritual crisis: parents declare that being able to maintain their beliefs and their faith is unbearable, they can no longer trust an entity that has taken away their child or that made an innocent being die (Gemma & Gemma, 2008; Nuzum et al., 2017). The stress theory emphasizes the subjective evaluation of the event and the situational difficulties of the person, which corresponds to the primary evaluation. Subsequently, the person analyzes the situations, understanding how to move away or eliminate the source of disturbance and re-evaluating meaning. Compared to the stress theory, avoidance is considered as a defense mechanism and adaptation that helps the bereaved person to temporarily retreat from the sources of pain, facing them later in a more opportune moment (Bonanno & Kaltman, 1999).

Coping strategies, regulators of psychosocial adaptation of the person, can therefore include escape, concern for the child and directing one's feeling towards a new object of love. The latter mechanism, in addition to a sense of altruism and religious beliefs, has been associated with a lower risk of depression (Videka-Sherman, 1982).

Some styles of coping, like reflection, are quite maladaptive after a loss. Even if emotion-centered coping is considered more effective than that one centered on the problem, it's better to be able to use both (Neria & Litz, 2004).

Furthermore, perceiving control over the situation and maintaining a sense of self-esteem have a moderating effect. As seen before, sudden losses led to poor well-being in bereaved people with low self-esteem and greater depressive and somatic symptoms than those who expected death and felt they had more control (Neria & Litz, 2004; Hill et al., 2017).

It is therefore important to remember to recognize the meaning of the loss, having obtained all the necessary information, to have the opportunity to see and touch the child according to personal needs, and to follow a psychotherapy regimen to achieve support for the bereaved parent (Stirtzinger & Robinson, 1989).

The work of mourning is the result of an interpersonal and relational psychic interaction. It is the functional set of these factors that allows the person to avoid serious psychological risks and consequences following the loss. It is therefore important for professionals to be able to understand the risk factors of the person and guide them towards specific and targeted help.



### 3.4 Gender differences

In addition to the many previously described consequences that the loss of a child in the perinatal period may involve, it is also important to underscore parents' differing reactions. The discrepancies in the expression of mourning are noteworthy, revealing how gender is a factor influencing the experience of loss (Wing et al., 2001).

According to evolutionary and attachment theory, mothers, who invest more time and resources in the fetus, would be more related to the child, experiencing more consequences and greater pain (Wijngaards-de Meij et al., 2005). Women declare that the return to 'normality' is more difficult, not only in terms of mental suffering and pain, but also in their routines and daily lives: it is generally the mother who takes care of the child and its nourishment, especially when he is very young (Cook, 1983).

Unlike men, women suffer more and for a longer period of depression, anxiety disorders, PTSD and complicated grief (Armstrong et al., 2009; Scheidt et al., 2007; Wijngaards-de Meij et al., 2008, 2005).

Generally, the symptoms decrease during the first year after the loss, although one-fifth of the women maintain the symptoms even after the first twelve months (Armstrong et al., 2009; Boyle et al., 1996; Hughes & Riches, 2003).

In addition to frequently requesting medical examinations over the next five years, women have more physical illnesses and greater risks of hospitalization for psychiatric disorders.

In both parents, disproportionate stress levels are recorded compared to control groups. In addition to influencing lifestyle, alcohol and tobacco consumption, diet and physical activity, stress can also lead to an increase in mortality rates (in particular in women and in both parents up to 35 years after the loss of the child) (Li et al., 2003).

Although with less severe and prolonged symptoms, fathers have more difficulty sleeping, more emotional distress and consumption of alcohol - while mothers are more inclined to take tranquilizers during the first months after loss- (Hughes & Riches, 2003; Vance et al., 1995; Vance et al., 1995).

The pain and grief of fathers is often underestimated and unrecognized (Due et al., 2017). Because they did not hold the child in the womb it is assumed that their perinatal attachment is inferior and more superficial than the maternal one. Contrary to these assumptions, even if with different reactions and less pathological disorders, the fathers experience a pain and an attachment similar to the mothers (Bennett et al., 2005; Schaap et al., 1997; Turton et al., 2006).

Moreover, the vision of the child through 3D images and ultrasound scans can influence this link: fathers who have 'seen' the child with very vivid images presented higher levels of grief than those

with a minor relationships with the child (Brier, 2008; Büchi et al., 2007; Johnson & Puddifoot, 1998; Klier et al., 2002).

The advance of pregnancy and contact with the child thus contribute to the increase of the bond and paternal affective attachment. Although to a lesser extent, fathers who lost their child during the third quarter presented higher and more severe PTSD levels compared to losses in the second quarter (Christiansen et al., 2014).

Bereaved fathers usually react differently from mothers. Often men feel that they cannot express their pain because this could harm the “fragile and vulnerable” woman. The social role of the male figure is to support the mother who, after a more "direct" relationship with the child, is supposed to suffer more than the father.

However, research shows that hiding one's own feelings to protect the other parent not only causes an increase in one's own pain but also that of one's partner, following a dynamic interpersonal process that is prolonged over time (Stroebe et al., 2013).

Furthermore, in addition to suffering, the ways in which the person lives and shares grief can also influence a post-traumatic growth (Büchi et al., 2009).

Some men feel unable to handle the situation, and to help the partner. This sense of frustration can make the husband more agitated, irritable and grumpy, increasing the sense of loneliness, lack of support, and emotional distance from the partner (Stirtzinger & Robinson, 1989). The woman can experience their partner's need for loneliness as a sign of insensitivity, and at the same time the man can perceive the emotional behavior of the wife as an intrusion, reacting with impatience or distance (Carlson, 1993; Dyregrov & Matthiesen, 1987b).

Furthermore, a sense of guilt can increase when one parent perceives that the partner considers her/him responsible for the child's death or views him/her as not being close enough at the time of death or illness (Dyregrov & Matthiesen, 1987b; Stirtzinger & Robinson, 1989).

Generally, the sense of maternal guilt is superior, as the woman perceives her body as injured and often she blames herself for not being able to carry on the pregnancy or to protect the child (Gold et al., 2018; Wing et al., 2001).

The different expressions of pain and high levels of anguish in one of the two partners can also cause marital dissatisfaction (Cacciatore, 2013). Fathers say they are aware of advancing in grief more quickly than women, particularly in the first few months following the loss. In spite of their improvement, they perceive that difficulties and family imbalance are evident throughout the year following the child's death (Hughes & Page-lieberman, 1989).

Difficulties in communication or unperceived support can also emerge in the form of sexual problems (Büchi et al., 2009; Schwab, 1998). 60% to 67% of bereaved parents experience a period of reduced

or absent sexual activity after the death of a child. They associate sex with the memory of conception and translate the perception of the partner's lack of support and the sense of guilt addressed to oneself or the other in sexual conflicts (Dyregrov & Gjestad, 2011; Wing et al., 2001).

In particular, the woman tends to experience sexual intercourse as a betrayal of the child, interpreted as an act of new procreation, of pleasure, and seen as incoherent in this moment of pain (accompanied by a strong sense of guilt). Instead, the father tends to view sex as a means of obtaining comfort, using contraceptives with a sense of relief for fear of losing another child, fostering the partner's anger (Cacciatore, 2013; Carlson, 1993).

Not all couples who have experienced a loss end their relationship with divorce or separation. Many parents say they felt closer to their partner after the tragedy (Avelin et al., 2013; Klass, 1987; Schwab, 1998).

Furthermore, the coping strategies utilized by the two parents are different. Generally, men tend to use the coping style centered on the problem (restoration-oriented coping), exercising greater control over the expression of painful emotions or through maladaptive strategies, such as negation, the use of substances or aggressive behavior. On the other hand, women use more expressive and affective forms of coping (loss-oriented), with feelings and actions centered on the relationship with the child, or both coping styles (Klier et al., 2002; Neria & Litz, 2004; Stroebe & Schut, 2001; Ware & Raval, 2007; Wijngaards-de Meij et al., 2008; Wing et al., 2001). The coping strategies implemented by men are also linked to those of their wives: the more the woman is oriented toward the reconstruction of her own existence (that is to the restoration), the more the values of depression and grief of her husband are inferior (Wijngaards-de Meij et al., 2008).

Being able to be flexible between the two coping modalities has a positive effect in parents' meaning-making. On the contrary, being exceptionally focused on a single strategy (in particular loss-oriented) risks producing negative effects (Albuquerque et al., 2017).

Moreover, even with symptoms similar to those of women - who express more feelings, through crying or seeking help and support - men are more inclined to look for a logical explanation and to internalize their grief. Fathers tend to deny their pain, especially the first two years after the loss, focusing on practical and bureaucratic issues (such as the funeral or working more) and controlling their emotions to support their wives (Carlson, 1993; Kersting et al., 2011; Stinson et al., 1992; Wing et al., 2001).

At the same time, the woman's lack of comprehension and loneliness with respect to the partner's emotional and supportive expression can influence and promote maternal depressive reactions (Beutel et al., 1996).

In contrast to fathers who rationalize and deny their grief, mothers tend to seek more support from their friends, generally expressing their emotional distress openly and explicitly and for longer periods (which can reach two-three years, compared to eight months for men) (Cacciatore, 2013; Schaap et al., 1997; Vance et al., 1995; Zeanah, 1989).

Furthermore, mothers say that after the tragedy they have reevaluated and reconsidered the importance and the quality of social relationships (Jenewein et al., 2008). The perception of comfort changes after the loss and in many cases, unlike the man, the woman views social support as superficial or non-existent, perceiving less support from the family and friends than the partner (Dyregrov & Matthiesen, 1987b).

There are several hypotheses that can explain and identify the causes of these differences. They could in fact be due to: differences between mothers and fathers in the bond or in attachments with the child during development; the various reactions to stress and coping strategies of the two genders; or the different social roles imposed by the community, which could influence socialization, emotional expressiveness and identity configurations (Vance et al., 1995; Wing et al., 2001). According to parents, the gender differences perceived in grief and the consequences of loss decrease over the course of twelve-fifteen years following the death of the child (Dyregrov & Dyregrov, 1999).

Moreover, what the fathers experience can be considered as a "double bond": they live the social pressure of having to support the partner and the request for emotional expression of mourning. The reaction response may be delayed due to external requests that add up after this tragedy: taking care of other children; arrangements for the funeral ceremony; keeping the family income, etc. Men are more reluctant to participate in support groups and, not finding emotional feedback in their peers, they tend to live their suffering alone or to deny it. In the hospital, holding the child, psychoeducation and encouraging rituals for shared memories can be fundamental early interventions for both parents and resources for any possible negative prognosis (Cacciatore & Flint, 2012; Crawley et al., 2013).

## **Chapter 4: The reactions of the bereaved family**

We have seen the consequences of a child's loss in the perinatal period for the parents, but it is essential to underscore and remember that grief does not involve only them, but all the members of the family.

With the term family we refer to the components of the primary nucleus: that is, children and grandparents.

The death of a child can produce consequences in the previous and subsequent siblings. Furthermore, the loss of a grandchild can also pose risks for grandparents, who experience a grief often forgotten and not considered.

### **4.1 Sibling reactions**

Perinatal loss affects every member of the family. Within the nuclear family, the same loss involves different reactions and feelings, depending on the age, role, personal experiences, etc. The unexpected event does not allow either parents or children to be prepared for loss (Hutton & Bradley, 1994). The grief can therefore provoke consequences in surviving siblings. Like the parents, the children suffer a double mourning: the loss of the child and the loss of their role as an elder brother or sister (Avelin et al., 2011).

According to Leon (2008), girls over the age of 4 years old, projecting themselves into a hypothetical maternal image, could also experience the loss of a desired child, in addition to the loss of a younger sibling.

The consequences and reactions that surround the child within the family are varied. It is important to consider that they depend on many variables, such as children's cognitive abilities, anticipation of the baby's arrival and the way parents cope with loss (Badenhorst & Hughes, 2007).

In fact, children generally follow the methods of elaboration and the manifestations of mourning expressed by the parent, their reference and protection figure (Debra, 2005).

The understanding of the event by the children is gradual and confusing, but not absent (Avelin et al., 2011; Badenhorst & Hughes, 2007). Focused on their own pain, parents may fail to perceive, misunderstand the reactions, or deny their children's grief (Debra, 2005).

Children show their suffering and feelings through actions and expressions that do not conform to those of the adult, for example through games, drawings, metaphors, etc. (Debra, 2005; Leon, 2008).

There are frequent cases of non-specific behavioral problems found in bereaved siblings (Hutton & Bradley, 1994). For example, they can take a resigned, impatient, indifferent or angry attitude (Leon, 2008). As in adults, in severe cases, siblings can then develop complicated grief, depression and

anxiety, sometimes expressed as somatic disorders (such as stomach ache and headache) (Debra, 2005; Leon, 2008).

Based on their cognitive and comprehension levels, it is common for preschoolers to confuse the causality of events, interpreting loss egocentrically - according to their perspective - and through "magical thinking" (Leon, 2008). In fact, children may feel sad and guilty of having killed their little brother by jealousy and by the mixed feelings perceived about his arrival (Badenhorst & Hughes, 2007; Crehan, 2004).

The child's sense of guilt can also be influenced and exacerbated by that of the parent, in the event that the latter considers the sibling responsible for the incident (Hutton & Bradley, 1994).

Children may also be afraid of dying or of a possible parents' disappearance (as that of the little sibling), adopting an overprotective attitude, staging fake funerals or asking many questions about what happens to the body (Crehan, 2004; Leon, 2008; Stirtzinger & Robinson, 1989).

Feelings of anger can be expressed at the parents - who allowed the child to disappear - or against the little sibling (Hutton & Bradley, 1994).

In particular, older children may suffer a profound sense of loss when the excessive pain of a parent could lead the latter to neglect the surviving children (Badenhorst & Hughes, 2007). Research by Pernilla et al. (2014) analyzed the experience of bereaved siblings in a stepfamily. The study showed that children, especially adolescents, perceived that they could not fully live their pain as "strangers" to the parent's family, with whom time is limited and partial. To the loss of the sibling, they mourned the loss of one parent, too distracted and focused on his/her own pain (Avelin et al., 2014; Murphy & Cacciatore, 2017).

Furthermore, bereaved children exhibit greater levels of empathy and attention to the feelings of others than the control groups (Leon, 2008).

Perhaps due to a possible reaction to excessive parental concern, some siblings have major social difficulties after the death (Bellini et al., 2013).

The adult must try to create for the children an environment of participation in which they can feel free to express themselves. It is important that parents are able to show their feelings to make the child understand that his reactions are completely normal (Erlandsson et al., 2010; Hutton & Bradley, 1994; Leon, 1986).

But how to help the child understand what happened? Touching the sibling and being present at the funeral can be a way to realize the event and perceive the deceased little sibling as a real person (Erlandsson et al., 2010; Murphy & Cacciatore, 2017; Søfting et al., 2016).

Parents must be able to explain in a simple way the causes of death and prepare the child for what he will see and hear. A surviving sibling must be reassured that the disease or event that caused the death will not happen to anyone older in the family and that it was not due to something he or she has felt or done (Leon, 2008).

The involvement of surviving children in the choice of the decoration of the coffin, the songs for the funeral and the placement of flowers and candles on the grave can be a set of activities that allow a child to better understand the event, including his own and his parents' reactions (Erlandsson et al., 2010; Murphy & Cacciatore, 2017).

Allowing a child to see the deceased is a decision influenced by the personal feelings and choices of the parents. The reluctance or absence of curiosity about a child's death is generally very unusual. This could be influenced by the rules imposed, implicitly or verbally, by the adults (Leon, 2008). Reading children's stories or fairy tales about death can help children to be able to relate and better understand the meaning of death and loss (Erlandsson et al., 2010).

Relationships between parents and surviving children following death can be complicated. Adults can become more anxious, fearful, overprotective and unable to provide all the attention needed to the living child in this moment of pain (Avelin et al., 2011; Murphy & Cacciatore, 2017). The parent can feel anger over the child's indifferent behavior or difficulty in answering too painful questions (Badenhorst & Hughes, 2007).

In other situations, the child can assume the parental role and worry only about adult suffering. In this situation, the "adult" or "parent" child will become a model of hyper perfection, trying to console the adult (Debra, 2005).

Despite all the problems that grief can involve within the family, the presence of a living child can be of great comfort and help for the adult (Erlandsson et al., 2011). Having already had a child represents for the bereaved parent one of the most important support factors on a psychological and physiological level, for example recording a lower risk of mortality during the following years (Li et al., 2003).

Very often parents seek help and mentorship in comparing their grief and their living children's behavior (Avelin et al., 2011). The support of health workers in the hospital is therefore not only fundamental in a parental perspective but for the entire family network (Erlandsson et al., 2010).

When parents are emotionally unable to concentrate or give their living children the usual attention, it is important that the latter are in a safe environment with people they know and feel comfortable with (for example, uncles, grandparents, etc.). It is important that parents and other adult figures accompany them in their pain, listening and answering their questions honestly (Avelin et al., 2011).

Children must be able to find support and someone to listen to them even outside of the nuclear family. Contact with other children who have experienced the same type of loss and the support of teachers and school are therefore a further priority (Idem).

In addition, individual therapy for children and family are suggested, especially if parents perceive difficulties in relating to the child or some complications in the sibling (Leon, 1986).

#### 4.2 Subsequent pregnancies

Following a tragic event such as the death of a child, what are the reactions and behaviors of the parent toward a subsequent pregnancy? Many parents wish to have another child obsessively (Hughes et al., 1999). Others feel a state of alertness and fear of having to face another loss (Carlson, 1993; O'Leary, 2004). In particular, fathers would often be ready to give up the idea of having a baby rather than risk losing it again (Meaney et al., 2017).

Wondering if the child is healthy, worrying that the subsequent pregnancy will end with a bereavement, feeling a strong sense of insecurity and of guilt are some of the main sentiments that re-emerge in the parents (Campbell-Jackson et al., 2014; Côté-Arsenault et al., 2001). They wait much longer to prepare the baby's bedroom and to feel nervous, excited, frightened and overprotective about their subsequent child (Armstrong et al., 2009; Carlson, 1993).

At the same time, mothers demonstrate less emotion (crying less) and no inhibitions in talking about their deceased child, probably dampening the ambivalent feelings and attachment for the "newcomer" (Côté-Arsenault et al., 2001).

Furthermore, parents do not feel confident about their decision-making skills and they are agitated and skeptical about medical care, not knowing if they can completely trust the hospital (Meaney et al., 2017; Warland et al., 2011).

Although not compromising their emotional investment and relationship with the next child, overprotective parents continue to feel this nervousness even a few months after birth (Armstrong, 2002).

The consequences of grief, such as anxiety and depression, persist in fact during the subsequent pregnancy (Blackmore et al., 2011; Murphy & Cacciato, 2017). The impact of perinatal loss therefore remains constant and does not decrease significantly despite the birth of a healthy child (Blackmore et al., 2011; Gravenstein et al., 2018).

The depressive symptomatology of mothers seems to be associated with strong feelings of self-criticism, interpersonal dependence and the number of previous losses. Instead, anxiety levels depend



on the belief that one's behavior affects the health of the fetus, assuming full responsibility for it (Franche & Mikail, 1999).

Furthermore, research has underlined the presence of other forms of coping implemented by the bereaved parents respect with their anxiety levels, namely: “guarded emotions, marking off or benchmarking the progress of the pregnancy, and individual coping mechanisms such as avoidance behaviors (avoiding foods, caffeine, exercise, alcohol, and additional information) or, on the other hand, seeking-out behaviors (identifying all resources of additional information regarding pregnancy)” (Lamb, 2002).

Most parents become pregnant again during the next twelve months following loss (Lee et al., 2013). This timing is, however, considered a risk factor for the psychopathological conditions of the parent. In fact, having a baby within a year may cause higher levels of anxiety, depression and PTSD and the prolonging of symptoms until the first year of a healthy baby's life (Hughes et al., 1999; Hunter et al., 2017; Rousseau, 1999; Turton et al., 2001; Zeanah, 1989).

Those who expected to feel completely prepared (with respect to guilt, grief, and fear of not being emotionally available to another child) were also more prepared for any emotional challenges of the next pregnancy (Lee et al., 2013).

At the same time, according to other scholars, waiting too long to have another child can increase symptoms of anxiety and depression due to fear of infertility, especially in the three years following death (Murphy & Cacciatore, 2017; Robinson, 2014) .

The differences between the two genders are also tangible with respect to the pregnancy after a stillbirth.

It is confirmed in this case that women generally suffer more from anxiety and depression than men. However, the latter report higher anxiety levels than mothers, if the delay in conception is considered exaggerated, and significant values of anxiety and PTSD (exclusively up to the time of delivery) (Turton et al., 2006).

Furthermore, numerous research reveals how perinatal loss and trauma have influenced the dyadic relationship between mother and child, causing a disorganized attachment style (Armstrong et al., 2009; Heller & Zeanah, 1999; Hughes & Riches, 2003; Turton et al., 2006; Üstündağ – Budak et al., 2015).

During the course of a subsequent pregnancy, parents are confronted with the difficult task of having to bond to the new baby, while also crying over the deceased child (the so-called 'ghost in the nursery') and fearing another loss (Markin, 2018; O’Leary & Thorwick, 2008; O’Leary, 2004).

The new pregnancy can reactivate the pain and suffering of death, and probably for this reason many mothers focus more on the practical aspects of pregnancy, avoiding the emotional experience and perceiving the child as less real (Markin, 2018; O'Leary & Thorwick, 2008).

Anxiety and a deliberately delayed attachment of the mother to the new baby could explain the disorganized / ambivalent attachment style and the numerous symptoms that the child might develop later (Warland et al., 2011).

According to O'Leary (2004), in order to resolve these conflicting feelings with respect to the new child, the parent must be able to mentally identify the two children as separate entities and not as a replacement.

The incapacity of mentalization can therefore be a risk factor for the development of serious problems in prenatal attachment. As expressed by Fonagy et al. (2002), adults with an insecure attachment style are more susceptible to mentalization difficulties. Mothers prone to avoidance tend to evade the feeling of pain and to relate to the new baby with coldness and detachment (Fonagy et al., 2010; Markin, 2018).

At the same time, mothers with an anxious-preoccupied style, who previously experienced death as an abandonment and are overwhelmed by the fear of another loss, can develop a distorted view of the child, not mentalizing him as a separate entity and fostering unrealistic expectations (Markin, 2018). "Exogenous factors such as social support, unrecognized loss within the community, avoidance and delayed grief can affect the maternal attachment with the next child" (Cacciatore, 2013).

In most of the cases, having another child is considered a support factor for parents (Büchi et al., 2007; Cacciatore, 2013). Particularly in mothers, the new pregnancy can support the use of better coping strategies and lower levels of despair (Franche & Bulow, 1999).

Parents who have lost a child have declared a greater need for reassurance during the subsequent pregnancy. Psychoeducation and the support of professionals and partners help them to hope that the pregnancy will end with the birth of a healthy child and to minimize anxiety (Azogh et al., 2018; Hada et al., 2018; Lee et al., 2013).

#### 4.3 Replacement and vulnerable child syndrome

Born in a climate of acute grief in which the new child is the parent's attempt to preserve or make the lost love object live again -to whom the same name is often given-, the next child is virtually suffocated by the image of the deceased sibling.

Often the substitute child tries to be able to satisfy the demands and expectations of the parent with respect to the image of the lost and idealized child, always feeling a strong sense of dissatisfaction and disappointment (Debra, 2005; Vollmann, 2014).

Cain and Cain (1964) coined the term "replacement child" for the first time, indicating the pathological relationship between the hypo-protective parent and the next child. The latter takes on the image of the missing sibling, growing in its shadow and without giving him or herself permission to develop a personal identity (Olson-Garriott et al., 2015; Reid, 2007).

The first studies on the subject of the replaced child were carried out by Streznzcka (1945) and Papanek (1946) with the treatment of Holocaust survivors and their descendants (Schellinski, 2014). In 1964 Cain and Cain published their work "On replacing a child", followed by Poznanski (1972), Sabbadini (1989), Porot (1993) and Anisfeld and Richards (2000) (Anisfeld & Richards, 2000; Porot, 1996; Poznanski, 1972; Sabbadini, 1989)

According to the various authors, a lack of acceptance of loss can determine intense narcissistic investments and the identification and hyper-idealization of the deceased child with respect to the subsequent one (Schellinski, 2014).

The child may therefore have to deal with a non-emotionally available parental figure, risking developing chronic diseases until adulthood (Üstündağ – Budak et al., 2015).

The replacement dynamics can in fact require coping skills unsuitable for a child's immature ego. Moreover, the child born after loss may be inclined to guilt, a transgenerational transmission of grief and morbid concerns (Leon, 1986a; Vollmann, 2014).

The parents may blame the subsequent child for his or her sibling's death, or not be fully emotionally available for fear of having to face another loss.

Siblings born after perinatal loss, to whom the burden of grief has been assigned by the parents before their birth, do not have permission to mourn the previously lost child. Their grief is not recognized, even if they share an indelible and misleading bond (Vollmann, 2014).

The vision of the deceased child could help the parent understand and identify the child as a separate entity from the next child.

Knowing the child thus coincides as a protective factor both for the parents' acceptance of loss and for later consequences on siblings (Carlson, 1993).

According to some authors, the reactions of the parent are part of a normative and asymptomatic framework, not associating this syndrome with a pathological prognosis (Davis et al., 1988; Grout & Romanoff, 2000; Phipps, 1986; Theut et al., 1992; Warland et al., 2011). The emphasis on the deceased child may indeed prove to be an effective way in which the parent includes the child in one's life and family (Grout & Romanoff, 2000). Grout and Romanoff (2000) prefer to use the terms

"replacement of a loss" and "substitutive parenting" rather than "substitution of a person": the next child has the role of filling the space created by loss, personifying the needs and wishes of the parents. Olson-Garriott and colleagues analyzed in particular the paternal grief reactions, highlighting how fathers generally use more "active" coping strategies. Men tend to focus more on the needs of the surviving children and consider the new pregnancy as an opportunity for rebirth rather than focusing on their own pain (Olson-Garriott et al., 2015). Moreover, with the clear representation of the uniqueness of the next child, the attempt to create the fraternal bond between the deceased and the next born child can be considered a further modality with which the parent keeps alive the memory of the lost child (Idem).

A variant of the replacement child's syndrome is the "vulnerable child", a term coined by Green and Solnit in 1964, according to which "parental reactions to an acute, life-threatening illness in a child may have long-term psychologically deleterious effects on both parents and children" (Green & Solnit, 1964).

Parents have a distorted view of the child's health. They constantly anticipate another loss and manifest an overprotective attitude (Badenhorst & Hughes, 2007; Davis, et al., 1989; Turton et al., 2009; Üstündağ – Budak et al., 2015).

Problems of separation, excessive anxiety, individualization difficulties and inappropriate parent behavior with respect to a child's age accompany the latter throughout the course of development (Lamb, 2002).

Hypervigilance and extreme parental concerns therefore risk causing maladaptive behavior (Heller & Zeanah, 1999). In fact, "vulnerable" children report separation anxiety, school problems, sleep disorders, hypochondria, scholastic and attention difficulties. Serious illnesses, premature births, congenital anomalies, diagnoses of anxiety and depression and unresolved losses can be some of the parents' risk factors for the development of this syndrome. The perception of the child's vulnerability can also be influenced by family stress, social support, poor assessment of one's own health and low socio-economic status (Kokotos, 2009).

Furthermore, a symptom of this disorder is a disproportionate request for medical support for the child. Those who have been "vulnerable children" and frequent visitors to the hospital develop more psychological disorders and frequent recourse to health care even in adulthood (Chambers, Mahabeggittens, & Leonard, 2011; Kokotos, 2009).

#### 4.4 Grandparents' reactions

The pain surrounding the death of a child in the perinatal period is often underestimated, not only with respect to parents but to all family members.

The grief of the grandparents is in fact defined as "forgotten" or "double pain" (Gilrane-McGarry & O'Grady, 2011; Murphy & Jones, 2014).

They find themselves experiencing a painful and difficult situation. In addition to their own suffering for their grandchild's death, they also suffer for their own children, for whom they would like to be a support and help, perceiving immense pain and a sense of impotence (Earle et al., 2017; Gilrane-McGarry & O'Grady, 2011).

Their grief is however often not recognized. They are relegated to assume the role of supporters of parents and siblings, without considering the impact the child's death on other family members like them (Bennett & Chichester, 2015).

Like the parent, the grandparent also activates a projective identification and narcissistic mechanisms - which we could define as intergenerational - towards the grandchild. As for the fathers, ultrasounds seem to affect the identification and the prenatal attachment of the grandparents (Harpel & Hertzog, 2010).

Probably for some social preconceptions, we are led to associate the elderly with the one who has experienced numerous losses and who must, therefore, have developed coping strategies, facing the death through stronger and "insensitive" ways, thus producing a further sense of isolation. In contrast to the general imagination, the different experiences of losses faced by the elderly are a risk factor for recovery, coping strategies and resilience skills (Gilrane-McGarry & O'Grady, 2011).

The death of a child is also the loss of the image of oneself as grandparent, of expectations and the beginning of a new life phase. Totally unprepared, grandparents cannot imagine surviving their children or grandchildren (Gilrane-McGarry & O'Grady, 2011; Murphy & Jones, 2014).

Perinatal loss can therefore cause serious reactions and consequences even in grandparents. In fact, research shows that their consequences are not so different from those of bereaved parents, such as: a sense of guilt; bitterness and anxiety; disappointment; anger; shock; loss of energy; inconsolable pain and the risk of increased consumption of drugs and alcohol (Aho et al., 2018; De Frain et al., 1992). Grandparents also perceive the need to commemorate the child's memory and include it in their own lives (Bennett & Chichester, 2015). In addition, although with less emotional reactions than parents, grandparents may develop physical reactions (such as lack of sleep, chest pain and difficulty breathing) and health problems (Galinsky, 2001; Murphy & Jones, 2014).

Also in this case, the differences of gender expressed before are confirmed; grandmothers perceive a greater need to express their pain compared to the grandfathers (Murphy & Jones, 2014; Ponzetti & Johnson, 1991; Youngblut et al., 2010).

In addition to individual reactions, loss can cause relational changes within the family. The bereaved parents could be too focused on their own grief and unable to recognize the grief of one of their own parents (Gilrane-McGarry & O'Grady, 2011). Some of them prefer to protect their parents and not share their suffering, thus creating an emotional distance. Others are grateful for the help offered by parents, considering it as fundamental (Murphy & Jones, 2014).

It is important for bereaved parents to perceive that the existence of the child is recognized by the grandparents and that the latter respect their pain, even during subsequent pregnancies (O'Leary et al., 2011). Having both lived a perinatal loss can contribute to the sense of understanding and comfort, sharing each other's experiences. On the contrary, some parents can feel anger and resentment toward the extended family members who seem to have forgotten the child's existence, not understanding that in some cases this "coldness" is exclusively the result of different cultural and religious education from another generation (Galinsky, 2001; O'Leary et al., 2011).

The pain of grandparents from perinatal loss are not recognized and considered serious even by health professionals. Probably due to this lack, not just the bereaved parents, but also grandmothers often use social networks as a source of support, confiding their experiences and discomforts online (Davidson & Letherby, 2014).

As shown, support services for the whole family, involving other siblings and grandparents, can be useful and effective for the work of mourning (Oikonen & Brownlee, 2002; Roose & Blanford, 2011). The recognition of pain and the comparison of each member is a fundamental aspect to which it is important to give more attention, clinical and social, in trying to protect and minimize the risk factors for the negative consequences of perinatal loss.

## Chapter 5: The child's recognition

The purpose of this chapter is to introduce and analyze the social implications of perinatal loss.

Therefore, this section includes the definition of perinatal loss and the various legal and juridical recognitions that both the child and the parent have in the different European countries.

In detail, the comparison includes the relevant regulations in the EU and Switzerland.

This chapter highlights how important the legal and social recognition of the existence of the child is, to help the parent deal with grief. Failure to acknowledge it can bring considerable psychopathological risks.

Social support proves to be one of the most important aspects for the parents' grief and also for their health, in the long term as well.

### 5.1 The legal recognition of perinatal loss in Europe

The recognition of the child is a fundamental aspect in the process of elaborating grief for the parents. Knowing that the child has rights, and therefore that he doesn't exist only in the memory of his parents but also in that of the community, is very important.

Furthermore, the parents' pain is not quantifiable and is not related to the moment of the pregnancy when the baby was lost, contrary to what happens at a legal level.

According to the juridical aspect, there are numerous rules that determine the legal recognition of the child, his rights and the rights of his or her parents.

In France the child mortality rate (namely the number of children deceased within their first year of life considered every 1000 births) was 3,8% in 2018 (Insee, 2018b).

The average in the EU countries was 3,6% in 2016. Finland is the country with the lowest mortality rate (1,9%), followed by Slovenia, Estonia and Sweden (2,5%). We can find the highest rates in Romania and Malta that respectively have rates of 7% and 7,4%. The United Kingdom instead has a rate similar to the one in France (3,8%) and they both are higher than the ones in Germany (3,4%), Italy (2,8%) and Spain (2,7%) (Insee, 2018a).

Analyzing data from 2016, the most recent year where they were published, in almost every country of the EU there was a decrease of child mortality since 2005. In Romania it decreased from 15% to 7%, and this reduction was also considerable in other countries, such as from 3% to 1,9% in Finland and from 3,7% to 2,7% in Spain. The decrease instead was less pronounced in such countries as Germany, France, or Italy. In general, the average that was 4,8% in 2005 was 3,6 in 2016 (Insee, 2018a).

It is important to highlight that definitions of perinatal loss vary from country to country, with different standards or conditions. Though this limitation doesn't affect the social and (most importantly) psychological aspects. Perinatal loss concerns the death of a child during the pregnancy or before the first 28 days of life. It also includes : early neonatal death (from birth to the first seven days) and late neonatal death (from 7 to 28 days) (World Health Organization, 2016).

The first days of a child's life are considered the most risky, since ¾ of newborn deaths occur during the first week (Oza et al., 2014; World Health Organization, 2016).

The tenth edition of the International Classification of Diseases (ICD-10) defined the fetal loss that takes place during the pregnancy, as a “death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy; the death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles without specification of the duration of pregnancy” (Da Silva et al., 2016).

According to the World Health Organization (WHO) and the ICD, stillbirth corresponds to the death of a fetus that reached a weight of 500g and 22 weeks of pregnancy. According to the ICD, deaths that happen after 28 weeks of pregnancy or with a weight over 1000g are considered late fetal death, while the ones between 22 and 28 weeks and a weight between 500g and 1000g as early fetal deaths (Da Silva et al., 2016).

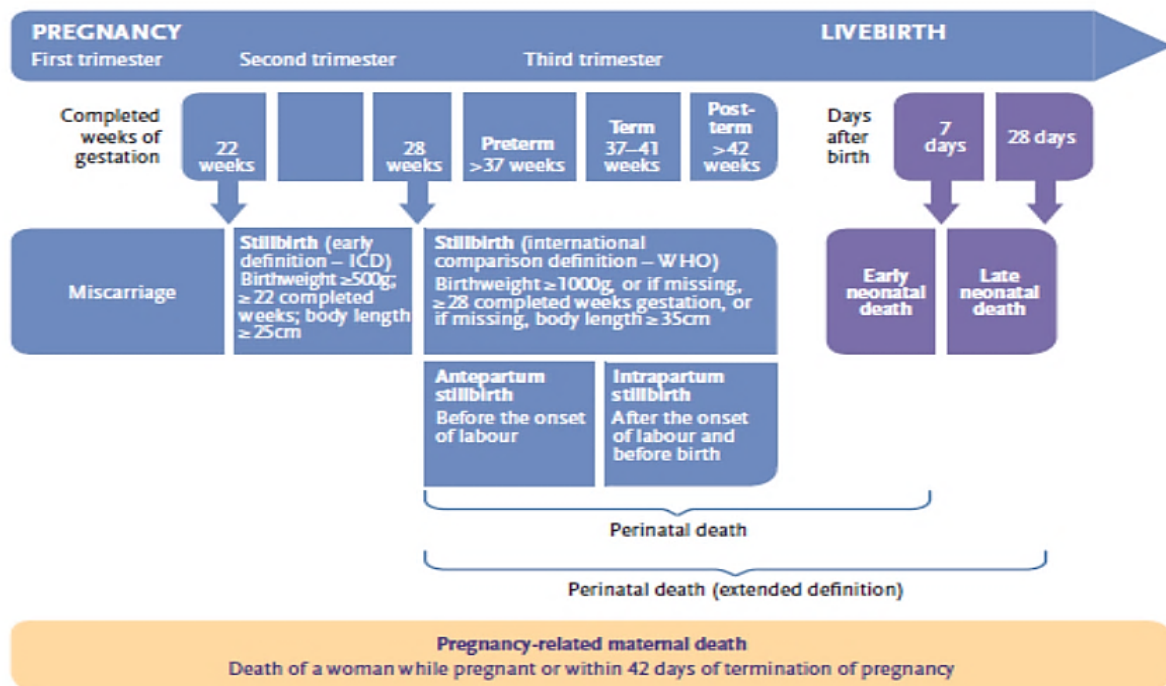


Figure 4 Pregnancy outcome definitions. Source: World Health Organization (2016)



As previously stated, neonatal mortality rate in the various EU countries is considered per 1000 live born children (World Health Organization, 2016). However, the WHO recommends including in the national statistics fetuses and newborns, stillborn or alive, that reach at least a weight of 500g, and for the international statistics instead to include children that weigh 1000g and starting from at least 28 weeks of amenorrhea (World Health Organization, 2016).

The analysis of premature deaths could change infant mortality rates and highlight how in many countries perinatal losses are underestimated. Furthermore, such definitions can also be influenced by the circumstances of the birth and by some cultural and religious aspects of the country evaluated (World Health Organization, 2016).

In France the legal recognition started in 1993 with the 93-22 law of January 8, 1993 (concerning the civil law, the family and the children rights) that became the 79-1 article of the Civil Code.

Starting from 1993, jurisdiction recognized the provision of the act of the lifeless child (*acte d'enfant sans vie*) only in the following cases:

- if the child died before the registration of the civil status and with a medical certificate (*Certificat Medical d'Accouchement - CMA*) saying he was born alive and vital;
- if the child was born alive but not vital and died before the declaration of civil status;
- if the child was born with no life starting from the 22nd week of amenorrhea or weighs at least 500g (Insee, 2016).

In order to request the acknowledgement of a child without life, parents must obtain the *Certificat Medical d'Accouchement - CMA* that states the circumstances of the birth and death.

The child who was born alive but died after has some rights: to receive a first and last name; to get a birth and a death certificate; to be registered within the family record book (*livret de famille*); and to get a funeral ceremony and maternity leave for the mother.

In the event that the child was born alive but not vital, the parents can register him or her in the family record book but only by indicating the surname and not a first name. Furthermore, the the parents have a maximum of ten days to reclaim the body.

It is important, though, to underscore what the law means by vital : this term refers to a child who presents signs of life such as respiratory and motor skills, and that had no need to be revived (Service des etudes juridique, 2018).

The criterion for which recognition occurs exclusively if the child was born from the 22nd week of amenorrhea or with a weight of at least 500g was taken from the directive issued in 1977 by the World Health Organization (Circulaire 2001-576 du 30 Novembre 2001, 2001). According to this rule, it is only from these criteria that society can acknowledge a child and therefore also a mourning. Below this threshold we must legally consider the child as a fetus, and his/her death as an abortion.

If a child is born without life under 22 weeks or 500g of weight, the parents are not entitled either to the Medical Birth Certificate (*Certificat Medical d'Accouchement - CMA*) or the Birth Certificate (*Acte de naissance*). In such circumstances, parents could request a certificate attesting the birth of a stillborn but not viable child and have the possibility of burying him (Service des études juridique, 2018).

In summary, the Medical Birth Certificate (*Certificat Medical d'Accouchement - CMA*), fundamental for the legal recognition of the child, is never delivered in the following cases: in the case of birth without life and under 22 weeks or 500g of weight; in the case of a voluntary interruption of pregnancy (*Interruption Volontaire de Grossesse - IVG*); in the case of Early Abortion (<15 weeks of amenorrhea) and in aspirations (*curetage aspiratif*) in which the fetal body is not identifiable.

A small specification also concerns the concept of the family record book (*livret de famille*). It is in fact an official French document established from 1877 that can be obtained after a marriage or at the birth of a first child of a married couple. This book is where the births of all the children of the couple are reported ("Livret de famille," 2018).

In addition to the regulations for perinatal loss, since 2008 new decrees have been established in order to regularize the right to paternity leave and the registration of the child regardless of parents' marital status (Decree No. 2008-800 of August 20, 2008, Decree No. 2008-798 of August 20, 2008 and circular June 19, 2009) ("Circulaire no 2009-182 du 19 juin 2009 relative à l'enregistrement à l'état civil des enfants décédés avant la déclaration de naissance et de ceux pouvant donner lieu à un acte d'enfant sans vie, à la délivrance du livret de famille, à la prise en charge des corps des enfants décédés, des enfants sans vie et des fœtus," 2016; Décret n° 2008-800 du 20 août 2008 relatif à l'application du second alinéa de l'article 79-1 du code civil, 2008). They state that «any child born lifeless due to childbirth can be registered in the civilian death record regardless of his level of development ».

Since 2008 the medical birth certificate, and therefore also the acknowledgement of a lifeless child, no longer depend on either the weight of the fetus or the duration of the pregnancy, and the child can be registered in the family record book even if he or she is the first child of an unmarried couple (3 Judgments of the Court of Cassation of 6 February 2008) (*Cour de cassation, civile, Chambre civile 1, 6 février 2008, 06-16.498, Publié au bulletin, 2008*).

This means that the birth certificate can be issued after a birth that is spontaneous, induced or linked to a Late Termination of Pregnancy (*Interruption Medical de Grossesse - IMG*), but never in the case of voluntary interruption or early abortion (Sani & Bacqué, 2018).

The amendment of June 19, 2009 introduced some clarifications regarding the child's status and the taking over of the body.

Specifically, it clarified that the civil recognition of the stillborn child can take place following the presentation of the lifeless child and the birth certificate, which is granted, not according to the week of amenorrhea or the weight of the child, but based on "a formed body - including congenitally malformed - and sexed, even though the process of maturation remains incomplete and excluding tissue masses without a morphological aspect" ("Circulaire no 2009-182 du 19 juin 2009 relative à l'enregistrement à l'état civil des enfants décédés avant la déclaration de naissance et de ceux pouvant donner lieu à un acte d'enfant sans vie, à la délivrance du livret de famille, à la prise en charge des corps des enfants décédés, des enfants sans vie et des fœtus," 2016). This, however, excludes cases of spontaneous or voluntary abortion occurring below fifteen weeks of amenorrhea.

Furthermore, according to this legislation, the burial or cremation of the child is mandatory. In the absence of this act, it was possible to carry out the funeral exclusively at the request of the parents. According to this 2009 legislation, some guidelines have also been introduced for professionals, in order to adequately support the parent, considering his needs and recognizing the child independently of his physiological criteria.

If the 2008 and 2009 acts were fundamental for the recognition of the child, in 2011 there were changes.

The ministerial instruction of 26 October 2011 declared that from 1 January 2011, France, as a member of the European Union, is obliged to indicate the infant and perinatal mortality rates. For this reason, the collection and coding of information will again be based on the recommendations of the WHO, according to which a deceased child is registered as lifeless in cases of spontaneous death or LTP starting from the twenty-second week of amenorrhea or 500 grams in weight (Ministère du travail, de l'emploi et de la santé & Secrétariat d'Etat à la santé, 2011).

Below is the translated version of a very clear and explanatory table published on the Agapa association website, outlining the processes and criteria for recognizing the child and the rights of the grieving parent according to the current regulations in France (Agapa, 2017).

		<b>Certificate of delivery</b>	<b>Registration to the civil status or family record book</b>	<b>Funeral</b>	<b>Social security benefits</b>
<b>Pregnancy interrupted before 15 weeks of amenorrhea</b>	Voluntary interruption of pregnancy	No	No	The health facility supports the cremation of the body	No
	Early miscarriage /Intrauterine death	No	No		No
	LTP	On medical decision	No		No
<b>Birth between 15 weeks of amenorrhea (WA) and 21 WA +6</b>	LTP / Intrauterine death	Yes	Possible	Possibility for the family to organize funerals, on request	No
<b>Birth beyond 22WA and/or 500g</b>	Living born child	Yes	Yes	The family organizes the funeral	Yes
	Child born lifeless	Yes	Yes, only in the rubric of deaths	Possibility for the family to organize funerals	Yes

Table 4 Regulations and rights of the child in France. Source : Dossier de press en association-agapa.fr/sinformer/ (2017)

Besides France, what are the regulations of other European countries? In Italy, for example, the defining criteria and the rights of both the child and the parent are divided into three different acts. The first law on perinatal loss is dated 1939 (law n. 1238 of article 74, July 9 1939), according to which the stillborn child is entitled only to a birth certificate. It therefore recognizes the child's existence exclusively following a birth, without making any reference to the weeks of gestation or the physical condition of the child, and thus excluding spontaneous abortion. Many years later, the Presidential Decree 09/10/1990 n.285 regulated the norms for the funeral rite and the burial of the child. According to this law, parents who have lost a child under 28 weeks of gestation have 24 hours from the birth (natural or induced) to request a burial permit. This application must be submitted to the ASL (Local Health Authority) and accompanied by a medical certificate

indicating the week of gestation and the weight of the child (Article 7 Paragraph 3 and 4 of the Presidential Decree n.285, September 10, 1990) (Sani & Bacqué, 2018). The law n.151 of 2001, which regulates maternity and paternity leave, also establishes that the mother is entitled to three months of leave in the case of voluntary interruption of pregnancy or late termination of pregnancy (LTP) if the death occurs after the 180th day of gestation or during maternity leave (d. PR 151, March 26, 2001) (Sani & Bacqué, 2018). For the first time, therefore, temporal criteria are introduced for the child born without life, or under the first 180 days of gestation. This means that before the 180th day the death of a child is considered an abortion, and the child himself is an «abortion product » or fetus.

In comparing the recognition of a child in different countries, we considered the European Union and Switzerland. The only countries where no information could be found (in english-based research) were Croatia, Czech Republic, Malta, Slovakia, Slovenia and Romania.

The definition and criteria of a stillborn also vary greatly according to the jurisdictions in different countries (Granet, 2001).

In Germany (§29, paragraph 3 of the decree implementing the law on civil status) and in Austria (in the instructions for the execution of the law on civil status and §8 paragraph 1 Z 2 of the law about midwives) the predetermined criterion for the recognition of a stillborn child is its weight at the time of birth, which must be at least 500g (Service des etudes juridique, 2018).

Belgium, Denmark, Spain, Luxembourg, Greece, Portugal, Great Britain and Holland consider instead the duration of gestation: 180 days in Belgium (art. 326 of the Civil Code), in Spain (art. 45 of the Civil Registry Act and art. from 171 to 174 of the Regulations of the Civil Registry), in Luxembourg and in Greece (Law 344/1976, art. 37 § 3); 24 weeks in Holland (art. 19i of the Civil Code and the Burial Law of 12 April 1995), Portugal (art. 209 of the Code of Civil Status) and in the United Kingdom; and 22 weeks in Denmark (Granet, 2001).

Estonia, Latvia, Lithuania, Ireland, Cyprus, Finland, Switzerland and Sweden (art. 66, paragraph 1, Ordinance on civil status) consider instead the double criterion of the WHO, that is the weight (at least 500g) and the duration of the gestation (at least 22 weeks of amenorrhea). In Poland (Art. 38 PASC), on the other hand, there are no conditions, neither about weight nor about the duration of pregnancy (Gourbin & Masuy-Stroobant, 1994, 1995; Granet, 2001; Stephansson et al., 2018).

Regarding Germany, Austria and Ireland, if a child has shown any sign of life at birth (regardless of any criterion of vitality, weight, gestation week, etc.), he is considered a living born child. For the other countries mentioned above, a child who shows any sign of life must have been born after the predetermined time criteria in order to be considered live born. Furthermore, there are also some other restrictions :

- In Spain, a child must « have a human figure » and he must have lived at least 24 hours after cutting the umbilical cord, otherwise he is considered a stillborn child (Service des etudes juridique, 2018);
- In Latvia, if a child is born living below the criteria established by the WHO, he must live for at least seven days to be recognized as live born (Gourbin & Masuy-Stroobant, 1995).
- In Bulgaria, a child must have been born with at least 800g of weight or at the 26th week of gestation and he must have lived for at least 72 hours to be considered « potentially viable » (Petrov, 2017).

Furthermore, children legally considered stillborn are registered in different registers, depending on the country of origin : they can be put in the birth register with a mention of death (in Germany, Italy, Greece, Poland, Switzerland, Cyprus, Bulgaria, Latvia, Estonia, Lithuania), in the register of deaths (in Belgium, Austria, Netherlands, Luxembourg, France and Finland) or they can be put in some particular register (as in Spain, Great Britain and Bulgaria) (“Civilstāvokļa aktu reģistrācijas likums,” 2017; Gourbin & Masuy-Stroobant, 1994; Granet, 2001; Lithuania Family Law (Civil Code), 2008; Service des etudes juridique, 2018; “Vital Statistics Registration Act – Riigi Teataja,” 2009).

In Spain the child is registered in the document of abortions (*legajo de abortos*), without mentioning either the name or the surname of the child but only the identity of the parents. In Great Britain, on the other hand, there is a special document for stillbirths, in which sex, the identity of the child and that of the parents are mentioned (Ministère de la justice, 2008).

In Bulgaria a specific civil status certificate for stillbirth is given to the parents, in which the information of both the birth and death certificates is summarized (Petrov, 2017).

In all the countries studied, except for Spain, Portugal, Latvia and Luxembourg, the stillborn can be given a name. The surname is instead attributed in Germany, Belgium, Great Britain, Ireland, the Netherlands, Estonia and Switzerland (“Civilstāvokļa aktu reģistrācijas likums,” 2017; Granet, 2001). Moreover, for all the countries mentioned above, stillborns apply under funeral legislation like any other deceased, and mothers have the right to maternity leave according to the ordinary law. In the case of an abortion, mothers do not benefit from maternity leave but, if necessary, can utilize sick leave. Furthermore, only in the Netherlands, parents have the chance to obtain a certificate acknowledging the stillborn child if he died between the 17th and 24th week of pregnancy (Service des etudes juridique, 2018).

In conclusion, the laws vary considerably from one country to another, and they have changed to meet the needs of parents over time. Despite these changes, there are still many gaps. For example, first of all, a clear generic definition of life and death is lacking, and the only criteria used to determine the legal rights of both the child and the parent are the medical and physiological ones, recognized

only following the input of a doctor (Granet, 2001). There is, therefore, a clear lack of recognizing the emotional aspect of a parent who lost a child, apparent, for instance, from the absence of paternity leave. At a legal level and below the pre-established medical limits, perinatal loss is often considered equivalent to a surgical operation, for which only the mother can take sick leave. It is therefore not fully recognized or defined as that type of mourning, an event that despite the timing and physiological characteristics remains devastating for parents. Its full recognition is still distant, but hopefully scientific research (psychological, medical, social etc.) developed in recent years may be able to raise awareness, as well as to contribute to changing the legal regulations in various countries.

## 5.2 Social recognition

In recent years, interest in perinatal loss has increased. More and more research has led to a better understanding of the causes, both among parents and among professionals (Stiffler et al., 2017).

This is a phenomenon that is not only psychologically but also statistically relevant. On a global scale, it is estimated that 4 million intrauterine deaths occur every year and that 1 in 110 pregnancies ends with a stillbirth-- sixth among the main causes of death of all age groups (preceded by diarrhea, HIV/AIDS, tuberculosis, traffic accidents and cancer) (Frøen et al., 2011).

It is important to highlight that these statistics may not be totally indicative since, as we have previously seen, they can be influenced and modified by the inclusion criteria of the different countries and by the official documents that are often lacking in developing countries (Cacciatore et al., 2009). Despite the greater awareness and the objective relevance, the death of a child in the perinatal period still remains the least understood loss in our society. It is in fact defined as «the invisible death », as the parents perceive a missed right to be able to mourn their child publicly, circumscribing the manifestations of pain inside their own home (Cacciatore, 2013; Frøen et al., 2011; Malacrida, 1999). Therefore, according to Cacciatore (2010), it can also be associated with the concept of «ambiguous loss » as defined by Pauline Boss, namely a pain aroused by a physical absence and a psychological presence (Cacciatore, 2010).

Generally speaking, a parent comes into contact with their child and with the idea of his/her death in the hospital. In a moment of complete loss, the helpless and frightened parent relies on the professionals that work in the hospital, who are the first witnesses to the existence of the child (Bacqué & Merg, 2015).

Until a few decades ago perinatal loss was still a taboo, and the hospital staff was very uninformed and unprepared to deal with these situations. Today though, we know the importance of not denying this grief. New practices have emerged in some hospitals with the aim of accompanying parents,

recognizing the child and facilitating the work of mourning (Dumoulin & Valat, 2001; Malacrida, 1999).

While not widely available yet, some maternity wards currently offer the possibility of getting to know the child and retrieving his personal items (such as fingerprints, bracelet, etc.), immediately after birth or in a later moment, according to the needs and requirements of the parents (Alexandre & Gaugue, 2016).

These opportunities comfort parents as a confirmation that their child did not exist only in their eyes, and that «the lack of life does not mean a lack of existence, identity or attachment to the child» (Bacqué & Merg, 2015). Furthermore, seeing the child and possessing a picture of him and his objects allow recognition of his role and identity within the family and take on a separating function between the parent and the real child (Alexandre & Gaugue, 2016).

It is therefore essential that the professionals are well trained, in order to accompany the parent on a medical, bureaucratic and human level focusing on the person and on the individual case, not in a standardized and general manner. The choices of the parents and the culture to which they belong should be respected. While in western cultures, seeing a dead child is an increasingly recognized and accepted phenomenon, in western Ghana, for instance, it is considered instead a bad omen that could lead the spirit of the child to return and take an eventual next child with him into the “other world” (Frøen et al., 2011).

Receiving respect, nonjudgmental listening, and empathy are characteristics that influence the grief of the parent and their future expectations, even in the long term (Cacciatore, 2010; Cacciatore & Bushfield, 2007).

This support from the medical profession is even more important when parents face a lack of support from those around them (Cacciatore, 2010).

Grief following perinatal loss is still not sufficiently recognized on a social level. The parents of the deceased child perceive a great sense of solitude, as if the tragic event did not matter to others (Malacrida, 1999). It is difficult for them to include the child in the mental representations of the community, and to be able to share their memories and emotions of a loved one who has not officially had time to live (Alexandre & Gaugue, 2016).

According to Bacqué (2015) «the acceptance of the death of the youngest is based on group recognition» (Bacqué & Merg, 2015). To be able to accept the loss and the possibility of expressing our own pain, it is important that the child gets his identity recognized at an intergenerational and community level (Malacrida, 1999; Stiffler et al., 2017). For instance, inclusion in the family record book is perceived as a confirmation of a child’s connection with his parents and the entire community,



not only an emotional one but also a bureaucratic and social one (Charlier & Clavandier, 2015; Malacrida, 1999).

The validation of a child's role and identity is fundamental and also concerns the psychopathological aspects of the parent. Absence of this validation, in fact, is an important risk factor for a complicated grief disorder, while the perception of sufficient support, in particular coming from the family circle (considered more effective than the one from the peers), reduces both stress and depressive symptoms (Cacciatore & Bushfield, 2007; Cacciatore et al., 2009; Malacrida, 1999).

According to Weiss (1974) there are six categories necessary for the individual to feel sufficiently supported, namely: secure attachment; social integration (belonging to a group); having a guide; a belief that one can rely on one another; reassurance of one's own values; and the opportunity to help another person in need, given by the belief that other people need us (Boyras et al., 2012; Weiss, 1974).

According to further theories, social support not only depends on the others' willingness to support the grieving person, but also on the latter's ability to accept this support. There is indeed a difference between the extraversion and neuroticism personalities. An extrovert would create a favorable environment for support, since this type of personality is oriented toward the social, the sense-making and benefit finding, contrary to that of neuroticism. Social support, fundamental for the search for meaning after the death of a loved one and for the work of mourning, can thus be helped or hindered by the personality type of the bereaved person (Boyras et al., 2012).

Moreover, an increase in the rituals surrounding the child's memory can be interpreted as a result of, and a protest against, the lack of recognition and social trivialization of mourning (Alexandre & Gaugue, 2016). Children's burials are not permitted in every cemetery, while in some others only collective places are available, leading to a situation where there is no uniqueness. We can hypothesize that a specific resting place for the body or the ashes of a child can feed the symbolization and accentuate the spirituality of the parent (i.e. the contact with nature, music, etc.).

As we have seen, support and social recognition are fundamental aspects of grief. The parents must be surrounded by unconditional emotional, exploitable (with the possibility of sharing and receiving information) and spiritual support (Cacciatore & Bushfield, 2007).

If, as it often happens, parents do not perceive themselves sufficiently supported by their primary network, it is essential that they succeed in finding additional support from outside, such as therapeutic support groups. These groups can help fill that gap. They allow parents to meet other people with similar experiences, providing a sense of community, a sense of understanding and a sense of freedom of expression, and reducing the feeling of isolation as well (Cacciatore, 2007; Cacciatore & Bushfield, 2007).

## Chapter 6: Perinatal loss and its rites

According to Bacqué (1997), death generates "a cognitive incongruity", an initially inconceivable event to be accepted, in which the rite assumes one of the main functions, favoring its metabolization (Bacqué, 1997).

The rites, characterized by a certain structure and repetition, have in fact a third function: facilitating a transformation, reshaping the relationship with the deceased through memories, symbolic objects, etc.; the transition, at a social level; and the connection, maintaining a link with the deceased (Romanoff & Terenzio, 1998). They mark the separation of the deceased's body with his soul and his entrance into the community of the dead (Bacqué, 1997). Their timing and predefined circumstances make it possible to prevent the mourning from becoming excessive, mitigating a possible loss of control and recognizing its meaning on a social level, thanks to the sharing of symbols with the entire community (Bacqué, 1997; Rando, 1986; Rubin, 1996).

This chapter aims to present how the rites, the expressions of mourning of the parents and their representations of the child have changed throughout history up to the present day. Studies have shown that rituals dedicated to children have always existed, according to different eras, cultures and societies.

Many of the concepts have been taken from two articles published in 2018 by Bacqué and collaborators (Bacqué et al, 2018a; Bacqué et al, 2018b). The work concerns in particular the geographical area of Europe and Christianity, (since those who practiced Judaism arrived in Europe starting in the tenth century and the Muslim influence was relevant primarily in Hispanic territories). Furthermore, the data collected in these studies do not refer exclusively to the perinatal period but to the loss of children of different ages and, in particular, to members of noble families, whose findings have been mostly preserved and kept intact (Bacqué et al, 2018a).

The oldest records date back to the Neanderthal era (75,000-60000 years ago), in which young children, including fetuses, were buried with their parents. It is therefore possible that the role of the child within the family was recognized and that death was already accompanied by ritualized and recognized practices since, in addition to the corpses, ornaments, shells, utensils and food were also introduced into the tombs (Cacciatore & Flint, 2012).

During the Bronze Age (starting from 3000 BC), the bodies of the little ones were cremated and the ashes were placed in ceramic containers kept at home. Older children were instead buried inside the house, in particular in the most frequented areas or passing halls (such as the kitchen, near the stairs, etc.), as a sign of closeness and protection for parents.

These practices, particularly for younger children whose teeth had not grown, remained present until the time of ancient Rome. At that time, older children were instead buried in the *necropolis* wearing

(if they descended from aristocratic families) masks or with medallions (*bullae*), symbols of lineage and Roman citizenship.

By the time of the ancient Greek and Roman civilizations, the funeral rites were already very rigid and institutionalized. The ceremonies varied according to the sex of the child, age and lineage, as indicated by the inscriptions on their graves. However, to be recognized and the children of the Roman Empire must have obtained a *cognomen* (surname) on the ninth day of life and have been registered in the register of births (Bacqué et al, 2018a).

Since then, parental roles and functions with respect to the loss of a child were quite distinct. Only the woman could mourn a deceased child publicly, while the man had to be strong, not expressing any emotion and continuing his work.

In general, the mourning had to be discreet and silent, and its duration depended on the age of the child: the more he had lived the more prolonged the grief.

Subsequently, one of the most drastic and important historical changes was the spread of Christianity, recognized as an official religion starting from the 4th century AD (Bacqué et al, 2018a).

The main concepts of the Catholic Church regarding the loss of a child were those of baptism and the afterlife. In fact, the child carried the original sin at birth, which could only be canceled by baptism, practiced exclusively on living persons, as deliberated by the Council of Carthage of 393 AD.

As it happened in the past, the manifestations of mourning had to be moderate and discreet. According to the principles of the Church, the parents had to be relieved and not sad, as the child had been called to heaven according to the will of the Lord. The only duty of the parent was therefore to ensure that the child was baptized. To preserve the beatitude and the ascent to Paradise, considering also the high risk of infant mortality (whose percentage reached 30% - 50% up to the XX century), from the XII century baptisms were practiced on the same day of birth or the day after (except for aristocratic families who had to organize a big celebration in order to present the child to the community) (Bacqué et al, 2018a).

They also began to bury children further from houses, in specific and common areas of the cemetery - located near the main church and considered a sacred space.

The funeral rite for the child was formal and structured. During the night preceding the funeral it was common to welcome the entire community gathered in prayer around the corpse with the parents.

With the baptism being a fundamental event, parents and priests could be punished for not being able to baptize the child in time. In order to appease the sense of guilt and to allow one's child to reach paradise, around the 11th century, pilgrimages to the *sanctuaires à répit* also began. These were shrines dedicated to the Virgin Mary where the parents (especially the father, since the mother was still recovering for the birth) carried the body of the deceased child, accompanied by relatives and

godfathers (who at that time had a fundamental role), to ask for the miracle of making the child resurrect just until the time of baptism (Bacqué et al, 2018a).

Gynecological and surgical practices also began to adapt to respond to parental needs. From the 11th to the 16th century AD the gynecological practice of the *ondoiment* (emergency baptism) was often carried out, that is the attempt to wet the unborn child's head through a cannula to baptize him in case he died before giving birth.

However, to be able to control pagan and unofficial rites, from the 12th century the Church established an additional "place", located between heaven and hell, namely the *Limbus Puerorum*, destined to the souls of unbaptized children (Bacqué et al, 2018a).

At an iconographic level, the child was represented as a small adult man until the 12th-13th century. A more authentic and real depiction emerged in the 13th century, when paintings and sculptures began to represent a baby Jesus and the images of angels and cherubs, symbols of the soul.

In the 14th century the first tombs of children also began to appear, where the children could be buried alone or with their parents.

Moreover, with respect to historical evolution, an important change occurred in 1517, the year of the publication of the 95 theses of Martin Luther and the beginning of the Protestant Reformation. According to Protestantism, the relationship between the believer and God was direct, denying the existence of intermediaries and thus undermining the role, until then sovereign, that the Catholic Church and the Pope had. Furthermore, according to the Protestants, God also accepted in paradise the souls of unbaptized children, contrary to what was expressed by the counter reform and in particular by the Council of Trent in 1563 (Bacqué et al, 2018a).

In England, following the establishment of the Anglican Church by King Henry VIII, unbaptized children were referred to as "chrisom children". The "chrisom" was initially the term used to name the oil with which the child was anointed, which then morphed and began to indicate the type of fabric, the clothes of the children worn during baptism, and finally the unbaptized children themselves.

Furthermore, generally speaking, if before the dead were first buried near the church or inside it (in particular the members of the royal families), starting from the XVIII century AD, for reasons of hygiene the cemetery became the only place for burials, since it was located away from the town (Bacqué et al, 2018a).

This was the *siècle des Lumières* or Enlightenment, which marked a profound and immense break with the past: society became more anthropocentric, medical sciences and scientific innovations modified the individual's relationship with the Church, and the expression of emotions after a loss became less codified and more intimate. Despite the development of medicine, baptism in utero was

practiced until the eighteenth and nineteenth centuries, when the use of caesareans on living women began to spread: in fact, it was previously banned because it was considered too dangerous for the mother due to the high risk of infection (Bacqué et al, 2018b).

The unbaptized children were allowed to be buried in the cemetery, but in an isolated and not blessed area, from which they were then "received" but excluded at the same time.

Furthermore, the expression of mourning and recognition of the existence and role of the child were also highlighted at an iconographic level. A clear example is the painting dedicated to Maria Antoinetta of Vigée-Lebrun in 1787, which shows all the living real children and a small empty coffin, in memory of the deceased son. Starting from the nineteenth century, portraits of royal families began to include deceased children, displayed in the living room along with living ones. On the tombs the use of epitaphs and sculptures dedicated to children, and the expression of parental pain, were more frequent and included in more ritualized funeral rites (Bacqué et al, 2018b).

After the revolution, France officially became a secular state: religion no longer belonged to the cultural, economic and political world. The child's salvation was no longer associated with that of his soul, but to trying to save his body, keeping it alive.

In 1804 the Neapolitan Code determined that each municipality had to build a public cemetery accessible to all, including unbaptized children, in which each tomb had to be personalized (Bacqué et al, 2018b).

This development also began to highlight a social democracy with respect to death, that was previously codified and ritualized in a different way with respect to social status and family lineage (Cacciatore & Flint, 2012).

Beginning in the nineteenth century, the transport of corpses was also prohibited, marking the drastic reduction of the *répit* practices, which had remained very present despite the prohibition of the Roman Curia of 1729.

After World War II, baptism became a more formal rite and the role of the godfather was much more marginal than it was in the past (Bacqué et al, 2018b).

In the 20th century, administrative laws totally replaced the old laws of the Church. As seen previously, it is now the State that defines the legal criteria for the recognition of a child, his rights and those of his parents, and these parameters are based on the weight, the time of death and the vital conditions.

The moment of birth is less ritualized and the role of hospital professionals is fundamental. They are the first to recognize the child and accompany the parent, also giving important elements for symbolic and psychic recognition (such as the bracelet, photos, fingerprints, birth certificate, etc.). Like

childbirth, commemoration rites are also less structured and parents have the freedom to give full responsibility to the hospital (Bacqué et al, 2018b).

Currently we are in fact witnessing a sort of "de-ritualization", a shelving of the social and religious rites that surround death. There is a tendency to reject death and its symbolism, resonant with the image of a perfect society (Besanceney, 1997). In Western culture it seems that it has become very difficult to acknowledge pain: death is cast aside and the mourners are isolated (Cacciatore & Flint, 2012).

Funeral rites have therefore gradually changed their function, and now they are more focused on humanizing the dead (Besanceney, 1997). Moreover, there are more and more civil funerals, less rigid than the religious ones, which allow survivors to have a "more active" role, choosing the place of the ceremony (a crematorium, a house, a public place, etc.), often associated with a strong symbolic connotation for the family, and paying homage to the deceased in a personalized way (through readings, songs, music, films, etc.) (Besanceney, 1997; Ruellan, 2011).

In the case of perinatal loss, rites also have the function of separating the body of the fetus from the one of its mother so that she recognizes the child as real. The child's presentation, washing and dressing are normal gestures for a child born alive, and are also meaningful for a stillborn child. The presentation and naming of the child allow him to be included in the family circle, just like photographing him in the arms of the parents, humanizing him and testifying to his existence (Cacciatore & Flint, 2012; Fellous, 2006).

Following perinatal death, ceremonies and rituals are fundamental to alleviate isolation and parental suffering, facilitating a search for meaning (Cacciatore & Flint, 2012; Rocle, 2012).

At the Père Lachaise cemetery in Paris, for instance, a memorial ceremony is held every three months, reading the dead children's names in front of parents and relatives. These ceremonies are a way to obtain social recognition, both of the child's existence and of parental status (Rocle, 2012; Shulz et al., 2018).

In a society that is often defined as post-modern and post-mortal, the goal of science is to overcome death and defeat any pathology. The funeral rituals, which have always had the purpose of transforming the unacceptability of death into the acquisition of immortality, confirm their purpose and, as it happened for each historical era, have been modeled and defined according to contemporary needs (Gamba, 2007, 2015). They have moved from the personal and intimate sphere to the public and interactive one (Cacciatore & Flint, 2012). In an age governed by technology and the internet, expressions of mourning and grief online have become more widespread in recent years, through the creation of websites, sharing of photo, video, experiences and advice within social networks, and the

creation of virtual cemeteries (born in China in 1995 to respond to the problem of an overpopulation of remains) (Gamba, 2015; Sani et al., 2019).

They are mainly characterized by unlimited accessibility, by total autonomy and control of the user and, in particular, by the idea of being able to achieve much-coveted immortality (Gamba, 2015).

There are blogs, forums and groups specifically dedicated to perinatal loss on Facebook, the most widely used and known social network on a global scale (Sani et al., 2019).

Moreover, in recent years the practice of publishing videos dedicated to the memory of children on YouTube has also begun to spread. These videos, created and published in particular by mothers, are about the moments spent with the child from the pregnancy to the moment of birth and death.

It is conceivable that they assume the connotation that baptism had in the Middle Ages, namely: presenting the child to the entire community and keeping his memory alive.

Users who view the video, touched by an identification process, often also start conversations and exchanges of informations and experiences, as a further sign of the parenting need to get to know other parents, even if from behind a screen (Sani et al., 2019).

In addition to these publications and sharing that may be considered modern funerary rituals, we have witnessed numerous historical changes with respect to the methods of displaying images and remembering the child. From the sculptures and epitaphs of the tombs, to the expositions of the noble and royal families' paintings in the church and living rooms, to a democratization and use of the dead's photos in the houses including those of young children, to a more modern practice and increasingly widespread, metaphor and symbol of the child: tattoos—these rites have evolved over time.

A tattoo is an indelible image, decided upon and controlled by the subject. The tattoo is therefore a message, a visible expression, a brand that constantly accompanies the person, perhaps to avoid the anxiety of loss? (Rocle, 2012; Shulz et al., 2018).

Tattooing may be seen as a new way of crying, a possible substitute for grief and black clothes, currently no longer practiced and less relevant. The position of the tattoo is not insignificant. It can be visible and thus encourage the word, which will promote the grieving process. However, often the tattoo is performed immediately after the loss, showing the urgency in the face of suffering. In this case, the drawing may be less elaborate and refer only to pain (Le Mazou Hafner, 2018).

The tattoo can take on a greater symbolic value if it is integrated with a ceremony: the date of the tattoo can correspond to a specific event (birthday, date of death, etc.) and the subject can go alone or with a guide (Le Mazou Hafner, 2018).

Pain is also an important part of tattooing: after a loss, it is the "price to pay", a symbiosis between physical and emotional pain, alleviating the fear of forgetting the deceased and keeping his memory intact on a personal level and with the outside world (Le Mazou Hafner, 2018).

Even today, parents do not feel legitimized in expressing their suffering. They do not perceive their grief as recognized, thus leading to the creation of new rituals and commemorative practices.

The rituals allow parents to maintain a bond with the child, to confront their loss thanks to a feeling of control and power, thus overcoming the feelings of vulnerability and honoring his memory (Cacciatore & Flint, 2012).

Furthermore, rituals are functional not only for parents but also for professionals, to be able to integrate death into their working practice without it becoming too invasive (Fellous, 2006).

The hospital is the place of the social recognition of a child's existence, the only place in which he or she is publicly named (Fellous, 2006). For this reason, it is essential that professionals understand the importance of rituals, to adequately accompany the bereaved family members and to avoid complicated consequences (Cacciatore & Flint, 2012; Romanoff & Terenzio, 1998).

As we have seen, the rites and representations of a dead child have changed over the historical epochs according to different cultures and societies.

Despite the evidence that the recognition of mourning has always existed, the parent does not yet feel supported. Rites and traditions around perinatal loss are therefore developing and modifying to try to minimize pain and recognize the child's existence on a social level. Despite its current desacralization, the rite is still constantly sought after and fundamental to be able to overcome a loss such as the death of a child (Gamba, 2007).



## Chapter 7: Psychological support

After identifying the interpersonal and social risks that surround the loss of a child, the question arises: how can we help bereaved parents and families? What are the most useful and effective techniques to support the parent and avoid possible risks and complications?

The following chapter introduces the most widely accepted therapeutic practices. It embraces different approaches, introducing the therapeutic issues and hypotheses that will be discussed in the experimental part of this research.

### 7.1 Psychotherapy

The theoretical framework presented has led us to the possible useful therapies employed to accompany the person in the work of mourning and to prevent psychopathological disorders (Murray et al., 2000).

However, the scientific literature offers limited experimental research with respect to psychotherapeutic support in cases of perinatal loss.

As previously mentioned, the studies on perinatal loss began around the 70s. In recent years, more and more scholars have researched the devastating consequences inflicted by this loss, but evidently they are still too limited and probably medicalized. In the psychological field, there are "guidelines" that aim to direct and help professionals in their work and in understanding and preventing patient reactions.

An interesting work by Markin (2017) has tried to summarize international studies on psychotherapies for bereaved families.

Markin cites Wenzel's works (2017) on cognitive-behavioral therapy, Jaffe (2017) on reproductive history, O'Leary (2004) on educational interventions, Diamond and Diamond (2017) on the relational psychodynamic approach and finally the work of Leon (2017) on the tasks of the therapist in the case of LTP (Late Termination of Pregnancy), according to the theory of attachment (Jaffe, 2017; Leon, 2017; Markin, 2017; O'Leary, 2004; Wenzel, 2017).

Although with different approaches, the therapeutic goal is to be able to accompany the person in doing the work of mourning and addressing the latent conflicts that loss triggered (Leon, 1987).

The therapeutic setting must be understood as an environment where patients are free to express their feelings without fear, including those reactions considered "unsuitable" or "dangerous" (such as having hallucinations of their crying child or the desire to steal a child from another woman) (Leon, 1987).

The main task of the therapy is to work on the felt or unrecognized pain and to facilitate the verbal and emotional expression necessary for the acceptance of loss and a new existence (Diamond & Diamond, 2017; Markin & Zilcha-Mano, 2018).

It is necessary to reassure and educate parents to understand the nature of pain and trauma, to avoid another possible narcissistic injury and the recurring thought that "something else does not work in them" (Diamond & Diamond, 2017). The therapist must be able to identify the separation conflicts that preclude the completion of the work of mourning, monitoring the resistance put in place by the patient (Worden, 1991).

According to Leon (1987), short-term psychotherapy can be a useful strategy to deal with the main features of perinatal loss. In this kind of psychotherapy, the end date of the work with the therapist is agreed from the beginning. This modality can help the patient prepare for separation and change expectations about therapy considered as "magical".

The parent can project at the end of the therapy or on the simple breaks between one session and the other (as for example, those of the summer holidays) the sense of loss and abandonment.

The way in which the patient reacts or decides to suddenly interrupt the therapy are symptomatic indices of his or her progress. In some cases, abandoning the therapy, the patient relives the unpredictability of loss, transforming himself or herself from "the one who has suffered" to "the one who acted", from passive to active, trying to make the therapist feel his or her own rage, pain and confusion. At the same time, an inability to succeed in terminating therapy is a symptom of rejection and denial of recognizing loss (Leon, 1987).

Both the patient and the therapist must be aware that the work done in therapy can bring out other complications, not necessarily linked to grief, thus requiring flexibility and a prolongation (Leon, 1987; Worden, 1991).

The therapist must be able to empathize, to understand the parent's experience and the emotional expression of the culture he/she belongs to. The social aspect is fundamental. Within the therapeutic relationship, the sociocultural dynamics of the external world are re-proposed and established (Markin & Zilcha-Mano, 2018). Speaking openly about the loss and feelings is a way to challenge the taboo, recognizing the pain and the existence of the child and providing the support often denied outside of therapy (Markin & Zilcha-Mano, 2018). Social recognition determines and influences the parent's grief reactions, often perceiving that he or she is not free to express oneself, inhibited by the community's expectations and requests (Sani et al., 2019).

The parent lives in a state of confusion with respect to his or her role, feeling trapped in a sort of social limbo, between the previous status of "childless" (to which he or she no longer feels to belong),

to that one of "parent", of which, according to the community, he or she is not part of (Côté-Arsenault et al., 2009).

Furthermore, it is important to be able to tell one's own reproductive story and integrate previous losses, both with respect to attachment and grief for the deceased child and for the investment and the relationship with a subsequent child (Diamond & Diamond, 2017; Leon, 1996a; Rosen, 1989).

It is important to remember that memories are a fundamental influence on the work of mourning. As previously expressed, perinatal loss is unique, characterized by the absence of memories and experiences with the deceased. For this reason, the therapist must encourage the parent to describe the moments of pregnancy and loss to make the child real (Leon, 1987). Therapy should help the patient to not bemoan the lack of relationship with the child, but rather to voice the desires, fantasies and hopes related to it (also as a prevention for a possible syndrome of the replaced child) (Leon, 1987).

It is important to be able to relive the memories of the deceased, to try to create a balance between the positive and negative ones, working on perceived feelings (Worden, 1991).

In the case of new pregnancies or births, a patient could manifest an avoidance in speaking of grief and an exclusive concentration on the subsequent child. This defense could be generated by the difficulty of reliving the pain or by becoming wary of telling one's own story as a result of social reactions (included those of previous therapists) (Diamond & Diamond, 2017; Markin & Zilcha-Mano, 2018).

As previously described, psychotherapy can help not only the bereaved couple, but also the whole family (Oikonen & Brownlee, 2002).

The use of stories and meta-narratives can be useful in family therapy for individuals to be able to communicate their pain and understand the pain of others, as well as to find meaning in the loss. The story can help family members to express feelings of guilt and to highlight the coping strategies put in place (Oikonen & Brownlee, 2002).

Even writing can be a useful strategy to succeed in externalizing one's own experience without censorship. Recording thoughts on paper help one clarify and realize his or her own progress (Oikonen & Brownlee, 2002; Rando, 1986).

Furthermore, it is important to include the deceased in therapy (in the case of perinatal mourning, carrying items and memories collected in the hospital) to be able to elude their denial (Oikonen & Brownlee, 2002; Rando, 1986). These objects (such as a garment, a stuffed animal or a picture) are "symbolic", similar to the transactional objects that the child uses when he is far from his parents. They play an important role in unresolved grief, through which the survivor maintains a link with the deceased (Worden, 1991).

Within the therapeutic setting, professionals have the opportunity to create rituals and traditions with the patient. Ritual help to give a sense of control and legitimization, and integrate grief (Rando, 1986). They are a symbol of the recognition of loss and they help the bereaved person to say goodbye to the deceased and to change the relationship with him (Markin & Zilcha-Mano, 2018). Parents who lost a child in the perinatal period are deprived of this recognition and this lack makes it even more difficult to accept the loss and to feel themselves legitimized in mourning the child (Côté-Arsenault et al., 2009; Markin & Zilcha-Mano, 2018).

As indicated by Rando, therapists should be able to understand and "use" the patients' coping strategies to accompany them in the difficult task of the unique work of mourning.

A complete acceptance and understanding of the patient's life is therefore fundamental. From what has been described, the importance of training and sensitization of professionals (psychologists, nurses, midwives, doctors, etc.) in cases of perinatal loss is clear. Various studies have shown parental reactions being highly affected by simple comments and even involuntary attitudes of professionals (Markin & Zilcha-Mano, 2018). It is therefore important to continue to research this issue in order to be able to help both professionals and parents in their grieving process.

## 7.2 Support groups

### 7.2.1 The origins of support groups

An additional form of psychotherapy is that of support groups. The use of the group in therapy has very ancient origins. At the beginning the medical and psychological aspects existed in a religious context, such as in the shrine of Asclepius in Pergamum, where, in the 2nd century AD, the priests interpreted dreams in group to be able to choose the most suitable therapeutic and pharmacological prescriptions (Neri, 2017).

As highlighted by Neri (2017), "the psychoanalytic group recognizes the descent - through a long series of experiences and reflections succeeded in time - by those first attempts to use the group for therapeutic purposes". Moving away from religious practices and especially from "miraculous healings", the origin of group psychotherapy is traced back to the work of the American doctor Joseph Pratt (1905), who began a practice of group discussion with 15 tuberculosis patients at Massachusetts General Hospital of Boston. Pratt's work is considered the first support group due to the participants' mutual commitment, common support among the group members, and a source of education and information about the disease.

Later, around the 1920s, the model began to establish itself in the psychiatric field, in particular thanks to Trigant Burrow (1927) (who first applied group therapy to neurotic patients and coined the term

“group analysis”) and Paul Schilder, pupil of Freud. It is important to remember that in 1921, in the work “Group psychology and analysis of the Ego”, Freud himself, even without any practice in conducting group therapy, describes and conceptualizes the mechanisms of insight and the transfer reactions that are activated within such a group. In particular, Freud, like other scholars of the early twentieth century, referred to the concept of a crowd, rather than group. For him, the study of the masses was a confirmation of psychoanalytic psychology (which therefore had to include both the individual and the collective one) (Antonio, 2014; Boccalon, 1999; Neri, 2017).

It was during the 1930s, through the work of Jacob Levi Moreno that the theories and the practice of group therapy began to take shape. Moreno, a Romanian psychiatrist, developed the technique of sociodrama and in particular that of psychodrama, inspired by the spontaneous theater of Vienna.

Psychodrama is an expressive therapy that does not fall specifically within group therapy but rather involves staging important experiences of each member (Antonio, 2014; Boccalon, 1999).

In the 1940s, during the Second World War, psychiatrists Bion and Foulkes began to experiment with group therapy with traumatized soldiers of the Northfield Military Hospital in Birmingham, England. Their attention was directed to small groups or subgroups of organized groups (patients of a hospital ward, military, etc.) with a determined purpose (Neri, 2017).

They began to hypothesize the existence of a transfer between the members of the group, not only between the single member and the therapist (Boccalon, 1999). According to the two psychiatrists, the group had a separate mental life, characterized by its own dynamics and mental processes, such as a group’s unconscious expressed as irrational processes put in place during the session. Both did not consider the group as a plurality of people linked by some common element but as something unique.

Foulkes based his theories on the group from studies on neural networks. He conceived of the group as a network model, in which each node could be seen as a person connected to others through links or relationships (Foulkes, 1984; Neri, 2017). If Foulkes spoke of networks, Bion (1948/1991) spoke of mentality, recognizing the group as an organized and innate mental state, according to which people together can produce a capacity of thought comparable to that of the individual (Bion, 1991; Neri, 2017).

Thanks to their work, the study and the practices of the support groups began to develop also in Europe, in particular through the approaches of the analytical groups (Antonio, 2014; Boccalon, 1999).

Toward the end of the 1940s, group theories and dynamics began to gain an ever greater diffusion and application, not only in the clinical field. The contribution of Kurt Lewin, a German psychologist and one of the founding fathers of social psychology and Gestalt psychology, was fundamental. He

introduced the concept of “field theory” (according to which the group is equivalent to more than the sum of the single individuals that compose it) and T-groups (“sensitivity training group”), that is groups whose goal is to know oneself better through interaction with others, feedback, problem solving and role-playing games. Lewin's work has been decisive in the development of social interventions, from small groups to organizations (Boccalon, 1999). In the same years (around 1946), Rogers and his collaborators began some group experiences to train people, to accompany them in their growth and to improve communication and interpersonal skills. Although with a similar purpose on a theoretical level, these groups were different from those of Lewin, characterized by "a more accentuated experimental and therapeutic orientation compared to the T-group" (Marrone, 2001; Rogers, 1978).

Another great contributor is Michael Balint, who after having trained with Sandor Ferenczi, a student of Freud, started working at the Tavistock Clinic in London, where he and his wife Enid Albu designed and validated Balint's groups, namely training groups for professional roles (originally addressed to family doctors) with the aim of improving the emotional-relational abilities with the patient and working well-being (Perini, 2013).

But since the 70s there has been a real explosion of the movement and study of therapeutic groups and group dynamics, including through the establishment of several research centers and institutes (such as the Esalen Center, the Western Institute for Group and Family Therapy in Watsonville, the East Side Institute in New York and the Center for the Study of the Person) (Marrone, 2001). Numerous authors have tried to identify the «therapeutic factors» able to implement change among the group members (Corsini & Rosenberg, 1955; Dierik & Lietaer, 1990; Gibb, 2013; Marrone, 2001; Yalom, 1985).

Irvin David Yalom is one of the leading scholars who dealt with the subject and contributed greatly to the identification of the factors initially defined as “healing” and subsequently as “therapeutic”, since “the result of psychotherapy is not healing [...] but it is instead a question of change, of growth” (Marrone, 2001; Yalom, 1985).

In 1974 Yalom (1974/1985) introduced the 10 fundamental factors (which later became 11 in 1994, with the addition of the "existential factors" category), namely:

1. Imparting information;
2. Instillation of hope;
3. Universality;
4. Altruism;
5. Corrective recapitulation of the primary family experience;
6. Development of socializing techniques;

7. Imitative behavior;
8. Interpersonal learning;
9. Group cohesiveness;
10. Catharsis;
11. Existential factors;

Although listed and indicated separately, these factors are linked by a relationship of interdependence, regulating the dynamics and progress of the group.

To provide information among the members about services and aspects of the disease or difficulty "may be beneficial, implying and conveying, as it does, mutual interest and caring" (Yalom, 1974/1985).

Hope is determined both by the expectations that the person has for the group and by the comparison with people who have lived the same experience. The stories of other people help to understand that it is possible to face the situation and that the symptoms or reactions are not abnormal or scandalous, but "universal", also limiting the sense of isolation. Moreover, being useful and supporting the other members of the group help the people's conviction about their own abilities, fueling a sense of self-esteem.

According to the author, within the group each one reports the behavioral modalities learned in the family, that is their own originating and primary group. In interacting and socializing with others, verbalizing one's own experiences and habitual behaviors, advice, feedback and the reactions of others is fundamental. These help the awareness and distinction between adaptive and maladaptive behaviors, including through imitative behavior and reflection on one's attitude (interpersonal learning).

Furthermore, group cohesion is a fundamental aspect. More than a factor of change, it corresponds to a necessary condition to succeed in reaching and developing the other factors and objectives.

Group cohesion is equivalent to the therapist rapport created between a patient and his psychologist. This feeling allows freedom of expression (including anger, criticism and discussion) and creates a sense of trust, solidarity and understanding that are necessary for individual and group change and growth.

The perception of a cohesive group also influences the constant and continuous participation of the members, confirming its relevance (Marrone, 2001).

Continuing the description of the therapeutic factors, we find catharsis. It was defined by Freud and Breuer as "the process of reducing or eliminating a complex by recalling it to conscious awareness and allowing it to be expressed" (Freud & Breuer, 1895/1966). As in individual therapy, even in group therapy, catharsis corresponds to "a part of the process" (Yalom, 1974/1985). According to

Rogers, in addition to clarifying fears and feelings of guilt that the person is aware of, this can also bring out hidden attitudes that exert an influence on behavior, favoring cohesion or interpersonal learning (Marrone, 2001).

Within the category of existential factors, Yalom includes a whole series of aspects of human life that are decisive for one's personal growth, namely: responsibility, fundamental solitude, contingency, the inconstancy of our existence and the recognition of mortality. Being able to understand and live with the factors that compose our existence allows the individual to achieve full growth and change (Marrone, 2001).

As previously expressed, we have seen how Yalom's factors are totally interconnected, not allowing a clear and limited division of tasks and characteristics.

The set of change factors within the group is one of the main therapeutic support aspects. As we have seen, the development of the group as a therapeutic organ has proven over the years (following progress and studies) to be a fundamental aid in many situations of distress, psychological disorders and disabling circumstances.

### 7.2.2 The basics of support groups

Group therapy is based on the interaction of the members that comprise it. It is in fact through this participation and interaction that the participants are able to improve, advance, be more aware, and acquire and experiment with new skills (Antonio, 2014).

There are several therapeutic approaches that influence the work of the group, such as the psychoanalytic, dynamic, family, cognitive, etc. According to the psychoanalytic approach, the group also experiences the different phases of psychic development (oral, anal, phallic and genital), recognizing the primary roles of libido and aggression.

The group is guided by unconscious forces and within it, we can find transfer processes and the activation of projection and re-introjection's mechanisms of oneself (Antonio, 2014). The psychodynamic approach considers transfer at the vertical (participant-therapist) and horizontal levels (participant-participant). Within the therapeutic setting, characterized by a sort of consciousness' flow, the participant can become aware of the mechanisms of projection and identification, bringing him or her to a full understanding and integration of oneself's parts.

The cognitive model, more focused on the symptoms, activates a process of reinforcement to modify and influence the implementation of behaviors considered more appropriate. The members of the group act as feedback, and it is through interaction and the examination of reality that the person becomes aware and acquires new skills. Gestalt theory is based entirely on the field theory expressed



by Lewin. According to this approach, knowledge of ourselves can only put in place if we are focused on the present and within the field in which we operate. The group is a container, the only one that can provide a support and a stimulus for the clinical development of the subject (Antonio, 2014; Bacqué & Hanus, 2014).

Beyond the theories that characterize each approach, we can consider the group as a microcosm, within which the social dimensions of the real world reside. Through interaction with other participants, members are able to emphasize, understand, modify and develop useful behaviors to relate to and manage the external reality (Lieberman, 1993).

The observation of the group by the therapist / facilitator is also useful in better understanding the difficulties and disturbances of the participants, their personalities and the modality of their interaction with others (Antonio, 2014).

According to Lieberman, "each group shares three basic elements: the intensity of the need to join the other participants; the request to share something personal; the resemblance in suffering".

The aim of the group is to face the situation together, to break the silence that surrounds the participants and their sense of isolation (Damageux, 2014). It provides emotional support and a sense of "normalization", as well as belonging. The members recognize themselves in the others and experience the group as a sort of refuge, or a family (Lieberman, 1993).

The group does not dispense "remedies" but through sharing, listening, participation and identification, in a climate of mutual respect, an individual can become more aware and able to find the tools necessary to face and overcome his or her situation. Fundamental is the concept of altruism and getting in touch with people who have similar experiences and who have overcome the crisis (Damageux, 2014).

Generally, people are aware of the existence of specific associations and support groups through the hospital context (Bacqué et al., 2015).

Within them, groups are always co-animated by two people and can fall into two different categories: open and closed groups. Open groups, as indicated by the word, have no limitations. This means that a person can attend the session at any time by joining the membership (Bacqué & Merg, 2015).

The closed groups are more structured, as are their therapeutic objectives. They are based on certain criteria such as objectives, times, and/or situations (such as groups of bereaved parents who lost a child during pregnancy, alcoholics, etc.) (Bacqué & Merg, 2015).

Generally, groups are characterized by opening rituals. These rites help each member to integrate, to feel part of the group and to express their difficulties, overcoming inhibitions and communicating with others (Lieberman, 1993).

As previously mentioned, the group is always animated by two facilitators. They have the task of being able to circumscribe the therapeutic setting and to moderate the speech in a climate perceived as safe and reassuring, in which everyone can feel free to express themselves (Damageux, 2014).

The animators must be able to focus their attention simultaneously on different levels, that is: on a single person, on the rhythm of the whole group, on verbal and non-verbal language. They must be able to handle situations of sadness, violent manifestations and silences (Damageux, 2014).

The animators are the group's reference point and organizers of the sessions, also at the logistic level (choice of room, connection between the members, informing about the beginning and the end of the meeting, etc.) (Damageux, 2014).

They may have experienced firsthand the situation on which the group is based (for example, being ex-alcoholics or mourners) (Lieberman, 1993). Their work as animators is totally voluntary and in order to be able to lead the group they must have already worked on themselves to be able to maintain appropriate distance, promote balance, and manage and listen to the interventions (Bacqué & Merg, 2015; Damageux, 2014).

Therefore, personal work is done by each animator, and training and supervision is crucial (Bacqué & Merg, 2015). The training provides useful tools to lead the group and to ensure its therapeutic quality (Damageux, 2014). Supervision is useful to have a more critical and objective approach to the different experiences (Bacqué & Merg, 2015). In supervision, the facilitator changes his role, becoming a participant again. The psychologist / supervisor can help him to interpret complex situations and guide the facilitator's attitude to achieve the group's goals (Damageux, 2014).

The climate of respect and trust that is created between the two facilitators of the group is also essential. They must be aware that they are not alone and can rely on the support and conduct of the other.

### 7.2.3 Support groups and perinatal loss

Group therapy, as mentioned previously, is one of the major therapeutic resources, and it has been mostly developed from the middle of last century

Currently there are numerous associations around the world that manage and organize group therapies for different situations and difficulties, including perinatal loss.

The first introduction that parents have to professional support following their loss generally takes place in the hospital. Increasingly, maternity, gynecology and neonatal medicine professionals are trained to accompany parents during the hospitalization, and giving a booklet and information on

available services deemed most appropriate, such as support groups (Bacqué & Merg, 2015; Damageux, 2014).

If curious and willing, a parent calls the reference number to speak with a volunteer or with the group's psychologist to better understand the logistics and therapeutic modalities (Bacqué & Merg, 2015). Generally, a preliminary interview is carried out. This is useful for assessing the person or couple's ability to engage in the group and identifying any risks of complicated grief or depression (with a possible referral to a professional) (Damageux, 2014).

If there are no restrictions, parents who are interested in participating in the group must know that it is possible that during the sessions some parents may become pregnant again. The comparison with parents who are expecting a new baby can be very violent and difficult for some members, resulting in a deep sense of anger, jealousy and envy (Soubieux & Caillaud, 2015). For this reason, it is important that this hypothetical is mentioned and clarified during the preliminary interview (Damageux, 2014).

The groups are often led by bereaved parents who have decided to become facilitators after personal therapy and training.

The training allows integrating one's grief with the facilitator's role. The latter must, in fact, avoid any themes and words during the session that limit the work (Damageux, 2014).

One of the feelings that lead parents to become animators is that of altruism. As previously expressed, altruism is one of the main factors that characterize the group (Bacqué & Merg, 2015).

Helping and guiding newly bereaved parents, directing them on the difficult bureaucratic, emotional and psychological paths, can influence and increase one's sense of cohesion and altruism (Videka-Sherman & Lieberman, 1985). Relating and verifying that parents have overcome this tragedy, can be a fundamental push for new parents, normalizing their reactions and pain (Bacqué & Merg, 2015; Leon, 1987).

At the logistical level, the perceived satisfaction of the participants is strongly linked to the structural characteristics of the groups, above all how it is guided (Dyregrov et al., 2013; Thuen, 1995).

As with other support groups, even those for perinatal loss can be open or closed.

According to Damageux, the organization of a closed group responds better to the problem of perinatal loss because its structure provides adequate continuity and allows support of each member during the anniversaries, as well as discussing different themes at each meeting (Damageux, 2014).

Some authors also suggest not including parents who have lost the baby before and after pregnancy in the same group, since parents who have lost the baby later may diminish and consider the pain of others less severe (Stirtzinger & Robinson, 1989).

It is also important to underscore that on a scientific level, empirical research on groups is still quite limited today. It is, in fact, difficult to succeed in proving its effectiveness because, as for other psychotherapies, the principles on which it is based makes it difficult to draw and identify a standard research evaluation framework (Ney et al., 2010; Koopmans et al., 2013; Lieberman, 1993).

Studies are generally conducted through qualitative analyses, based on observations, interviews, surveys, etc. (Umphrey & Cacciatore, 2011).

Several studies have shown that participation in support groups for bereaved people can have positive effects on depression, stress, sense making, the sense of isolation and the symptoms of Post-Traumatic Stress Disorder (Cacciatore, 2007; Umphrey & Cacciatore, 2011).

In fact, most mourners consider it essential to receive professional support, especially when the loss is considered unnatural and/or traumatic (Dyregrov et al., 2013).

Thuen (1995) has shown that generally, bereaved parents are more likely to participate in support groups than people who have lost partners. In addition, participants who have suffered an unexpected loss declare themselves more satisfied with the groups than those who mourn for an expected one.

Groups are perceived as a safe haven where everyone can express their own sadness, loss, anger, and bitterness, free from the minimization of pain and criticism, which are often perceived with respect to friends and family members (DiMarco et al., 2001; Dyregrov et al., 2013; Leon, 1987).

In living an unusual loss such as the perinatal one, parents feel the weight of having little or no memory to evoke and of the narcissistic wound inflicted on their Ego and their role. The silence surrounding this complexity increases the feelings of isolation and total social incomprehension (Damageux, 2014).

In this whirlwind of feelings, support groups are a useful aid for the recognition and overcoming of grief (Dyregrov et al., 2013; Stirtzinger & Robinson, 1989).

Fundamental to completing the work of mourning following the death of a child is the meeting between the social consensus and the individual acceptance of reality. The group can be crucial support for achieving this goal (Bacqué & Merg, 2015).

In fact, it has the ability to accompany bereaved parents in their search for meaning, assuming the role of new social support through the creation of rituals, the recognition of mourning, its normalization, and free expression. Distancing itself from a purely medical perspective, it fulfills the emotional and affective aspect of mourning, giving parents the possibility of accepting bereavement and giving existence to the child (Bacqué et al., 2015; DiMarco et al., 2001; Dyregrov et al., 2013; Guyard-Boileau, n.d.; McCreight, 2007).

Moreover, if twenty years ago support groups of bereaved parents after perinatal loss were mainly made up of women, now more and more fathers participate in the groups, recognizing their usefulness

(Bacqué et al., 2015). Within the couple, the narcissistic wound of perinatal loss causes a psychic regression in the parent, making it difficult to recognize and to accept one's own state and that of one's partner. This difficulty translates into a possible emotional detachment and denial. This immature ego and the procrastination of the work of mourning can find resolution through comparisons with the collective representations of the group and in the verbalization of one's own experience (Bacqué et al., 2015; Soubieux & Caillaud, 2015).

The rituals performed at the beginning of each session allow each member (even the new ones) to feel themselves as an integrated part of the group, also facilitating the openness and interaction of the most introverted people, such as fathers. For this reason, participation with one's own partner can bring benefits within the couple. The groups help to establish contact and to listen to the experiences and feelings of the other, a very difficult task in such a delicate moment as the loss of a child (Lieberman, 1993; McCreight, 2007; Wilson & Soule, 1981).

Its intra and inter-relational action operates on three different levels: the individual, the couple and the group.

Even if each group and the dynamics that act in it are different, the literature has emphasized that there are recurrent and inevitable themes that emerge, such as: the story of the child's death; the return home; anger; the sense of guilt; contact with the child; siblings; the discord in the couple; the indifference of friends; the story of the other participants; the legislative and bureaucratic difficulties; the vocabulary used by hospital professionals and the feeling that this has determined, etc. (Cacciatore, 2007; Damageux, 2014; Guyard-Boileau, 1999; McCreight, 2007; Soubieux & Caillaud, 2015; Umphrey & Cacciatore, 2011).

The stories of each member give life to common and personal reflections which are fundamental for the individual and group work (Guyard-Boileau, 1999). The groups are useful in bringing out the difficulties and paradoxes that the bereaved person can perceive with respect to one's own pain and to the demands imposed by society (Côté-Arsenault & Freije, 2004).

It is functional to express feelings such as anger, contempt, and aggression, even if these can be disturbing because they are totally unusual and foreign to own personality. For example, mothers can perceive themselves as "wrong", "broken" or "angry at seeing other women who can have a baby". These are common feelings after a perinatal loss that can be understood and shared within the group. The parent must be able to accept and bring to light such exhausting feelings, whose repression can instead block and prevent the grieving process (Soubieux & Caillaud, 2015).

The role of participation in support groups by bereaved parents is therefore clear. Although it is difficult on an empirical level to demonstrate their efficacy, they have a fundamental therapeutic function, able to accompany the person toward resolution following loss.

### 7.3 Internet and its online peer groups

In recent years the Internet has assumed a primary role in our lives. In fact, according to scholars, we are currently experiencing what has been defined as a “post-industrial society” (Bell, 1976) or “third industrial revolution” (Rifkin, 2013), dominated by technology, digitalization and a disproportionate use of the Internet.

In 2018, 4.021 billion people used the Internet on a global scale. Of these, again in 2018, 3.196 billion used social media, 13% more than the previous year (Kemp, 2018).

The Internet is an IT tool that aims to improve and facilitate people's lives, where everyone can find any information and satisfy every need. Inside there are the Social Networks, or sites of connection and communication between an enlightened number of users. The most common are currently Facebook, Instagram, MySpace, YouTube, etc. (Baker & Perez Algorta, 2016).

In these, following a registration request, people start to share different aspects of their lives and to create, through feedback and comments, a sort of telematic relationship with people known or unknown, without any geographical or temporal limitation.

There are also forums, blogs, and groups on Facebook (the most famous and used social network), where each person can interact and exchange information and stories on a specific topic. Many users have claimed to have "tried" different groups before finding one considered the most suitable (Turner, 2017).

There are several reasons why people register and use these groups.

They present the phenomenon of online “social sharing of emotions” of Rimé, which corresponds to an interpersonal process based on the tendency to discuss and share an event and one’s reactions with others, characterized by a “socially shared language, and at least at a symbolic level, an addressee” (Rimé et al., 1991).

Furthermore, they offer a means to search for psychological and emotional support, often perceived as absent or unsatisfactory in "real" life (Mathiesen et al., 2012; Swartwood et al., 2011; Turner, 2017; Villecourt-Couchat, 2018).

The social sharing of emotions, stories and experiences creates a sense of connection between users and a useful exchange of information that is sometimes difficult to find (such as medical, bureaucratic, etc.) (Lowe et al., 2009; Turner, 2017). In some cases, in fact, the classic sources of information do not seem to be sufficient and the Internet is able to provide necessary clarifications in a direct and immediate way (for example, without having to wait to make an appointment with an expert). Moreover, these clarifications obtained from informal sources also show more personal experiences, touching the human and identifying aspect (Lowe et al., 2009).

The Internet also makes it possible to bring into contact people who are experiencing the same situation and might not meet in other circumstances, such as those with a rare or congenital disease (Mathiesen et al., 2012). It can be a very useful tool for those with limited social support or who live in rural areas with difficult access to information (Swartwood et al., 2011).

Furthermore, the Internet is based on two unique and very important concepts for users: anonymity and a sense of control, that is, the possibility to choose when and how to participate by protecting one's identity (Aho et al., 2012; Lowe et al., 2009; Niela-Vilén et al., 2014; Turner, 2017).

At the same time, not knowing the other people can be a risk. Behind a false pseudonym can hide several objectives: there are the so-called *trolls*, or those who are intended to cause problems; the *fakers*, those who pretend to have lived the same experiences; those who register only for advertising purposes, etc. (Carlson et al., 2012).

Moreover, since the websites are not controlled by any professional, the information can also be erroneous and confusing (Lowe et al., 2009; Mathiesen et al., 2012; Turner, 2017).

Furthermore, it is obvious that such groups are different from true in-person support groups. They totally lack a therapeutic framework, a special setting and the supervision and facilitation of professionals.

The mechanism of an interaction in front of a screen cancels the human aspect of communication, that is, hearing the tone of voice, observing facial expressions, etc. (Carlson et al., 2012; Turner, 2017).

The interaction can in some cases also be discontinuous. Certain conversations can be isolated and unanswered, further fueling the possible sense of isolation and misunderstanding of the user (Swartwood et al., 2011; Turner, 2017).

It is estimated that approximately 2.7 to 3.3 million adults use online peer support annually (Gold et al., 2016).

They are generally women, Caucasians, adults under age 50, people with a high level of education, a decent income and with basic knowledge of using the Internet (Gold et al., 2016; Swartwood et al., 2011).

The infrequent use of these websites by men confirms their reticence and rare emotional sharing (Mathiesen et al., 2012).

According to Villecourt-Couchat (2018), women who use the Internet may have a narcissistic fragility and a lack of processing capacity. Sharing on groups could be "a passage to the act that replaces the psychic elaboration because of an ego overflow", an attempt at narcissistic reparation with respect to a difficult situation.

Several studies have shown that the influence of social networks' regular use on the mental health of a person depends on several factors.

Indeed, some researchers have pointed out that the perception of the quality of the interaction with other users (Davila et al., 2012) or what people do while connected (Wright et al., 2013) is more fundamental than the actual connection frequency (Baker & Perez Algorta, 2016). To remain active for too long on the Internet can however create dependence and difficulty in real socialization (Turner, 2017).

At the moment it is not yet possible to generalize these results. The psychological well-being of a person as related to the use of social networks depends on numerous variables, situational and individual: connection time; the mode of participation; expectations; the lack or presence of real social support, etc. At the same time, the perception of support, of being able to satisfy one's needs, the ability to obtain information and suggestions can have positive results (Baker & Perez Algorta, 2016; Banjanin et al., 2015; Takahashi et al., 2009).

In all comparative studies, very few confirm the positive value and effectiveness of online peer Internet support. However, it has been shown that these may have an effect on parenting skills and a reduction in anxiety and stress levels in the parents of sick children (always keeping in mind that they cannot replace any professional support) (Niela-Vilén et al., 2014).

With respect to perinatal loss, there is no empirical research at the moment to define the possible effect of the use of these groups. Many studies are based on the administration of validated questionnaires (such as the Edinburgh Postnatal Depression Scale - EPDS) (Gold et al., 2016), on open questions to assess the perception that people have about the groups (Gold et al., 2012) or on ethnographic research with respect to topics and communications between users (Davidson & Letherby, 2014; Döveling, 2015).

It is important to underscore how these groups, obviously different from the therapeutic ones, are rapidly multiplying. Currently, bereaved parents' groups account for about 10% of all online support groups, as well as being the third most common (Carlson et al., 2012; van der Houwen et al., 2010). In them there is a more active involvement of mothers, but there are also fathers and grandparents (Davidson & Letherby, 2014).

The hypothesis is that this diffusion and evolution is a response to the lack of social support perceived by those who have lost a child (Swartwood et al., 2011).

Participation in such groups can foster a sense of belonging and cohesion among the participants, who often use terms such as "friends" or "family" to refer to the other users. In addition to reducing the sense of isolation, communication and sharing can help the parent to understand the normality of their reactions, without the fear of being judged (Carlson et al., 2012; Gold et al., 2012).



Furthermore, unlike in support groups, on the Internet parents can decide and have full control over when to interrupt a conversation (Carlson et al., 2012). Some women interviewed have declared that they feel more comfortable in front of the computer screen, having more time to answer and without the fear of facing another person if they are overwhelmed by emotions (Gold et al., 2012).

While women show a greater need for emotional support and a sense of belonging, men seek instead an affirmation of their paternity, often socially minimized with respect to the maternal role (Niela-Vilén et al., 2014). For both genders, the exchange of information and experiences is reassuring. Even so, they criticize social media for its lack of physical contact, off-topic discussions or possible repetition (Niela-Vilén et al., 2014).

Furthermore, in addition to a safe refuge in which to tell one's own story and exchange information and advice on topics such as legal recognition or commemoration rites, it would seem that the perception of offering psychosocial support to other parents is also very impotent for users (Gold et al., 2012; Swartwood et al., 2011).

According to Callister (2006) and Earle (2012), the exchange of messages and conversations between users could also help the bereaved parent create sense of meaning from the loss (Callister, 2006; Davidson & Letherby, 2014; Earle et al., 2012).

Research has also shown that those participating in such groups have high levels of depression (Gold et al., 2012; Klemm & Hardie, 2002).

As seen previously, this disorder is characterized by a series of symptoms, such as a lack of motivation, fatigue, difficulty in concentration, etc. which would also entail the difficulty of leaving home and seeking social contact. Such circumstances could, therefore, lead to more frequent participation in online groups, instead of looking for external support and professional therapeutic help (Gold et al., 2012).

With respect to the risk of depression and participation in online or therapeutic groups, there are currently no significant differences. This means that participation on social networks does not correlate to a greater risk of depression than those who frequent support groups (Idem).

These are the results we currently have in the literature, but it is interesting and necessary to continue to carry out more research given the important role that the Internet and social media groups are taking on within our contemporary society.

## Conclusions

The purpose of this first part was to present a general theoretical framework of perinatal loss.

The bibliographic research has enabled us to know, identify and understand the main characteristics of this loss, on a psychological, physiological, relational and social level.

As we have seen, the psychological implications can be risky and lasting. For this reason, psychotherapeutic and social support are essential.

This loss does not only concern a single parent, but also the couple, the siblings, the grandparents and the subsequent children.

The training and awareness of professionals is an aspect on which research must aim to assist the bereaved person.

The seven chapters and the bibliographic research presented were carried out to better present the topic and the main hypotheses on which this study is based.

The clinical part of this research will be introduced below: a longitudinal study conducted for 18 months thanks to the constant and active participation of 29 French parents who lost their child in the perinatal period.

## **PART B. CLINICAL PART**

What is grief? More specifically, what is a perinatal loss? What does it entail and how does it fit into the fabric of our society?

These are some of the questions which the first part of this research project tried to answer describing and presenting the most important studies conducted in relation to the topic of perinatal loss, treating them in the order in which they were carried out.

The second part of this project will introduce the objectives that will serve as the basis for our scientific interest and the methodology used to answer and confirm the initial hypotheses.

This clinical part will be divided into two chapters. The first chapter will introduce the objectives, tools and research procedure implemented, while the second part outlines the characteristics of the participants and the selection criteria.

Twenty-nine French parents were met for a total of five times, over the course of eighteen months, every three to six months.

The purpose of this investigation was to understand and delineate the psychological consequences that can develop following a perinatal loss and the possible effects of psychological support.

The methodology used to achieve these objectives was composed of a mix of quantitative and qualitative methods.

Participants were given two questionnaires: the Inventory of Complicated Grief (ICG), highlighting the risk of complicated grief; and the General Health Questionnaire-28 (GHQ-28), a global self-assessment questionnaire for mental health disorders.

In addition to the quantitative part, the meetings also involved a series of semi-direct interviews, later analyzed through the Alceste program and the Interpretative Phenomenological Analysis (IPA).

The data obtained from these results will be presented and described specifically in Part C which is dedicated to the results.

## Chapter 8: Methodology

This chapter on methodology aims to outline the main objectives of this study and the tools that have been selected and used to achieve our goals.

The methods and procedures which were used to respond to the project questions outlined above, and, more specifically, to understand the consequences of perinatal loss will thus be introduced below.

### 8.1 Objective

Perinatal loss is a topic that is not sufficiently addressed in the cultural and social world. It still represents a taboo which is a contradiction in itself because the number of perinatal losses remains high, despite the development of new technology and medical discoveries.

Studies found that around three million deaths occurred annually worldwide within the first month of a child's life and 2.6 million during the third trimester of pregnancy (Ezechi & Odberg-Petterson, 2012; Lawn et al., 2016).

According to INSEE, in France the infant mortality rate per 1,000 births in 2018 was 3,8 (Taux de mortalité infantile en 2018 | Insee, 2018)

Perinatal loss corresponds to the death of a child after the 22nd week of amenorrhea or from a minimum of 500g (as recommended by the World Health Organization) up to the first month of life of the child (World Health Organization, 2016).

In this study, the term perinatal loss will be used in a broader manner. As a result, stillbirths, late termination of pregnancy and losses occurring after birth within the first months of life are all included under the term perinatal loss.

According to the researchers, the distinctions and the bureaucratic criteria do not correspond to the social and psychic ones. We refer in particular to the fact that the perinatal loss does not exclusively include the death occurred within the first month of the child's life. This restriction is too rigid. This is why we have also considered parents who lost their child during the first months of life.

However, we took on the criterion of the 22nd week of pregnancy, in order to be able to highlight the psychic evolution of the parents who lost a child during already advanced pregnancies.

Furthermore, as seen above, the risks and consequences are different and vary in duration, and do not affect only the parents, but all family members (living and subsequent children, grandparents, etc.) (Aho et al., 2018; Avelin et al., 2011; Blackmore et al., 2011; Harper & Thompson, 2011).

In particular, parents may exhibit physical and psychological diseases. For example, symptoms may include cardiovascular problems, depression, anxiety, Post-Traumatic Stress Disorder (PTSD) and Complicated Grief disorder (CG) (Bennett et al., 2008; Murphy et al., 2014; Rogers et al., 2008).

The primary interest of this thesis will be the latter: Complicated Grief disorder. CG was defined by Prigerson for the first time in 1995, and was called “Traumatic”, “Complicated” and finally “Prolonged Grief Disorder” in 2009 (Prigerson et al., 2009; Prigerson et al., 1995; Prigerson & Jacobs, 2001; Prigerson & Maciejewski, 2005).

Nonetheless, despite the disorder’s various names, the criteria that define it have remained more or less unchanged and today, in the scientific world, the term complicated grief is still commonly used (Doering & Eisma, 2016; Kentish-Barnes et al., 2015; Newson et al., 2011; Prigerson et al., 2009; Shear, 2015; Shear et al., 2016; Tal et al., 2017).

This disorder is characterized by the non-acceptance of death and may include symptoms such as: depression, disbelief, isolation, intrusive and recurring thoughts, avoidance of places or situations that may recall memories of the missing person, sleep disorders, loss of interest and anger (Bacqué & Merg, 2015).

There may also be forms of self-hyper-involvement in bereavement, such as thinking and speaking about the deceased person constantly, often going to the cemetery or not getting rid of the deceased's items or clothing. This is therefore a psychic state with dysfunctional psychological and social effects that can lead to co-morbidities with behavioral problems, substance abuse and alcohol, self-injury and suicidal ideation (Lombardo et al., 2014).

In our society, the loss of a stillborn or the death of a young child is often diminished on emotional level.

The goal of this research project is to highlight and demonstrate how perinatal loss is an important but underestimated type of grief.

Following parents for eighteen months provided a detailed description of their psychological evolution. This timeframe was chosen in order to allow for a thorough and complete evaluation of the progress, the work of mourning and the possible anniversary reactions. In particular, we aimed to confirm the difficulties of the parent and the possible complicated grief disorder following the loss of a child in the perinatal period and to examine the possible effects of both individual and group psychotherapy.

In particular, meeting people who have experienced the same drama within support groups, perceiving complete freedom of expression, having a timetable and a defined place where talking and remembering the child thanks to the accompaniment of professionals provide effective psychological support for the parent's work of mourning.

Within the scope of the research project, a third element will also be considered: the support and the effect provided by participation in groups present on the internet, in particular with respect to specific groups dedicated to perinatal loss on social networks (such as Facebook, blogs, forums, etc.).

According to the findings which have emerged through the meetings with participants, the parents confuse these online groups dedicated to perinatal loss with supportive therapeutic ones.

In considering the role of online support groups it is therefore important to determine whether participation in these groups is useful for the work of mourning by confirming the participants' perception of these online groups.

The online groups in question are generally closed groups made up of users who feel the need to meet and comfort other parents going through a similar experience, even if the members of the group remain anonymous. Often to be part of these groups, the candidate must register and explain their motivation for wanting to join.

The defining characteristic of these groups is their active participation which takes place on a daily basis through commenting often on posts, starting debates, sharing stories and photos, as well as creating a private correspondence with other group members.

Within the context of our contemporary society it is impossible to ignore the role and importance that internet is taking in our lives. It is therefore important to highlight its effect on the parents' grief in order to examine its use and risks.

In a scientific and social context, this research project will make an important contribution to the study of perinatal loss and of the most effective support methods.

As outlined above, in order to address the research questions, a mixed methodology was used, drawing on qualitative interviews and two quantitative questionnaires (Inventory of Complicated Grief and General Health Questionnaire 28). These two questionnaires were selected because most suitable for answering questions about complicated grief and the additional possible psychopathological consequences that may arise after the loss of a child.

The IPA was chosen to analyze the interviews conducted because it is known to be a validated and useful method for this task (Smith, 2004; Smith & Osborn, 2008). The interviews were also examined and compared through the use of the Alceste statistical program.

The comparison between quantitative and qualitative data seemed the most appropriate choice to obtain a greater validity and solidity and evaluate the results.

For this reason, in order to use both methods, we had fixed the number of participants at 30, considering this quantity a compromise between the classic high numbers of quantitative research and the smaller ones of qualitative studies.

Furthermore, the basic sample required for a quantitative analysis is 30 participants (Field et al., 2012).

In the early stages of the project, 31 participants were willing to collaborate, but over time, two people quit and the number of bereaved parents dropped to 29.

Having already started the study and given the time sensitive nature of the study, the researchers decided not to recruit any other participants.

The number therefore remained unchanged after the third meeting (T3), as it was considered sufficient for the predefined objectives.

To conclude this section on methodology, the research conducted will prove useful for future parents who are experiencing a sense of isolation by allowing them to realize that their grieving process is not unique and to become aware of the possible effects that can be generated by different types of support. This is made possible by the use of a mixed quantitative/qualitative methodology, the expanded definition of perinatal loss, and the consideration of a range of therapy groups.

In addition, this study will help raise the awareness of professionals (psychologists, doctors, midwives, etc.) and the micro and macro social contexts surrounding bereaved parents about the long-term consequences following perinatal loss.

## 8.2 Procedure

29 bereaved French parents (21 women and 8 men, including 8 couples) were met for a total of five meetings distributed over eighteen months. After the initial meeting the participants were met after three months, six months, one year and eighteen months.

For 7 participants based in Alsace, the meetings were always conducted in person, reached by train or by car in their homes. Those who do not live in Alsace were interviewed via Skype, Messenger, WhatsApp or by phone. The meetings were held according to the availability of the participants and usually during the evening. Each participant signed a consent form where the objectives of the research, use and conservation of sensitive data were clarified.

The study was also submitted and obtained the approval of the ethics committee of the University of Strasbourg.

The participation was totally free and parents knew that they could withdraw from the study at any moment according to any difficulties or needs they experienced.

Each meeting was characterized by the semi-directive interview and subsequent administration of the two selected questionnaires: the Inventory of Complicated Grief (ICG) and General Health Questionnaire-28 (GHQ-28).

In addition to the two questionnaires, which correspond to the quantitative methodology of the work, at a qualitative level for the estimation of the interviews and to complete the pre-established study, the Interpretative Phenomenological Analysis and the French statistical program Alceste were used (Smith, 1996).

All interviews were recorded after obtaining the oral consent of each participant. The questionnaires were given in person or through the use of the Qualtrics program.

Participants could only access the questionnaire once through a link sent by email.

For couples, the interviews were conducted in turn and without the partner present, in order to allow each participant freedom of expression.

As described above, the meetings were held every three or six months, trying to respect the same dates for each meeting.

The meetings with the parents began in June 2017. The first interviews were therefore conducted from June to December 2017.

### 8.3 Semi-directive interviews

Each meeting with the participants was characterized by a semi-directive interview conducted individually, in person or via Skype, Messenger, etc.

The interviews were always recorded after obtaining the oral consent of the participants.

The choice of the semi-directive interview seemed to us the most appropriate in order to start interview with predefined questions but also to be able to develop other spontaneous topics, useful for a greater understanding of the participant.

Each interview was characterized by preliminary explanations in which the researcher reminded all participants that the interview could be interrupted at any time and that they were free to request a break based on their wishes and needs.

Following primary questions, that is the collection of anamnesis of the participants (name, surname, age, job, family situation), the researcher asked pre-established questions. The goal was to obtain an explanatory and complete picture of the psychological and social situation of the person. The main topics of questions concerned the objectives of the study, namely the psychological consequences and the therapeutic support.

1. The psychic state of parent: "Can you tell me what happened to you?", "How do you feel about what has happened to you?", "Recently, it was the anniversary of your son's death, how do you feel?", "The last time you told me that you felt these difficulties, how are you now?",



"The last time we met was six months ago, how are you going?", "In relation to your difficulties, you said that they are getting better and better, how did you manage to overcome or limit them?".

These questions were asked with the aim of being able to encourage the parents to express themselves and start useful reflections.

2. Psychological support: "Are you followed by a professional?", "Have you ever been followed by a professional?", "Do you participate in support groups?", "Are you interested in participating in support groups?", "Do you continue to participate in online groups?".

These questions were asked to understand the psychological support of the parents and their needs and resistances. The question about online groups was added later, based on the confusion of parents who considered therapeutic support groups equivalent to online ones.

Starting from these predefined questions, the evolution of the interviews followed a spontaneous and linear course. When the participant discussed or cited interesting concepts, the researcher requested and encouraged their explanations.

Since the research was longitudinal, some questions were asked taking up the topics of the previous interview and based on individual cases (such as questions about new pregnancy to parents waiting for a new baby, "what month are you? How do you feel?").

For parents with greater difficulty in verbalizing their experience, especially with respect to men, the researcher had to repeat the question several times, trying not to be invasive or authoritarian.

Furthermore, the average durations of the interviews was very variable. As time passed, the interviews got longer, up to 150 minutes (with a mean of 25, 31, 43, 61 and 52 minutes for each meeting). Women tended to prolong the interview more than men, whose participation was characterized by shorter interviews.

This difference in response demonstrated across gender may be due to the social role assumed by men and the difficulty of expressing feelings and emotions, rather than individual and character differences (Dyregrov & Matthiesen, 1987).

The general increase in the duration of the interviews can also indicate how the participants began to lower their defenses and to feel more comfortable with the researcher, opening up and sharing more details and nuances of their grief.

## 8.4 Instruments

To have a complete and defined vision of the consequences that follow perinatal grief, the study uses two different types of methodology: a quantitative and a qualitative one.

At the quantitative level, two questionnaires were used: the Inventory of Complicated Grief and the General Health Questionnaire - 28. The quantitative variables from data analysis were measured and analyzed through the analytics software Jamovi.

The quantitative operations concerned the descriptive and variance analysis based on the results obtained following each administration and the variables taken into consideration.

Furthermore, seeing as the interactions with parents comprised of not only the administration of the tests but also an interview, for the qualitative element of the study the Interpretative Phenomenological Analysis and Alceste, a French statistical program for qualitative analysis, was used.

### 8.4.1 Inventory of Complicated Grief

The Inventory of Complicated Grief is an instrument devised by Prigerson and her collaborators in 1995 and is used to highlight the risk of complicated grief disorder (CG) (Prigerson et al., 1995). She is thus the same author to have named the disease and invented the questionnaire (ICG) useful for the diagnosis.

As explained above, complicated grief is a disease that can develop as a result of losing a loved one. Its possible onset, intensity, and duration vary according to different circumstances, such as the age of the deceased, the anticipation of death, the degree of relationship with the deceased, etc. (Shear et al., 2011). Initially it is not possible to define the presence of uncomplicated or complicated grief because, for the first six months following the loss, the symptoms are generally the same. For this reason, according to the author, this is the most appropriate reference time frame for diagnosing a possible clinical picture.

Its symptomology includes: a sense of disbelief regarding the death; anger and bitterness over the death; recurrent pangs of painful emotions, with intense yearning and longing for the deceased; preoccupation with thoughts of the loved one, often including distressing intrusive thoughts related to the death (Shear et al., 2005).

It is also associated with maladaptive social, occupational and family life, sleep disturbances, suicidal thoughts and increased consumption of alcohol and tobacco (Lannen et al., 2008; Prigerson et al., 1997; Shear et al., 2011). Complicated Grief disorder shares similarities with depression and post-traumatic stress disorder (PTSD). In cases of PTSD and Complicated Grief Disorder alike, patients

tend to exhibit sadness, guilt, social withdrawal, sleep disorders, as well as suicidal thoughts associated with depression, a sense of disbelief, intrusive images, difficulty in concentration and avoidance of PTSD (Horowitz et al., 1997; Prigerson et al., 1995; Prigerson et al., 2000; Shear et al., 2005).

The questionnaire consists of 19 items. It is very simple and it takes 5 minutes to complete.

Each item is characterized by four scores (from 0 to 4), depending on how frequently the patient has experienced the described condition (0 = never; 1 = rarely; 2 = sometimes; 3 = often; 4 = always).

Prigerson and collaborators analyzed and validated the questionnaire through research carried out on 97 conjugally bereaved elders.

The total score showed a high association with the Beck Depression Inventory (BDI), the Texas Revised Inventory of Grief (TRIG) and the Grief Measurement Scale (GMS), used to verify the validity of the instrument compared with grief and other diseases related to it.

The questionnaire therefore revealed a high internal consistency of the 19 items (Cronbach's  $\alpha$  of 0.94) and a test-retest reliability of 0.80 (Prigerson et al., 1995).

In addition, Prigerson et al. saw that with a ICG score  $>25$  there was a higher risk of negative psychic functioning, thus defining this measure as the cut-off to define the clinical picture, that is  $> 25$ .

The French version which was used to for the participants was Zech (2006), with a Cronbach's  $\alpha$  of 0.93, which was then slightly modified to better adapt the questions to the situation (Zech, 2006). In particular, the generic term “deceased” was modified with “child” to eliminate any neutrality or vagueness, while not affecting the validity and construction of the questionnaire. This change was validated by the author Prigerson, who was contacted in order to confirm the efficacy of this minor adaptation.

#### 8.4.2 General Health Questionnaire – 28

The General Health Questionnaire - 28 (GHQ-28) is a self-assessment questionnaire for psychopathological disorders. It was designed by Goldberg in 1978 and translated into 38 different languages. It is one of the most reliable tests for detecting possible disorders and comorbidity, with a sensitivity of 94%, a specificity of 87% and a correlation coefficient ( $r$ ) of 0.77 (Goldberg & Hillier, 1979; Goldberg, 1972; Goldberg, 1978; Sterling, 2011).

The first General Health Questionnaire dates back to 1972, followed by four other versions: GHQ-60; GHQ-30; GHQ-28 and GHQ-12 (Sterling, 2011).

The GHQ-28, as can be inferred from the name, consists of 28 items, divided into four subscales of 7 item. The questionnaire is characterized and designed to define possible distress: somatic symptoms

(items 1 to 7); anxiety and insomnia (items 8-14); social dysfunction (items 15-21) and severe depression (items 22-28) (Goldberg, 1978).

Each item gives by four possible answers which allow the patient to delineate and describe the frequency of a given feeling or thought.

The questionnaire is simple and fast to complete and requires a maximum of ten minutes.

There are two possible methods for collecting results. It is possible to score each response with a grade from 0 to 3, with a total of 23/24, or alternitavely by using a binary method in which the responses “Not at all” and “Not more than usual” as 0 and “Rather more than usual” and “Much more than usual” as 1. The latter was used in this study. The threshold used to identify any possible presence of distress is 4 (Goldberg, 1986; Sterling, 2011).

The French version was used in the study, translated in 1992 by Pariente (Pariente et al., 1992). It was administered to 158 psychiatric patients and it showed an internal consistency with the  $\alpha$  coefficient of 0.91, a sensitivity and specificity of 59% and 87% respectively, thus confirming the validity of the translation and its usefulness and appropriateness .

#### 8.4.3 Alceste

*Alceste (Analyse lexicale par Contexte d'un Ensemble de Segments de Texte)* is a French statistical program that carries out a qualitative analysis of various texts (interviews, magazine articles, literary works, etc.) (Delavigne, 2003). It was conceived in 1980 by Max Reinert and developed and marketed since 1986 by the IMAGE company under the license of the CNRS of the University of Toulouse (Image Ltd., Toulouse, France).

Much scientific research has gone into analyzing and confirming the effectiveness of Alceste. These studies were conducted in the field of social psychology and sociology (Geka & Dargentas, 2010; Gonin, 2008; Kalampalikis, 2005; Lahlou, 1998; Scharnitzky & Kalampalikis, 2007; Temple & Denoux, 2008; Viaud et al., 2007), social and educational sciences and clinical psychology (Aubert-Lotarski & Capdevielle-Mougnibas, 2002; Metz et al., 2019; Truc, 2011), etc.

The program tries to highlight the use of words and their connection based on their appearances and positions within the text (Bart, 2011). The method used is the “hierarchical classification from top to bottom”. Starting from the central body of text, the program subdivides the text and extrapolates classes of more representative words (Delavigne, 2003). Classes are therefore not based on the meaning of words but on a distributive statistical analysis (Delavigne, 2003). Finally, the classes can be visualized – this is the analyst’s main object of interest (Delavigne, 2003).

Alceste provides a kind of detailed profile for each class. This means that the analyst has access to the list of the most significant words of each class, of each unit and to their co-occurrence (that is, the position of the words and their use). At the statistical level,  $\chi^2$  highlights and classifies the degree of belonging (strong or weak) of a word to a class and the most significant terms (Delavigne, 2003). Specifically, the analysis is characterized by four stages. In the first one, Alceste recognizes the initial context units (*u.c.i.*, according to French acronyms), or the segments that compose the body of text (in our case, for example, the *u.c.i.* are the different interviews of the participants).

Moreover, the program selects and distinguishes the “necessary words”, useful for the syntactic construction (such as articles, conjunctions, preposition, etc.) from the “full” words (nouns, verbs, adjectives, adverbs), which are the only ones to be analyzed (Bart, 2011).

Subsequently, the body of text is divided into units of elementary context (*u.c.e*), in other words, one or more consecutive lines of text, and is classified according to the distribution and the statistical link between the forms (the suffixes of the words) and the classes created.

The last two stages consist of the presentation of the first results, providing the profiles and characteristics of the different classes (analyzed words, ignored words, their frequency, etc.), and the generation of complementary calculations, such as: crossing a part of the text with a particular variable or word (*deux types de tris croisés*); and Factorial Analysis of Correspondences (AFC). This allows the investigator to explain any relationships of attraction or distance between classes and forms; and create a hierarchical ascending classification which shows closeness between words (Bart, 2011; Delavigne, 2003).

In general, the analysis of Alceste therefore concerns:

- the lexicon, through the account of words and the co-occurrence of forms;
- the content, given by the segmentation of text;
- and the quantitative data, through ascending and descending textual classification.

Furthermore, at the end of the analysis it is possible to display the degree of relevance of the treatment (low, medium, high or very high). The relevance of the treatment is based on the percentage of the text unit that the program has managed to classify. For this reason it is advisable to obtain a high or very high degree of relevance.

After having inserted the body of text in the program, the researcher is able to modify the analysis parameters, which determine the degree of relevance. The parameters include, but are not limited to deciding on the type of classification, the minimum number of classes, etc.

In our case, the high degree of relevance was achieved without having made any changes but through the standard and predefined criteria of the program.

This means that the selection of the U.C.E. (Unit Elementary Context) is automatic (*ETAPE A*). Furthermore, the units of the context are analyzed through a double descending classification and with a determined number of standardized words by both classifications (*Valeur DONN.1* and *2*). According to the predefined Alceste criteria, the number of classes for each descending classification is a maximum of eight and a unit of content must be present at least four times (*Fréquence minimale d'une forme analysée*).

In addition, the minimum size of a class with respect to the number of units is automatic, ranging from a value between 1 and 3000 (*ETAPE C*).

Finally, Stage D (*ETAPE D*) corresponds to complementary calculations, i.e., how to perform the ascending hierarchical classification, the number of textual units displayed in the analysis results (in this case 100), etc.

Figure 5 The interface of the elementary and predefined parameters of Alceste to determine the analysis criteria.

The screenshot shows the 'Paramétrage' window of the Alceste software. The window title is 'Alceste Paramétrage'. The main content area is titled 'Paramétrage simplifié' and contains the following settings:

- Etape A : Lecture du texte et calcul des dictionnaires**
  - Lemmatisation
  - Calcul automatique de la taille des u.c.e
  - Prendre les paragraphes du texte comme u.c.e
- Etape B : Définition des u.c.e et classification**
  - Classification double sur les unités de contexte (u.c)
  - Classification simple sur les unités de contexte initiales (u.c.i)
  - Classification simple sur les unités de contexte élémentaires (u.c.e)
  - Valeur DONN.1 pour la première classification: Auto [infos+](#)
  - Valeur DONN.2 pour la seconde classification: Auto [infos+](#)
  - Nombre de classes terminales par classification: 8 [infos+](#)
  - Fréquence minimale d'une forme analysée: 4 [infos+](#)
- Etape C : Définition des classes et calcul de l'A.F.C.**
  - Nombre minimum d'u.c.e. par classe: Auto [infos+](#)
- Etape D : Calculs complémentaires**
  - Nombre d'u.c.e. colorées et affichées par classe: 100 [infos+](#)
  - Recherche des segments répétés
  - Classification Ascendante Hiérarchique

At the bottom of the window, there are two buttons: 'Valider' and 'Annuler'.

After Alceste has completed the analysis, the first window that appears is a summary of all the data obtained, namely the classification of the classes, the percentages of the treatment, the dictionary, the list of terms of the double and ascending classification, etc. (Figure 6).

In addition to this first window, there are also other functions available, such as: displaying classes and co-occurrences in a spiral pattern or word by word analysis, etc.

The numbered and colored classes appear in order of appearance. Their number depend on the homogeneity of the words, while the percentage on the presence of the class's words within the text. For each class, the Khi2 coefficients are also indicated, which is an association coefficient that measures the relationship between a word and its class: the higher the coefficient, the stronger the connection.

Moreover, the classes of Alceste are called "lexical worlds" of the subject, which allow for a semantic interpretation of the words that compose them.

After the program has carried out its analysis, it is up to the researcher to understand and interpret the results.

Our assessment focused specifically on the study of descending classifications and the detailed report provided by Alceste. The first one corresponds to the results shown in the center of the main window that appears after the program has finished the analysis (Figure 15), while the second one includes the summary of all the information and analyses carried out, including fragments of sentences with respect to the selected words.

Figure 6 Interface of the main window of the analysis of Alceste.



Within our research, Alceste was used for a qualitative analysis of the semi-direct interviews carried out with the participants.

In particular, two different types of analysis were created to validate our initial hypotheses.

The first analysis dealt with the psychological consequences that follow perinatal loss, and specifically complicated grief disorder. The time criterion for a possible diagnosis is the presence of symptoms for more than six months after loss, according to the criteria established by Prigerson and collaborators (2005).

Although with similar diagnostic and psychometric properties, research has shown that, compared with the Persistent Complex Bereavement Disorder (PCBD) of DSM-5 (2013), for which the disorder can only be present 12 months following a loss, the 6-month time criterion required of complicated or Prolonged Grief Disorder (PGD) seems to be the most inclusive and appropriate (Boelen & Prigerson, 2012; Bonanno & Malgaroli, 2019; Killikelly & Maercker, 2017; Prigerson et al., 2009; Shear et al., 2011).



The 29 participants were split into three different groups, based on how much time had passed from the loss, namely: the interviews that took place within six months of grief (Group I); those carried out between 6 and 12 months after the loss of the child (Group II); and those that took place after 12 months (Group III).

The goal is to demonstrate that there is a change of discourse with the passage of time and relevant aspects of complicated grief disorder.

Furthermore, the second analysis concerns the evaluation of the effectiveness of psychotherapy. The participants were divided into other three groups: those who didn't follow any therapy; those who were followed by a psychotherapist and/or participated in support groups; and those who participated in the social networks.

The time established for psychological care was 10 sessions. Participants were included in the second group, i.e. those who followed therapy, if they attended a minimum of 10 sessions before or during participation in the research. This data was extrapolated through specific questions during the interviews.

After selecting the participants in accordance with these variables (time elapsed from loss and psychological support), all interviews for each participant were included within a single text of the reference group.

The aim was, therefore, to verify whether each group had a different type of language / discourse, and what the main themes were in each group.

#### 8.4.4 Interpretative Phenomenological Analysis

The Interpretative Phenomenological Analysis (IPA) is a qualitative methodology which aims at understanding the interpretation that the subject has given to his experience.

Conceived in 1996 by Smith, IPA is based on three fundamental concepts: phenomenology, hermeneutics and upon an idiographic approach (Smith, 1996; Smith et al., 2009).

Phenomenology, a philosophical method of investigation based on the thought of Edmund Husserl, entails the study of phenomena which is unique and distinguishable from others. It highlights how events appear to the conscience and assume a universal and logical meaning. However, this method is far from conventional and known preconceptions.

Heidegger's hermeneutics (a term deriving from the ancient Greek, "to interpret", "to make clear") informs the analysis of the results, studying the meaning and the interpretation of the phenomenon by the individual as a thinking being.

Finally, the idiographic approach involves taking a single case study and using it to produce general and predefined categorization (Pietkiewicz & Smith, 2014; Smith & Osborn, 2015). The IPA is therefore an inductive process of analysis about what meaning the individual attributes to his or her own intimate experiences.

In addition to the main basic concepts expressed above, it is also important to consider the role of the experimenter in what could be defined as “double hermeneutics”: an active dynamic process in which the researcher will try to make sense of the vision of other people’s world through his or her personal conceptions (Pietkiewicz & Smith, 2014; Smith & Osborn, 2008).

The data was collected through the transcription of semi-structured interviews, the most recommended method (Smith, 2004). During the interviews, participants were encouraged to describe their experience in-depth.

What drives the IPA are predefined issues, with the aim of evaluating the hypotheses of the study. The analysis procedure begins by re-reading the text numerous times and, next to the individual sentences, taking some notes and keywords, to underline the identified concept.

Starting from this summary, the investigator will start a “bottom up” analysis: from the annotations and summaries, he or she will begin a process of encoding the meanings (“codes”, marked line-by-line), trying to create categories of more general or “superordinate” arguments, including sub-categories (Larkin & Thompson, 2011; Reid et al., 2005; Smith, 2004).

The annotations can be written in the margins of the transcripts and with the intensification of the study, the experimenter will begin to focus exclusively on the summaries, and eventually on the categories.

The literature suggests using this analysis for a homogenous and limited number of participants (Collins & Nicolson, 2002; Eatought & Smith, 2017; Smith, 2004; Smith & Osborn, 2003).

Therefore, in our research, after carrying out a first analysis with the first 3 interviews conducted with 29 parents, for a more in-depth IPA, we selected only 4 participants.

The final analysis was therefore dedicated to only 20 interviews (that is the five meetings effected with 4 parents, 2 women and 2 men).

After an initial general analysis, these 4 participants were considered the most representative of the IPA categories that emerged from the preliminary analysis and as useful case studies with respect to the consequences of grief.

Our research was carried out exclusively by a single person, who tried to be as more lucid as possible in identifying the issues during the course of long-term research.

Following the directions of the main author (Smith, 1996), the researcher began the analysis starting from a careful reading of each interview. After reading the interviews twice, only from the third one the researcher noted summaries of the concept / sentences at the edge of the page.

To try to highlight the concepts in a lucid manner, the researcher let a few days pass between each reading.

After having marked and checked the first summaries several times, a process of codification and categorization took place. Over time, the researcher focused exclusively on annotations, and then tried to give a title to each concept that emerged. Starting from this preliminary phase, the researcher tried to put in relation each identified code to find general categories and sub-categories.

The aim was to enclose through these denominations the specific aspects that emerged during the interviews, in a general and exhaustive manner.

The coding work required about three processes, to be able to find the relevant codes and enclose the issues in as few categories as possible.

In closing, the IPA was chosen because it provides a comparison between the participants and highlights the person's functionalities. It makes possible to evaluate the phenomenon of loss and how it was experienced by parents, as well as taking into account their perception and understanding of loss.

In summary, perinatal loss, an event often culturally underestimated but still very frequent, risks determining the development of numerous psychopathological disorders.

Our aim is to highlight the psychic functioning of the parent, in particular, focusing on the risk of developing complicated grief disorder and the possible efficacy given by therapeutic support.

The therapeutic support concerns in particular personal psychotherapy and / or participation in support groups. Furthermore, active and prolonged participation in groups dedicated to perinatal loss on social networks (Facebook, blog, forum, etc.) was also considered. It is important to consider that these groups are confused by parents with therapeutic ones.

To achieve these goals, we have designed a longitudinal study. 29 French parents were met for a total of five times distributed over 18 months: the first, three months, six months, a year and eighteen months after the first meeting.

The methodology used was mixed. Each meeting was characterized by a semi-directive interview (later analyzed through the Interpretative Phenomenological Analysis - IPA and the French qualitative statistical program Alceste) and the administration of two questionnaires.

The purpose of the IPA is to understand the interpretation that the subject has given to the event that he lived. It also includes the active role of the researcher ("double hermeneutics"), who must try to make sense of another person's vision of the world (the interviewee).

Alceste is a statistical program that categorizes the words based on their frequency and position within the text (co-occurrence).

The two questionnaires were: the Inventory of Complicated Grief, a questionnaire with 19 items to assess the risk of developing a complicated grief disorder, and the General Health Questionnaire-28, with 28 items to assess the person's overall mental health.

This methodology was considered the most appropriate in order to achieve our goals and to obtain valid and effective results.

## Chapter 9: Participants

Participants were between 26 and 41 years old, in particular in the age group between 26 and 30 years old (45%), and with a mean of 31.4 years old.

7 people (4 women and 3 men) live in Alsace, 21 live in other regions of metropolitan France and a mother in Guadelupe (non-metropolitan France).

The majority of participants are *pacsé* (34,5%) (Table 8). The PACS (*pacte civil de solidarité*) is the French contractual form of civil union between two adults of the same or different sex.

Since 1999, the year of its institutionalization, the percentage of couples who choose PACS has increased significantly every year. As the data confirms, it has become one of the main choices among the different types of union, especially among younger couples (24-35 years) (Ferret, 2018).

The same percentage of parents (34,5%) live with their partner and are neither *pacsé* nor married. The rest of participants are married (28%) or single (3%).

Most of the participants are employed (86%) and they obtained a professional diploma (41%), followed by a master's degree (24%), a high school diploma (17%), a bachelor's degree (14%) and a middle school diploma (3%).

The jobs conducted by participants are very heterogeneous, such as nurses, teachers, employees, shop assistants and housewives, etc. They are very different and difficult to categorize.

Out of 29 participants 4 do not work, or rather they are officially unemployed looking for a job (3 women) or do not receive any salary (1 woman is a housewife).

Furthermore, even if for most of the participants their professional career started early and with it, probably, economic independence, there are no significant differences between the parent's educational qualification, age and the number of children present within the family (7 in total). In most of the cases the deceased child was their first child (82.8%) and only 17% of the participants had already become a parent, of at most 2 children.

Table 5 *Demographic factors among 29 French bereaved parents\**

	n	%
<b>Sex</b>		
F	21	72.4%
M	8	27.6%
<b>Status</b>		
Married	8	27.6 %
PACS	10	34.5 %
Partner	10	34.5 %
Single	1	3.4 %
<b>Employment</b>		
Employed	25	86.2 %
Unemployed	4	13.8 %
<b>Title of study</b>		
Bachelor's degree	4	13.8 %
High school diploma	5	17.2 %
Master's degree	7	24.1 %
Middle School	1	3.4 %
Professional diploma	12	41.4 %
<b>Presence of other children before</b>		
0	24	82.8 %
1	3	10.3 %
2	2	6.9 %

\*The parents are 31-45 years old (mean 31.4, median 31).

### 9.1 Participants criteria

In France, the criteria for studies of infant and perinatal mortality rates are based on the recommendations of the WHO, i.e. with respect to the spontaneous death of a child or an LTP occurred starting from the 22nd week of amenorrhea or 500 g of weight of child (Ministère du travail, de l'emploi et de la santé & Secrétariat d'Etat à la santé, 2011). These indications have therefore determined the selection criteria based on the time of the child's death.

Due to the study's linguistic focus, it was also necessary for participants to be native French speakers. Of 29 participants 2 of them are Belgian, residing in France.

Initially, we sought to recruit people who had lost a child as recently as possible. Given the difficulties of finding parents available to participate in the research, it was necessary to extend the time criterion between the death of the child and the first interview, including only parents who have lost a baby up to ten months before the first interview. This time constraint was considered not too distant but sufficiently useful to recruit parents willing to participate. This means that the time between the loss of the child and the start of the research is not the same for all participants.

Table 6 *Frequencies of children sex.*

Selection criteria
Perinatal death (from the 22nd week of amenorrhea or 500g of weight until the first year old of the child);
To be a native French speaker;
Deceased child maximum ten months before from the first interview.

## 9.2 Selection of participants

The selection of the participants lasted almost one year.

Initially the research took place in Alsace, in particular through collaboration with the association “Nos Tout Petits d'Alsace”.

The association has offices in Strasbourg and Mulhouse and the parents meet once per month, in the evening, for about two hours. The groups are run by bereaved parents who have followed adequate training organized by the association and once a month the group leaders meet with a psychotherapist for supervision.

The research was proposed to the participants at one of their monthly meetings in Strasbourg and Mulhouse and during the association’s annual meeting where all the members of the association were present.

Furthermore, two hospitals in Strasbourg were contacted (Hautepierre and CMCO hospitals), requesting in particular the collaboration of psychologists and midwives.

For fear of confusing parents, psychologists did not make themselves available while the midwives have started to introduce the research to the patients through a leaflet, where the objectives, timings and contacts for the study were explained.

The partnership with the midwives in hospitals lasted only a few months, from March 2017 to July 2017. After seeing the logistical issue (that is, the few and infrequent meetings with bereaved parents

and probably also the difficulty in proposing the project in a very painful and delicate moment), the midwives stopped collaborating, but remained available for further studies and recruitment methods. So, in the first seven months, just four participants (two couples) were recruited in Alsace.

As the search for the participants was difficult and challenging, associations distributed throughout the French territory, blogs and forum pages about perinatal loss were contacted by email and/or by phone, found through an inquiry on the web search engine Google.

The associations contacted were:

- “Apprivoiser l’absence”, association of support groups for parents and siblings, based in Paris, Marseille, Vannes and Grenoble;
- “Jonathan Pierres Vivante”, association of support groups and forums throughout France;
- “Naitre et vivre”, who organizes support groups in Paris;
- “Adep56”, who organizes groups in Quéven and Vannes ;
- “Vivre son deuil”, association in Lyon who support the activities of the various associations by promoting the exchange of information, coordinating a help for bereaved people, offering innovative training, etc.;
- “Association Deuil Espoir”, who organizes support groups in Nancy;
- “Association SPAMA”, an association based in Lille, Grenoble, Lyon and Rennes that promotes palliative care and parents’ support, offering a crisis line, a forum, events, and promoting research;
- “Lou’Ange”, association based in Saint-Etienne that makes kits and baskets for hospitals;
- “L’Enfant sans nome – Parents endeuillés”, associations with support groups based in Valdahon, Lyon, Chalon Sur Saone and Saint Cloud;
- “Souvenange”, association located throughout France who offers parents professional-quality photographs of their deceased baby;
- “L’association Chemin des étoiles”, association that organizes support groups and events for parents in Libourne.

The forums and blogs contacted were:

- “L’envolée – Deuil perinatal” (forum that also organizes events for parents, based in Vineuil);
- “Mamansendeuil.centerblog”;
- “Nos petits anges au paradis”;
- “Parentsendeuil”;
- “A notre tres chere solene over blog”;



- “Hesperanges17”;
- “Petite emilie”.

Of these, the associations Viviane, SPAMA, Souvenange and the forums and blogs Mamansendeuil, Hesperanges17 and Petite Emilie were the most collaborative.

They posted an explanation of the study in their Facebook and blog pages, providing contacts to possible parents who fell within the selection criteria.

Furthermore, a “professional” Facebook’s profile of the main researcher was created and the same explanatory post about the study was sent to various Facebook pages and closed groups, asking for permission beforehand by means of a private message to the administrators.

To look for the pages, the keywords *deuil périnatal* (perinatal loss), *parent en deuil* (bereaved parents), *parents endeuillés* (grieving parents) were used.

The groups and pages where the announcement was published are:

- “Adep56 “Accompagner le Deuil Périnatal” (125 members);
- “Le deuil périnatal – Stop au tabou! ” (98 members);
- “Le Ruban du Deuil Périnatal” (271 members);
- “15 Octobre - Journée de sensibilisation au deuil périnatal” (527 members);
- “Deuil périnatal mamange” (personal blog with 102 members) ;
- “Nos Tout petits de Savoie - Deuil périnatal” (407 members);
- “Solidarité pour parents endeuillés” (978 members);
- “Déployez vos ailes: Soutien et accompagnement au deuil périnatal” (158 members);
- “Nos anges deuil périnatal à Marseille” (54 members);
- “Deuil périnatal - La Vie après la perte de bébé” (286 members);
- “Accompagnement du Deuil Périnatal” (152 members);
- “Soutien au Deuil Périnatal” (206 members);
- “Deuil périnatal 64 - groupe pour parents endeuillés” (15 members);
- “Deuil périnatal Événements 2017” (360 members);
- “Enfants Papillons - Deuil Périnatal” (168 members);
- “Par'anges deuil périnatal” (383members);
- “Deuil périnatal, tous les événements” (1221 members);
- “Souvenange” (3627 members);
- “Deuil Périnatal : Une Etoile au Paradis” (14 members);
- “Accompagnement Deuil périnatal” (228 members);

- “Association Extr'AIME, prématurité et deuil périnatal” (725 members);
- “Petits Anges. Deuil périnatal” (954 members);
- “Grossesse espoirs- suite à un deuil périnatal ❤️” (436 members);
- “Groupe de parole : Association l’Envolée-Deuil périnatal” (342 members);
- “Img et deuil périnatal” (545 members);
- “Quelques mots ensemble : deuil périnatal” (400 members);
- “Deuil périnatal, portrait montage photo pour vos anges” (160 members);

Parents responded to the post by sending a private message on Facebook, and email or by commenting on the post. The most participants were recruited on the following pages:

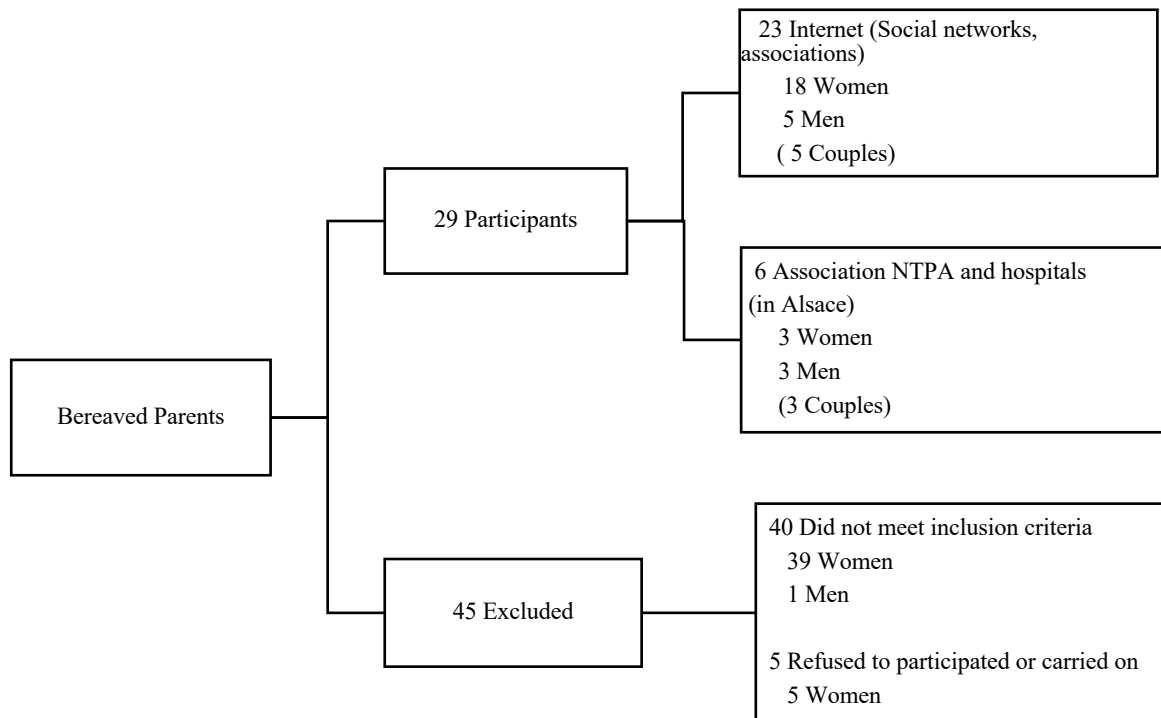
- “Grossesse espoirs- suite à un deuil périnatal ❤️ ” (436 members);
- “Groupe de parole : Association l’Envolée-Deuil périnatal” (342 members);
- “Img et deuil périnatal” (545 members);
- “Quelques mots ensemble: deuil périnatal” (private group of about 400 members, of which the administrator accepted the application and asked to remove the publication after a while to protect the privacy and the discussions of members);
- “Deuil périnatal, portrait montage photo pour vos anges” (160 members);
- “Enfants Papillons - Deuil Périnatal” (168 members) ;
- “Deuil périnatal 64 - groupe pour parents endeuillés” (15 members);
- “Souvenange” (3627 members);

Responses to the study came from the pages with a high number of members and especially the most active pages, as in some of them the last posts and discussions dated back to 2015. It is also interesting to note the number of pages, blogs and associations that are scattered and active throughout France. It was thanks to the announcement published on social networks that many bereaved parents contacted the main researcher declaring themselves available to participate. Of these, 40 people (39 women and 1 man) were excluded because they did not match the selection criteria, in particular with respect to the time elapsed since the child's loss.

In addition, three women who initially had agreed to participate decided later to withdraw from the research, saying they did not feel ready to talk about their grief (in addition to two women that, as already indicated before, stopped collaborating in the first months).

Besides three couples recruited in Alsace, thanks to other associations and social networks in a few months, another 23 people knew about the research and agreed to participate.

Figure 7 *Flow of participants*



### 9.3 Children lost

Of the 32 deceased children, 21 were females (67%) and 11 males (34%) (Table 7). Three participants had lost twins.

The maximum time between the date of child's death and the first meeting was around ten months (namely nine months and twenty-seven days), while the minimum was twenty-two days. The baby's deaths occurred from November 2016 until November 2017 and in 16% of cases the cause of the child's death was unknown.

Furthermore, as reported in Table 6, 50% of deaths (11 females and 5 males) occurred due to medical problems (respiratory problems, heart and general malformation, genetic diseases, premature delivery, necrotizing enterocolitis, etc.).

Because of malformations and diseases (i.e. trisomy 21), 34% of parents decided to carry out a Late Termination of Pregnancy (LTP) (8 females and 3 males).

Compared with the anamnesis collected on children, only 22% of children lived. One baby lived a few moments (3%), one a few hours (3%), four babies (12,5%) for some days (maximum two weeks) and 6% children for almost three months (up to a maximum of 96 days). 75% died during pregnancy, starting from the twenty-second week of amenorrhea.

Most of the children (75%) were cremated. Moreover, 53% of the children, cremated or not, received a tombstone. In the remaining 47% of cases, the ashes were instead dispersed or taken to the hospital.

Table 7 *Demographic characteristics of children*

	n	%
<b>Sex</b>		
F	21	65.6 %
M	11	34.4 %
<b>Unknown cause of death</b>		
Known	27	84.4 %
Unknown	5	15.6 %
<b>Cause of loss</b>		
Medical Problem	16	50.0%
Unknown	5	15.6%
Late termination of pregnancy	11	34.4%
<b>Lived children</b>		
Days	4	12.5 %
NO	24	75.0 %
Hours	1	3.1 %
Months	2	6.3 %
Moments	1	3.1 %
<b>Remains</b>		
Burial	8	25.0 %
Cremation	24	75.0 %
<b>Stela or tomb</b>		
NO	15	46.9 %
YES	17	53.1 %

In summary, 21 women and 8 men were met for a total of five times distributed in eighteen months. The average age is 31 years old. Most parents are married, with a job and a professional degree. At the beginning, there were some difficulties in recruiting the fixed number of participants (i.e., 30). Two methods were the most useful for recruiting parents willing to participate: the publication of announcements on social networks and collaboration with French associations for bereaved parents. Compared to the anamnesis of the children, the parents lost the child from a minimum of 22 days to a maximum of about 10 months before the first meeting. The children were mostly females (65%). In general, 50% of children died for medical reasons, 15.6% for an LTP and 16% for unknown causes. Most of them died during pregnancy and only 22% of children lived for a minimum of a few minutes to a maximum of 96 days.

## **PART C. RESULTS**

This third part of the study introduces the results obtained during the five meetings (T1, T2, T3, T4 and T5) carried out with the 29 bereaved parents in eighteen months.

The first meeting (T1) took place after a maximum of ten months and a minimum of twenty-two days from the date of the child's loss. The other meetings were organized after three, six, twelve and eighteen months later with respect to T1.

The results are presented based on the methodology used, that is through the qualitative and quantitative analysis.

Specifically, the analyses were conducted in order to understand the psychological consequences that may arise following the loss of a child in the perinatal period and the possible effects of psychological support.

In addition to these specific and predefined objectives, the research highlighted other important data concerning the parents and their work of mourning, such as the presence of children born before or after the loss, social support, etc.

All these variables have then been analyzed through the results of two questionnaires, the ICG and GHQ-28 (which characterize the quantitative analysis), while the semi-directed interviews were evaluated thanks to the IPA and the use of the Alceste program, which instead correspond to the qualitative analysis.

The analysis of the results will be analyzed in depth in the next part, the Part D.

## Chapter 10: Quantitative Analysis

### *Inventory Complicated Grief and General Health Questionnaire 28's scores*

As previously expressed, the parents were met for a total of five times distributed over eighteen months: the first (T1), three months (T2), six months (T3), one year (T4) and eighteen months later (T5) the first meeting.

The time between the loss of the child and the first meeting is not the same for all participants. The shortest period is 22 days to a maximum of about ten months.

During the first interview (T1) the parents obtained very high values in ICG (Table 8). Subsequently, the results showed a clear improvement, with the passage of time the values clearly decreased. The results showed an average of 44.9 in T1, 35.5 in T2, 30.4 in T3, 28.7 in T4 and 23.9 in T5 for women. Meanwhile for men, the average was 44.8 in T1, 37 in T2, 35 in T3, 25.6 in T4 and 21.5 in T5.

From the very beginning of the study, the values were practically the same, without gender differences. In T2 and T3 the men scored higher, while in T1, but above all, in T4 and T5 women did. Both started in T1 with an average of about 45 (a very high result compared with the reference cut-off, i.e. >25) until arriving in T5 to a common average of about 23.2.

With respect to the frequencies of the results above or below the reference cut-off (i.e. 25) (Figure 8), both men and women showed a majority of results above the cut-off up to T4, underlining and confirming a linear decrease in risk towards the end of the study. This effect was registered in particular in women, since, considering the population, the 8 men showed an improvement much more slowly than the 21 mothers. In fact, out of 24 women, the highest values of 25 were present in 18 mothers in T1, 13 in T2, 12 in T3, 11 in T4 and 8 in T5, while for the 8 men: 8 in T1, 7 in T2, 7 in T3, 4 in T4 and 3 in T5.

Furthermore, variance analyses showed that the decrease in ICG averages was significant, in particular, between the first interview (T1) and the other four (T2, T3, T4 and T5) ( $p < 0.005$ ,  $p < 0.001$ ,  $p < 0.001$  and  $p < 0.001$ ).

Another difference concerns the comparison between the results obtained in T2 and T4 ( $p < 0.011$ ) and T5 ( $p < 0.001$ ), and between T3 and T5 ( $p < 0.007$ ).

This data confirms (as previously suggested) that the general values of the tests, and therefore the risk of CG's development, decreased over the course of the interviews and the months.

Concerning the significant differences with respect to the participants' gender, the decrease was significant in women, particularly compared with T1 and other T's (mean of 44.9 in T1 Vs 35.5, 30.4, 28.7 and 23.9 in T2, T3, T4 and T5,  $p < 0.05$  and  $p < 0.01$ ) and between T2 and T5 (mean of 35.5 in T2 Vs 23.9 in T5,  $p < 0.004$ ).



In the case of men, on the other hand, the significant difference of the average was between T1 and T4 and T5 (mean of 44.8 Vs 25.6 and 21.5,  $p < 0.004$ ,  $p < 0.001$ ), and T2 and T5 ( $p < 0.04$ ).

A year after beginning research and data collection, the men obtained a score of 21.5, approximately 28 points less than the beginning, while the women had a score of 26.

There were no significant differences between the results of women and men with respect to the comparison made within each T.

The only difference highlighted was at a longitudinal level between the result of women in T1 and that of men in T5 ( $p < 0.058$ ).

Furthermore, as previously mentioned, the General Health Questionnaire-28 includes four different subscales through which it is possible to evaluate the presence of possible diseases (through a score  $> 4$ ), such as: somatic disorders, anxiety and insomnia, social dysfunction, and severe depression.

For both men and women, starting from the second interview the results obtained in the four subscales of the GHQ-28 showed considerable changes and improvements.

The values of Somatic Symptoms were below the reference threshold ( $< 4$ ) from the beginning, data also confirmed by the frequency of the results above or below the cut-off (Figure 9).

In T1 the recorded average was 2.9 for women and 2.75 for men, reaching 0.905 and 0.5 in T5: a significant difference was found between the general results in T1 and T5 ( $p < 0.001$ ) while the analysis of variance carried out considering the 5 results obtained during the different Ts and the gender of the participants did not present any significant difference.

Compared to the Anxiety and Insomnia subscale, the results showed that in T1 the mean values were slightly higher than the reference threshold ( $> 4$ ), particularly in men who obtained an average of 5.13. Furthermore, a significant difference is highlighted between the values in T1 and those of the subsequent results ( $p < 0.014$ ,  $p < 0.016$  and  $p < 0.001$ ), and T2 and T3 respect to T5 ( $p < 0.016$  and  $p < 0.014$ ). In particular, considering the gender of participants, the different scores recorded in T1, T4 and T5 by women (mean of 4.76 Vs 2.67 and 1.86,  $p < 0.029$  and  $p < 0.001$ ) and by men (mean of 5.13 Vs 1.13 and 0.62,  $p < 0.004$  and  $p < 0.001$ ) were significant. Moreover, there were some differences between the results of women in T1 and men in T4 and T5 ( $p < 0.019$  and  $p < 0.004$ ) and between that of men in T1 and women in T5 ( $p < 0.05$ ).

As for the previous subscales, even under Social Dysfunction, the participants recorded higher values than the reference threshold in T1 (in particular women, with a mean of 4.57), then highlighting a decrease and therefore an improvement in subsequent results (data also confirmed by the frequencies of the results higher or lower than the reference cut-off, that is 4) (Figure 11). In T5 the general average was 1.19 for women and 0.375 for men.

Concerning the significant differences, women have shown a significant improvement: their averages went from 4.57 in T1 to 2.37 in T2, 1.71 in T3, 1.52 in T4 and 1.19 in T5. In addition to the difference between the values recorded by women, the comparison between the results of women in T1 (mean = 4.57) and those of men in T2, T4 and T5 (mean = 1.13, 0.62 and 0.37) was also significant ( $p < 0.009$  and  $p < 0.001$ ).

Furthermore, the values of the sub-scale of Severe Depression were always below 4. In particular, men always demonstrated very low values, both with respect to the reference threshold ( $>4$ ) and to women.

Significant differences were recorded with respect to T1's general values compared with those of T2 ( $p < 0.013$ ), T3, T4 and T5 ( $p < 0.001$ ).

Women showed significant differences in T1 values (mean = 3.71) compared with T3, T4, and T5 (mean = 1.86, 1.43 and 1.10,  $p < 0.002$  and  $p < 0.001$ ). Furthermore, they also recorded a significant difference with respect to the men's results in T2, T4, and T5 (that is a mean of 2.38 for women Vs 0.625 in T2, 0.375 in T4 and 0.125 in T5 for men).

Except for the subscale of somatic disorders (which had recorded scores  $<4$  already in T1), the improvement and lowering of the other three subscales' average appeared clearly from T2.

Despite the alternation of values, generally in T5 mothers presented higher values in all subscales of questionnaire (Somatic Symptoms, Anxiety and Insomnia, Social Dysfunction and Severe Depression).

Both questionnaires' results have undergone a marked change, evidenced by the significant differences that emerged in the analysis of the variance between the results of T1 and T2, T3, T4, and T5, both for women and for men ( $p < 0.05$ ).

Table 8 Psychometric analysis of ICG and GHQ-28 questionnaires' scores in T1, T2, T3, T4 and T5.

	Mean		SD		p-values
	F	M	F	M	
<b>T1</b>					
ICG	44.9	44.8	14.7	15.3	T1>T2*, T3**, T4**, T5**
GHQ-28	2.29	2.75	1.68	1.39	T1>T5**
Somatic symptoms					
GHQ-28	4.76	5.13	2.45	1.89	T1>T2*, T3*, T4**, T5**
Anxiety &Insomnia					
GHQ-28	4.57	3.00	2.31	2.45	T1>T2**, T3**, T4**, T5**
Social dysfunction					
GHQ-28	3.71	1.50	2.59	1.69	T1>T2*, T3**, T4**, T5**
Severe depression					
<b>T2</b>					
ICG	35.5	37.0	17.5	8.9	T2>T4**, T5**
GHQ-28	1.71	1.88	2.08	1.81	T2>T5*
Somatic symptoms					
GHQ-28	3.43	2.50	2.69	1.93	
Anxiety &Insomnia					
GHQ-28	2.38	1.13	2.50	1.55	
Social dysfunction					
GHQ-28	2.38		2.77	0.74	T2>T5*
Severe depression		0.625			
<b>T3</b>					
ICG	30.4	35.0	19.7	12.1	T3>T5*
GHQ-28	1.43	1.75	1.66	2.05	T3>T5*
Somatic symptoms					
GHQ-28	3.19	3.25	3.03	2.49	
Anxiety &Insomnia					
GHQ-28	1.71	1.88	2.41	1.73	
Social dysfunction					
GHQ-28	1.86	0.875	2.48	1.46	
Severe depression					
<b>T4</b>					
ICG	28.7	25.9	18.4	14.1	
GHQ-28	1.76	0.375	1.95	0.52	
Somatic symptoms					
GHQ-28	2.67	1.13	2.58	2.03	
Anxiety &Insomnia					
GHQ-28	1.52	0.625	2.27	1.77	
Social dysfunction					
GHQ-28	1.43	0.375	2.20	0.52	
Severe depression					
<b>T5</b>					
ICG	23.9	21.5	21.2	13.6	
GHQ-28	0.905	0.500	1.30	1.41	
Somatic symptoms					
Anxiety &Insomnia	1.86	0.625	2.26	0.91	
GHQ-28	1.19	0.375	2.14	0.52	
Social dysfunction					
GHQ-28	1.10	0.125	1.89	0.35	
Severe depression					

\*p<.05

\*\*p<.01

Figure 8 *Frequency of results above and below the reference cut-off of the ICG questionnaire.*

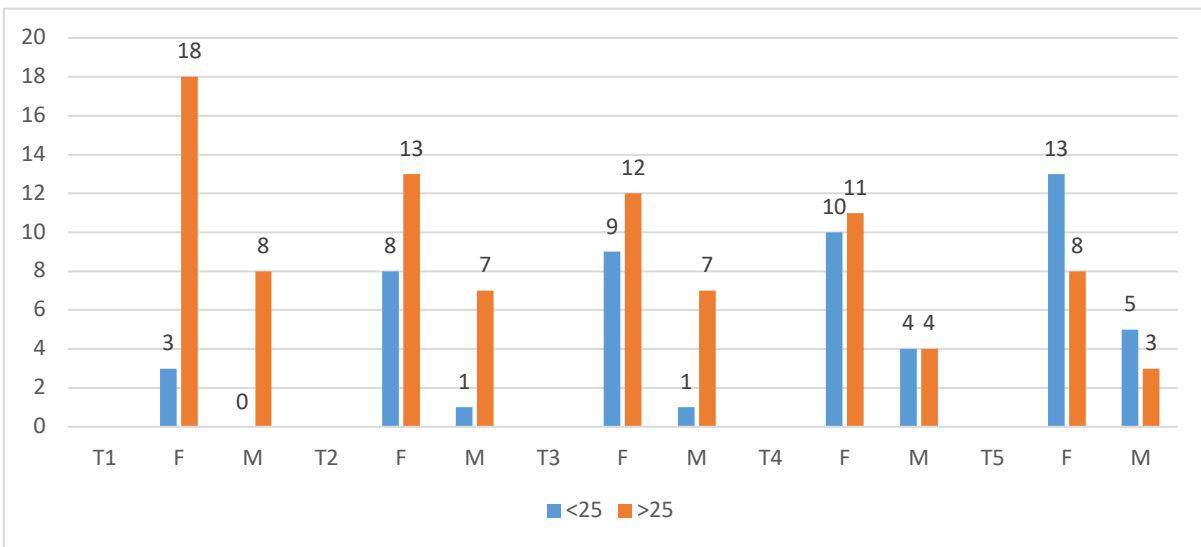


Figure 9 *Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale.*

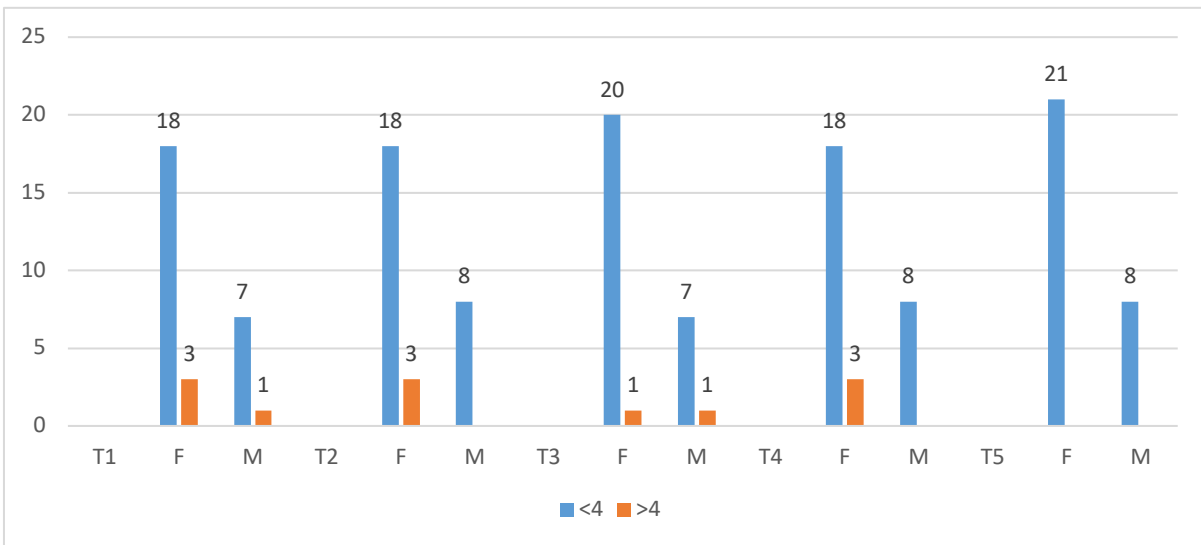


Figure 10 *Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale.*

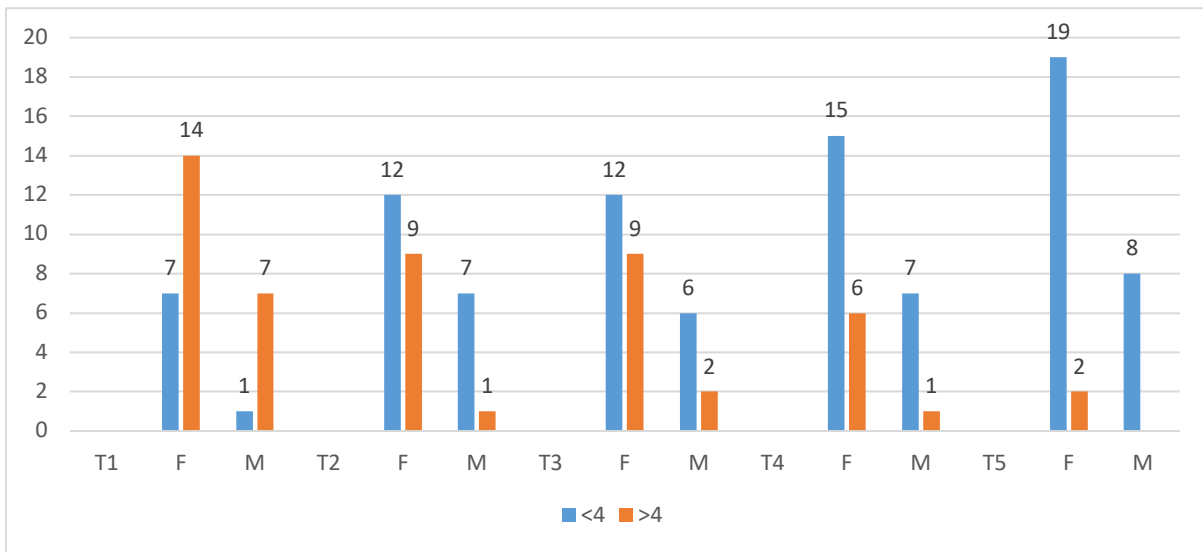


Figure 11 *Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale.*

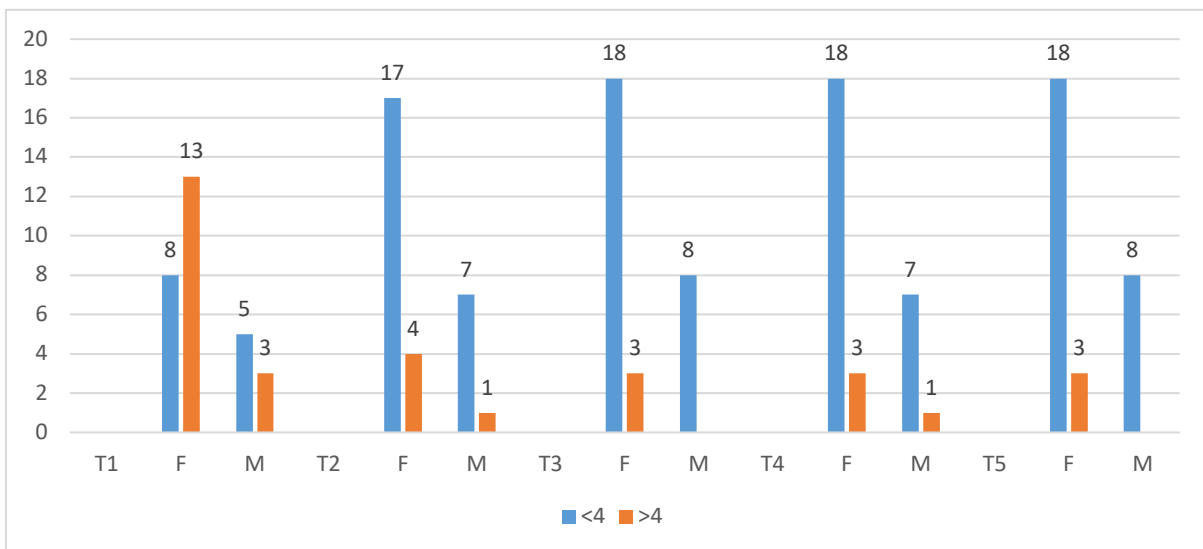
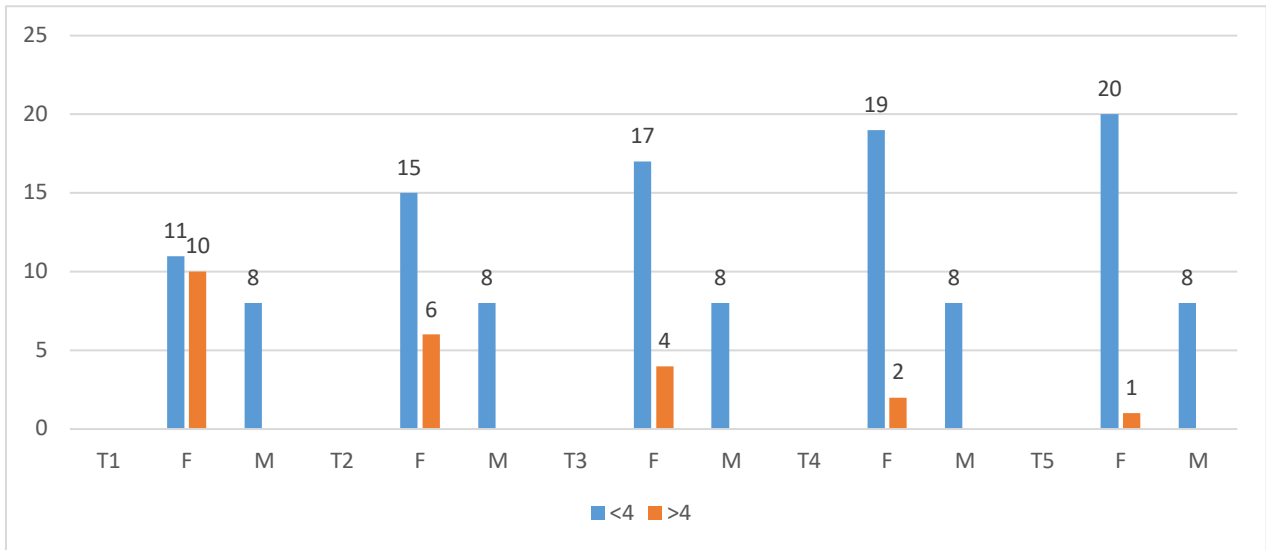


Figure 12 *Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale.*



### *Child sex and the causes of the child's death*

Evaluating the possible risk of psychopathological diseases, no significant data emerged between the questionnaires' results and the child's gender. Moreover, concerning the reason of loss (Table 9), at the time of the first two interviews (T1 and T2), the causes of the death of the child were divided with a percentage of 37.5% of children who died for medical problems, 34% for a Late Termination of Pregnancy (LTP) and 28% for an unknown reason. In the next months, four parents (two in T3 and other two in T4) discovered the reason for their child's death, so that the proportions changed to: 44% (T3) and then in 50% (T4 and T5) for those who died for medical reasons; 22% (T3) and 16% (T4 and T5) for unknown causes. For those who waited for the autopsy results over the months in which the study was conducted, the doctors confirmed that there were no apparent causes and the reason for the loss remained unknown. The percentage of LTP has always been constant for all the five interviews at around 34.4%.

Furthermore, concerning the averages of the ICG questionnaire and the frequencies about the reference cut-off (i.e. the number of participants who presented a greater or less result than the reference cut-off) with respect to the variables of the cause of child's death obtained during the eighteen months, from the comparison we can see a general improvement. The results of those who lost their child for medical reasons and who did not know the cause of death recorded progressively lower values.

Parents who lost the child for medical reasons went from a general average of 37 in T1 to one of 22 in T5, furthermore, if in T1 only 3 out of 10 parents had presented a result lower than the reference cut-off (that is, 25), in T5 they were 9 parents out of 14.

Participants who did not know the reason of loss had a general average of 53 in T1 (all had in fact obtained a result higher than the reference cut-off), reaching the mean of 15 in T5, where 4 parents out of 5 scored less than 25.

Moreover, parents who decided to perform the LTP always showed the highest values, both in T1 (mean = 45), in T2 (mean = 39.8), in T3 (mean = 35), in T4 (mean = 31.2), and T5 (mean = 29.5).

Even with respect to the frequencies, this population consistently showed a greater result than > 25 (except in T5, with a percentage of 50%).

From the analysis carried out through the two questionnaires, only the ICG highlighted significant differences in T1, particularly compared with losses for medical reasons and unknown causes (mean of 36.8 Vs 53.4) ( $F(1, 29) = 3.41, p < 0.033$ ) (Table 10).

Those who did not know the reason of death showed a greater risk of developing complicated grief disorder.

From the comparison between the results of the ICG and GHQ-28 administered in T2, T3, T4, and T5 and the variable of cause of death, no significant difference emerged.

Table 9 Descriptive and effective analysis between ICG and cause of child's death.

	n (%)	Mean	SD	Frequencies >25	Frequencies <25	p-values
<b>T1</b>						0.033*
Late termination of pregnancy	10 (35.9%)	45.1	11.1	10	0	
Medical Problem	10 (35.9%)	36.8	16.7	7	3	
Unknown	9 (28.1%)	53.4	11.2	9	0	
<b>T2</b>						0.319
Late termination of pregnancy	11 (34.4%)	39.8	15.2	7	3	
Medical Problem	12 (37.5%)	29.9	15.5	5	5	
Unknown	9 (28.1%)	38.3	15.4	8	1	
<b>T3</b>						0.734
Late termination of pregnancy	11 (34.4%)	35.0	16.0	7	3	
Medical Problem	14 (43.8%)	31.0	22.3	7	5	
Unknown	7 (21.9%)	28.0	12.8	5	2	
<b>T4</b>						0.675
Late termination of pregnancy	11 (34.4%)	31.2	14.3	7	3	
Medical Problem	16 (50%)	27.3	20.3	6	8	
Unknown	5 (15.6%)	22.8	13.6	2	3	
<b>T5</b>						0.376
Late termination of pregnancy	11 (34.4%)	29.5	18.57	5	5	
Medical Problem	16 (50%)	21.6	21.67	5	9	
Unknown	5 (15.6%)	15.2	9.83	1	4	

\*p<.05



Table 10 *Post Hoc Test Error between the causes of death and ICG scores in T1.*

Comparison		Cause of death T1	Mean Difference	SE	df	t	ptukey
Cause of death T1							
Late termination of pregnancy	-	Medical problem	10.43	5.96	25.0	1.750	0.320
	-	Unknown	-8.34	5.96	25.0	1.400	0.511
	-	Medical Problem	-10.90	13.61	25.0	0.801	0.853
Medical problem	-	Unknown	-18.78	6.12	25.0	3.071	0.025*
	-	Medical Problem	-21.33	13.67	25.0	1.560	0.419
Unknown	-	Medical Problem	-2.56	13.67	25.0	0.187	0.998

\*p<.05

*Children who died during pregnancy and those who lived some days*

The results of the questionnaires were analyzed regarding possible differences between the life span of the child.

In Table 11 we can see the averages and frequencies of the ICG at different times.

In T1, those who achieved the highest scores were the parents who lost the child during pregnancy (registered as NO) (mean = 46.7, and 20 out of 21 parents with a result higher than the reference cut-off), followed by who lost the child after a few hours of life (mean = 46, a single parent with the result > 25), after some months (mean = 44.5, and 1 in 2 parents with a result greater than the cut-off reference), after a few moments (mean = 40, 1 parent with the result > 25) and after a few days (mean = 34.3, the lowest, and with 3 out of 4 parents with results greater than 25).

In T2 the scores decreased by about 10 points (25 points the participant who lost the child after a few moments of life), except for those who lost the child after a few days, obtaining a score of 36.8 (about two points more than the previous three months).

With respect to the frequencies, all the values have remained constant. The only ones that changed were compared to parents who lost the baby during pregnancy (of which in T2, 15 out of 21 parents presented values greater than 25, or 5 participants less than T1), and the parent who lost the baby after a few moments, which showed a result lower than the reference cut-off.

Starting from T2 the progression of the values has not always been constant, such as the higher or lower averages of the variables. For example, in T2 those who obtained the highest average was the

mother who lost the child after a few hours and in T3 those who lost the child during pregnancy (however, presenting a frequency of 14 out of 21 parents with a value above 25). In T4 the highest values were those who lost the child after a few moments of life and in T5 who knew and lost the child after some months.

Even with respect to the frequencies, while the results of the other variables have changed over time recording an ever lower average and the results increasingly lower than 25, the only data remained constant are compared to those who lost the baby after a few months: 1 in 2 parents has always recorded a result above the reference threshold. Furthermore, the effect size analysis revealed that there is no big difference between those who lost a child during pregnancy and those who lost a living child.

*Table 11 Descriptive analysis of ICG's Lived children variable in T1, T2, T3, T4 and T5.*

	Lived children	N	Mean	SD	Frequencies >25	Frequencies <25
T1	Days	4	34.3	13.6	3	1
	Hours	1	46.0	NaN	1	0
	NO	22	46.7	13.8	20	1
	Months	2	44.5	29.0	1	1
	Moments	1	40.0	NaN	1	0
T2	Days	4	36.8	16.2	3	1
	Hours	1	37.0	NaN	1	0
	NO	22	35.8	15.9	15	6
	Months	2	35.5	24.7	1	1
	Moments	1	15.0	NaN	0	1
T3	Days	4	23.0	18.8	2	2
	Hours	1	31.0	NaN	1	0
	NO	22	33.3	17.2	14	7
	Months	2	31.5	36.1	1	1
	Moments	1	29.0	NaN	1	0
T4	Days	4	28.3	21.1	2	2
	Hours	1	30.0	NaN	1	0
	NO	22	27.0	16.0	10	11
	Months	2	35.0	36.8	1	1
	Moments	1	37.0	NaN	1	0
T5	Days	4	13.5	21.0	1	3
	Hours	1	4.00	NaN	0	1
	NO	22	24.6	16.4	9	12
	Months	2	37.0	46.7	1	1
	Moments	1	19.0	NaN	0	1

According to the subscales of the GHQ-28's scores (Table 12), as well as the ICG's results, also in this case, the significant decrease was constant, especially with respect to the results recorded in T1 and those of the last meetings.

Concerning the subscale of Anxiety and Insomnia, it has always obtained the highest values, at the level of general averages and frequencies above 25.

*Table 12 Descriptive analysis of GHQ-28's Lived children variable in T1, T2, T3, T4 and T5\*.*

		<b>Days</b>	<b>Hours</b>	<b>NO</b>	<b>Months</b>	<b>Moments</b>
<b>T1</b>	<b>N</b>	4	1	22	2	1
	<b>Somatic Symptoms</b>					
	Mean	2.00	5.00	2.41	2.00	3.00
	SD	0.81	NaN	1.71	0.00	NaN
	Frequencies >4	0	1	3	0	0
	Frequencies <4	4	0	18	2	1
	<b>Anxiety&amp;Insomnia</b>					
	Mean	4.75	6.00	4.91	4.00	6.00
	SD	2.73	NaN	2.22	4.24	NaN
	Frequencies >4	3	1	15	1	1
	Frequencies <4	1	0	6	1	0
	<b>Social Dysfunction</b>					
	Mean	3.00	6.00	4.27	4.00	5.00
	SD	3.16	NaN	2.41	1.41	NaN
	Frequencies >4	1	1	12	1	1
	Frequencies <4	3	0	9	1	0
<b>Severe Depression</b>						
Mean	1.75	6.00	3.23	3.00	2.00	
SD	3.50	NaN	2.41	2.83	NaN	
Frequencies >4	1	1	7	1	0	
Frequencies <4	3	0	14	1	1	
<b>T2</b>	<b>Somatic Symptoms</b>					
	Mean	1.00	3.00	1.77	2.50	0.00
	SD	1.41	NaN	2.02	3.54	NaN
	Frequencies >4	0	0	2	1	0
	Frequencies <4	4	1	19	1	1
	<b>Anxiety&amp;Insomnia</b>					
	Mean	3.00	7.00	3.00	3.50	7.00
	SD	2.16	NaN	2.41	4.95	NaN
	Frequencies >4	1	1	6	1	1
	Frequencies <4	3	0	15	1	0
	<b>Social Dysfunction</b>					
	Mean	2.00	7.00	1.86	1.50	0.00
	SD	1.83	NaN	2.34	0.70	NaN
	Frequencies >4	0	1	4	0	0
	Frequencies <4	4	0	17	2	1
	<b>Severe Depression</b>					
Mean	0.75	5.00	1.86	3.00	1.00	
SD	1.50	NaN	2.51	4.24	NaN	
Frequencies >4	0	1	4	1	0	
Frequencies <4	4	0	17	1	1	
<b>T3</b>	<b>Somatic Symptoms</b>					
	Mean	1.00	3.00	1.50	2.00	0.00
	SD	1.15	NaN	1.82	2.83	NaN
	Frequencies >4	0	0	2	0	0
	Frequencies <4	4	1	19	2	1

	<b>Anxiety&amp;Insomnia</b>				
	Mean	3.75	7.00	2.91	3.50
	SD	2.99	NaN	2.74	4.95
	Frequencies >4	2	1	6	1
	Frequencies <4	2	0	15	1
	<b>Social Dysfunction</b>				
	Mean	1.50	7.00	1.68	0.50
	SD	3.00	NaN	1.94	0.70
	Frequencies >4	1	1	1	0
	Frequencies <4	3	0	20	2
	<b>Severe Depression</b>				
	Mean	1.00	4.00	1.55	2.00
	SD	2.00	NaN	2.34	2.83
	Frequencies >4	0	0	3	1
	Frequencies <4	4	1	18	1
<b>T4</b>	<b>Somatic Symptoms</b>				
	Mean	1.75	5.00	1.09	2.00
	SD	2.87	NaN	1.38	2.83
	Frequencies >4	1	1	1	0
	Frequencies <4	3	0	20	2
	<b>Anxiety&amp;Insomnia</b>				
	Mean	3.25	7.00	1.77	3.00
	SD	2.63	NaN	2.22	4.24
	Frequencies >4	1	1	4	1
	Frequencies <4	3	0	17	1
	<b>Social Dysfunction</b>				
	Mean	0.50	6.00	1.32	0.00
	SD	1.00	NaN	2.17	0.00
	Frequencies >4	0	1	3	0
	Frequencies <4	4	0	18	2
	<b>Severe Depression</b>				
	Mean	0.25	2.00	1.09	3.00
	SD	0.50	NaN	1.90	4.24
	Frequencies >4	0	0	1	1
	Frequencies <4	4	1	21	1
<b>T5</b>	<b>Somatic Symptoms</b>				
	Mean	0.00	0.00	1.00	0.500
	SD	0.00	NaN	1.45	0.707
	Frequencies >4	0	0	0	0
	Frequencies <4	4	21	1	2
	<b>Anxiety&amp;Insomnia</b>				
	Mean	0.750	1.00	1.77	0.500
	SD	1.50	NaN	2.22	0.707
	Frequencies >4	0	0	2	0
	Frequencies <4	4	1	19	2
	<b>Social Dysfunction</b>				
	Mean	0.00	0.00	1.00	3.00
	SD	0.00	NaN	1.77	4.24
	Frequencies >4	0	0	1	1
	Frequencies <4	4	1	20	1
	<b>Severe Depression</b>				
	Mean	0.250	0.00	0.864	2.00
	SD	0.500	NaN	1.75	2.83
	Frequencies >4	0	0	1	0
	Frequencies <4	4	1	20	2

\* Number of participants: days=4, hours=1, NO=22, months=2, moments=1.

### *Distance between loss and interviews*

As mentioned previously, the initial selection criterion for the participants was that they had experienced the loss of a child as recently as possible. The difficulty of recruiting the participants, however, determined the widening of the time's range considered acceptable between the date of the child's death and the first meeting.

Some parents who volunteered for the study had lost the child nine months and a few days before the first interview, determining ten months as the maximum time between loss and the beginning of participation.

At the quantitative level, in order to analyze the data in accordance with this temporal variable between the loss and the various meetings, temporal criteria were assigned based on a distance of three months. This means that the assigned loss' values after each interview are: <1 month; <3 months; <6 months; <9 months, etc.

Thus in T1, the temporal variables between loss and first meeting vary from <1 month (the minimum) to <12 months (the maximum) (Table 13).

Furthermore, as we can see from the figure below (Figure 14), most of those who lost the baby in the perinatal period recorded ICG levels higher than the reference cut-off until the first year of grief.

The values decreased considerably (i.e., showing results below 25) especially 21 months later the child's loss.

Compared to the results of the subscales of Somatic Symptoms (Figure 15) and Severe Depression (Figure 18), except after the first month of grief where 1 out of 2 parents showed a result greater than 4, the majority of the frequencies of values was always lower than the cut-off.

Considering the Anxiety and Insomnia subscale (Figure 17), up to the first nine months following the death, parents mostly recorded a majority of results above 4, then radically changed (therefore with results lower than the reference cut-off) after the first year.

Finally, except in the very first period (that is, until the first three months of grief), the parents showed a majority of results lower than 4 compared to the Social Dysfunction subscale (Figure 18).

Table 13 *Frequency table about the time between child's loss and T1.*

Levels	Counts	% of Total	Cumulative %
<1	2	6.3 %	6.3 %
<3	10	31.3 %	37.5 %
<12	5	15.6 %	53.1 %
<6	10	31.3 %	84.4 %
<9	5	15.6 %	100.0 %

Figure 13 *Plots of the time between loss and T1, T2, T3, T4 and T5.*

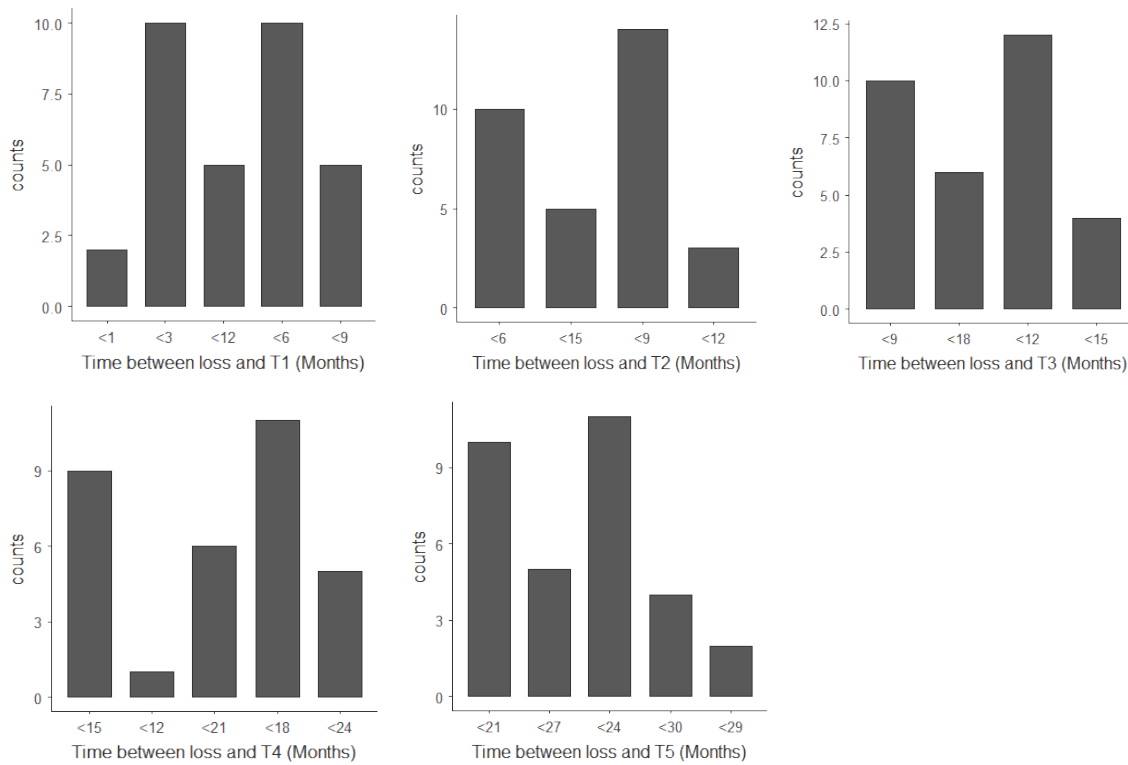


Figure 14 *Frequency of results above and below the reference cut-off of the ICG questionnaire with respect to the time of loss.*

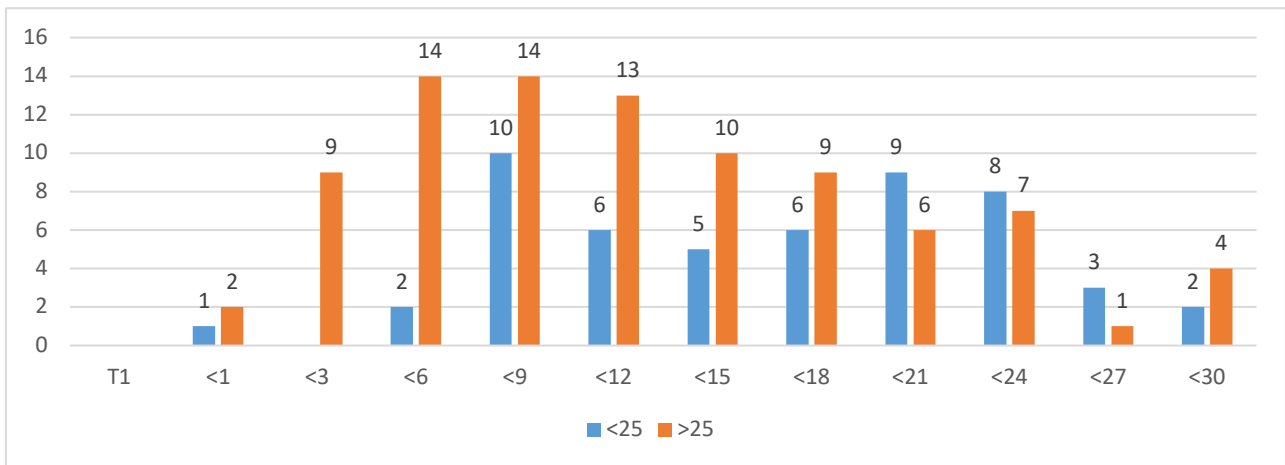


Figure 15 *Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time of loss.*

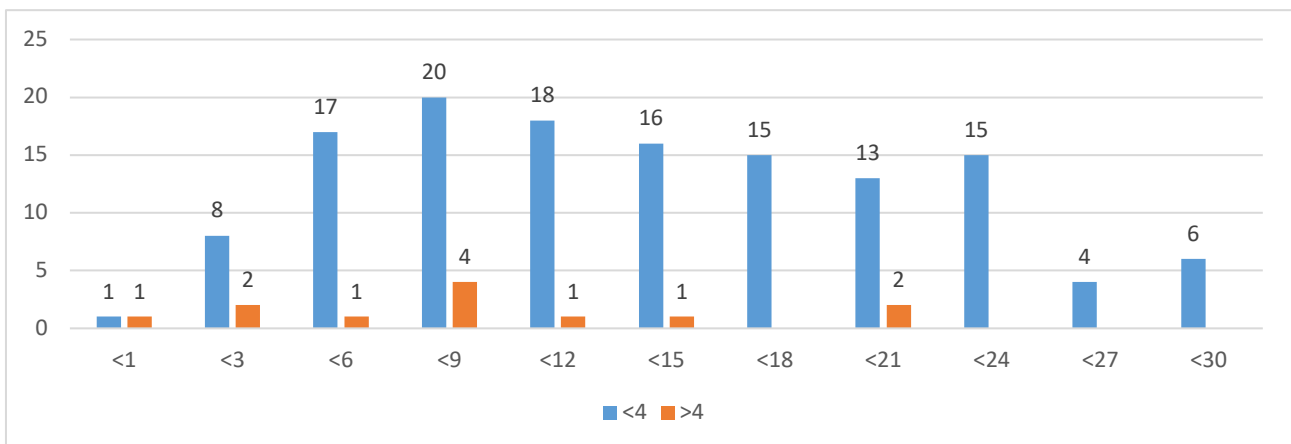


Figure 16 *Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and loss.*

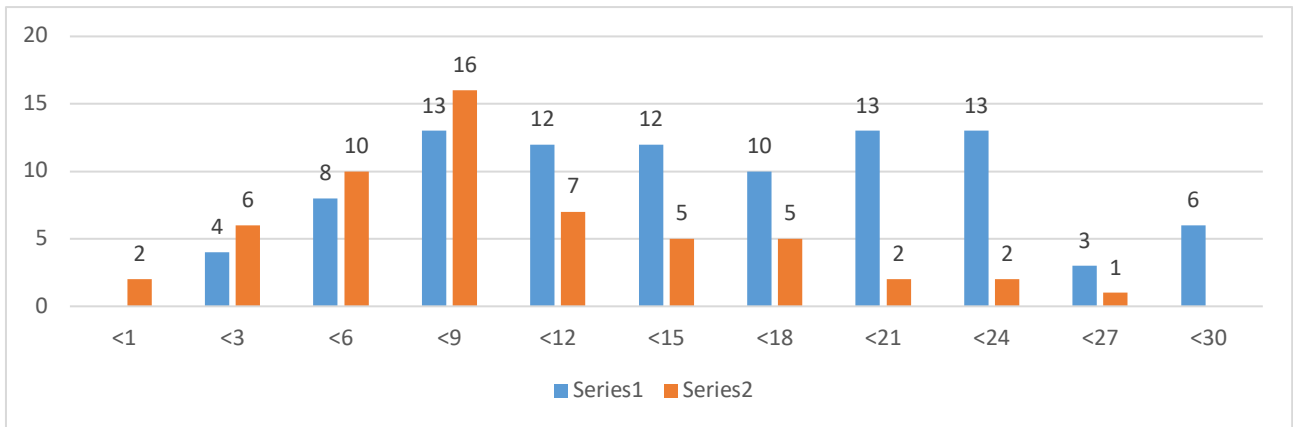


Figure 17 *Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and loss.*

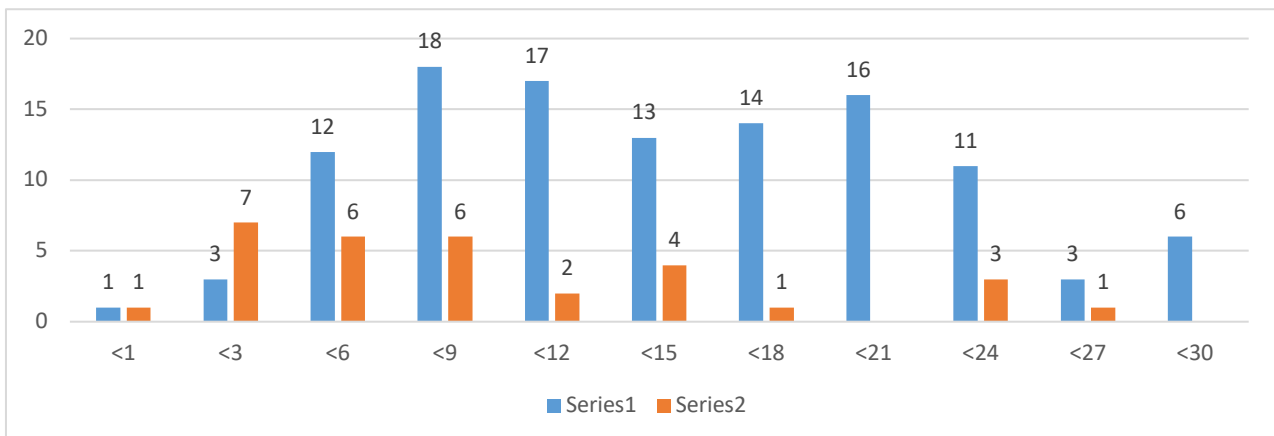
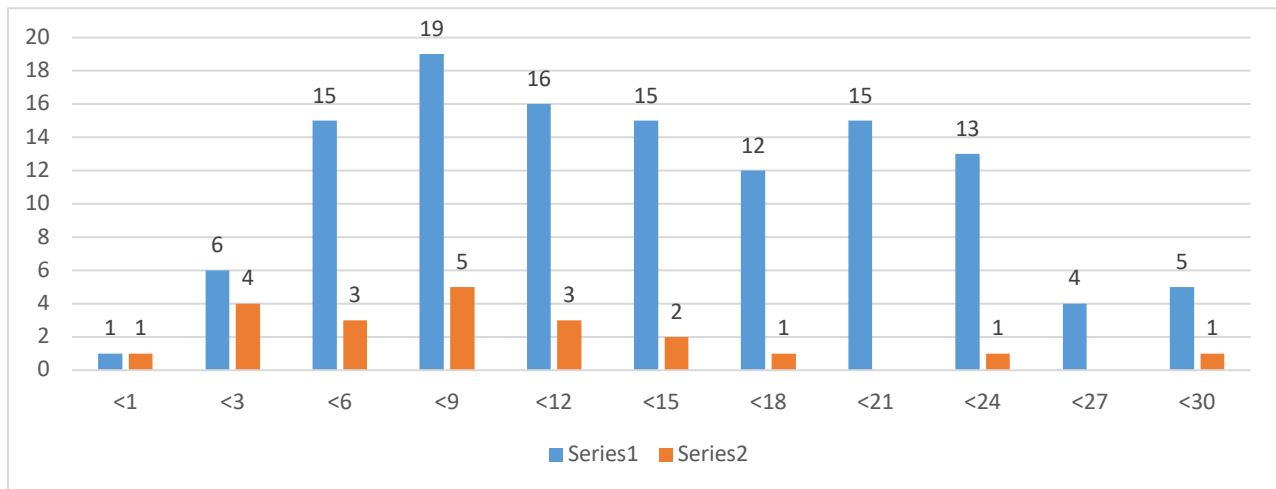




Figure 18 *Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and loss.*



#### *Presence of other children before and after death*

It was also important to verify the hypothetical significance between of the presence of living children born before the loss.

As we have seen in one of the previous tables (Table 7), out of 29 participants, only 5 of them had already become parents before their child's death. 2 parents had 2 children and 3 parents had 1 child. According to the analyses between the presence of other children before child's death (24 vs 5) and the scores of ICG and GHQ-28 results, no significant difference was observed.

Compared to the frequencies, initially, all participants (both who had already become parents and who lost the first child) presented values greater than 25 from T1 to T4 (Figure 19).

In T5, the risk of developing a CG has linearly decreased for everyone:

- out of 24 parents who had not had any child previous the loss, 10 had a result greater than 25;
- while out of 3 participants who had already become parents of 1 living child, only 1 parent obtained a value higher than the reference cut-off.

Compared to GHQ-28, the data of the Somatic symptoms (Figure 20) and Severe depression subscales (Figure 23) showed that most of the participants always obtained a result lower than 4. The only exception regards the subscale of Somatic symptoms in T1 and T3, where 2 out of 3 parents who had already become parents of a child showed a greater result than the reference cut-off.

In the Anxiety and Insomnia subscale (Figure 21), most parents scored higher than 4 in T1, then progressively reduced: in T5, only 1 parent who had not previously had a child and 1 who already became a parent of a living child before loss obtained a result higher than 25.

Finally, compared to the Social dysfunction subscale (Figure 22), in T2, T4, and T5 most of those who lost the first child scored less than 4, while in T1 and T3 the percentage was 50%. Those who had become parents of two children (that is, 2 participants) never passed the reference cut-off, except in T1. For those who had already had a child, except in T2 and T3, 2 out of 3 parents always recorded a result higher than 4.

Figure 19 *Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children before the loss.*

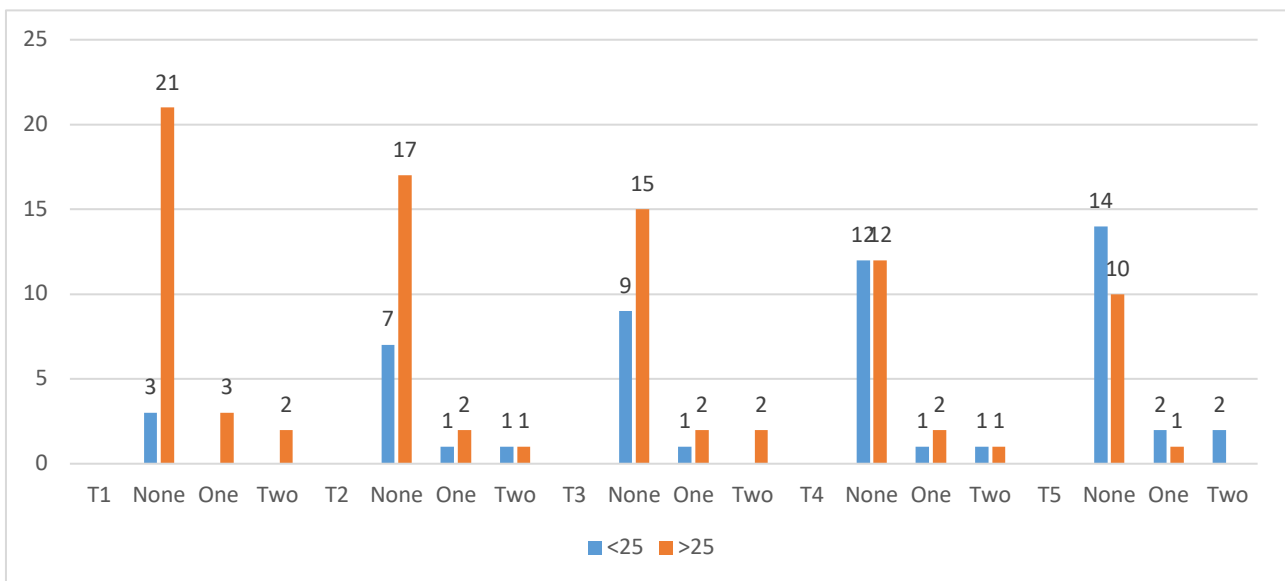


Figure 20 *Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children before the loss.*

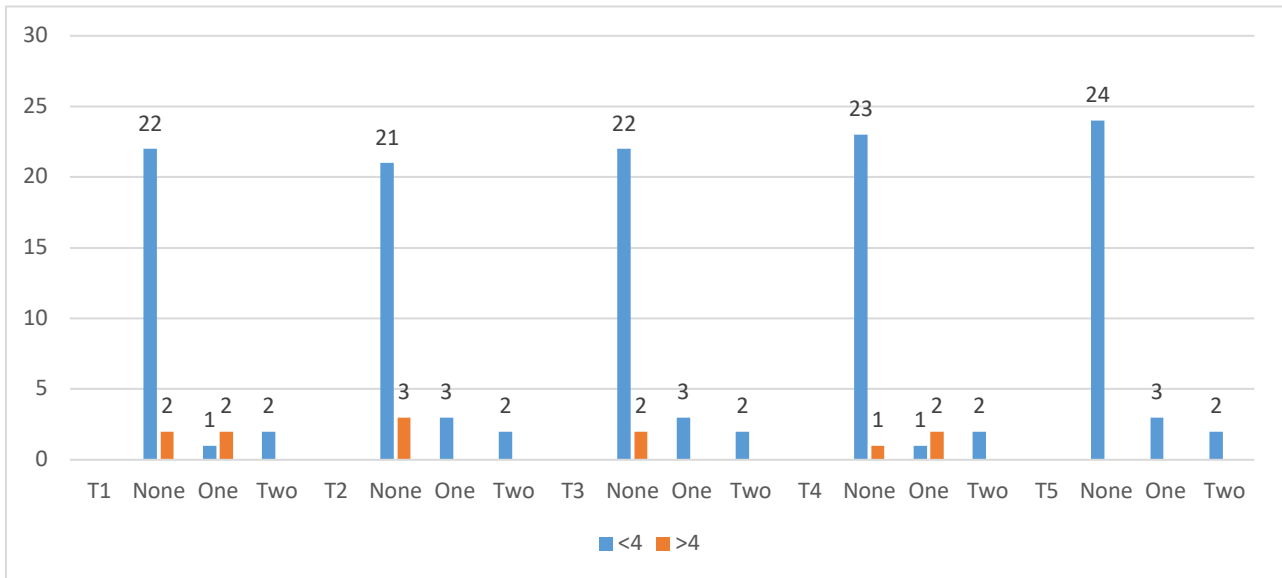


Figure 21 *Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children before the loss.*

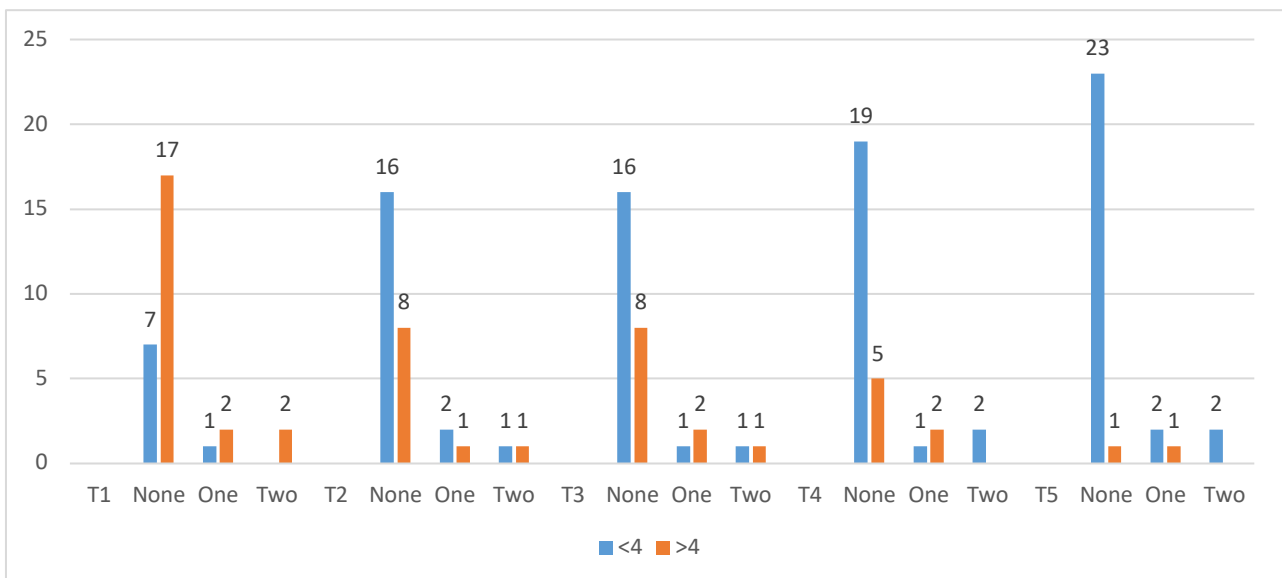


Figure 22 *Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children before the loss.*

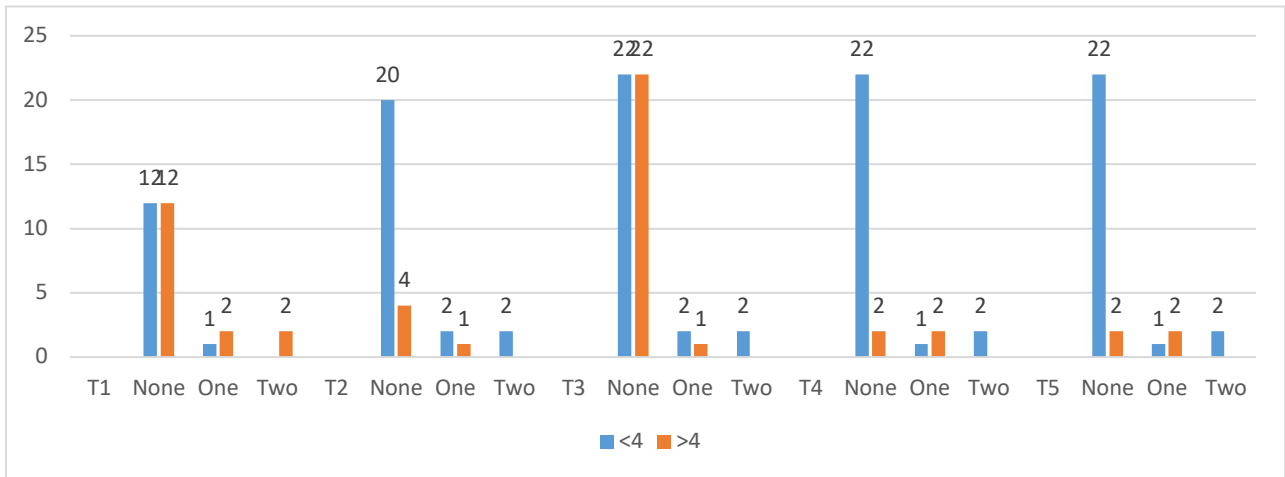
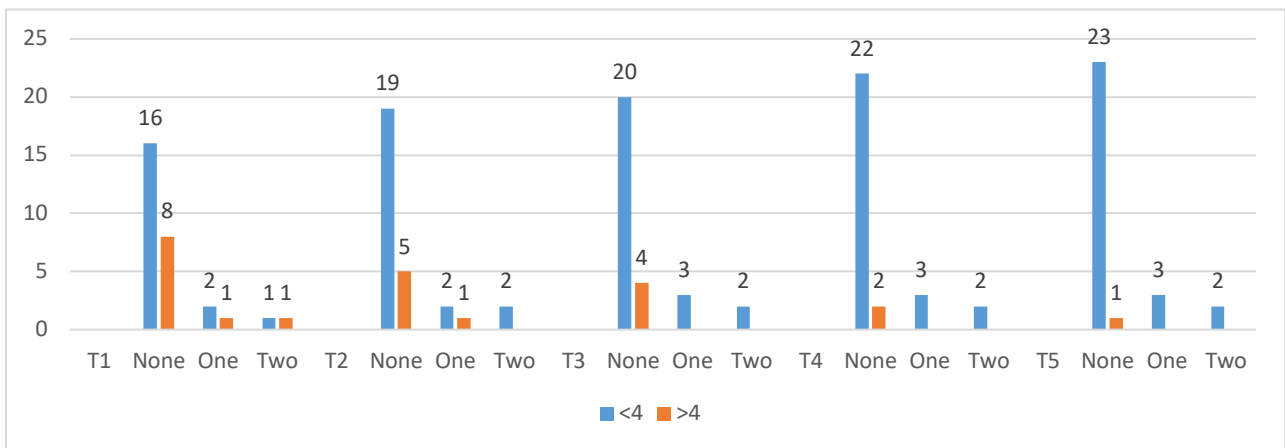


Figure 23 *Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children before the loss.*



Furthermore, concerning the conception and birth of subsequent children, during the first interview, 5 participants (17%) were waiting for another child (Table 14).

Compared with the following interviews, in T2 a mother gave birth (3%) and 7 others were waiting for a new baby (24%) (Table 43), while in T3, a couple and a woman had a new baby (10%), one couple had a miscarriage (7%) and seven other people were pregnant (24%), and in T4, 9 parents gave birth to a child (31%) and 9 others were pregnant (31%). This also means that one year after the start of the research 38% of the participants did not have a subsequent child. Finally, in T5, 55.2% of participants had given birth to a child, while around 14% were expecting a child, and 31% were not trying to conceive or had some fertility difficulties.

As we can see in the figures below, the course of new pregnancies was linear.

In the first three meetings the percentage of those who did not have and were not expecting a new child was significantly higher. With the passage of time, in particular with respect to T4, the percentage of those who gave birth and those who were pregnant was similar to those who did not have any subsequent children.

In T5 a clear majority of participants had had another child (YES), born during the eighteenth months of the study.

Furthermore, the comparison between the results of ICG questionnaire and the subscales of the GHQ-28 with the conception or the birth of other children did not reveal any significant data or 'large' effect size. The comparison was obviously made with respect to all the interviews times.

Compared to the frequencies of the results greater or less than the reference cut-off of the ICG (Figure 25), the majority of those who did not have another child after the loss registered a result lower than 25 only towards the end of the study, that is in T4 and T5, while for those who were expecting another child this value was highlighted only in T2. For the latter, they obtained higher results of the reference cut-off in T1, T3, and T4 and showing in T5 a percentage of 50% (i.e., 8 parents with a higher value of 25 and 8 with a lower result).

Compared to parents who had a child after the loss, the decrease of the risk for most of them was only shown in T5 (3 out of 4 parents).

Compared to GHQ-28, except for the subscales of Anxiety and Insomnia (Figure 27) and Social dysfunction (Figure 28), where most of the participants presented results greater than 4 in T1, in the sub-scales of Somatic symptoms (Figure 26) and Severe depression (Figure 29), most parents have always shown values lower than the reference cut-off.

Table 14 *Frequencies of Presence of other children after the loss.*

	<b>Variable</b>	<b>n</b>	<b>%</b>
<b>T1</b>	NO	24	82.8%
	Pregnant	5	17.2%
<b>T2</b>	NO	21	72.4 %
	Pregnant	7	24.1 %
	YES	1	3.4 %
<b>T3</b>	Miscarriage	2	6.9 %
	NO	17	58.6 %
	Pregnant	7	24.1 %
	YES	3	10.3 %
<b>T4</b>	NO	11	37.9 %
	Pregnant	9	31.0 %
	YES	9	31.0 %
<b>T5</b>	NO	9	31.0 %
	YES	16	55.2 %
	Pregnant	4	13.8 %

Figure 24 Plots of births of subsequent children after loss in T1, T2, T3, T4 and T5.

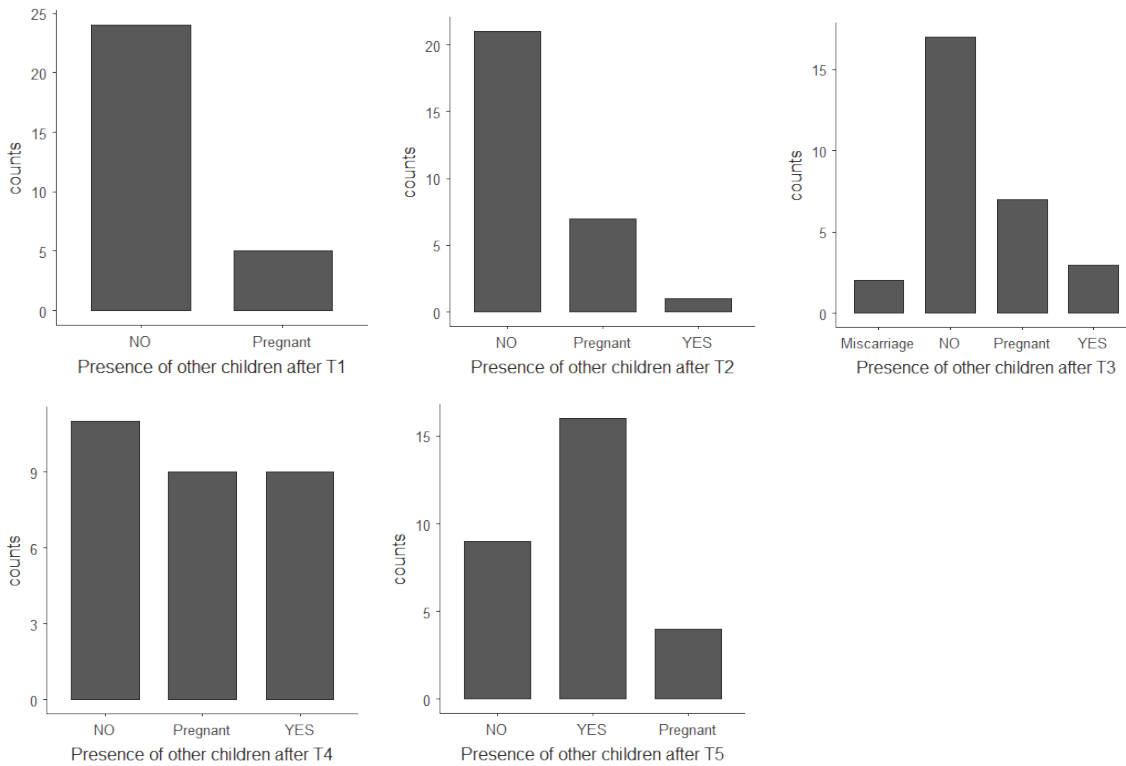


Figure 25 Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children after the loss.

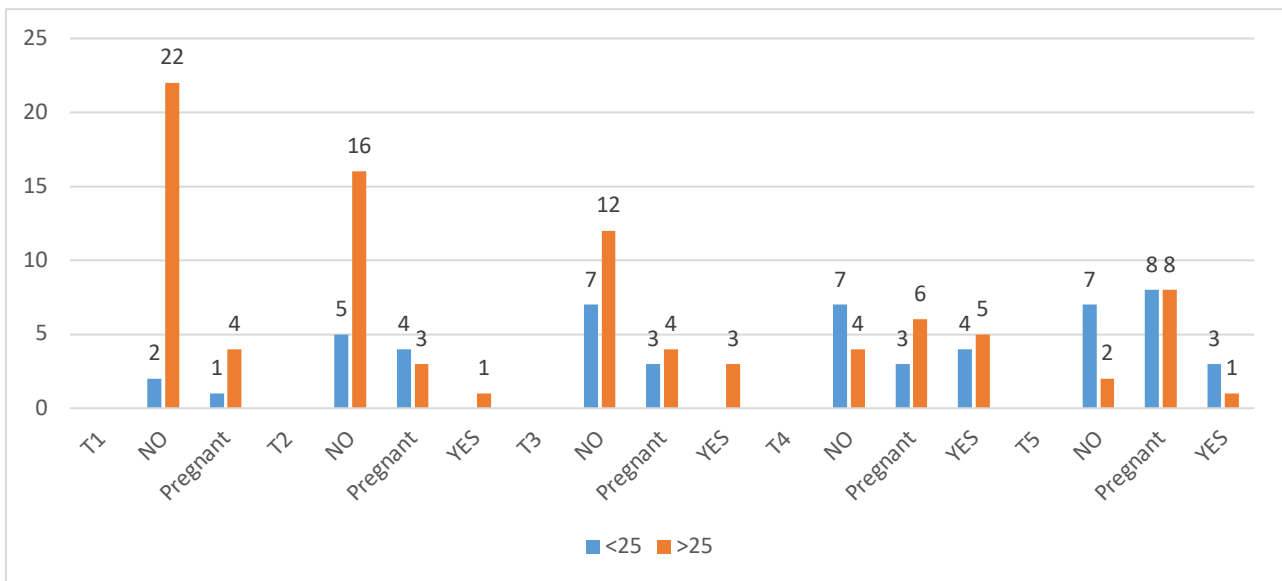


Figure 26 *Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children after the loss.*

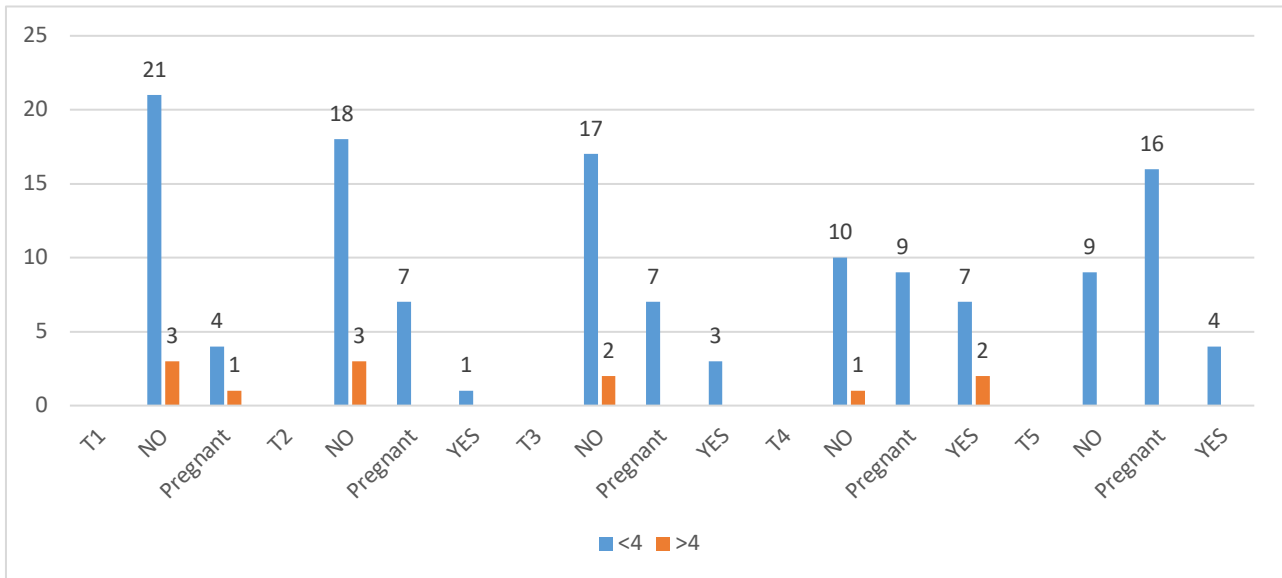


Figure 27 *Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children after the loss.*

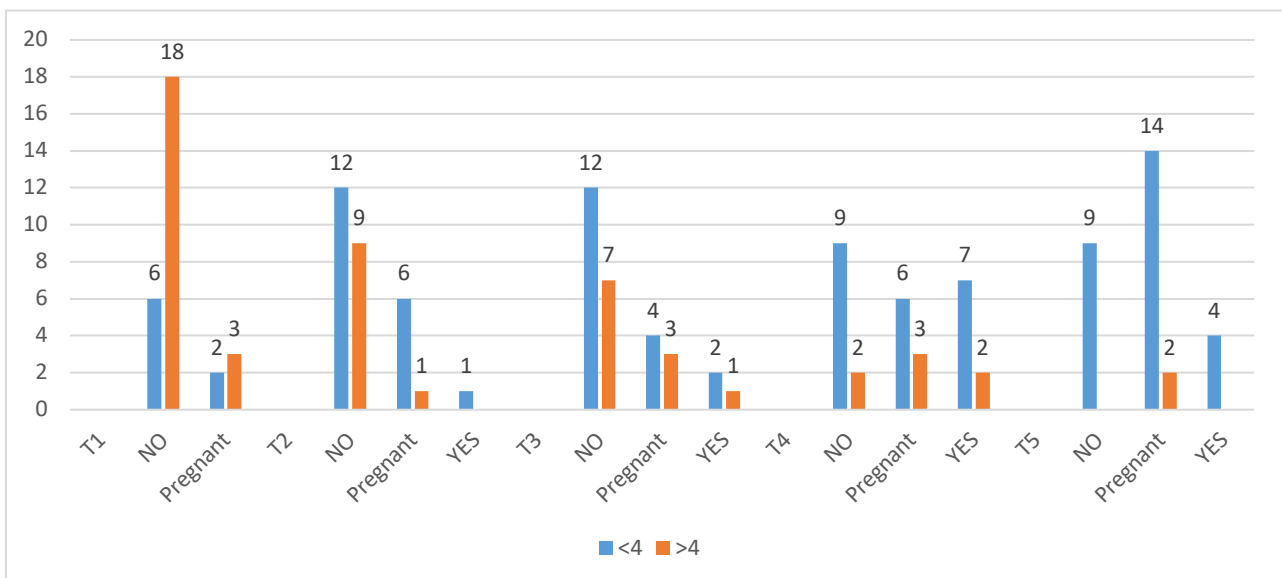




Figure 28 *Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children after the loss.*

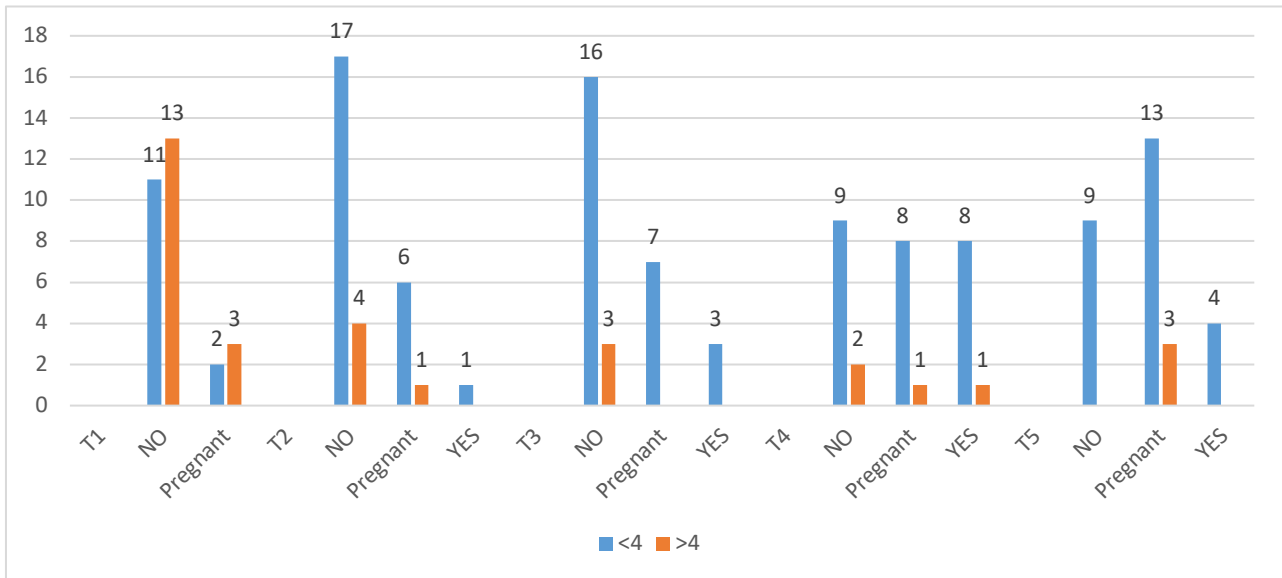
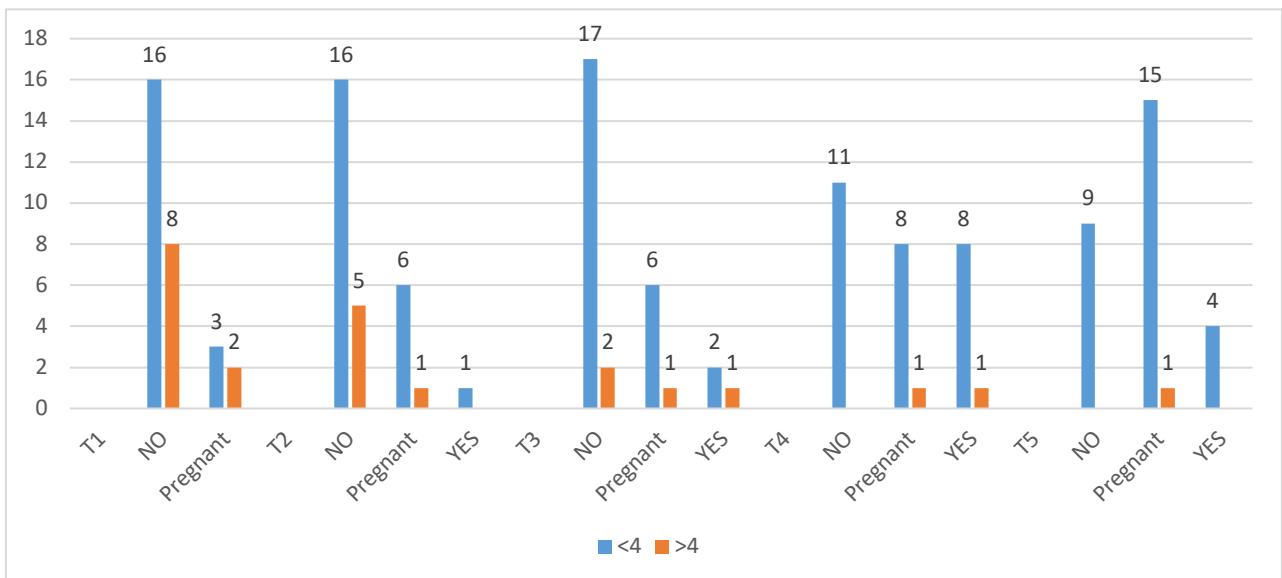


Figure 29 *Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and the presence of other children after the loss.*



### *Psychological support*

As we can see from Table 15, at the time of the first interview (T1) most of the parents (64,5%) were followed by a psychologist, that is 17 women and half of the men (4).

According to the statements that emerged in T2, 7 people (3 men and 4 women) quit therapy. The number of men followed by a psychologist thus decreased to 1. During the second interview the majority (51%) chose not to undertake (and one chose to interrupt) psychological treatment.

Compared with the third interview (T3), as in T2, around 48% of participants were followed by a psychologist, namely 2 men and 12 women (one man more and one woman less than T2). Therefore, more than half of the parents continued to not require any psychological support, stating that they did not feel the need.

In T4, participants who carried on psychotherapy decreased further, eventually reaching the 27.6% (only 8 women and no men).

The percentage of those who were followed by a professional in T5 was the same as in T4 (27.6%), with a total of 8 participants, all women and no men.

As we can see from Figure 30, the course of psychological support was inverse and linear. If at the beginning it was clear that the majority of participants undertook personal therapy, during the 18 months about 45% of the parents decided to stop this support, reaching 72.4%.

Those who have decided not to start or interrupt any therapeutic support stated that they progressed sufficiently in their grief, thus considering therapy useless. Others instead emphasized their distrust of the therapists and the presence of a supportive and inclusive social entourage which they deemed sufficient for their needs.

It is worth noting that no participant undertook therapy without their partner.

Compared to the frequencies of those who presented a score higher or lower than the reference cut-off of ICG (Figure 31), up to T3, both for those who had requested a therapeutic support and for those who had not perceived this need or had decided to quit, most of the participants presented values higher than 25. In T4 and T5 most of those who did not go to the psychologist obtained values lower than the reference cut-off, while for those who requested such support, the results have always been greater than 25, from T1 to T5.

Considering the questionnaire GHQ-28, compared to the subscales of Somatic symptoms (Figure 32) and Severe depression (Figure 35), most of the participants registered values lower than the reference cut-off.

Compared to the Anxiety and Insomnia subscale (Figure 33), those who had not requested professional support presented results greater than 4 in T1, while those who went to psychotherapist showed this result compared to the values of T1 and T3.

Finally, considering the Social Dysfunction subscale (Figure 34), most of the participants always showed levels below 4, only in T1 most of those who perceived the need to contact a therapist showed higher values to the reference cut-off.

Furthermore, the analysis carried on the psychological support variable, that is whether the participant had decided to undertake personal psychotherapy or not, and the results of ICG questionnaire did not show any significant difference.

Although from the cut-off frequencies, in T5 only 1 person out of 8 who followed a therapy presented a higher result than 4 (Figure 35) and a significant difference emerged with respect to the Anxiety and Insomnia subscale of GHQ-28 ( $F = 5.68, p < 0.02$ ) (Table 17).

Those who were followed by a psychotherapist (only 8 women) were more at risk of developing anxiety and sleep disorders, presenting an average of 2.88. This score was significantly higher than the mean of those who had not felt the need to request psychological support (1.00).

Table 15 *Frequency of parents who are followed by a psychologist.*

Psychological support T1	Sex	
	F	M
NO (27.6%)	4	4
YES (72.4%)	17	4

Psychological support T2	Sex	
	F	M
NO (51.7%)	8	7
YES (48.3%)	13	1

Psychological support T3	Sex	
	F	M
NO (51.7%)	9	6
YES (48.3%)	12	2

Psychological support T4	Sex	
	F	M
NO (72.4%)	13	8
YES (27.6%)	8	0

Table 15 Frequency of parents who are followed by a psychologist.

Psychological support T1	Sex	
	F	M
NO (72.4%)	13	8
YES (27.6%)	8	0

Psychological support T5	Sex	
	F	M
NO (72.4%)	13	8
YES (27.6%)	8	0

Figure 30 Plots of parents' psychological support in T1, T2, T3, T4 and T5.

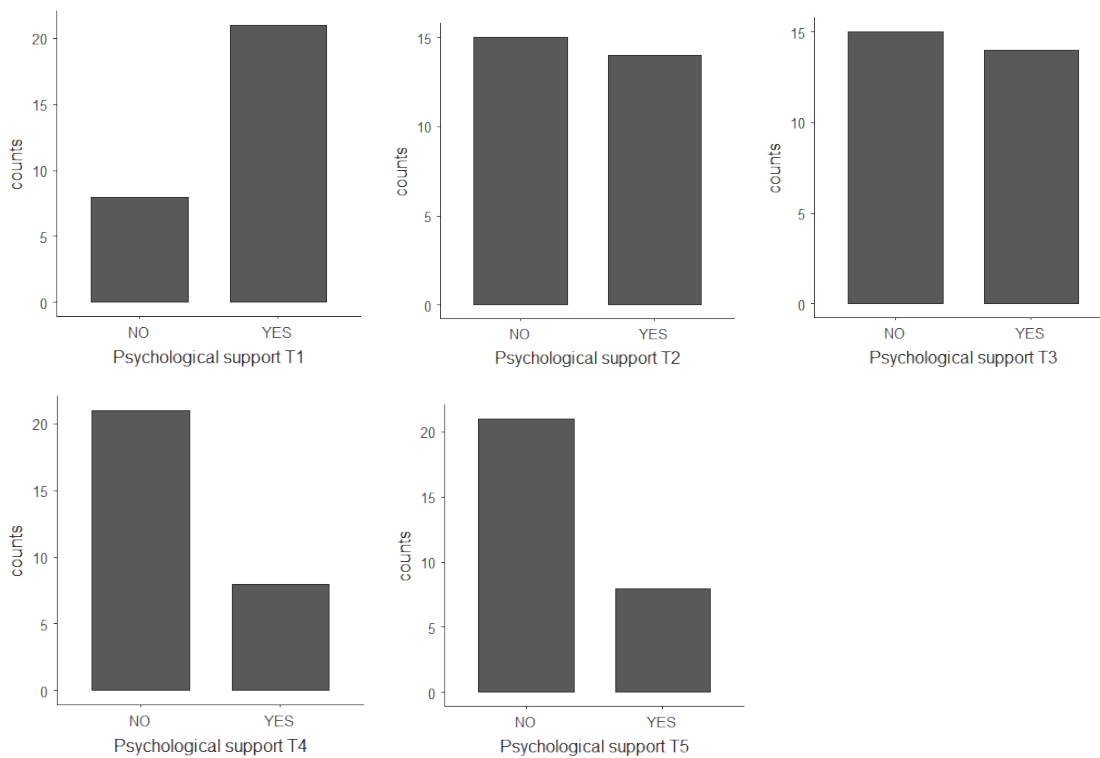


Figure 31 *Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and psychotherapy.*

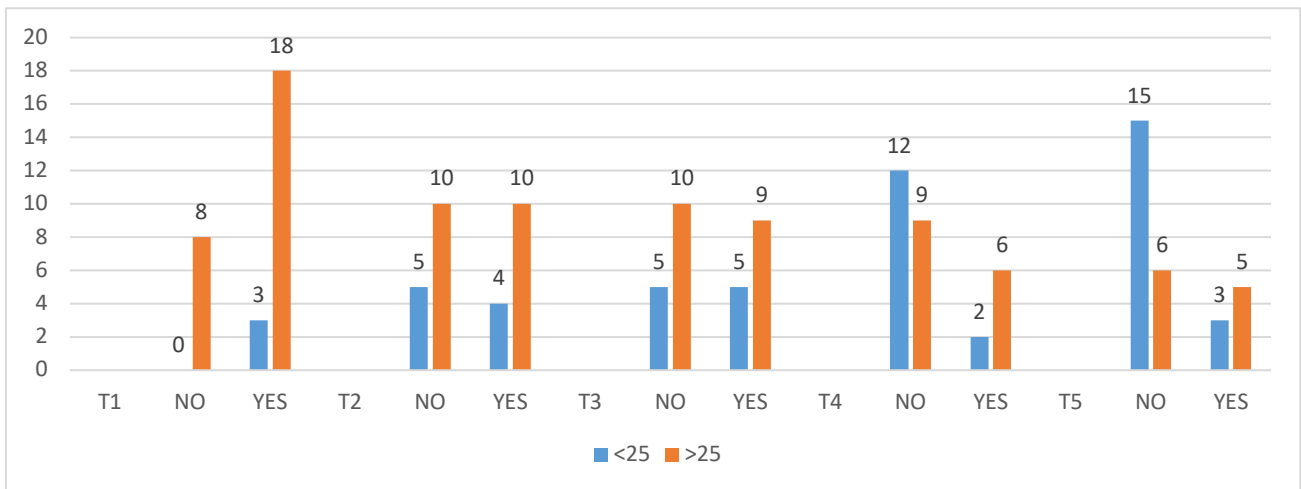


Figure 32 *Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and psychotherapy.*

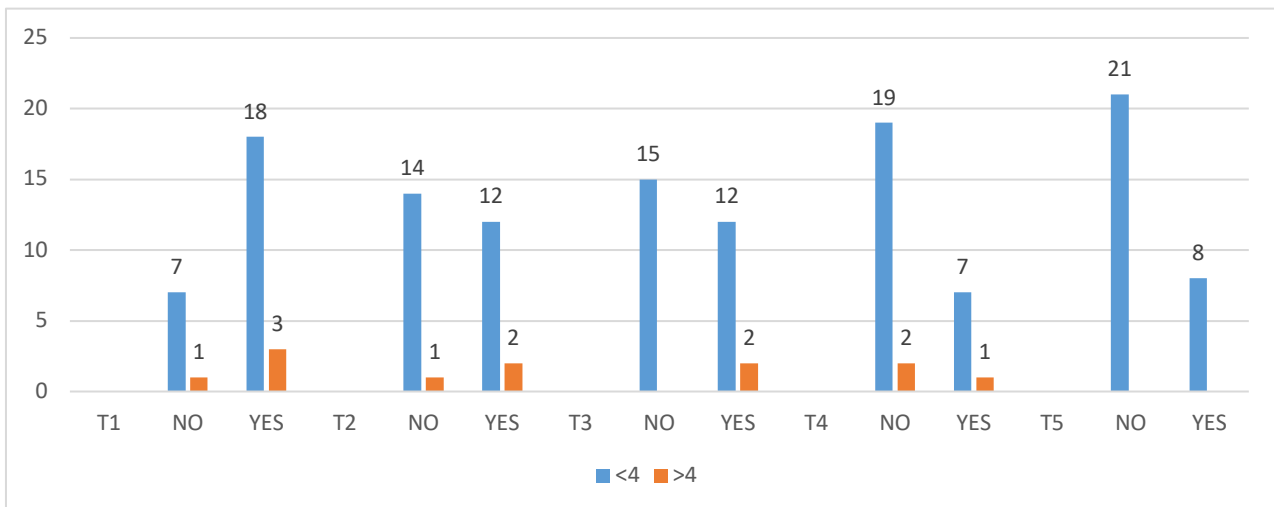


Figure 33 *Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and psychotherapy.*

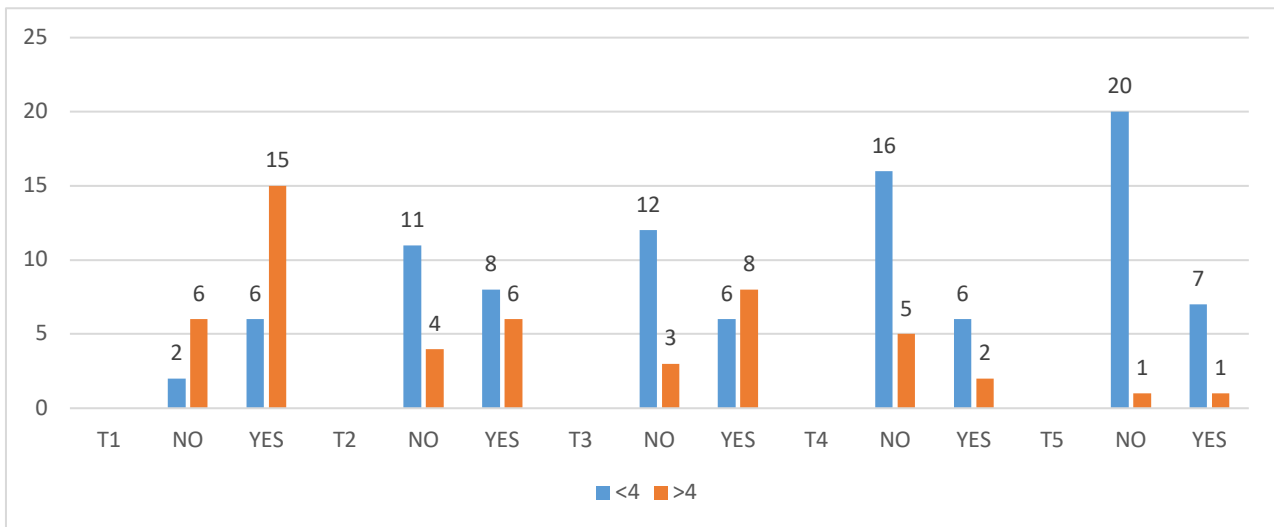


Figure 34 *Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and psychotherapy.*

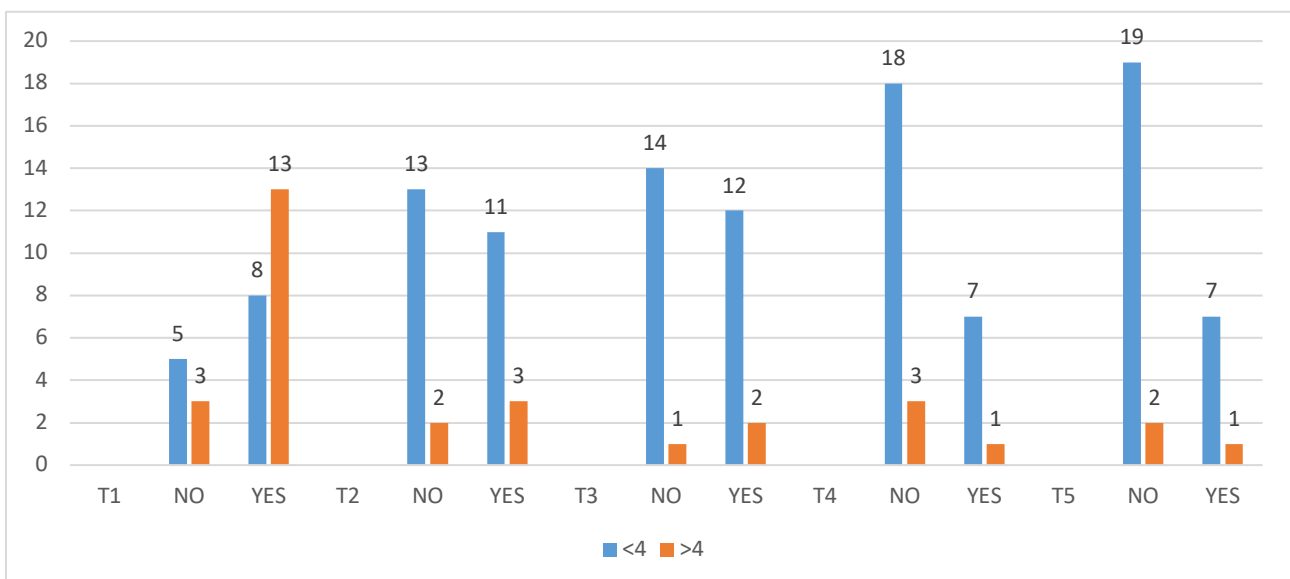


Figure 35 Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and psychotherapy.

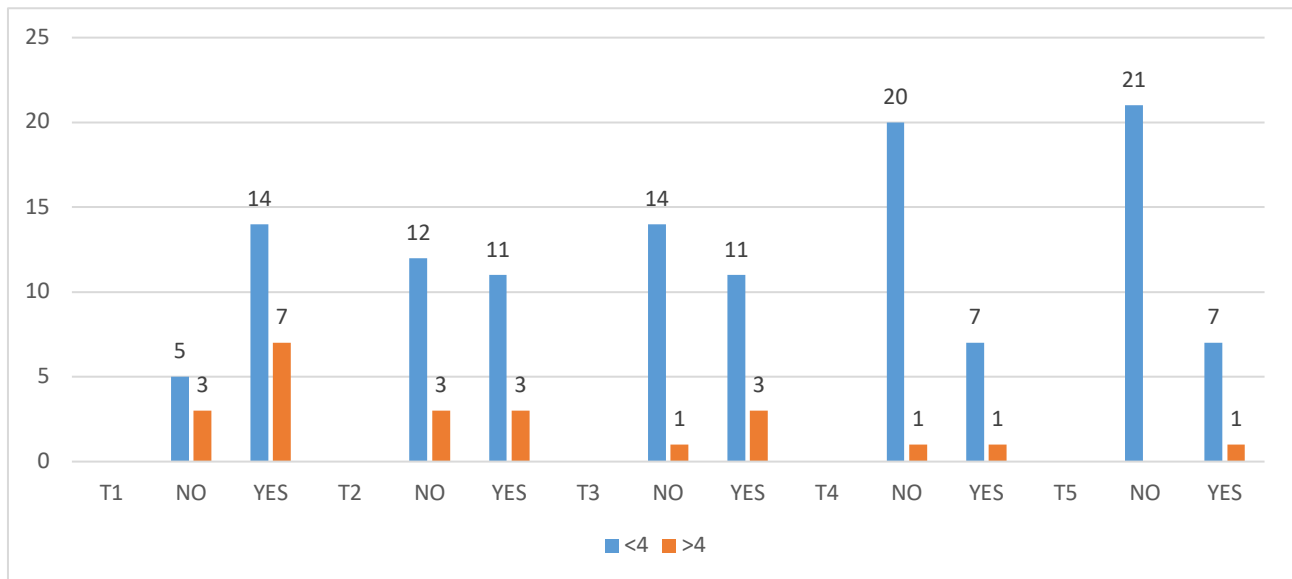


Table 16 Effective analysis of the hypothesis between psychological support and Anxiety and Insomnia scores in T5.

	Sum of Squares	df	Mean Square	F	p
Psychological support T5	20.4	1	20.37	5.68	0.024*
Residuals	96.9	27	3.59		

\*p<.05

Table 17 Probabilities for Post Hoc Tests Error between psychological support and Anxiety and Insomnia scores in T5.

Comparison		Mean Difference	SE	df	t	ptukey
Psychological support T5	Psychological support T5					
NO	- YES	-1.88	0.787	27.0	-2.38	0.024 *

\*p<.05

Table 18 *Descriptive values of psychological support and Anxiety and Insomnia scores in T5.*

<b>Psychological support T5</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
NO	21	1.00	1.73
YES	8	2.88	2.30

### *Participation in support groups*

As we can see in the Table 19, according to data from the first interview, just 7 (24%) of the parents participated in support groups: 6 of whom were women and one of whom was a man.

The 6 women who participated in the support group undertook psychotherapy at the same time, unlike the one man.

4 women and 3 men decided not to start any therapeutic support.

11 women and 4 men did not receive therapeutic support from a professional.

In T2 the percentage of participants in support groups was 27.6%, with the addition of one man compared with T1, thus reaching a total of 6 women and 2 men, including two couples.

As in T1, also in T2 women were also followed by a psychologist.

At the same time, several parents suspended personal therapy. Those who didn't not follow any therapy were 8 women and 5 men, while 7 women and 1 man, even if they didn't participate in any support groups, were followed by a psychologist.

After another three months (in T3), 24% of parents participated in a support group. Of these, there were 5 women and 2 men.

In the three months between T2 and T3, one mother decided to quit because she was pregnant. She stated that the choice was motivated by logistical and practical reasons: being part of the support group became difficult and she didn't want to upset the other members of the group. She considered her decision as temporary, willing to come back as soon as the child was born. Furthermore, at the time of T3, there were 4 mothers who met with a psychologist who also participated in support groups, 2 fewer than T2, and 0 men (as in T1 and T2). Instead, 8 women and 2 men undertook exclusively psychotherapy (1 woman and 1 man more than T2) and 8 women and 4 men didn't participate in any group and were not followed by a psychologist. In T4, there were 5 women and 1 man participating in the support groups (1 man less than T3).

Of the 5 women, 3 were followed by a psychologist.

Only 5 women were undergoing psychotherapy. 79.3% of participants (11 women and 7 men) decided not to participate in any group and not to be helped by any professional.



The data in T5 compared with T4 remained almost the same. 17% of bereaved parents participated in support groups: 5 people, that is 4 women and 1 man, one woman fewer than T4.

As before, this man was not followed by any professional.

Those who participated exclusively in the group as a form of psychological support were this one man and another woman.

About 83% of parents (13 women, 2 more than T4, and 7 men) were not professionally followed by either a psychotherapist or participating in the group.

Finally, 4 women were followed exclusively by a psychotherapist (1 woman less than T4).

Moreover, compared to the ICG cut-off frequencies (Figure 36), both for those who participated in the support groups and for those who had decided or could not request such support, the values for the majority of the participants were higher than 25 up to T4, while in T5 for the majority of parents the values were below the reference cut-off: 15 vs 9 for those who did not participate and 3 vs 2 for those who did.

Considering the GHQ-28, most of the participants always presented results levels below 4, except for the T1 results in the Anxiety and Insomnia (Figure 38) and Social Dysfunction (Figure 39) subscales where most of the parents who did not participate in support groups showed levels above 4.

Furthermore, there was a significant difference between participation in support groups and the scores of the ICG questionnaire in T1 ( $F = 11.4$  and  $p < .002$ ) (Figure 41). Those who did not participate in the support groups had a score of 49.2 and therefore a higher average than those who participated, who instead had a score of 31.

The same was carried out when examining the other results.

The comparison between the variable of participation in the support groups and the results of the two questionnaires (ICG and the subscales of the GHQ-28) did not show any significant difference compared with the data collected in subsequent meetings (T2, T3, T4 and T5).

Table 19 *Frequency of participants in support groups compared with personal therapy.*

Participation support group T1	Psychological support T1	Sex	
		F	M
NO (74.9%)	NO	4	3
	YES	11	4
YES (24.1%)	NO	0	1
	YES	6	0

**Frequencies of Participation support group T2**

Participation support group T2	Psychological support T2	Sex	
		F	M
NO (72.4%)	NO	8	5
	YES	7	1
YES (27.6%)	NO	0	2
	YES	6	0

**Frequencies of Participation support group T3**

Participation support group T3	Psychological support T3	Sex	
		F	M
NO (75.9%)	NO	8	4
	YES	8	2
YES (24.1%)	NO	1	2
	YES	4	0

**Frequencies of Participation support group T4**

Participation support group T4	Psychological support T4	Sex	
		F	M
NO (79.3%)	NO	11	7
	YES	5	0
YES (20.7%)	NO	2	1
	YES	3	0

Participation support group T5	Psychological support T5	Sex	
		F	M
NO (82.8%)	NO	13	7
	YES	4	0
YES (17.2%)	NO	1	1
	YES	3	0

Figure 36 Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and participation in support groups.

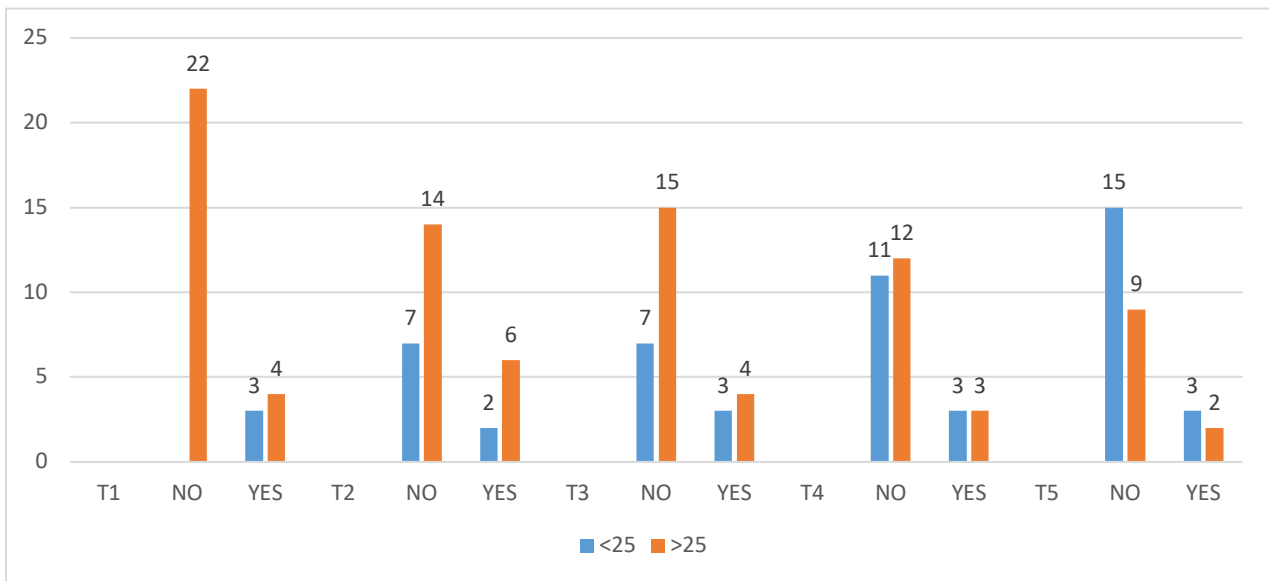


Figure 37 Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and participation in support groups.

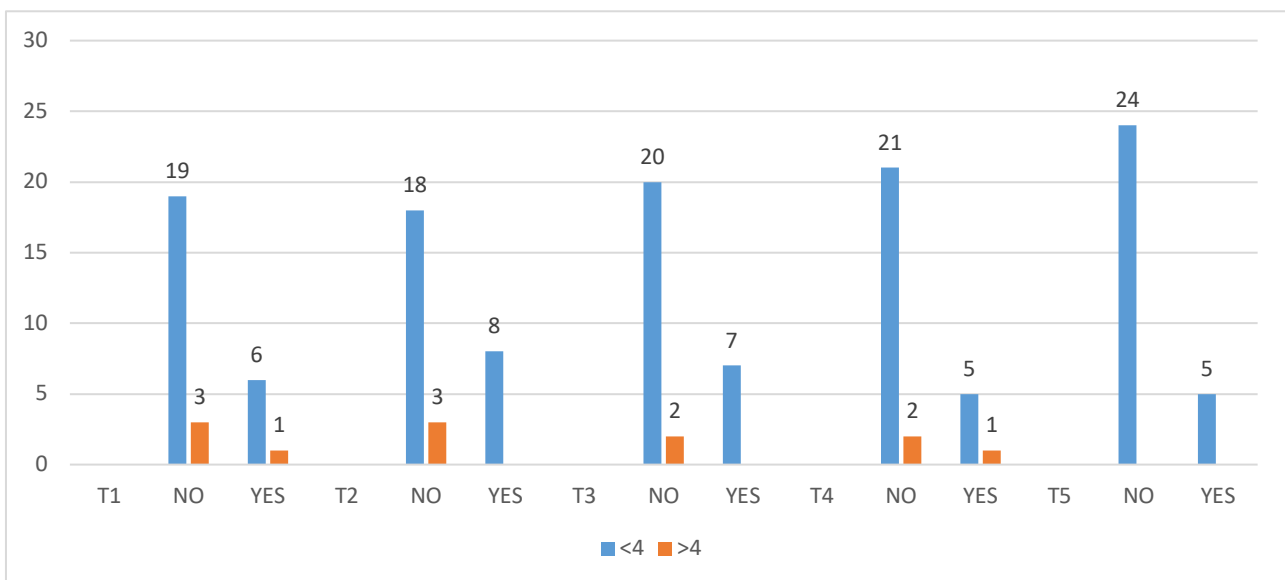


Figure 38 *Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and participation in support groups.*

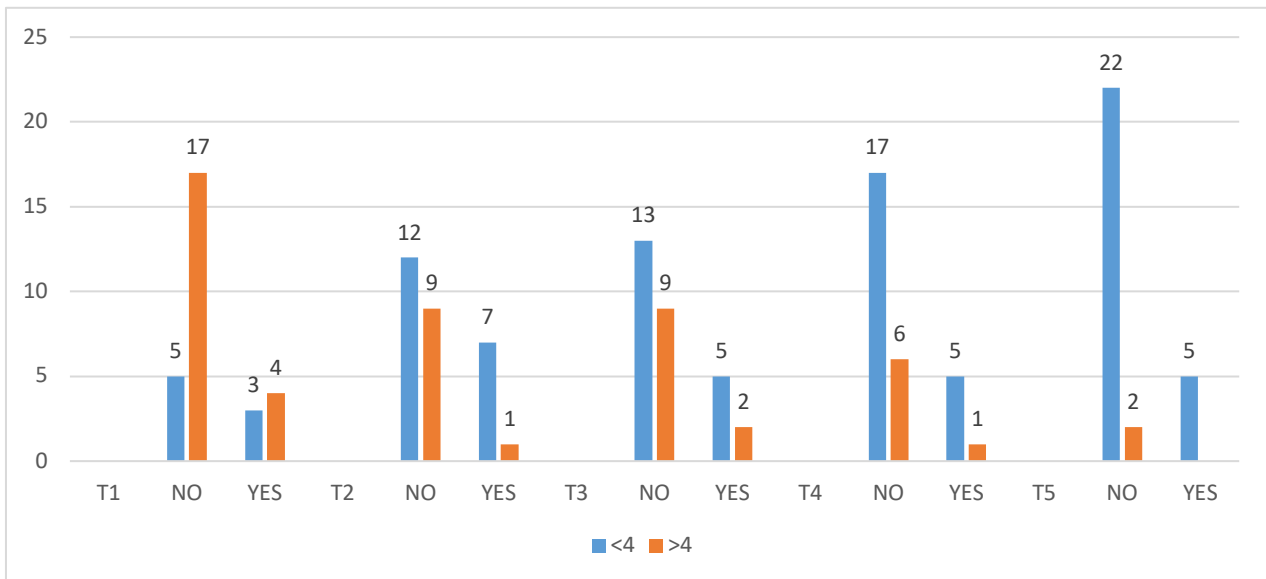


Figure 39 *Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and participation in support groups.*

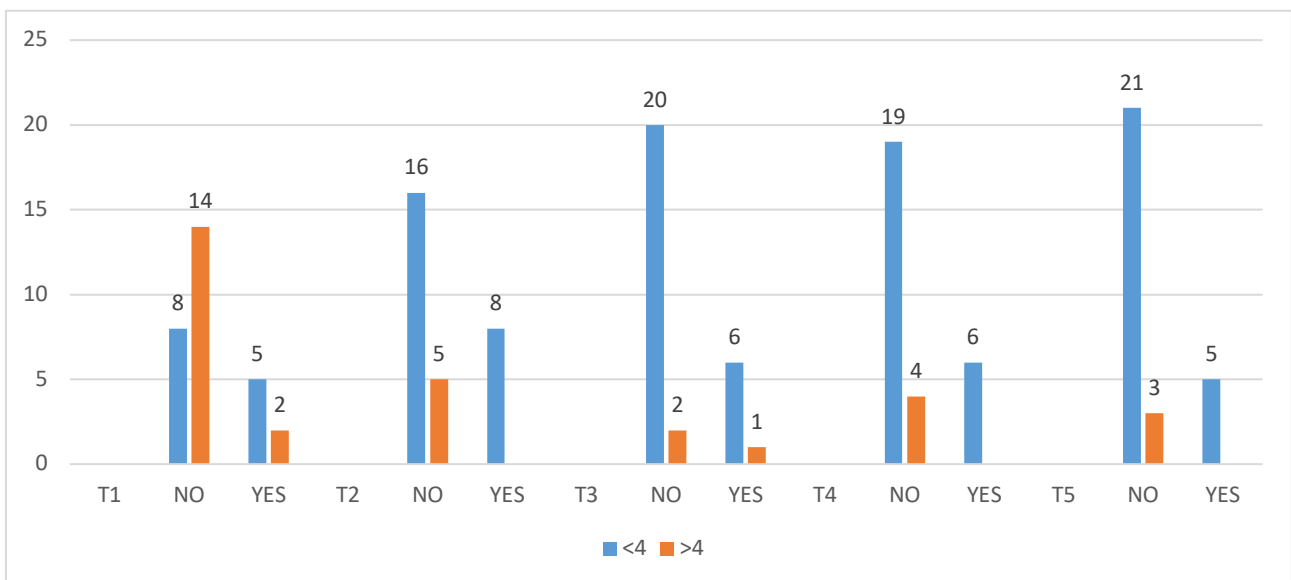


Figure 40 *Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and participation in support groups.*

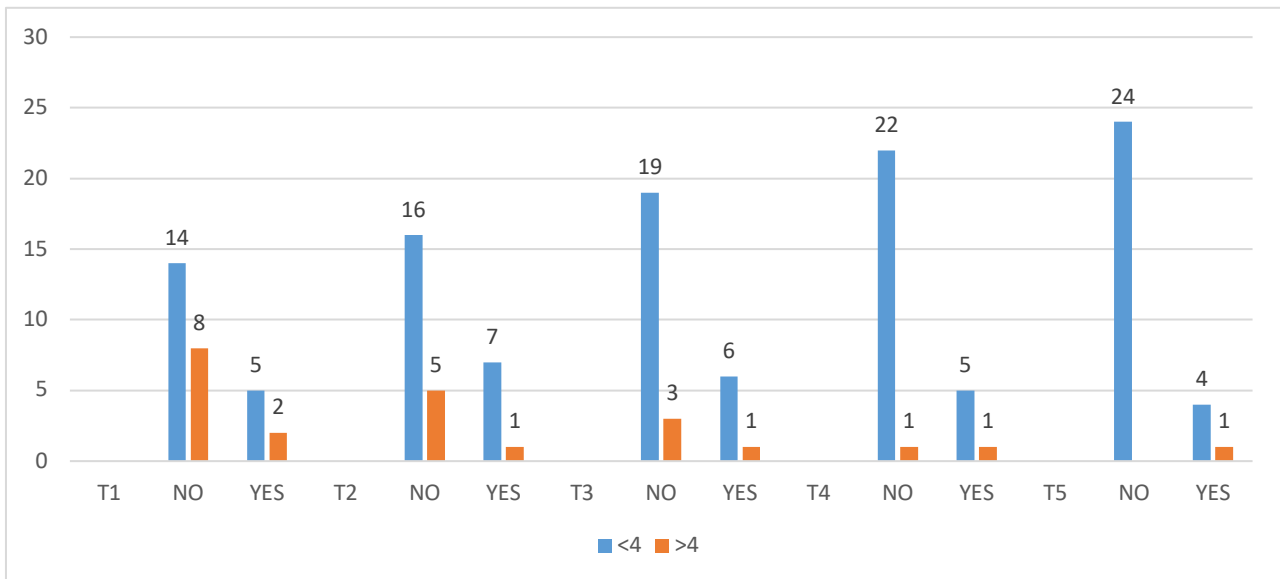
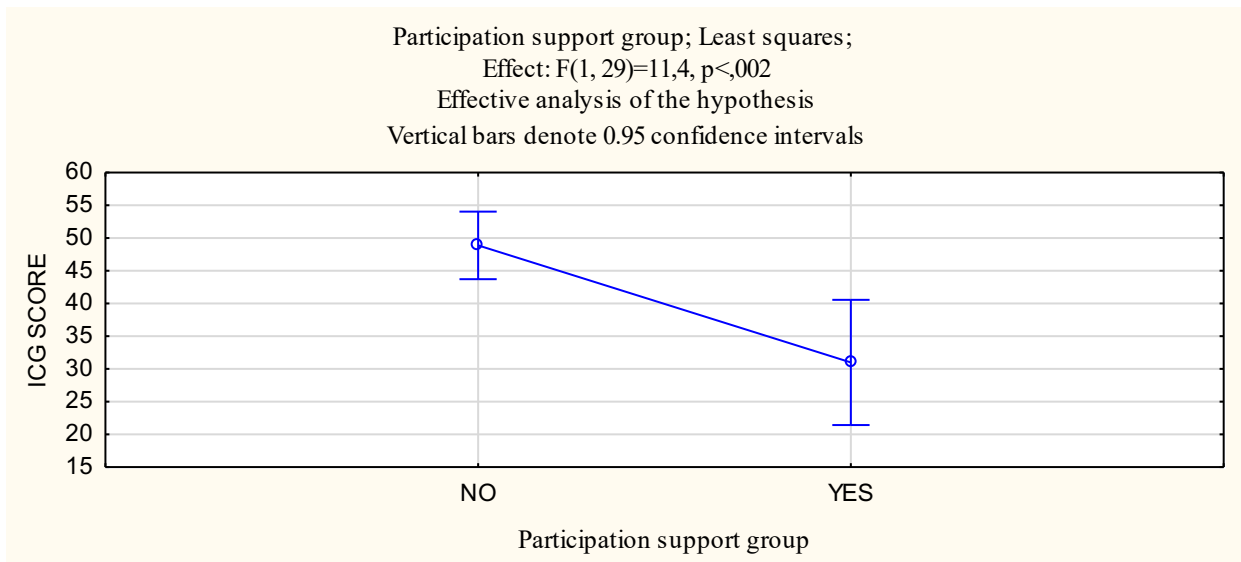


Figure 41 *Effective analysis between the participation in support group and ICG scores from T1.*



### *Active participation in online group about perinatal death*

As emerged from the interviews, some parents consider the groups available on Facebook, forums and blogs as therapeutic and equivalent to the support groups.

As for the previous variables, this variable is also dichotomic, classified by a YES or NO answer as to whether parents declared participation in online groups about perinatal loss. Only active participation was considered, that is a constant connection, exchange and sharing of information, of comments and pictures with the other users of the groups.

As we can see in Table 20, only women actively participated in online groups.

At the beginning (T1), out of a total of 17 women, 10 were followed by a psychotherapist and 4, in addition to personal psychotherapy, participated in the support group.

In the following three months (T2), 13 women participated in online groups (44.8%) and of these, 4 were followed by a therapist and 3 required both the personal and group support.

In T3, out of 8 women (27.6%), 4 women (as in T2) were followed by a therapist, 1 woman by both the therapist and the support group, 2 participated only in the support group and 1 exclusively in online groups.

In T4, that is six months later, 17.2% of women (2 women) participated only in online groups, 2 were followed by a psychotherapist and 1 who required all types of support (support groups, IT groups and personal therapy).

Finally, in T5, 17.2% (as in T4) consisted of 1 woman who participated exclusively on social networks, and 2 women who were also followed by a therapist, 1 of whom participated in support groups and 1 who followed both a personal and group therapy.

In general, we can therefore see that in the first months of the study most of those who participated in the groups available on social networks were also followed by a therapist and very few also participated in support groups.

As the months passed, as has been seen previously, participation in any form of therapy drastically decreased, including participation in online groups. Involvement in online groups went from 58.6% in T1 (more than half of the participants), to 17.2% in T4 and T5 (Figure 42). Many of them interrupted their membership not considering the groups useful anymore.

Table 20 Frequency of participants on IT groups compared with support groups and psychotherapy.

Participation on online groups T1	Participation support group T1	Sex	Psychological support T1	
			NO	YES
NO (41.4%)	NO	F	1	1
		M	3	4
	YES	F	0	2
		M	1	0
YES (58.6%)	NO	F	3	10
		M	0	0
	YES	F	0	4
		M	0	0

Participation on online groups T2	Participation support group T2	Sex	Psychological support T2	
			NO	YES
NO (55.2%)	NO	F	2	3
		M	5	1
	YES	F	0	3
		M	2	0
YES (44.8%)	NO	F	6	4
		M	0	0
	YES	F	0	3
		M	0	0

Participation on online groups T3	Participation support group T3	Sex	Psychological support T3	
			NO	YES
NO (72.4%)	NO	F	6	4
		M	4	2
	YES	F	0	3
		M	2	0
YES (27.6%)	NO	F	2	4
		M	0	0
	YES	F	1	1
		M	0	0

Participation on online groups T4	Participation support group T4	Sex	Psychological support T4	
			NO	YES
NO (82.8%)	NO	F	9	3

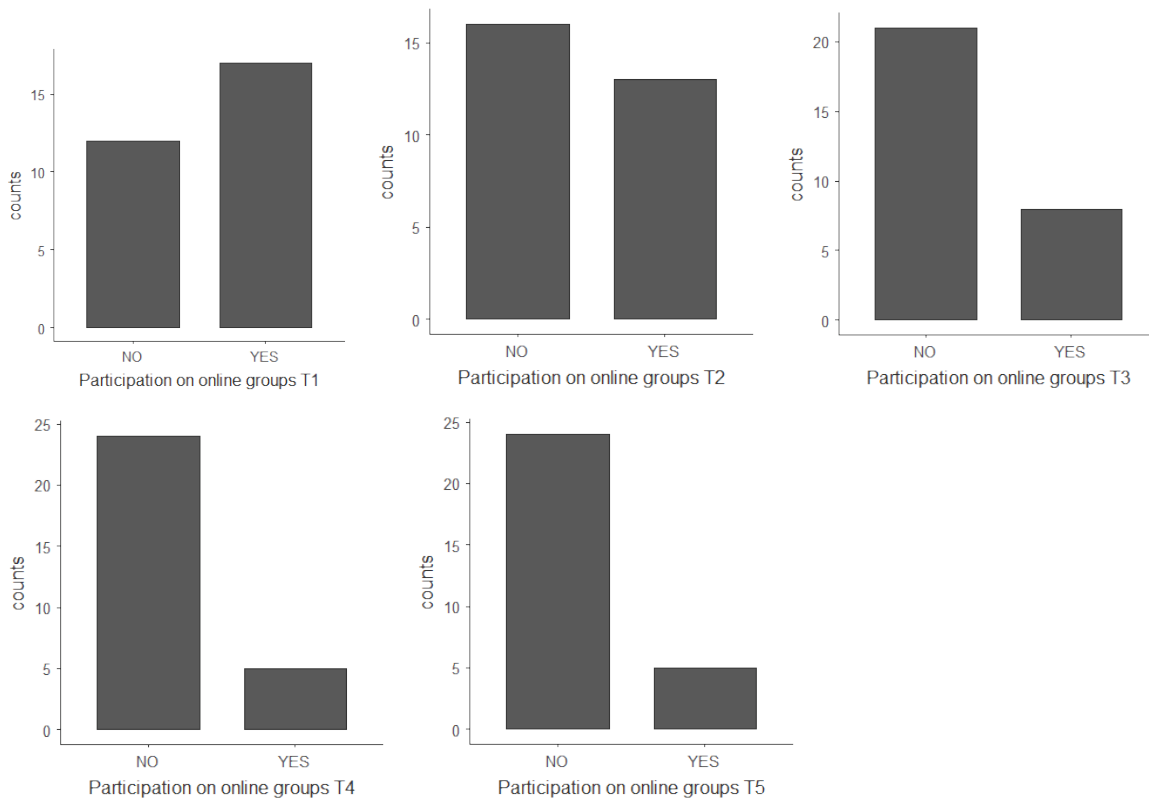
Participation on online groups T1	Participation support group T1	Sex	Psychological support T1	
			NO	YES
YES (17.2%)	YES	M	7	0
		F	2	2
	NO	M	1	0
		F	2	2
	YES	M	0	0
		F	0	1
		M	0	0
		M	0	0

Participation on online groups T5	Participation support group T5	Sex	Psychological support T5	
			NO	YES
NO (82.8%)	YES	F	0	2
		M	1	0
	NO	F	11	3
		M	7	0
YES (17.2%)	YES	F	1	1
		M	0	0
	NO	F	1	2
		M	0	0



Figure 42 *Plots of parents' participation on IT groups in T1, T2, T3, T4 and T5.*



Compared to those who presented levels below or above 25 (that is the reference cut-off of the ICG questionnaire), from the figure below (Figure 43), we can confirm the decrease in participation in online groups and underline that most of the mothers who participated always recorded levels above 25. Considering the results of those who did not participate or have stopped being part of these groups, until T3 the frequency was higher than 25, while in T4 this was equal (i.e. 12 vs 12), up to T5 with a majority of results lower than the reference cut-off (16 vs 8).

Considering the frequency of results higher or lower than the cut-off of the GHQ-28 questionnaire compared to participation in online groups, in all four subscales, most of the parents always recorded a majority of values lower than 4.

The only exception was for the results in T1 of the Social dysfunction subscale (Figure 47), where the majority of those who participated in the IT groups showed a result greater than 4.

Figure 43 Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and participation in IT groups.

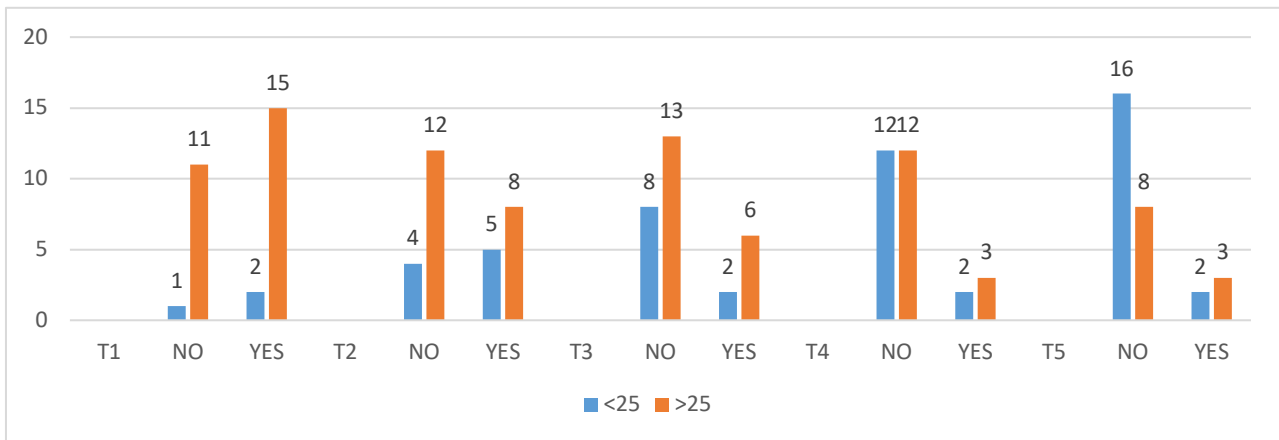


Figure 44 Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and participation in IT groups.

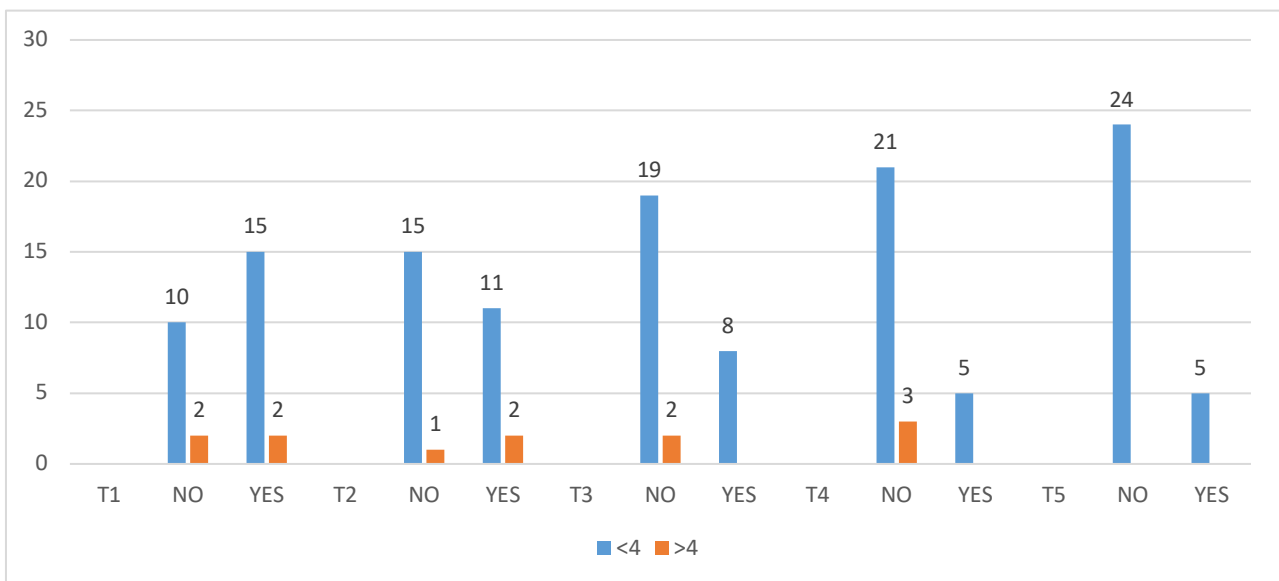


Figure 45 Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and participation in IT groups.

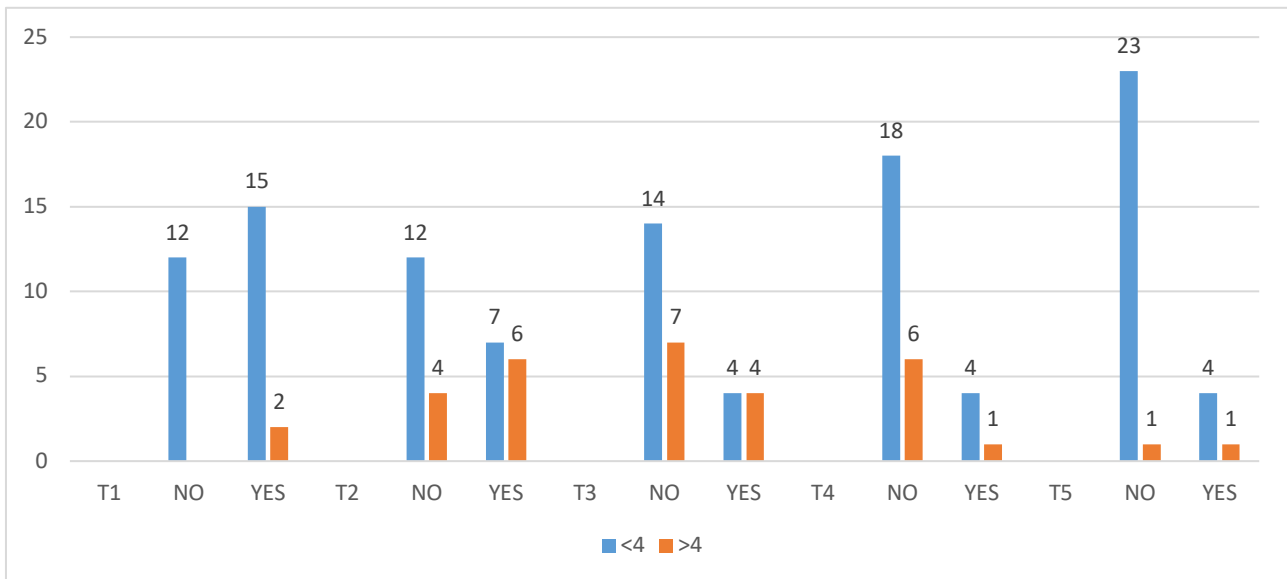


Figure 46 Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and participation in IT groups.

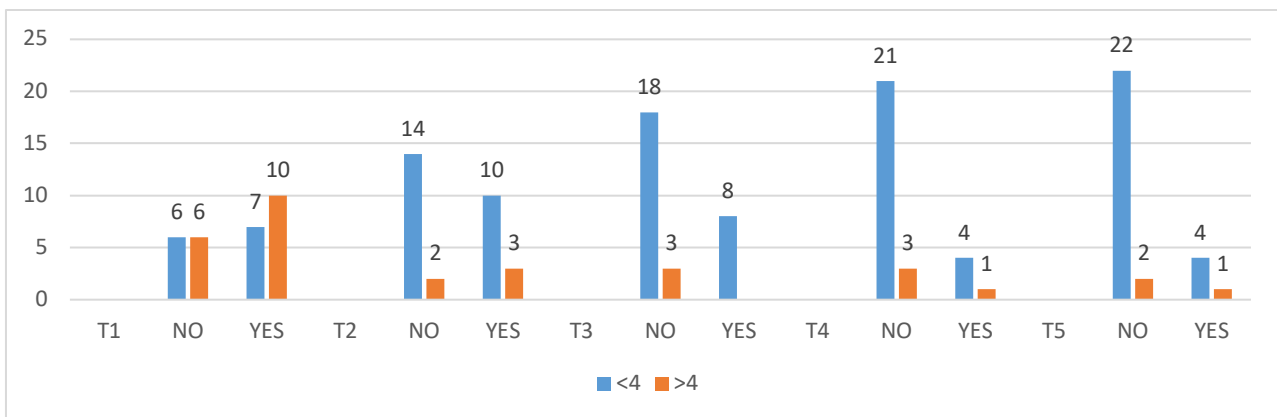
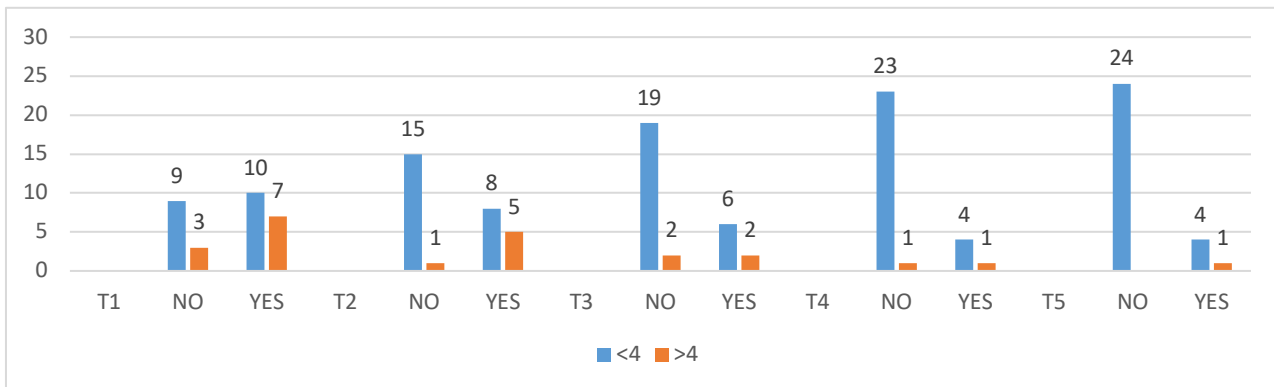


Figure 47 *Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and participation in IT groups.*



Considering the results obtained from the comparison with the ICG and the subscales of the GHQ-28, a significant difference emerged with respect to the GHQ-28's Severe Depression subscale in T4 ( $F=6.69$  and  $p < 0.015$ ) (Table 21).

Those actively participating in online groups recorded an average of 3, which was significantly higher than the average of those who do not belong to these groups, that is 0.75.

In T5 all the questionnaires showed significant values, except for the subscale of the Social Dysfunction.

In particular, the analysis of variance showed that those who participate in online groups have a greater risk of developing a Complicated Grief Disorder ( $F = 7.56$ ,  $p < 0.010$ ).

Those who did not take part obtained an average of 19.2, significantly lower than 42.6, the mean of those who actively participated in online groups.

Concerning the GHQ-28, except for the subscale of Social dysfunction, differences have emerged with respect to the subscales of Somatic Symptoms ( $F = 3.88$ ,  $p < 0.059$ ), Anxiety and Insomnia ( $F = 4.61$ ,  $p < 0.041$ ) and Severe Depression ( $F = 15.5$ ,  $p < 0.001$ ).

The mothers who participated in the Social Networks groups dedicated to perinatal loss obtained a significantly higher average and therefore more dangerous compared with those of those who were not part of such groups.

Table 21 *Effective analysis of the hypothesis between participation on IT groups and ICG and GHQ-28 scores in T4 and T5.*

	Participation in online groups		No participation in online groups		F	p-values
	n	Mean	n	Mean		
<b>T4</b>						
ICG	5	33.2	24	26.7	0.54142	0.491
GHQ-28 Somatic Symptoms		1.40		1.37	0.00103	0.975
GHQ-28 Anxiety & Insomnia		2.40		2.20	0.02744	0.874
GHQ-28 Social dysfunction		2.00		2.20	0.59372	0.473
GHQ-28 Severe depression		3.00		0.75	6.6935	0.015*
<b>T5</b>						
ICG	5	42.60	24	19.20	7.56	0.010**
GHQ-28 Somatic symptoms	5	1.80	24	0.58	3.88	0.59
GHQ-28 Anxiety & Insomnia	5	3.20	24	1.16	4.61	0.041*
GHQ-28 Social dysfunction	5	2.00	24	0.75	1.93	0.176
GHQ-28 Severe depression	5	3.00	24	0.375	15.51	<.001**

\*p<.05

\*\*p<.01

*Perception of partner support received*

The percentage of parents who felt supported by their partners was consistently very high, especially in the first three meetings (89.7% in T1 and 86.2% in T2 and T3) (Table 58). In T4, a greater number of parents (31%) one year after the first interview, said they felt alone and no longer supported by their partner. This statistic increased to 44.8% in T5, suggesting an increase of a sense of loneliness after the child's loss.

In T5, only 55.2% of participants said they felt supported by their partner. This figure showed that still more than half felt supported, but the figure is drastically lower than about 90% of T1.

Table 22 *Frequency of parents' perception of partner support.*

Perception of partner support T1	Sex	
	F	M
NO (10.3%)	3	0
YES (89.7%)	18	8

Perception of partner support T2	Sex	
	F	M
NO (13.8%)	3	1
YES (86.2%)	18	7

Perception of partner support T3	Sex	
	F	M
NO (13.8%)	4	0
YES (86.2%)	17	8

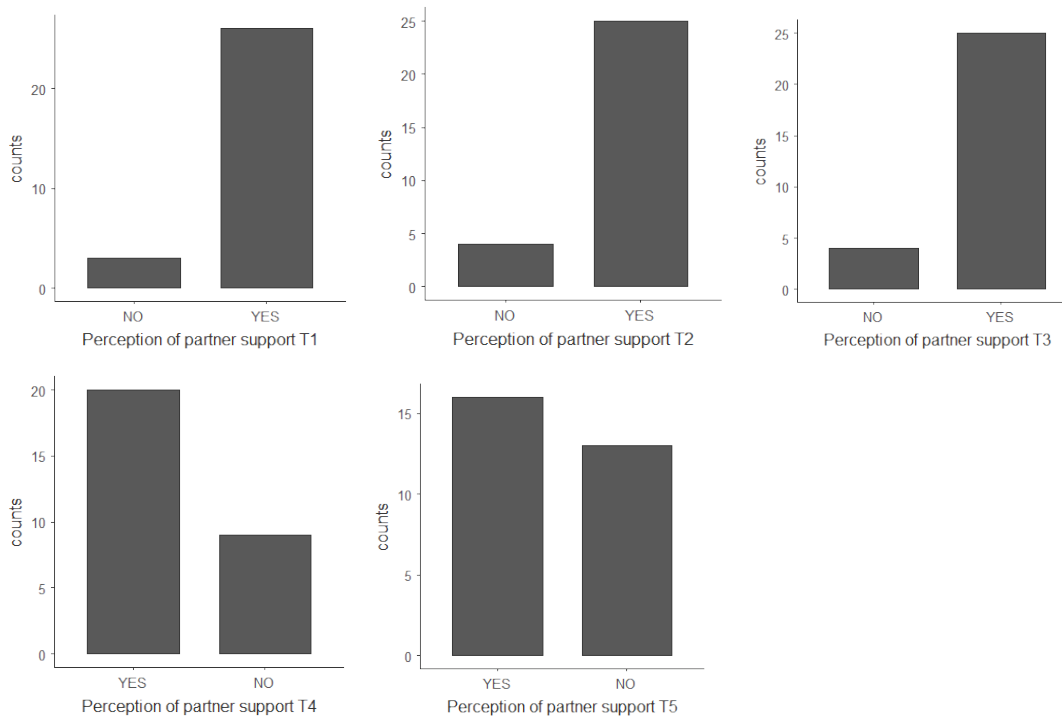
  

Perception of partner support T4	Sex	
	F	M
YES (69.0%)	14	6
NO (31.0%)	7	2

Perception of partner support T5	Sex	
	F	M
YES (55.2%)	10	6
NO (44.8%)	11	2

Figure 48 *Plots of partner support's perception in T1, T2, T3, T4 and T5.*



Considering the frequencies of the values with respect to the reference cut-off of the ICG (Figure 51), up to T3 the results of those who perceived or not perceived the support of the partner were in most cases greater than 25.

In T4 only those who did not feel the partner as a help showed a majority of results above 25, while in T5 both parents who perceived the partner's support and those who felt isolated showed a majority of results below the cut-off.

Considering the frequencies of the values with respect to the cut-off of the GHQ-28, the results of the Somatic symptoms subscale (Figure 52) showed a constant majority of results lower than 4, with a total majority in T5, without therefore that no parent obtained a score higher than the cut-off.

As for the Anxiety and insomnia subscale (Figure 53), the majority of values above 4 was highlighted in those who perceived the partner's support in T1 and in those who felt isolated in T5, while for the remainder of the values, on the other hand, the majority always was lower than the cut-off.

In the Social dysfunction subscale (Figure 54), the majority of results greater than 4 were highlighted in those who perceived the partner as support in T1 and T2, while in subsequent results values lower than 4 were in a clear majority.

Finally, in the Severe depression subscale (Figure 55), most of the values was always lower than 4. Only a minimum number of participants recorded results superior to the cut-off, for the NO: 1 in T1; 2 in T2, T3, and T4; 1 in T5. While for the "YES": 9 in T1, 4 in T2, 2 in T3.

Figure 49 *Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and partner support's perception.*

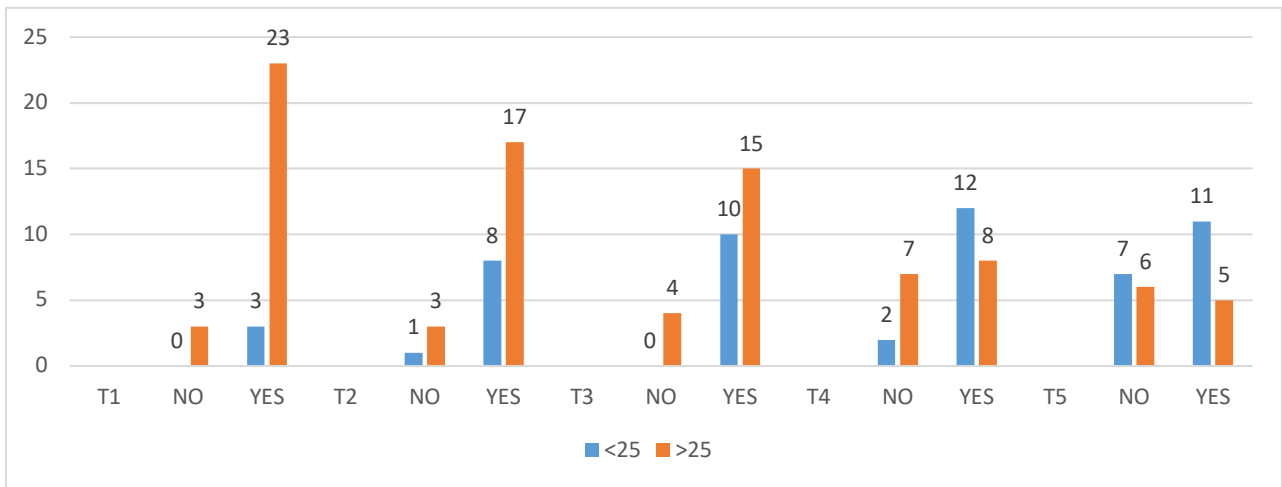


Figure 50

*Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and partner support's perception.*

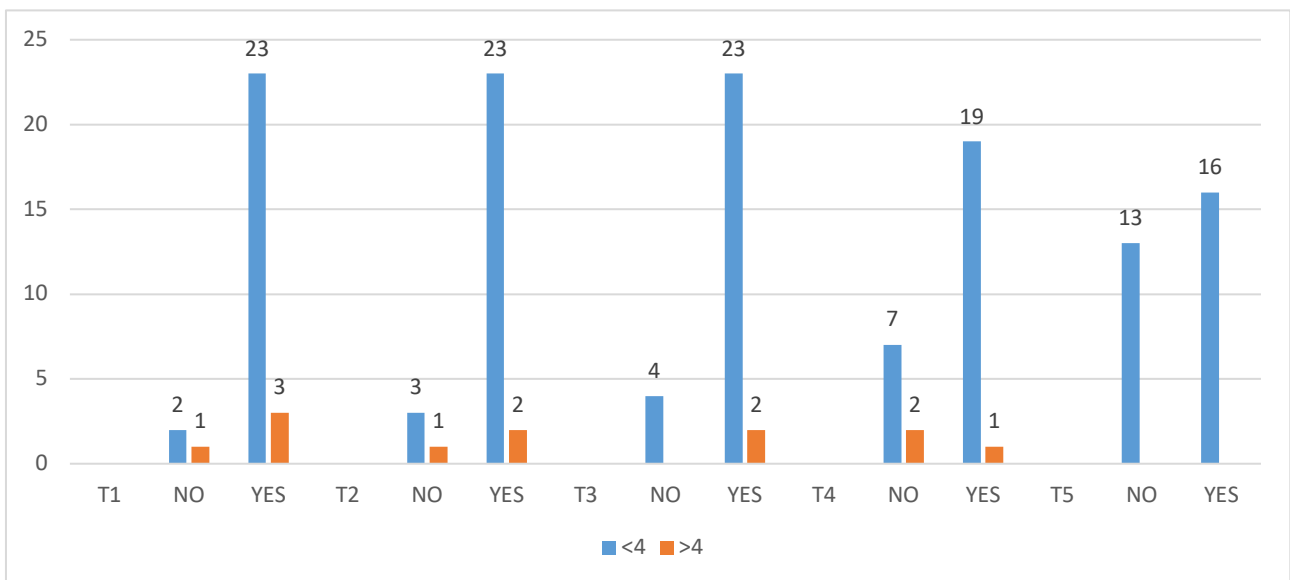




Figure 51 *Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and partner support's perception.*

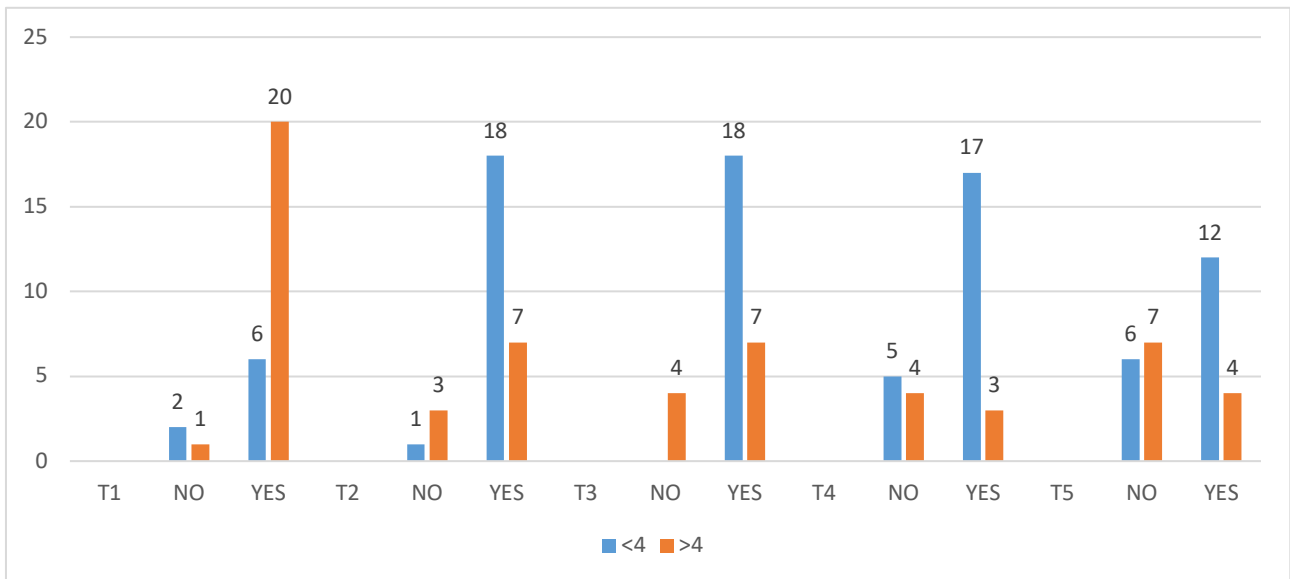


Figure 52 *Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and partner support's perception.*

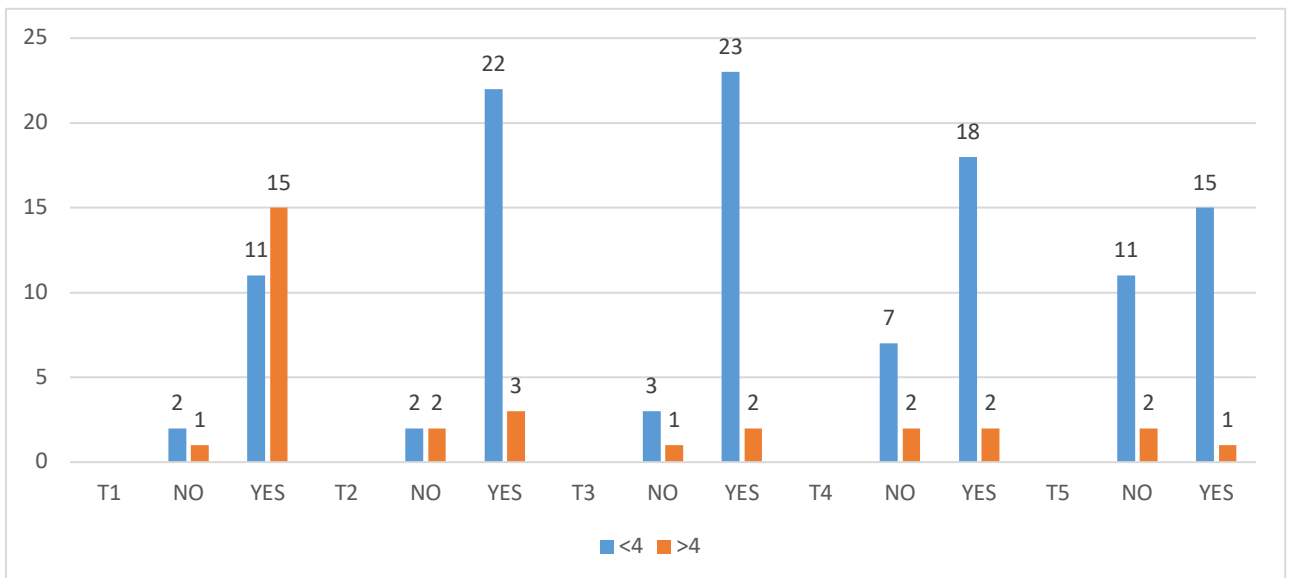
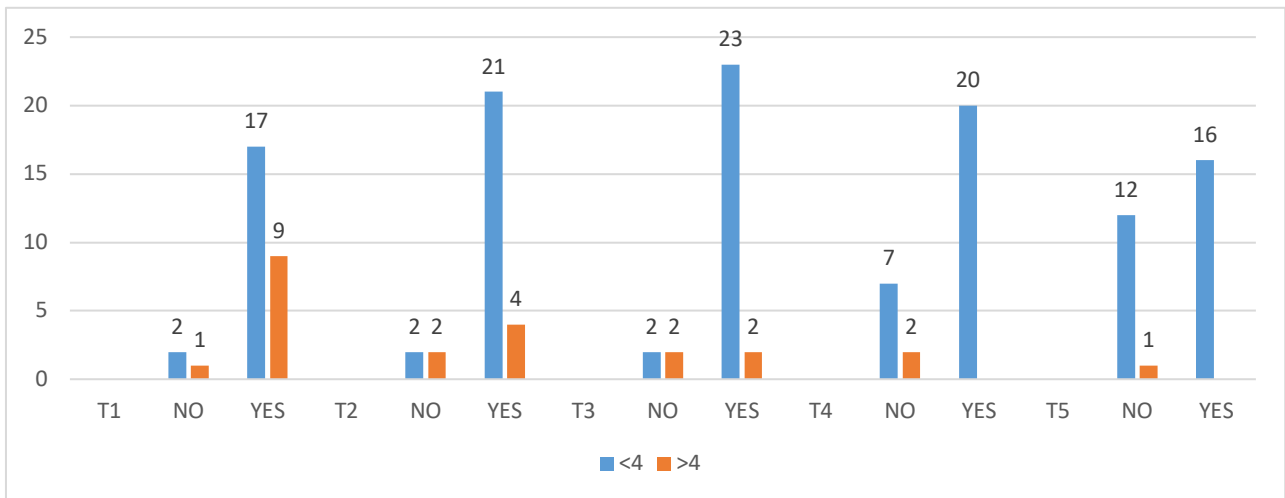


Figure 53 *Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and partner support's perception.*



Furthermore, the comparison between the results of the questionnaires in T1 regarding perception of the partner support did not reveal any significant difference.

As we can see in the tables below, in T2 and T3, those who didn't feel supported by their partner showed significantly a greater effect size ( $d > 0.8$ ) in Somatic Symptoms (T3) ( $d = 0.840$ ), Anxiety and Insomnia (T3,  $d = 1.353$ ), Social Dysfunction (T2,  $d = 0.882$ ) and Severe Depression (T2 and T3,  $d = 0.887$  and  $d = 1.184$ ), highlighting such support as a protection factor (Table 24).

Table 23 Means and effect sizes of ICG and GHQ-28's scores and partner support's perception variable in T2 and T3.

	Group	n	Mean	Median	SD	SE	p	Cohen's d
ICG SCORE T2	NO	4	40.00	36.00	8.72	4.36	0.581	0.301
	YES	25	35.28	36.00	16.36	3.272		
GHQ-28 Score (Somatic symptoms) T2	NO	4	2.25	2.00	2.22	1.11	0.601	0.285
	YES	25	1.68	1.00	1.97	0.395		
GHQ-28 Score (Anxiety&Insomnia) T2	NO	4	4.75	6.00	3.30	1.65	0.180	0.741
	YES	25	2.92	3.00	2.34	0.469		
GHQ-28 Score (Social dysfunction) T2	NO	4	3.75	4.00	3.30	1.65	0.113	0.882*
	YES	25	1.76	1.00	2.09	0.417		
GHQ-28 Score (Severe depression) T2	NO	4	3.75	4.50	2.63	1.31	0.111	0.887*
	YES	25	1.60	0.00	2.40	0.480		
ICG SCORE T3	NO	4	42.25	41.50	14.315	7.157	0.208	0.695
	YES	25	29.96	27.00	18.05	3.610		
GHQ-28 Score (Somatic symptoms) T3	NO	4	2.75	3.50	1.893	0.946	0.130	0.840*
	YES	25	1.32	1.00	1.68	0.335		
GHQ-28 Score (Anxiety&Insomnia) T3	NO	4	6.25	6.50	0.957	0.479	0.018	1.353*
	YES	25	2.72	3.00	2.75	0.549		
GHQ-28 Score (Social dysfunction) T3	NO	4	2.25	1.00	3.304	1.652	0.641	0.254
	YES	25	1.68	1.00	2.08	0.415		
GHQ-28 Score (Severe depression) T3	NO	4	3.75	4.00	2.872	1.436	0.037	1.184*
	YES	25	1.24	0.00	2.01	0.401		

\*d >0.8

The rest of the effect size analysis confirmed the results of Anova. Compared with T4, the results showed significant differences (Table 25): those who felt the partner support reported an ICG's average of 23.3, significantly lower ( $p < 0.03$ ) than those who did not feel supported in their grief (mean = 38).

Significant differences were also highlighted with respect to the General Health Questionnaire-28. All the scales, except that of Social Dysfunction have shown how the lack of partner support significantly affects the risk of possible somatic, anxious and depressive disorders.

In the somatic symptoms subscale, those who felt supported recorded an average of 0.8, significantly less risky ( $p < 0.007$ ) in comparison to 2.66, the mean of participants who did not feel this way.

Even compared with the subscale of Anxiety and Insomnia, those who did not perceive the partner support, suggesting a possible feeling of loneliness, recorded an average of 4.33, compared with 1.30. The value, besides being significantly different ( $p < 0.001$ ), was also higher than the reference threshold of the questionnaire's subscales ( $> 4$ ).

As previously expressed, also the Severe Depression subscale also showed a significant difference between the averages ( $p < 0.023$ ).

Those who felt the partner support obtained an average of 0.6, significantly lower than those who did not perceive the partner to be emotionally close (who recorded a mean of 2.33).

Significant differences have also emerged in T5, in particular concerning the subscales of Anxiety and Insomnia and Severe Depression.

The analysis of variance has shown that those who did not perceive the support of the partner were more at risk of developing sleep and anxiety disorders ( $F = 4.81, p < 0.037$ ).

Moreover, in T5 those who did not feel supported by their partner obtained an average of 1.538 in the Severe Depression subscale, significantly higher ( $p < 0.036$ ) than those who claimed to be able to count on their partner (mean = 0.250).

Table 24 *Effective analysis between the perception of partner support and ICG, Somatic symptoms, Anxiety&Insomnia and Severe Depression subscales in T4 and T5.*

	Perception of partner support		No perception of partner support		Mean difference	p-values
	n	Mean	n	Mean		
<b>T4</b>						
ICG	20	23.3	9	38.0	-14.7	0.030*
GHQ-28 Somatic symptoms	20	0.80	9	2.66	-1.87	0.007*
GHQ-28 Anxiety &Insomnia	20	1.30	9	4.33	-3.03	0.001**
GHQ-28 Social dysfunction	20	0.85	9	2.22	-1.37	0.114
GHQ-28 Severe depression	20	0.60	9	2.33	-1.73	0.023*
<b>T5</b>						
GHQ-28 Anxiety &Insomnia	16	0.813	13	2.385	-1.57	0.037*
GHQ-28 Severe depression	16	0.250	13	1.538	-2.20	0.036*

\* $p < .05$

\*\* $p < .01$

### *Perception of family support*

In T1, more than half of the participants (58.6%) perceived support from the family of origin after loss. This percentage decreased over the months, a trend which began in T2, reaching 31% in T4 (Table 24).

In T5 the percentage of those who received family support increased to 52%, more than half of participants, and was almost restored to the initial percentage of T1.

Compared to the frequencies of the participants who presented a result lower or higher than the cut-off of the ICG questionnaire (Figure 57), we have seen that those who did not perceive the support of the family showed a majority of values above 25 until to T4. Even those who felt the family as an aid (that is, the "YES"), up to T3 the majority of the values was higher than the cut-off, while in T4 among the YES there was a proportion of 50%: 7 parents showed a result lower than 25 and other 7 a higher one. Finally, in T5 both those who perceived this support or not showed a majority of results lower than the cut-off.

Compared to the GHQ-28 subscales, those of Somatic symptoms (Figure 58) and Severe depression (Figure 61) had similarities. In both variables, the majority of the values were consistently lower than the reference cut-off.

For the subscales of Anxiety and Insomnia (Figure 59) and Social Dysfunction (Figure 60), both the majority of those who perceived the family as a support and the parents who felt isolated showed values higher than 4 in T1, while starting from T2, for both, the most of the values were lower than the cut-off.

Table 25 *Frequency of parents' perception of family support.*

<b>Perception of family support T1</b>	<b>Sex</b>	
	<b>F</b>	<b>M</b>
NO (41.4%)	10	2
YES (58.6%)	11	6

<b>Perception of family support T2</b>	<b>Sex</b>	
	<b>F</b>	<b>M</b>
NO ( 55.2%)	13	3
YES (44.8%)	8	5

<b>Perception of family support T3</b>	<b>Sex</b>	
	<b>F</b>	<b>M</b>
NO (51.7%)	12	3
YES (48.3%)	9	5

<b>Perception of family support T4</b>	<b>Sex</b>	
	<b>F</b>	<b>M</b>
NO (69.0%)	15	5
YES (31.0%)	6	3

<b>Perception of family support T5</b>	<b>Sex</b>	
	<b>F</b>	<b>M</b>
YES (51.7%)	8	7
NO (48.3%)	13	1

Figure 54 Plots of family support's perception in T1, T2, T3, T4 and T5.

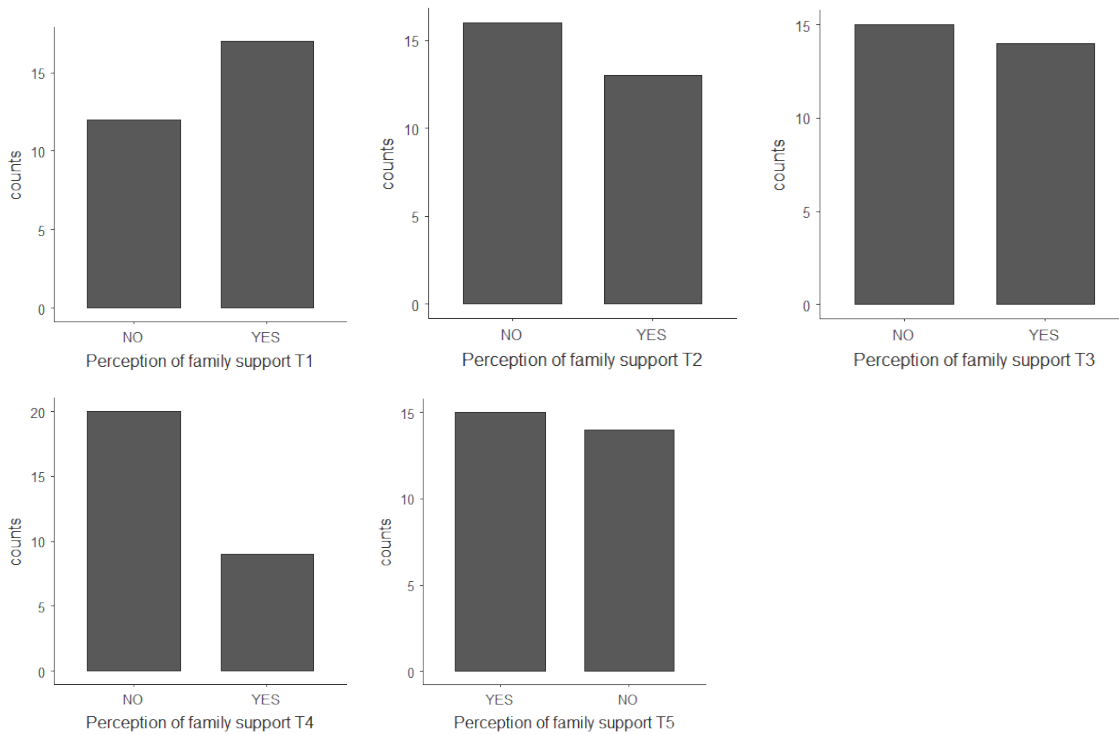


Figure 55 Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and family support's perception.

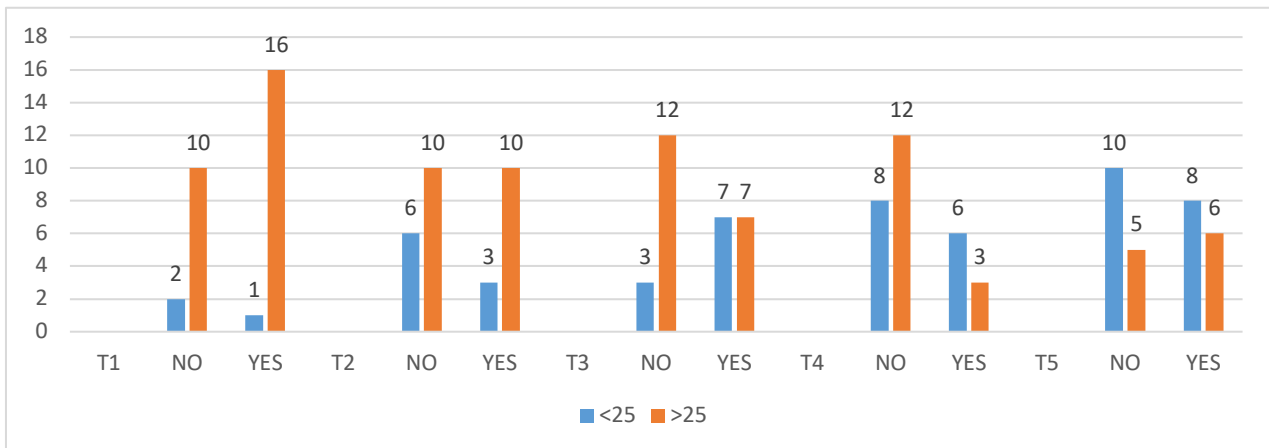


Figure 56 Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and family support's perception.

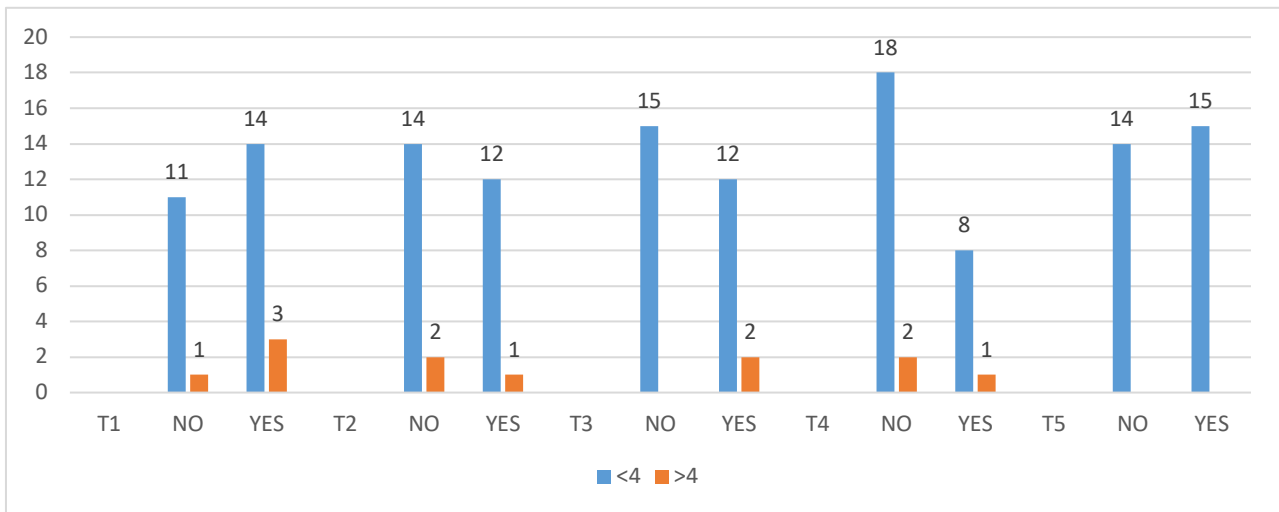


Figure 57 Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and family support's perception.

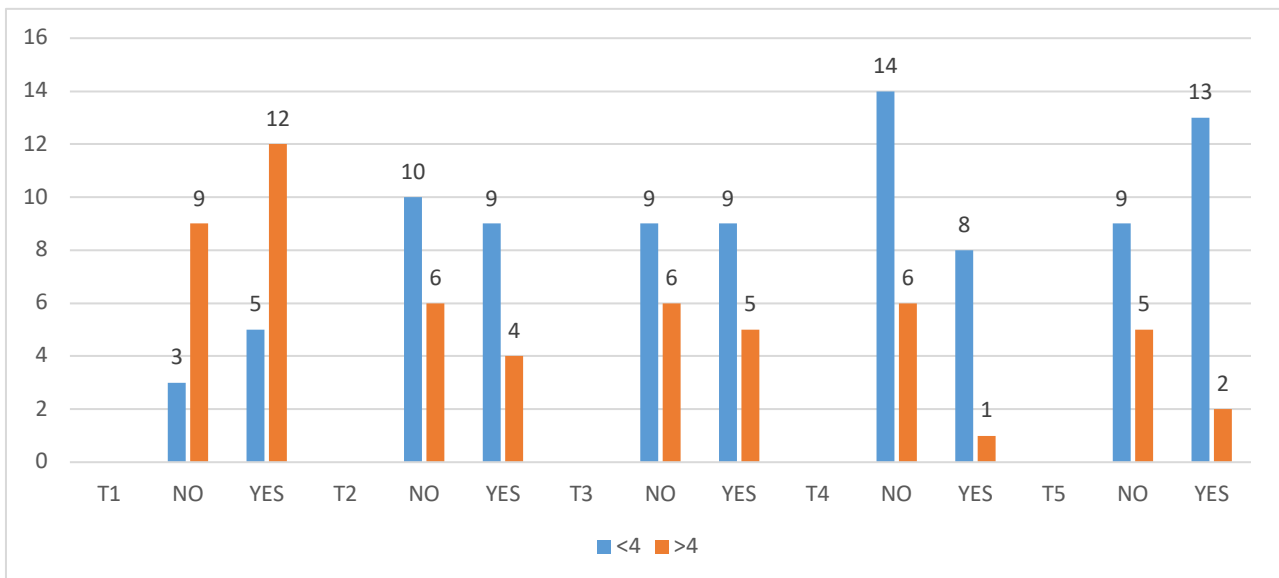




Figure 58 Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and family support's perception.

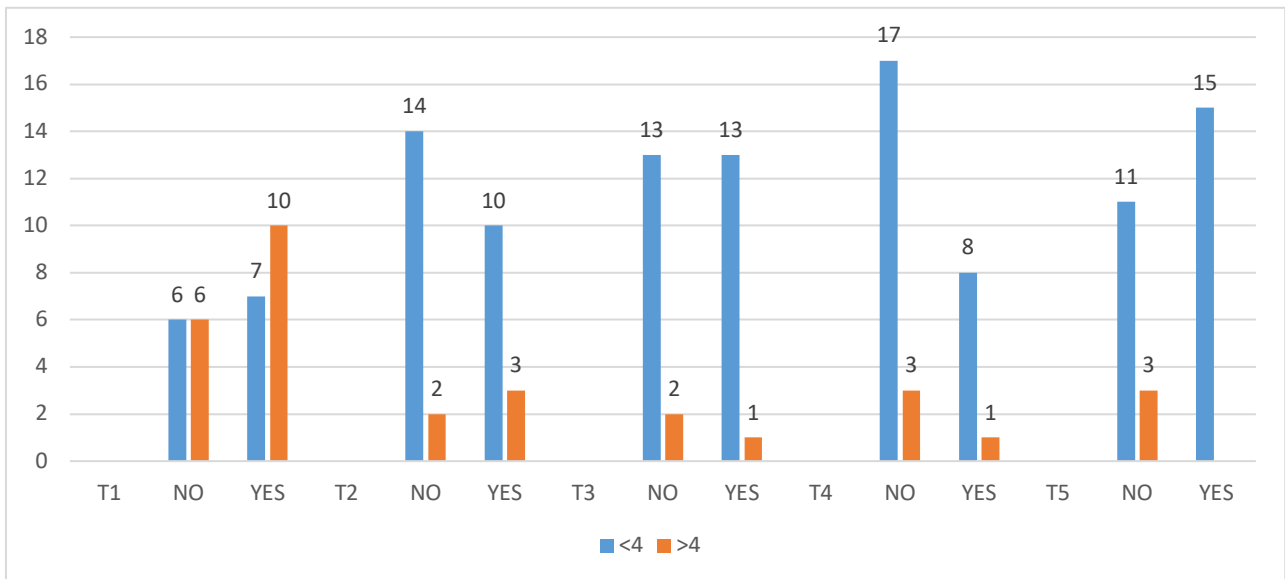
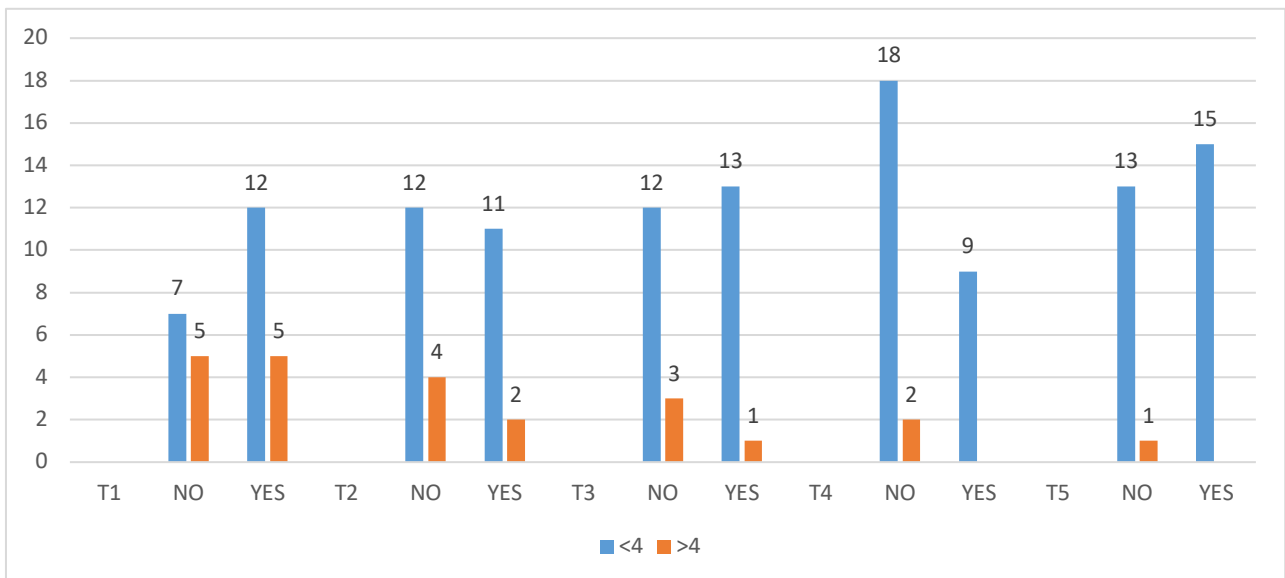


Figure 59 Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and family support's perception.



The first difference between the averages of the questionnaires given out during the various meetings and the support received from the family was in T4, concerning the results of the ICG ( $p < 0.02$ ) (Table 26).

31% of parents who felt supported by their family obtained an average of 17.2, compared with 32.6 recorded by those who did not perceive any support. Even months after the first meeting (that is one year) and the child's death, this value recorded an average higher than the reference threshold of the questionnaire (that is > 25).

Significant differences also emerged in T5. These did not concern the perceived support by the family and the risk of complicated grief but, specifically, the possible consequences highlighted by the four subscales of the GHQ-28.

Those who did not feel supported by their family showed a significant value and an increased risk of somatic symptoms ( $F = 4.20$ ,  $p < 0.05$ ) with an average of 1.286, superior to those who instead found their family to be supported, who obtained an average of 0.333.

The Anxiety and Insomnia subscale also showed that in T5 those who did not perceive the family as supportive were more at risk of developing anxiety and sleep disorders ( $F = 5.25$ ,  $p < 0.030$ ). They had an average of 2.53 compared with that one of 0.733, of those who saw the family as an aid.

Family support is an obvious protection factor even for the difficulties that can arise at a relational and social level ( $F = 3.97$ ,  $p < 0.057$ ) (i.e. a mean of 1.643, compared with 0.333, the mean of those who perceived this support), and a severe depression ( $F = 6.40$ ,  $p < 0.018$ ).

Table 26 *Effective analysis between the perception of family support and ICG and GHQ-28 in T4 and T5.*

	Perception of family support		No perception of family support		Mean difference	p-values
	n	Mean	n	Mean		
<b>T4</b>						
ICG	20	32.6	9	17.2	15.4	0.022*
<b>T5</b>						
GHQ-28 Somatic symptoms	15	0.33	14	1.28	-0.952	0.05*
GHQ-28 Anxiety &Insomnia	15	0.73	14	2.35	-1.62	0.030*
GHQ-28 Social dysfunction	15	0.33	14	1.64	-1.31	0.057*
GHQ-28 Severe depression	15	0.13	14	1.57	-1.44	0.018*

\* $p < .05$

\*\* $p < .01$

### *Perception of friends' support*

The third kind of social support analyzed is support from friends.

Most parents (over 50%) consistently felt supported by friends.

In T4, a year after the first meeting, the percentage of those who did not perceive any emotional support increased more than 10% (48.3%) compared with previous interviews, where this percentage was always more or less constant (around 35%) (Table 69).

If, therefore, the diminution of the perception of the friends' support was steadily increasing, in T5, after only 6 months from T4, about 4% of parents changed their opinion declaring that they felt this kind of help with respect to their grief.

Considering how many parents presented results higher or lower than the reference cut-off, for the ICG (Figure 63), both the majority of those who perceived the support of their friends and who did not showed values higher than 25 up to T4, especially the participants who felt poorly supported (for example, in T1 all NOs recorded values higher than the reference cut-off).

Over time, gradually and for both (that is, the YES and the NO) the proportions have changed, they arrive in T5 with a majority of results lower than 25: 7 out of 13 for the NO and 11 out of 16 for the YES.

Regarding the frequencies of the GHQ-28 questionnaire, for the subscale of the Somatic symptoms (Figure 64), both those who felt their friends as a support and those who felt they were not helped and understood presented a constant majority of values below 4.

For both, there were very few parents who during the study recorded a value greater than 4: 1 and 3 for NO and YES in T1, 2 and 1 in T2, in T3 2 parents who felt supported, and 2 and 1 for NO and YES in T4, arriving in T5 with total values lower than the reference cut-off for both.

For the Anxiety and Insomnia subscale (Figure 65), both YES and NO showed a majority of values above 4 in T1, then showing a significant majority of results below 4. In T5, out of 13 parents who did not feel supported by their friends, 2 showed a result higher than 4, while for all those who perceived social support the level was lower than the cut-off.

Finally, for both the Social Dysfunction (Figure 66) and the Severe Depression subscales (Figure 67), for those who felt understood and helped by friends, the majority always showed values lower than 4, as well as those who did not perceive such support. On both subscales, however, the NO showed a majority of results superior to the cut-off only at the beginning, in T1.

Furthermore, according to the Severe Depression subscale of the GHQ-28 questionnaire, a significant difference was observed in T1 ( $F(1, 29) = 4.13, p < 0.052$ ) (Table 28).

Those who did not perceive this support had an average of 4.27, a score greater than who considered the friends supportive (mean = 2.39).

Furthermore, six months after the first data collection, that is in T3, the perception of support from friends showed a positive effect with respect to the risk of complicated grief disorder ( $F(1, 29) = 7.25, p < 0.012$ ).

Those who perceived the support of friends recorded an average of 25.8 in the ICG, compared with the average of 42.8 of those who felt alone and not supported.

In T4 and T5, there were no significant differences compared with the variable of perception of friends' support and the results of the two questionnaires, ICG and GHQ-28.

As previously expressed, the only differences concerned the risk of depression in T1 and complicated grief in T3.

Table 27 *Frequency of parents' perception about friends' support.*

Perception of social support T1	Sex	
	F	M
NO (37.9%)	8	3
YES (62.1%)	13	5

Perception of social support T2	Sex	
	F	M
NO (34.5%)	8	2
YES (65.5%)	13	6

Perception of social support T3	Sex	
	F	M
NO (34.5%)	8	2
YES (65.5%)	13	6

Perception of social support T4	Sex	
	F	M
NO (48.3%)	10	4
YES (51.7%)	11	4

Perception of social support T5	Sex	
	F	M
NO (44.8%)	8	5
YES (55.2%)	13	3

Figure 60 Plots of the perception of friends' support in T1, T2, T3, T4 and T5.

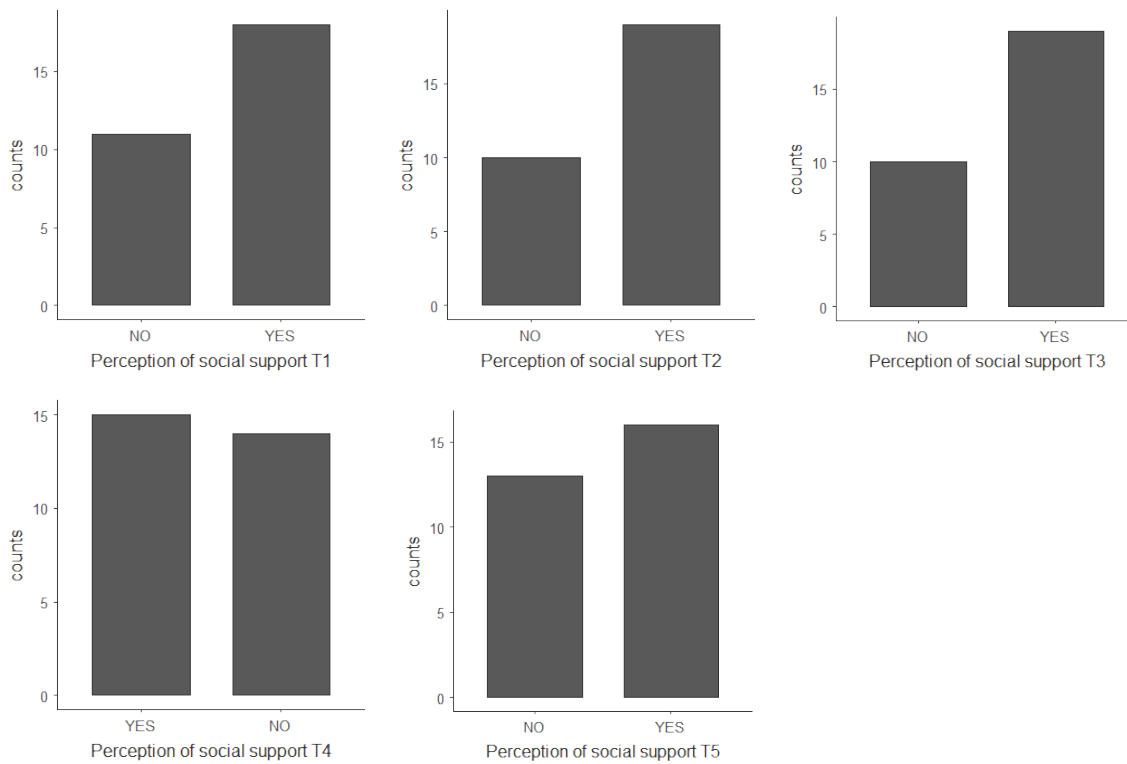


Figure 61 Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and social support's perception.

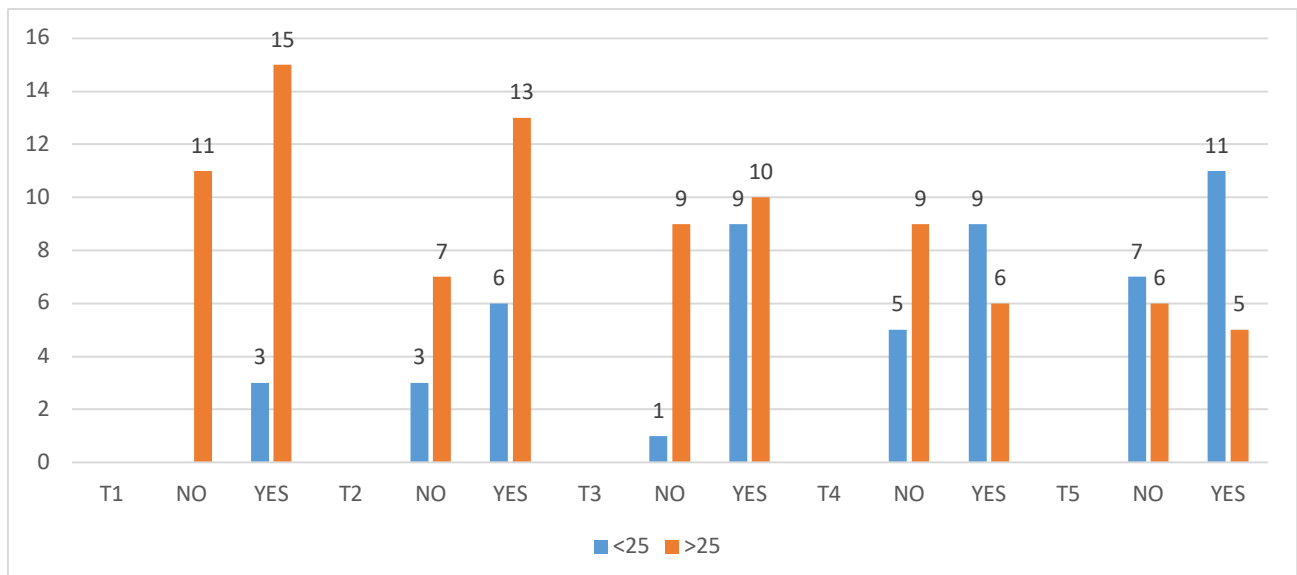


Figure 62 *Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and social support's perception.*

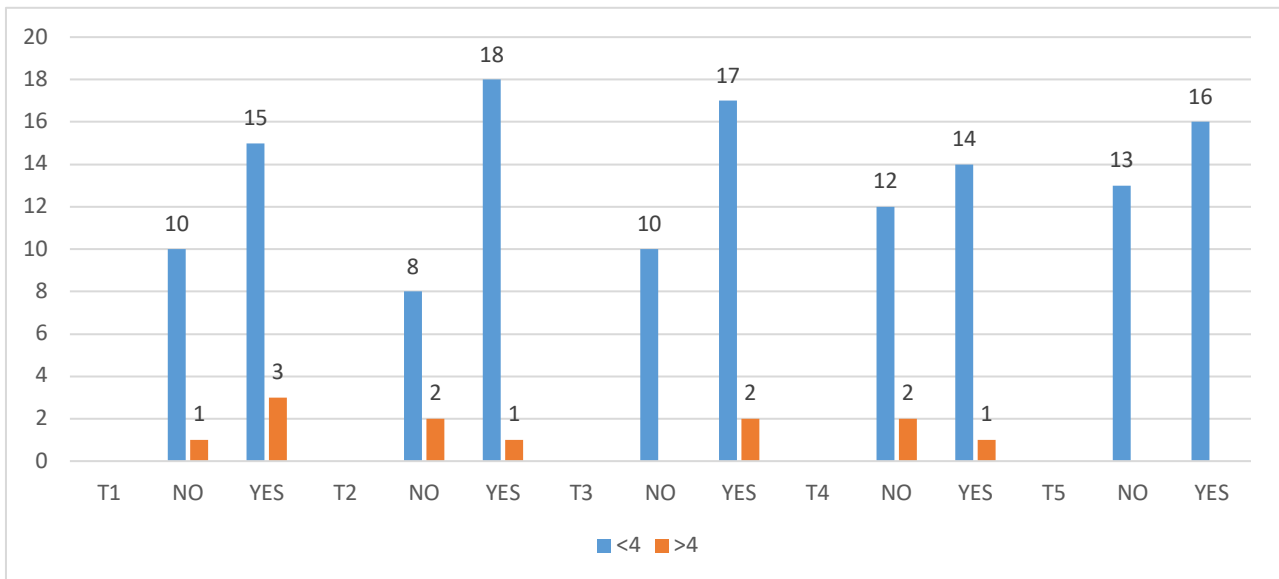


Figure 63 *Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and social support's perception.*

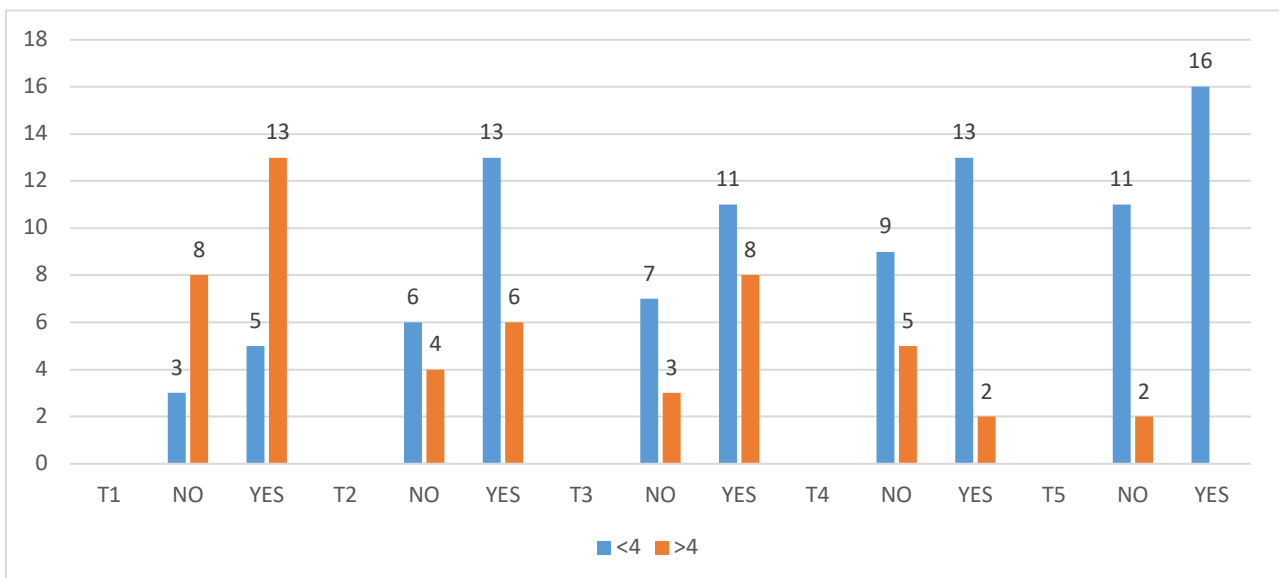


Figure 64 *Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and social support's perception.*

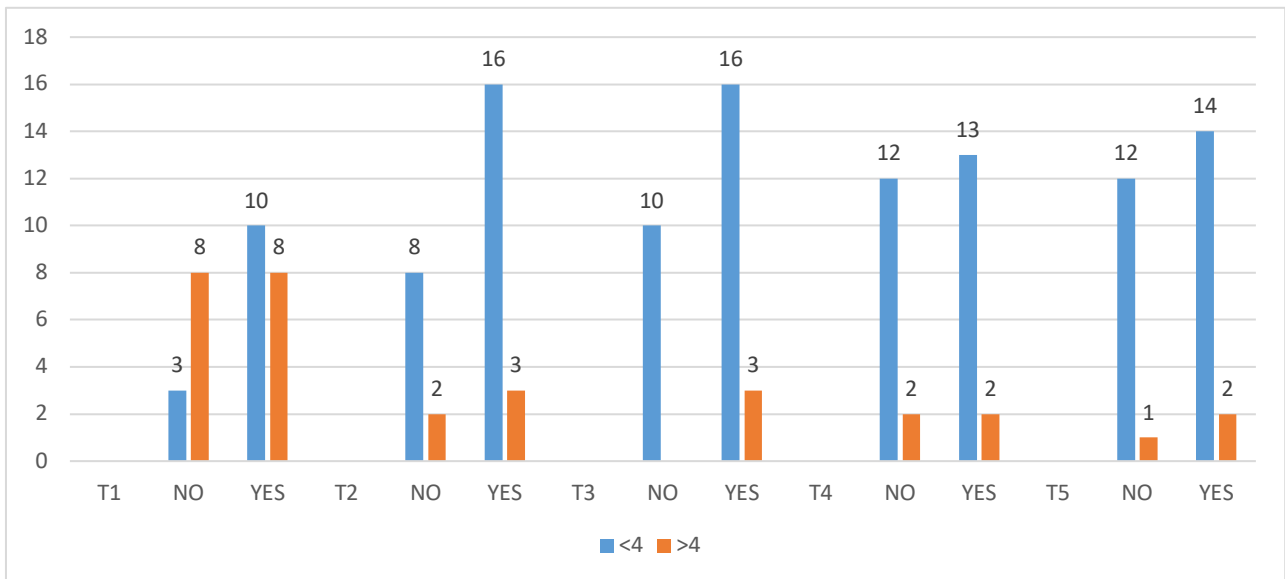


Figure 65 *Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and social support's perception.*

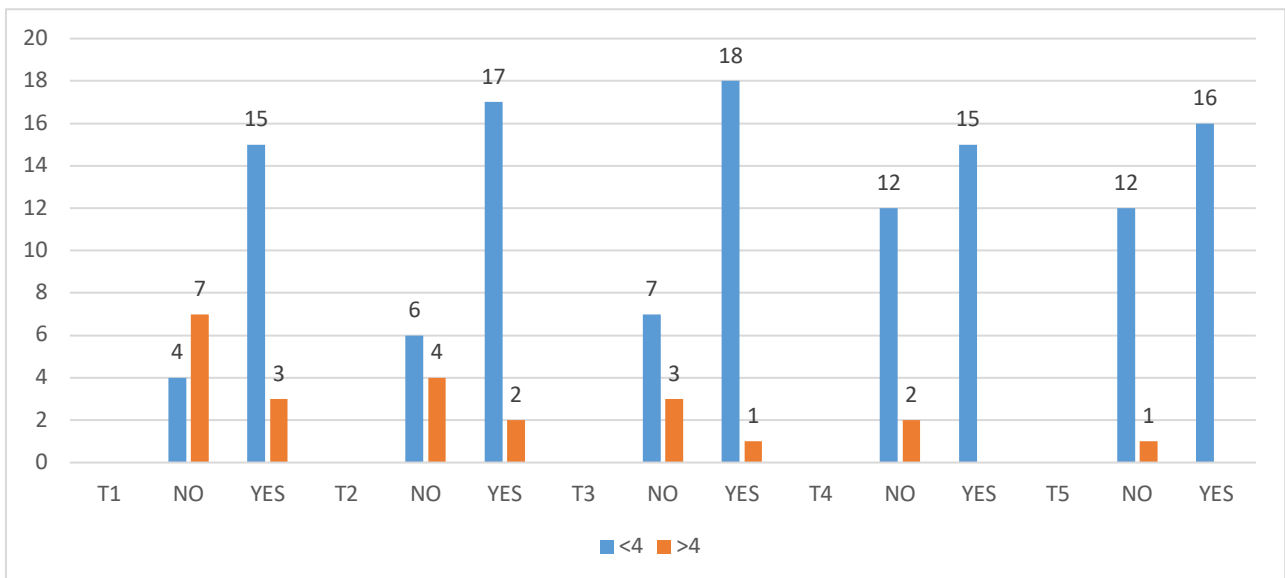


Table 28 *Effective analysis between the perception of social support and ICG and GHQ-28 in T1 and T3.*

	Perception of social support		No perception of social support		Mean difference	p-values
	n	Mean	n	Mean		
<b>T1</b>						
GHQ-28	18	2.29	11	4.27	1.88	0.05*
Severe depression						
<b>T3</b>						
ICG	19	25.8	10	42.8	17.0	0.012*

\*p<.05

\*\*p<.01



### *Medicine consumption*

As a further question, participants were asked if they took some medicine (Table 29).

In T1 75.9% of parents did not to use any drug. The remaining 24.1% (7 women), on the other hand, took anxiolytics, depression and sleep medication.

With the passing of the months, the number of those who took medicines decreased considerably. In T2, 3 women (10.3%) said they took sleeping pills (1 participants), anxiolytics (1 participant) and antidepressants (1 participant). Starting from T3, only two people stayed on medication (6.9%): 1 mother who took anxiolytics and another one who took antidepressant. The latter one was followed pharmacologically for about 10 years following the diagnosis of major depression.

Table 29 *Frequency of parents' medicine consumption.*

---

Levels	Counts	% of Total	Cumulative %
NO	22	75.9 %	75.9 %
YES	7	24.1 %	100.0 %

---

#### **Frequencies of Medicine Consumption T2**

---

Levels	Counts	% of Total	Cumulative %
NO	26	89.7 %	89.7 %
YES	3	10.3 %	100.0 %

---

#### **Frequencies of Medicine Consumption T3**

---

Levels	Counts	% of Total	Cumulative %
NO	27	93.1 %	93.1 %
YES	2	6.9 %	100.0 %

---

#### **Frequencies of Medicine Consumption T4**

---

Levels	Counts	% of Total	Cumulative %
NO	27	93.1 %	93.1 %
YES	2	6.9 %	100.0 %

---

#### Frequencies of Medicine Consumption T4

Levels	Counts	% of Total	Cumulative %
<b>Frequencies of Medicine Consumption T5</b>			
Levels	Counts	% of Total	Cumulative %
NO	27	93.1 %	93.1 %
YES	2	6.9 %	100.0 %

Furthermore, considering the frequencies with respect to the results above or below the ICG's reference cut-off (Figure 68), all parents showed a majority of results greater than 25 up to T4: value exclusively present in T5 in those who took the drugs.

Compared to the results of GHQ-28, most subscales showed values less than 4 for the entire population, except for the results of the Anxiety and Insomnia and Social Dysfunction subscales in T1 (Figures 70 and 71).

In addition to the ICG, the Anxiety and Insomnia subscale is also the only one with a constant majority of values above 4 in parents who took drugs.

Furthermore, there was a great effect size on those who took or did not take medicines. In particular, a greater risk for those taking drugs has been identified with respect to ICG values, somatic symptoms and anxiety and insomnia in T2, T3 and T3 (Table 30), social dysfunction in T2 and T3 (Tables 76 and 77), and severe depression in T2.

In conclusion, in T2, T4, and T5 significant data emerged in particular on complicated grief, somatic symptoms and anxiety (whose effect size has remained constant since T2). It is important to note that 3 participants took these medicines in T2 and 2 in T4 and T5 (10.3% and 6.9%) and therefore were not representative.

The drugs taken were, however, coherent with some of psychopathological risks that can develop as a result of the loss.

Figure 66 Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and medicine consumption.

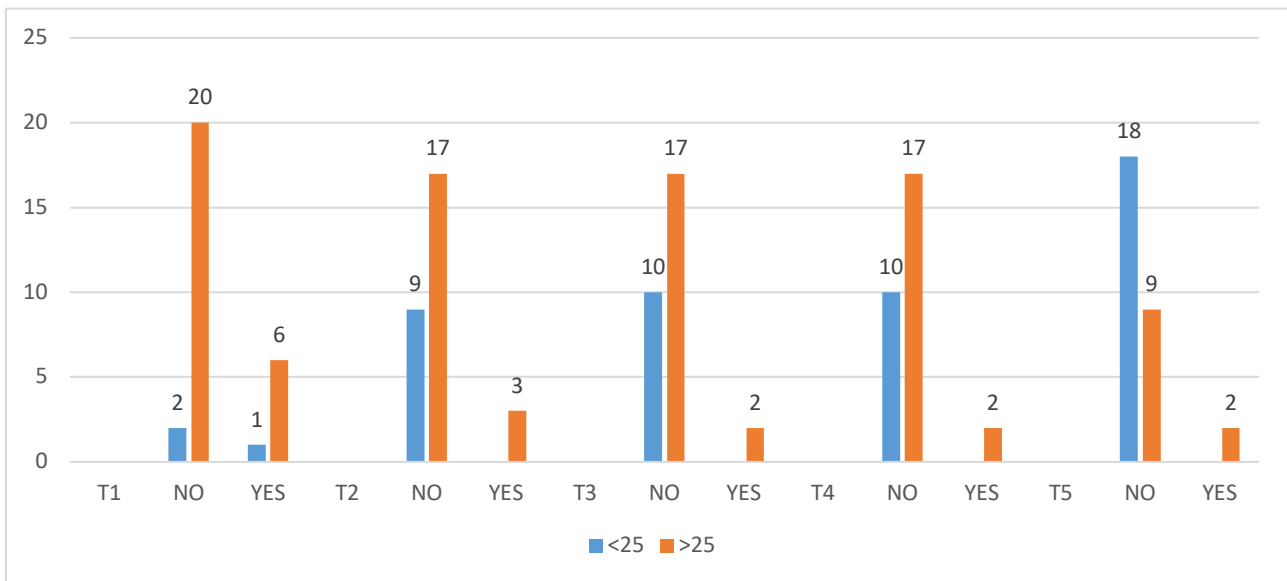


Figure 67 Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and medicine consumption.

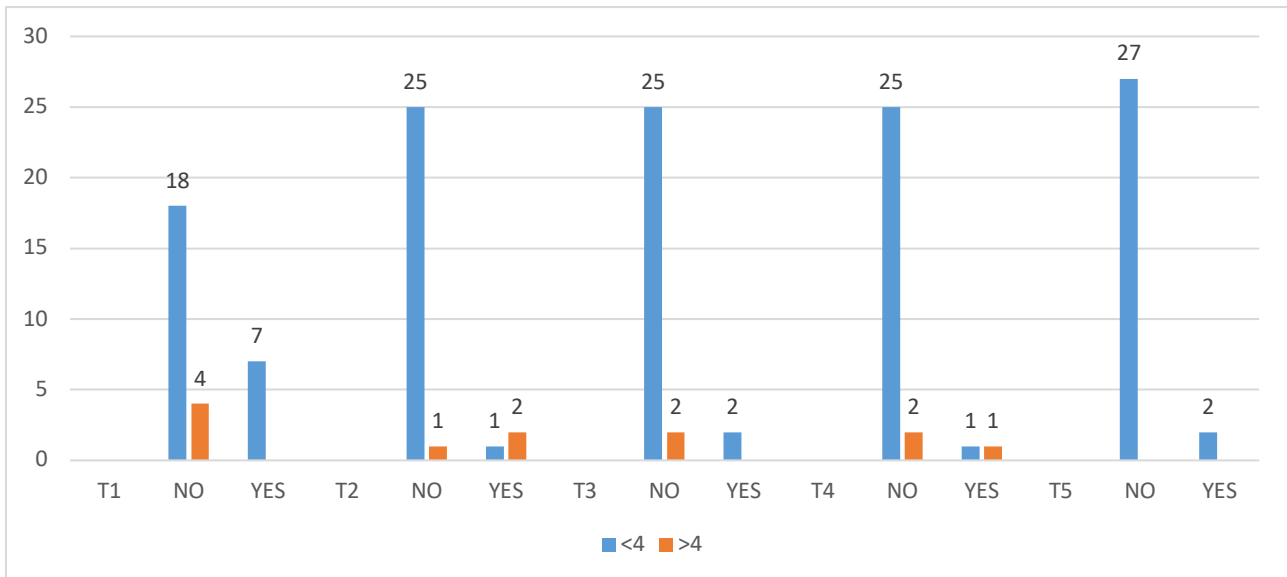


Figure 68 Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and medicine consumption.

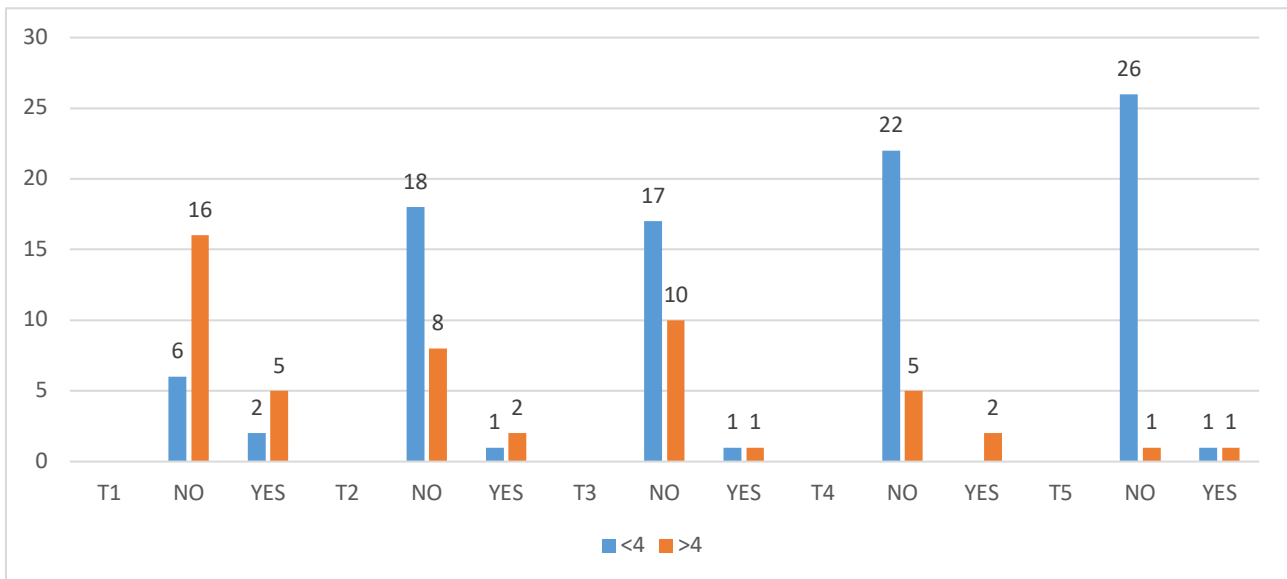


Figure 69 Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and medicine consumption.

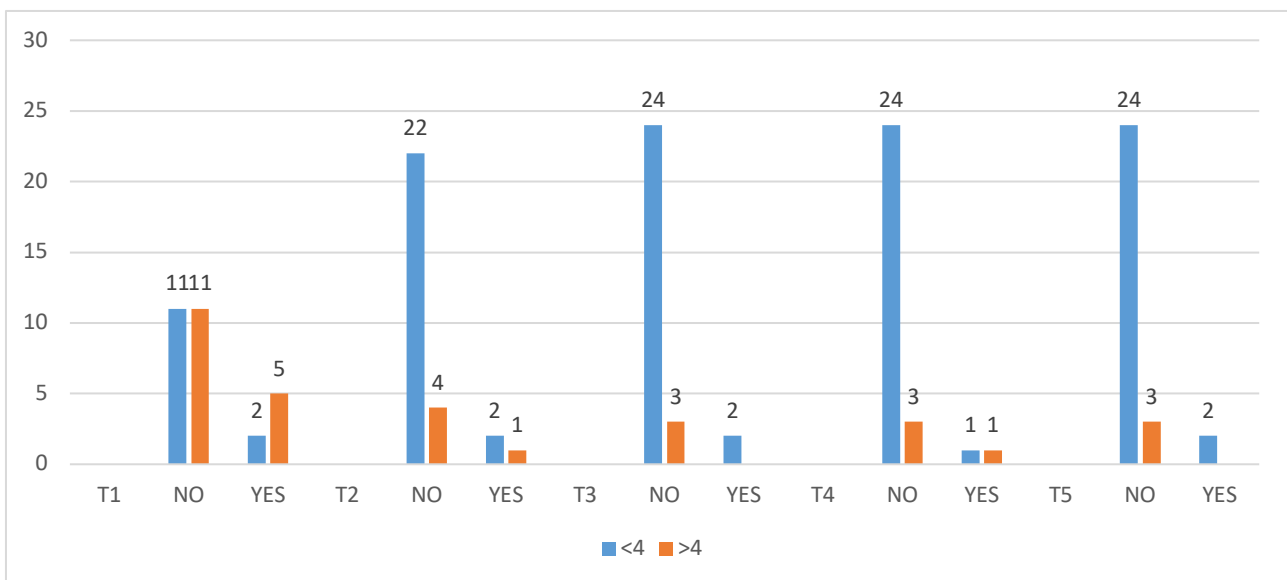


Figure 70 Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and medicine consumption.

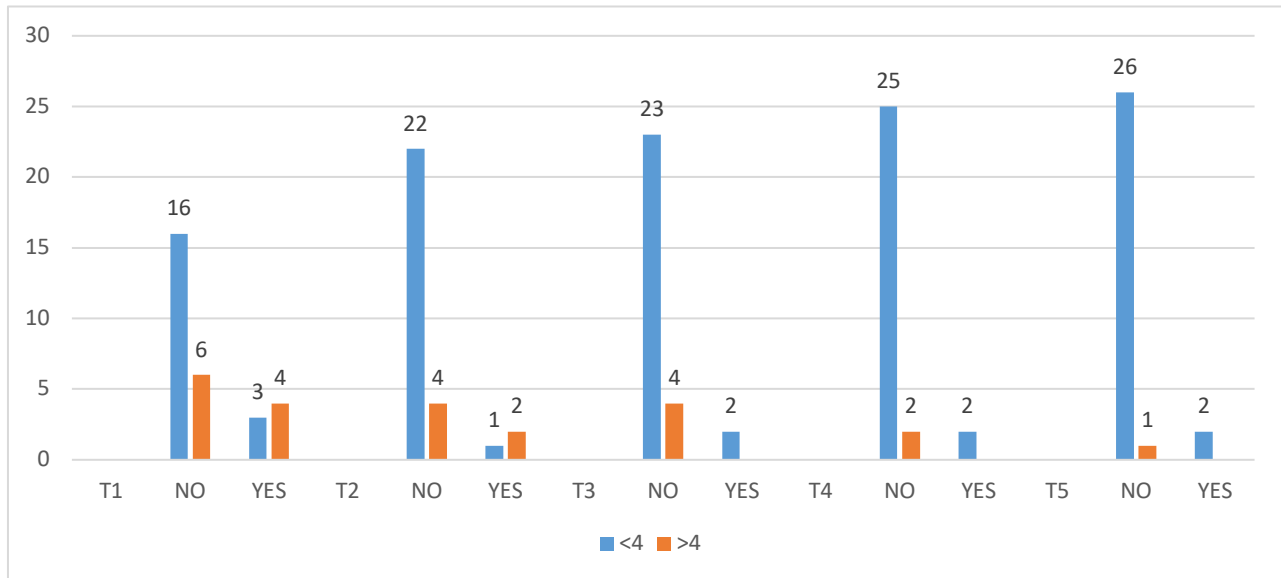


Table 30 Effect sizes of ICG and GHQ-28 and Medicine consumption variable in T2 and T4.

	statistic	df	p	Cohen's d
ICG SCORE T2	-2.24	27.0	0.034	-1.364*
GHQ-28 Score (Somatic symptoms) T2	-2.22	27.0	0.035	-1.351*
GHQ-28 Score (Anxiety&Insomnia) T2	-1.90	27.0	0.068	-1.160*
GHQ-28 Score (Social dysfunction) T2	-1.59	27.0	0.123	-0.970*
GHQ-28 Score (Severe depression) T2	-1.86	27.0	0.074	-1.135*
ICG SCORE T4	-2.21	27.0	0.036	-1.616*
GHQ-28 Score (Somatic symptoms) T4	-2.88	27.0	0.008	-2.114*
GHQ-28 Score (Anxiety&Insomnia) T4	-2.38	27.0	0.025	-1.742*
GHQ-28 Score (Social dysfunction) T4	-1.55	27.0	0.132	-1.137*
GHQ-28 Score (Severe depression) T4	-1.03	27.0	0.312	-0.755
ICG SCORE T5	-2.0771	27.0	0.047	-1.5221*
GHQ-28 Score (Somatic symptoms) T5	-1.3607	27.0	0.185	-0.9972*
GHQ-28 Score (Anxiety&Insomnia) T5	-2.7776	27.0	0.010	-2.0355*
GHQ-28 Score (Social dysfunction) T5	-0.0267	27.0	0.979	-0.0195
GHQ-28 Score (Severe depression) T5	-0.1486	27.0	0.883	-0.1089

\* d>0.8

Figure 71 The average difference between ICG and GHQ-28 questionnaires and Medicine consumption variable in T2.

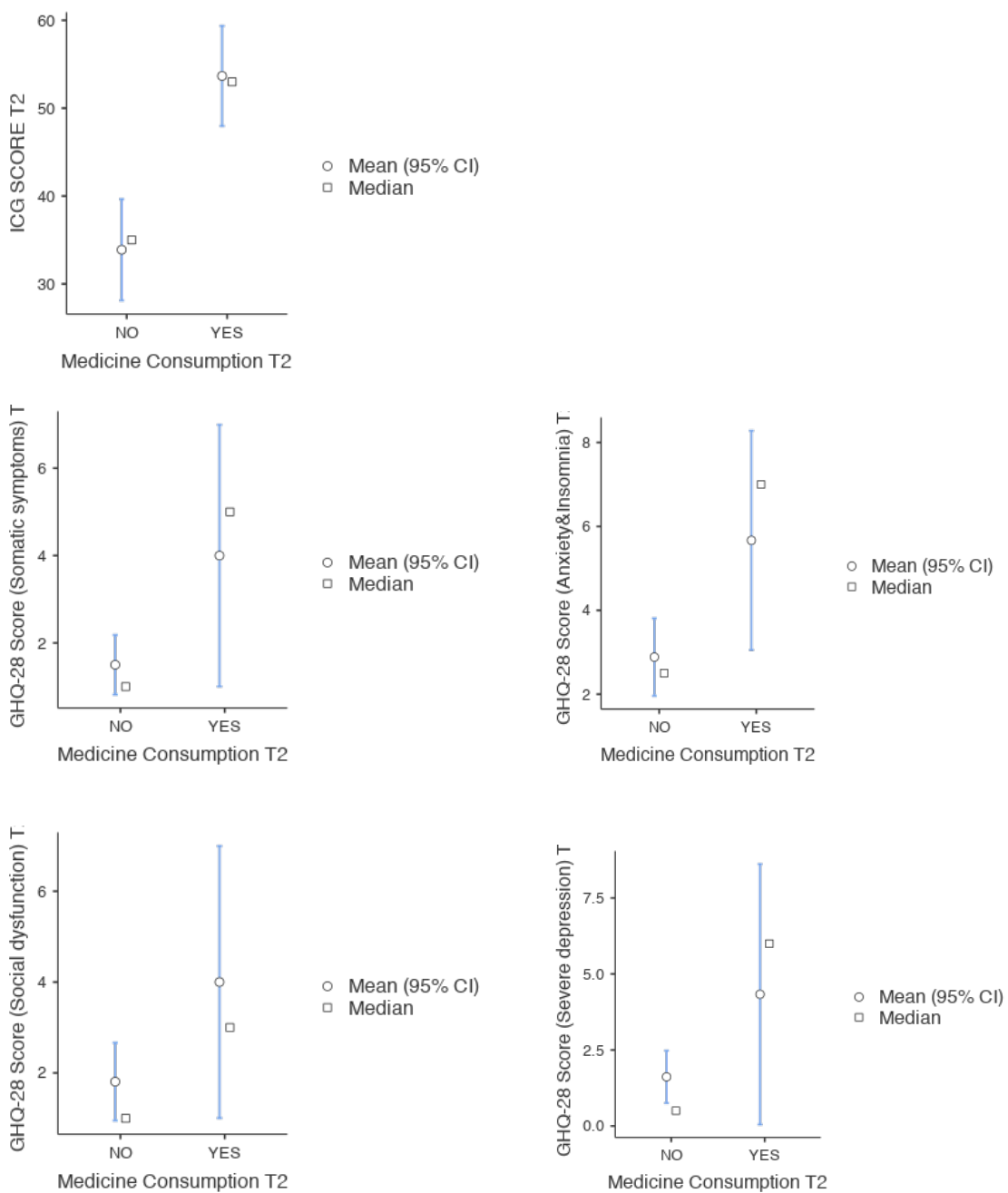


Figure 72 The average difference between ICG and GHQ-28 questionnaires (Somatic symptoms, Anxiety and Insomnia, Social dysfunction) and Medicine consumption variable in T4.

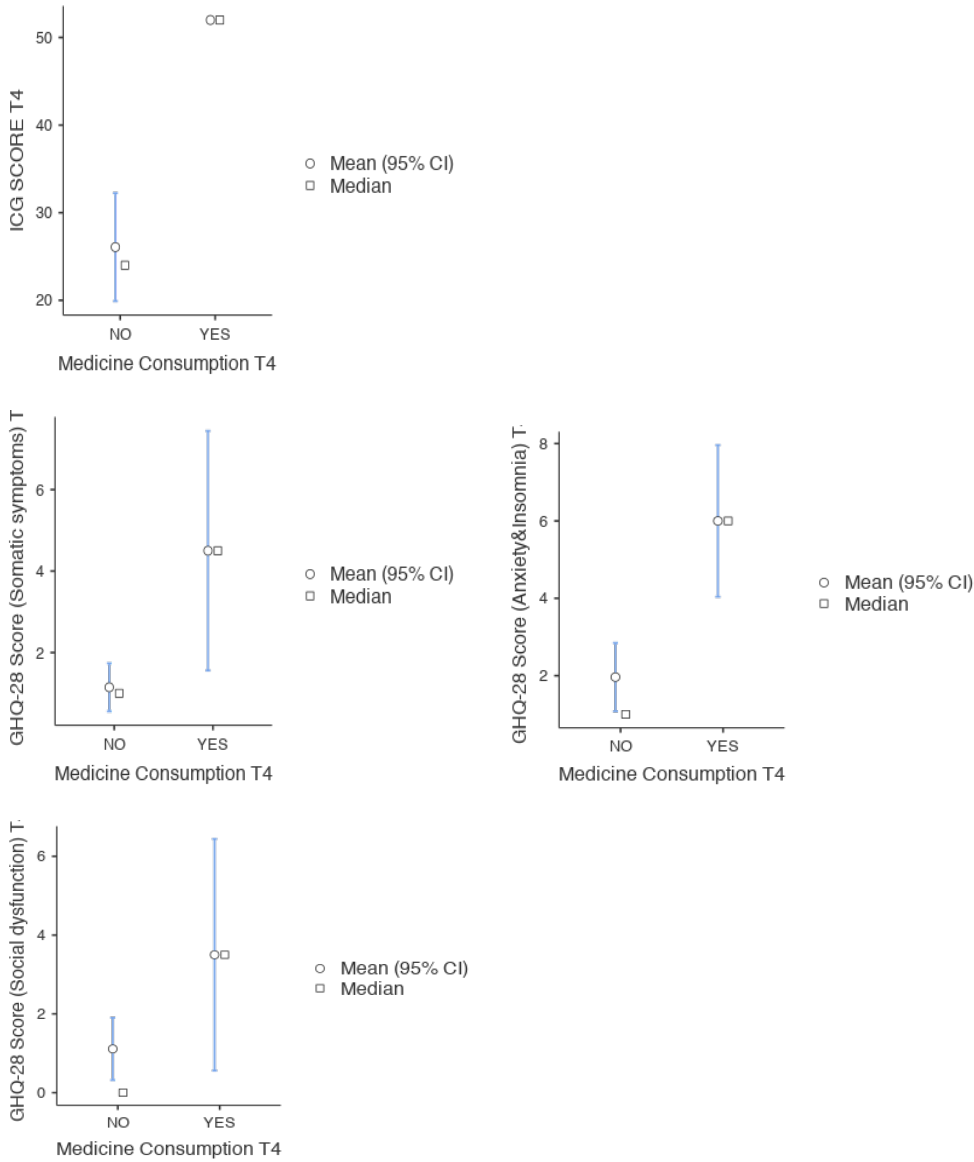
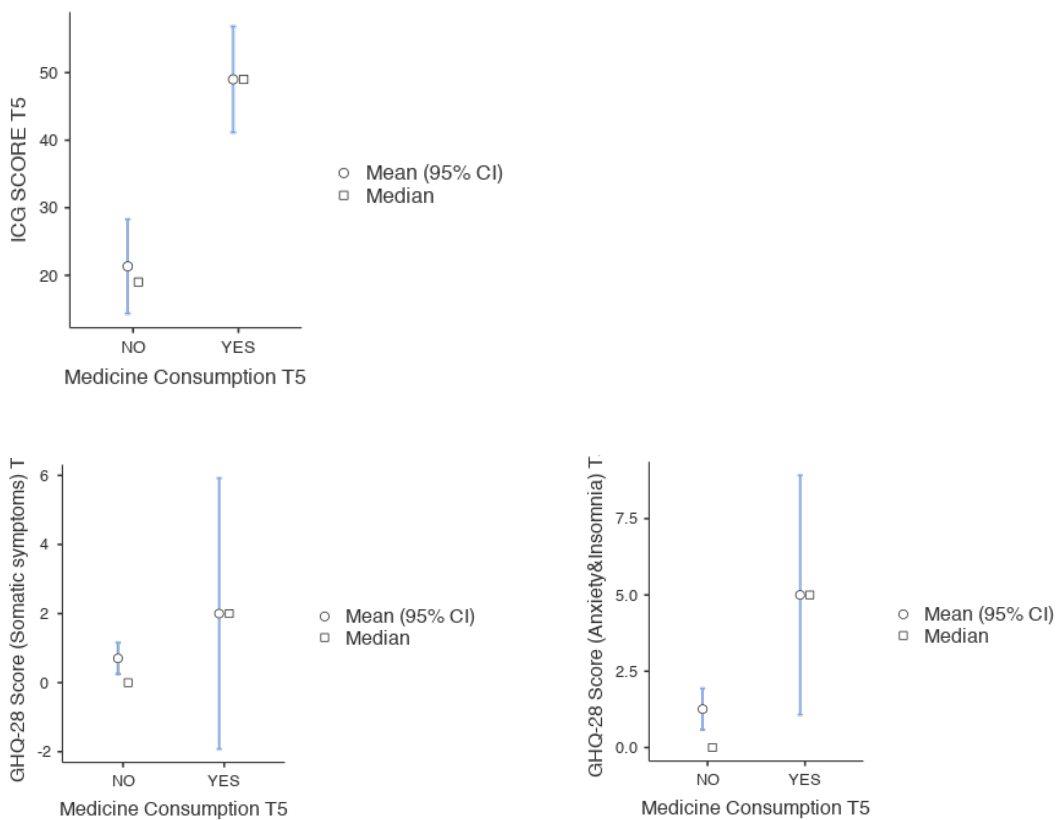


Figure 73 The average difference between ICG and GHQ-28 questionnaires (Somatic symptoms and Anxiety) and Medicine consumption variable in T5.



### Moving after child's loss

An additional variable considered was included after interviews and the parents' stories as some parents changed homes following the loss. 31.1% of the participants felt the need to move to a new home and, in the case of one couple, even to a new city.

With respect to the frequencies of the values higher or lower than the cut-off of the ICG questionnaire, up to T4 both parents who continued to live in the same house or who moved instead showed a majority of results greater than 25, and then radically changed (i.e. with values <25) in T5 (Figure 76).

Compared to GHQ-28, for all subscales, except for those of Anxiety and Insomnia and Social Dysfunction, the majority of values has always been <4 in all five Ts, while in these two for both variables the majorities recorded in T1 they were higher than the cut-off (Figures from 77 to 90).

However, at the beginning, the move did not significantly affect the risks of possible psychopathological disorders analyzed by the ICG and the four subscales of the GHQ-28 in the first interviews.



Only in T4 a significant difference with respect to the GHQ-28 severe depression subscale was detected.

The analysis of variance showed that those who remained in the same house after the child's loss recorded an average significantly lower than those who moved ( $F(1, 29) = 4.60, p < 0.041$ ), with an average of 0.650 for the former and of 2.222 for the latter.

With respect to the frequencies of the values above or below the cut-off, in T4 all the 20 participants who stayed in the same house presented results below 4, while out of 9 parents who moved, 2 obtained a score higher than the cut-off reference.

Figure 74 Frequency of results above and below the reference cut-off of ICG with respect to the time between T1, T2, T3, T4 and T5 and moving after child's loss variable.

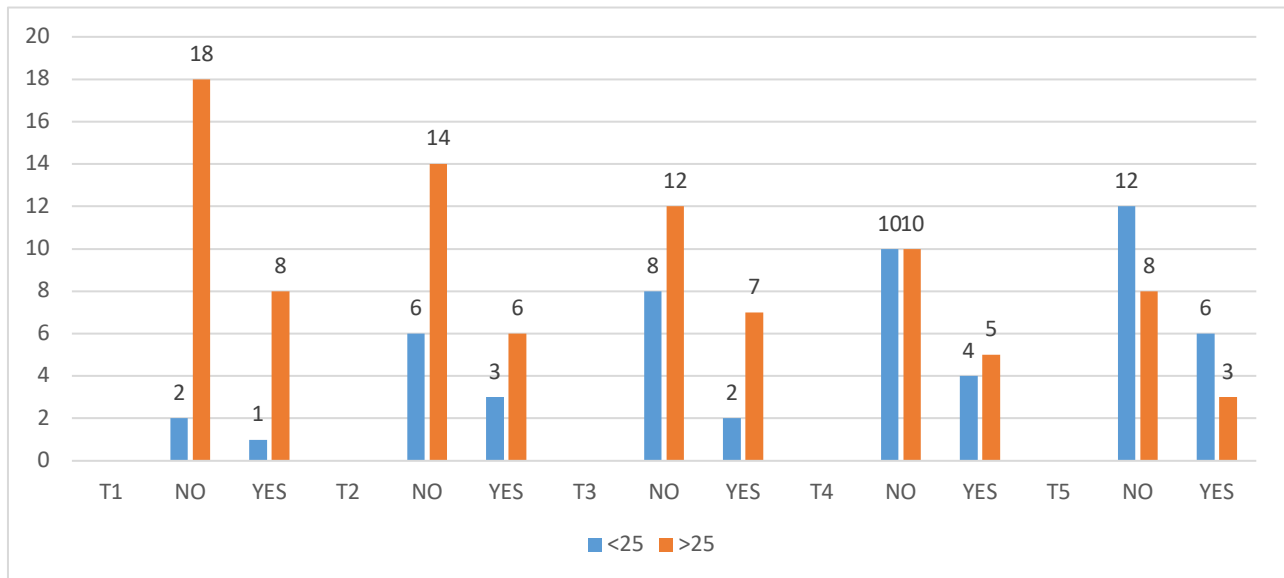


Figure 75 Frequency of results above and below the reference cut-off of the GHQ-28's Somatic symptoms subscale with respect to the time between T1, T2, T3, T4 and T5 and moving after child's loss variable.

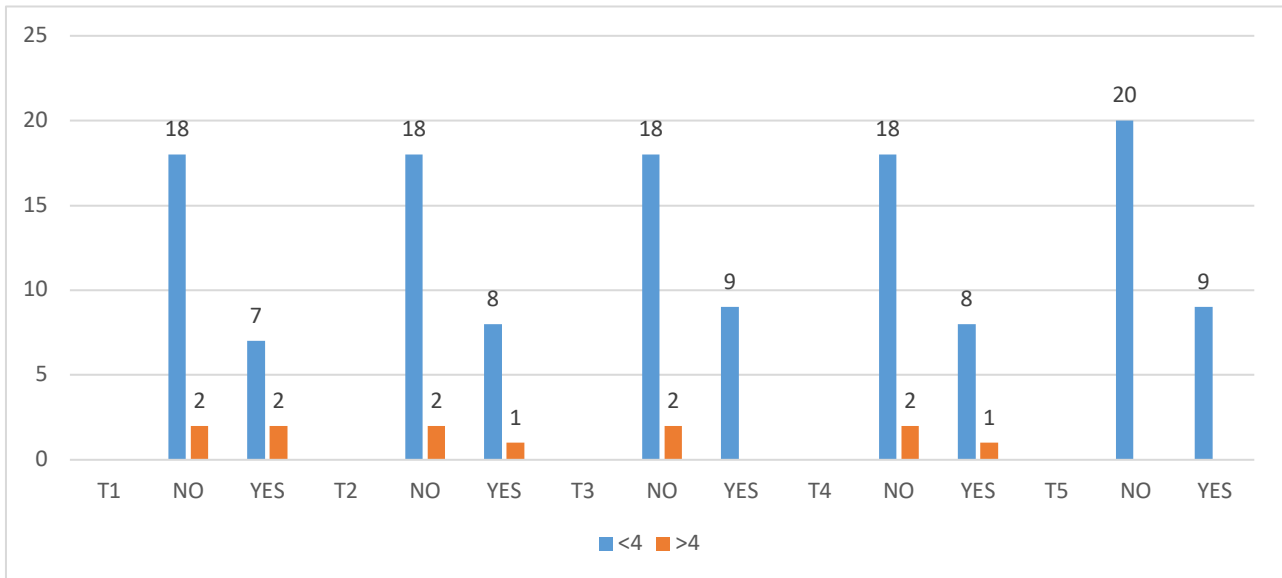


Figure 76 Frequency of results above and below the reference cut-off of the GHQ-28's Anxiety and Insomnia subscale with respect to the time between T1, T2, T3, T4 and T5 and moving after child's loss variable.

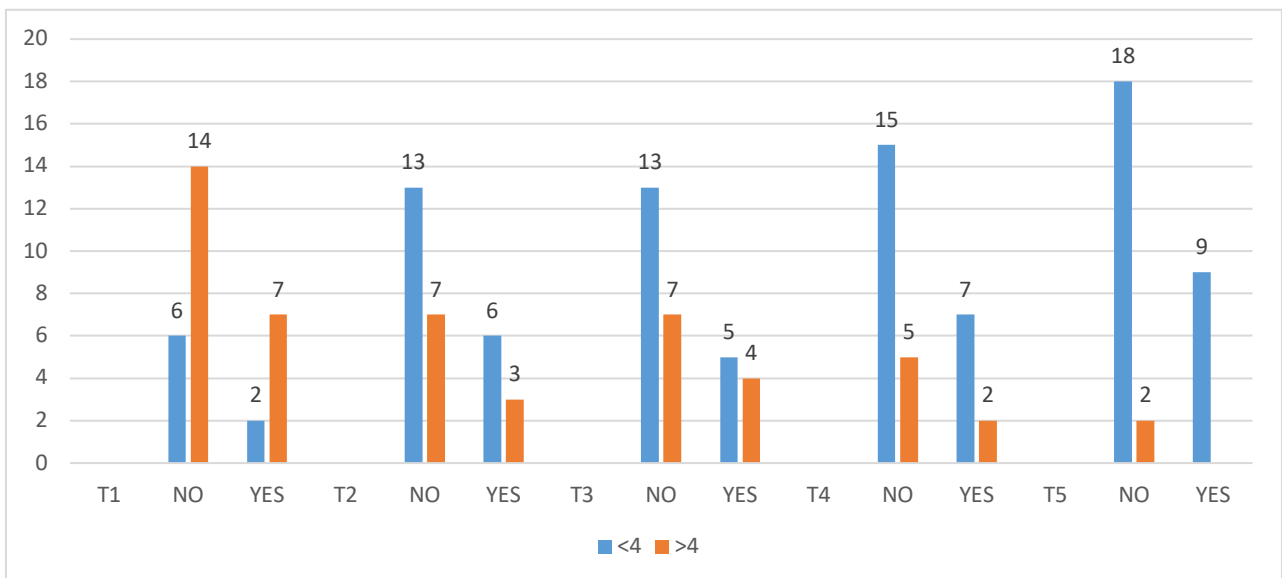


Figure 77 Frequency of results above and below the reference cut-off of the GHQ-28's Social dysfunction subscale with respect to the time between T1, T2, T3, T4 and T5 and moving after child's loss variable.

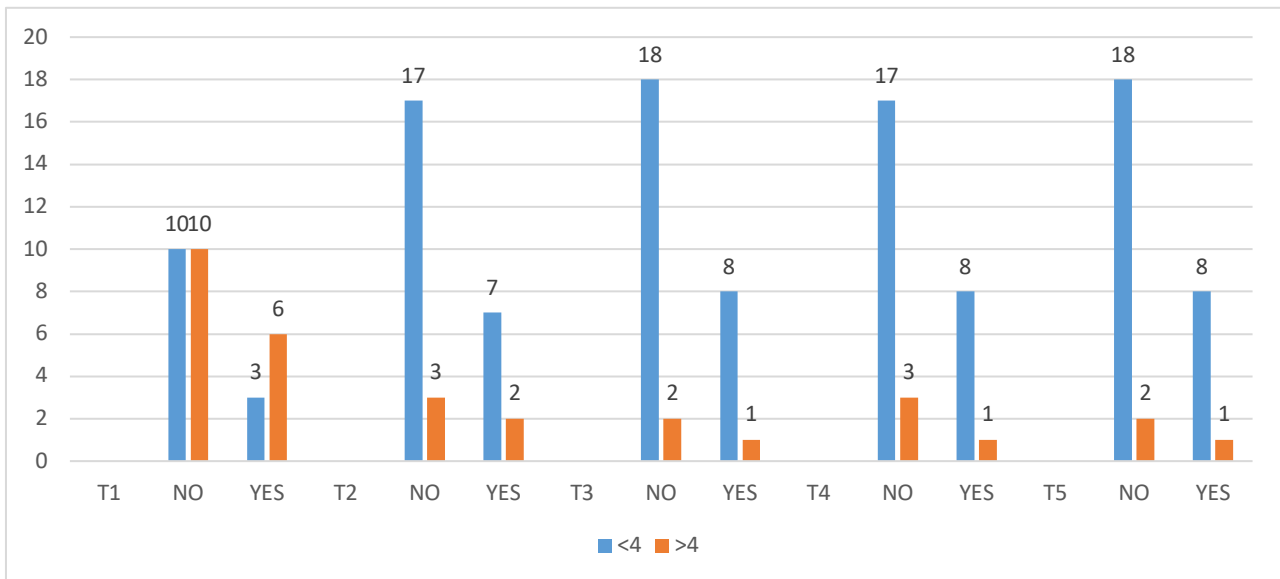
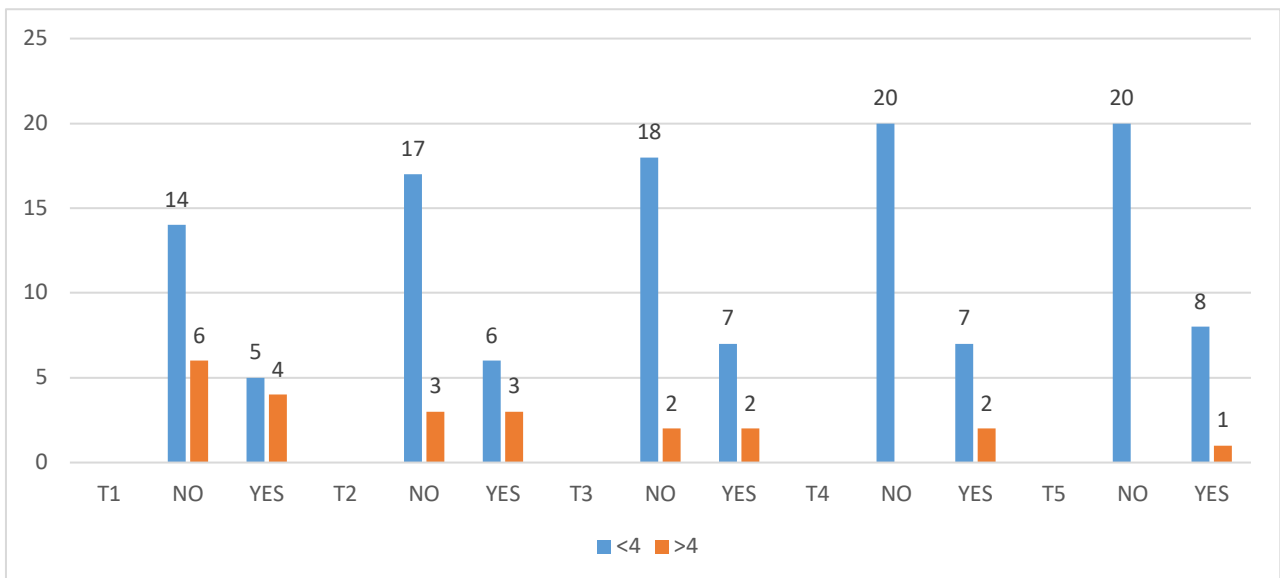


Figure 78 Frequency of results above and below the reference cut-off of the GHQ-28's Severe depression subscale with respect to the time between T1, T2, T3, T4 and T5 and moving after child's loss variable.



In summary, over the months the general averages of both questionnaires (the Inventory of Complicated Grief and the General Health Questionnaire – 28) improved significantly. These results showed a gradual decrease in the risk of developing psychopathological disorders, such as complicated grief disorder (evaluated through the ICG questionnaire), anxiety disorders, somatic disorders, social disorders and depression (i.e. the subscales of GHQ-28).

In particular, the parents' general average reached the uncomplicated grief threshold only eighteen months after the start of the study (and a frequent majority of values below the cut-off 21 months after the loss). Compared to the GHQ-28, the results of all the sub-scales showed lower values than the reference cut-off from the second meeting (T2).

In general, any differences between women and men's values were not highlighted.

Furthermore, with respect to the causes of death, the results of those who lost the child due to unknown causes showed a risk of CG only in T1. Those who performed an LTP consistently showed general averages and a higher frequency of results above the reference cut-off.

On the other hand, considering the time of death, parents who lost the child during pregnancy experienced a lower risk of developing CG while those who lost a child after a few months obtained the highest general averages in T5 and results consistently above the reference cut-off.

In addition, Cohen's *d* in T4 and cut-off frequencies confirmed that those who lost the baby during pregnancy have a lower risk of developing anxiety and insomnia disorders.

Compared to those who had already become parents before death (17%), those who had had a previous child showed a greater risk of anxiety, somatic and social disorders in T4.

This latter one was also confirmed by the frequencies of the results above and below the cut-off: those who had already had a living child recorded a value above 4 in the Social dysfunction subscale in T1, T4, and T5.

After the loss, during the eighteen months of the study, 38% of parents had a new child. Without showing any significant difference, they recorded a higher frequency of values than the reference cut-off of the ICG up to T4.

Compared to psychological support, in the beginning, about 64% of parents were followed by a therapist (including 17 women and 4 men), reaching the percentage of about 28% (8 women) at the end of the study. The only significant difference concerned the results obtained in T5. Those who had requested a professional support showed a greater risk of developing symptoms of anxiety. At the cut-off frequency level, in T5 only one parent out of 8 who had requested therapeutic support had registered a value greater than 4. Although not significant, this population has also consistently shown a level above 25 compared to the ICG.

Furthermore, concerning the support groups, those who initially participated were 24%, then reaching 17% in T5.

This participation was a support factor in T1, in particular with respect to the development of CG, data confirmed also by the frequencies: all the 22 parents who did not participate registered a value higher than the reference cut-off of the ICG, while only 4 out of 7 participants obtained a score higher than 25. In addition, the non-participants also showed a total majority of results greater than 4 in the sub-scales of Anxiety and insomnia, and Social dysfunction, always in T1.

Furthermore, in T1 about 59% of parents participated in IT groups (women only), reaching 17% in T5. Active and prolonged participation in online groups has shown a greater risk of complicated grief, depression, anxiety and somatic disorders compared to the results obtained in T4 and T5. In T5, out of 5 women, 3 presented a value higher than 25 respect with the ICG, while compared to those who did not participate: 16 people out of 24 obtained a result lower than the cut-off.

At the level of emotional support, those who perceived partner support showed a lower risk of anxiety (in T3, T4 and T5), complicated grief and somatic disorders (in T4) and depression (in T4 and T5). We have seen a large effect size of the subscales of Social dysfunction and Severe depression in T2, results also confirmed by the frequencies of the results above or below the cut-off, and with respect to the Somatic symptoms, Anxiety and Insomnia, and Severe depression subscales in T3. Furthermore, there was a significant difference in T4 with respect to the ICG and the somatic symptoms subscale, always confirmed by the cut-ff frequencies.

Perceiving family support was a protective factor for the risk of developing complicated grief (in T4), somatic disorders, anxiety, social dysfunction and depression (in T5). Those who instead perceived emotional support from friends showed a lower risk of depression in T1 and of complicated grief in T3. This data was also confirmed by the frequency of the results above and below the cut-off: for the subscale of Depression in T1, 7 out of 11 parents who did not perceive such support recorded a value greater than 4 and of those who felt supported, 15 out of 18 parents achieved a lower value than the cut-off; while considering the ICG in T3, 9 out of 10 parents who did not feel supported achieved a result above 25.

Parents who took medicines (about 6%) showed a risk of developing complicated grief, somatic symptoms and anxiety disorders (in T2, T4 and T5), social dysfunction (in T2 and T5), and severe depression in T2.

Finally, 34% of parents who moved after loss showed an increased risk of depression in T4.

In addition to the quantitative data, the research is also composed of a qualitative analysis, the results of which will be presented below.

A mixed methodology was therefore found to be appropriate and relevant to the predefined purposes.

Both methodologies were useful in evaluating the main hypotheses of the study, as well as finding a correct comparison and also confirmation in the results of each analysis.

## Chapter 11: Qualitative analysis

The qualitative analysis includes the use of two different instruments:

1. Alceste, French software that is used for qualitative analysis;
2. Interpretative Phenomenological Analysis (IPA).

Together, these two methods of analysis help to give an indepth understanding of the semi-directive interviews carried out with the participants.

In order to decrease the possible generalization of the data provided by Alceste and according to a purpose and predefined hypotheses, two different types of analyses were carried out with Alceste. This split the participants into different groups: three groups of participants for each analysis.

Compared to IPA, in order to obtain the maximum validity and efficiency, researchers focused on the study of 4 participants – two females and two males – for a total of 20 interviews.

It is possible to see below the data from the analysis of Alceste and the IPA, whose results will be discussed in the section dedicated to them in the following chapter.

### 11.1 Alceste

The use of Alceste for the qualitative analysis of semi-structured interviews was conceived to answer the main questions of the study (the psychological consequences following a perinatal loss and the efficacy of professional support). This was done by highlighting co-occurrences and words classes of the text unit.

In general, there are several concepts on which the analysis of Alceste is based. First of all, there is the concept of co-occurrence. The co-occurrence corresponds to a quantitative data, analyzed through Khi2, which counts the frequency and position of a word.

Starting from this analysis, Alceste extrapolates classes of words.

The number of classes is descending. This means that the first class will have the highest co-occurrence degree.

In each class are therefore collected the words that appeared in the text with the same frequency and that are close to each other (such as, for example, mother-child).

Each class has a further percentage. The percentage corresponds to the amount of text where Alceste has selected the words contained in each class.

For example, the first class of the our first analysis shows a percentage of 9.88%. This means that the words that have been inserted in the first class, therefore with a stronger co-occurrence, are present only in 10% of the total text.

If we wanted to associate words with the metaphor of fishes, the ocean would be our total text. In it, the most frequent word, for example "mother" is associated above all with the term "child". The fishes "mother" and "child", in spite of their number, are present only in a small part of the ocean.

The fourth class of the first analysis presents a percentage of 51%. This means that the words present in the third class, for example "brother" and "bedroom" have often been quoted together and with the same frequency (same class, same co-occurrence). Their presence is not concentrated in a small part of the ocean (like the first class) but on a larger area (51% of the ocean / text).

Moreover, the analyses carried out with Alceste have all detected a degree of relevance of data processing as high or very high. The relevance of the treatment is based on the percentage of the text unit that the program has managed to classify.

In our study, two different analyses were then carried out.

1. The first concerned the evaluation of participants' psychic functioning and of possible modifications of the topics of the interviews with respect to the passing of time after the loss and the risk of complicated grief. For this reason, three different groups have been created, considering the distance from the loss. The interviews that took place within six months of grief were included in the first group (Group I), those carried out between 6 and 12 months after the loss of the child in the second group (Group II) and those that took place after 12 months in the third group (Group III).
2. The second analysis focused on the comparison of the classes between those who have and have not received any psychological support (that is, psychotherapy and/or support group), and those who participated in social networks. This last category was inserted since, from what emerged during the interviews, the parents confused and associated the groups of social networks with therapeutic ones.



### *First analysis*

Compared with the first analysis, the participants were gathered into 3 groups, based on the time elapsed between the child's loss and the interviews:

- in the first group, there are interviews of the participants who lost the baby within 5 months (Group I);
- in the second group, there are interviews of parents who have lost the child from 6 to 11 months (Group II);
- while in the third group those who have experienced loss for more than a year (Group III).

The distribution of the interviews within the three groups is not the same for each participant.

It is important to remember that the maximum time between the loss and the first interview is about 10 months, while the minimum is 22 days. This means that T1 (the first meeting) did not take place in the same period that follows the loss for all participants.

Following the first interview (T1), the other four were conducted after 3 (T2), 6 (T3), 12 (T4) and 18 months (T5) the first meeting.

These groups were created to identify and track semantic changes in parental interviews and possible psychological consequences.

Below, we can see a summary table of the three groups (Table 32). To protect the identities of the participants, only the letter of the name will be indicated and if the letters coincide, a number will be placed next to distinguish the parents.

<b>GROUP I (&lt;6 months)</b>	<b>GROUP II (6-11 months)</b>	<b>GROUP I (&gt;12 months)</b>
L. T1-T2	L. T3	L. T4-T5
F. T1-T2	F. T3	F. T4-T5
A.(1) T1-T2	A.(1) T3	A (1). T4-T5
	A.(2) T1	A. (2) T2-T3-T4-T5
A.(3) T1	A.(3) T2-T3	A. (3) T4-T5
C.(1) T1	C.(1) T2-T3	C. (1) T4-T5
C.(2) T1	C.(2) T2-T3	C. (2) T4-T5
Y. T1	Y. T2-T3	Y. T4-T5
D.(1) T1	D.(1) T2-T3	D. (1) T4-T5
D.(2) T1-T2	D.(2) T3	D. (2) T4-T5
B.(1) T1-T2	B.(1) T3	B.(1) T4-T5
	E. T1	E. T2-T3-T4-T5
	B.(2) T1	B. (2) T2-T3-T4-T5
J.(1) T1-T2	J.(1) T3	J. (1) T4-T5
D.(3)T1-T2	D.(3) T3	D. (3) T4-T5
J.(2) T1-T2	J.(2) T3	J. (2) T4-T5
	J.(3) T1-T2	J. (3) T3-T4-T5
	J.(4) T1-T2	J. (4) T3-T4-T5
J.(5) T1	J.(5) T2-T3	J. (5) T4-T5
M. T1	M. T2-T3	M. T4-T5
	P. T1-T2	P. T3-T4-T5
	S. T1-T2	S. T3-T4-T5
	M-F. T1	M-F. T2-T3-T4-T5
M.(1) T1-T2	M.(1) T3	M. (1) T4-T5
M.(2) T1-T2	M.(2) T3	M.(2) T4-T5
	N.(1) T1	N.(1) T2-T3-T4-T5
	N.(2) T1	N.(2) T2-T3-T4-T5
O. T1	O. T2-T3	O. T4-T5
W. T1-T2	W. T3	W. T4-T5
Tot.= 19 parents / 30 interviews	Tot.= 29 parents / 41 interviews	Tot.= 29 parents / 74 interviews

Table 31 List of participants grouped with respect to the date of death and interviews.

The first group includes 19 parents and a total of 36 interviews. On the other hand, there is a total of 29 parents and 41 interviews for the second and 74 for the last group.

As we can see from Figure 81, in Group I of the first analysis (i.e. those who lost the child since 6 months), Alceste selected 2,045 units of the elementary context or U.C.E., which corresponded to 81% of the text analyzed through the double hierarchical descending classification, with a high relevance and divided into five classes.

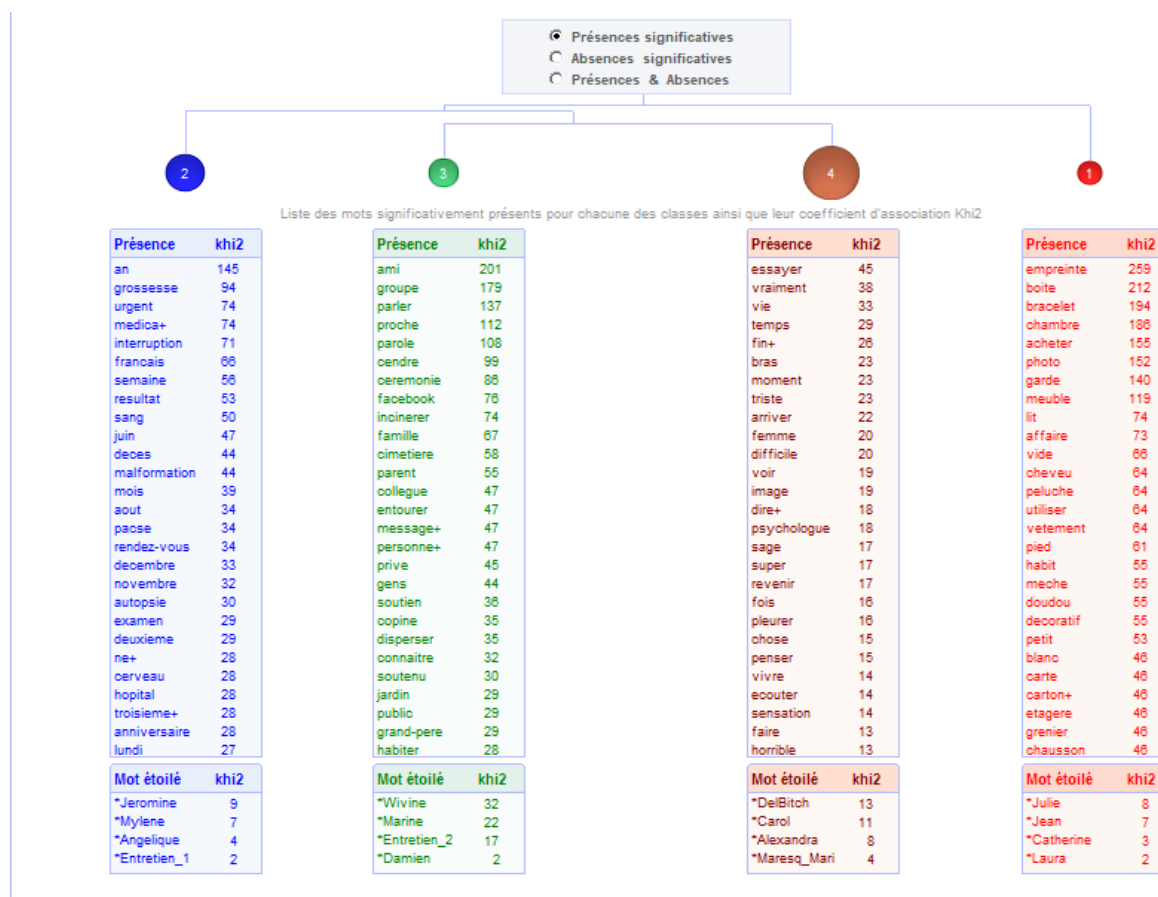


Figure 79 Word Classes of Group I (<6 months).

The first class of Group I (<6 months) includes 9.88% of the U.C.E.

The semantic analysis underlined that the vocabulary of this first class refers in particular to the objects associated with the child (footprint - *empreinte*, box - *boite*, bracelet, photo, keep - *garde*, thing - *affaire*, hair - *cheveu*, plush - *peluche*, clothing - *vêtement*, foot - *pied*, blanket - *doudou*, etc.) and the home or the child's bedroom and memories arranged inside the house, especially in the living room (room - *chambre*, buy - *acheter*, furniture - *meuble*, bed - *lit*, empty - *vide*, use - *utiliser*, decorative - *décoratif*, shelf - *étagère*).

There were no special things, they just made his hand and footprints and the little card that they put on the cradle. We put it as well, and we got it together with the photos.

*Y a avait pas de choses particulières, ils ont juste fait ses empreintes de main et de pied et la petite carte qu'ils mettent sur le berceau. Nous l'avons mise aussi, et on a récupéré ça en même temps que les photo.*

(J. (1), T2)

We give it another function in the bedroom, we put our clothes on, we removed the decorations, we just left the furniture.

*On lui donne une autre fonction à la chambre, on y met nos vêtements, on a enlevé les décorations, on a juste laisse les meubles.*

(L., T2)

It [the memory box] is upstairs and we have memories, as you can see. They gave us a little lock of hair. In the box there are prints, there was his bracelet, his little slippers that we had put on. So we put one on him and keep the other.

*Elle [la boîte] est en haut et nous avons des souvenirs, comme vous voyez. Ils nous ont donné une petite mèche de cheveux. Dans la boîte il y a des empreintes, il y avait son bracelet, ses petits chaussons qu'on avait mis. Du coup, on lui en a mis un et garde l'autre.*

(L., T1)

Everything is exposed. In the living room there is a small shelf, each with a small photo of them, their little socks and their bracelets.

*Tout est expose, en fait, dans le salon il y a une petite étagère, chacun avec une petite photo d'eux, leurs petites chaussettes et leurs bracelets.*

(C. (2), T1)

We did that, we emptied all the furniture. The clothes are still in the dresser. There are still a few clothes to let out.

*On a fait ça, on a vidé tous les meubles. Il reste encore les vêtements dans la commode. Il reste encore un petit peu de vêtements à trier.*

(D. (1), T1)

We made a frame, we put a picture of him and me, and we added the footprints, so they are hung in the living room.

*On a fait un cadre, on a mis une photo de lui et moi, et on a rajoute les empreintes dedans, donc elles sont accrochées dans le salon.*

(M. (2), T2)

The second class (24.30% of the U.C.E.) concerns the description of the event (year - *an*, urgent, week - *semaine*, juin, loss - *décès*, month - *mois*, August - *aout*, meeting - *rendez-vous*, blood - *sang*, exam - *examen*, hospital - *hôpital*, juin, December - *décembre*, November - *novembre*, anniversary - *anniversaire*, Monday - *lundi*) and the cause of loss (pregnancy - *grossesse*, termination - *médical*<sup>1</sup>, late - *interruption*, result - *résultat*, malformation, autopsy - *autopsie*, brain - *cerveau*).

Throughout the pregnancy, everything went well, there was never a problem, the ultrasounds were fine, the doctors had no worries, and then one day, I didn't feel her move anymore, so we started to worry.

*Tout au long de la grossesse, tous s'est bien passe, il n'y a jamais eu de souci, les échographies étaient nickel, les médecins n'avaient aucune inquiétude, et puis un jour, je ne la sentais plus bouger, donc on a commencé à s'inquiéter.*

(J. (1), T1)

It was her heart surgery that got complicated and didn't go as planned, that is ... that caused her death. She entered the hospital on August 9.

*C'est son opération cardiaque qui s'est complique et qui s'est pas passe comme prévu, qui est...qui a causé son décès. Elle est entrée à l'hôpital le neuf aout.*

(D. (1), T1)

They did an ultrasound and they realized there was a brain problem. So there we were transferred to the antenatal center of J.D.F. [city name]. Three, four days after I had an amniocentesis with a blood test to see if it was not genetic, so a blood test for my husband and me.

*Ils ont fait un échographie et ils se sont rendus compte qu'il y avait un problème au niveau di cerveau. Donc là on a été transfères au centre anténatal de J.D.F. [nom de la ville], trois,*

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<sup>1</sup> The lexical translation of the words "interruption" and "médical" should be "interruption" and "medical". However, they were translated as "late" and "termination" since they refer to the Late Termination of Pregnancy, which in French is called "Interruption Médical de Grossesse".

*quatre jours après ou j'ai ait une amniocentèse avec une prise de sang pour voir si c'était pas génétique, donc prise de sang pour mon mari et moi même.*

(J.(2), T1)

About the death of E. [child's first name], it was a late termination of pregnancy due to the chromosome problem that she had like her little, her big brother.

*Du décès d'E. [prénom de l'enfant], c'est une interruption médical de grossesse suite au problème de chromosomes qu'elle avait comme son petit, son grand frère.*

(J., T1)

On September 11 we had an ultrasound and it was there that we were told that our little girl had malformations.

*Le 11 septembre on a fait l'échographie et c'est là qu'on nous a annoncé que notre petite fille avait des malformations.*

(A.(1), T1)

The third class (14.72% of the U.C.E.) presents more lexical forms connected to social support (friend - ami, close - *proche*, family - *famille*, parent, colleague - *collègue*, surround - *entourer*, support - *soutien*, grand-father - *grand-père*) and to support groups (group - *groupe*, support - *parole*<sup>2</sup>, talk - *parler*, meet - *connaître*) and various groups on social networks that are related to perinatal loss (Facebook, message, private - *privé*, public) and rites (ceremony - *ceremonie*, ashes - *cendre*, cemetery - *cimetiere*, garden – *jardin*).

I told my story on the forum, we chatted a lot.

*J'avais raconté mon histoire sur le forum, on m'a beaucoup parlé.*

(D.(2), T2)

I feel a lot of support from my family, my close friends. They're really with me, they listen to me when I need to talk about it, and I talk about it often, I often need to talk about it.

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<sup>2</sup> The literal translation of the word "parole" should be "word", but in this case, the references concern the support groups that in French are called "groupe de parole". For this reason the translation of the term is not the literal one but the semantic one.

*Je ressens beaucoup de soutien de ma famille, de mes amis proches. Ils sont vraiment avec moi, ils m'écoutent quand j'ai besoin d'en parler, et j'en parle souvent, j'ai souvent besoin d'en parler.*

(W., T1)

On groups, it is rare that I speak in public but in private, always in private.

*Sur les groups, c'est rare que je parle en public mais en prive, toujours en prive.*

(M. (1), T2)

About twenty people. We really wanted it to be something private [the ceremony], we didn't bring the whole family back, we really brought back the main ones, those who supported us the most.

*Une vingtaine de personnes. On voulait vraiment que ce soit quelque-chose de prive [ la cérémonie], on a pas ramené toute la famille, on a ramené vraiment les principaux, ceux qui nous ont le plus soutenus.*

(J.(2), T2)

We wanted to collect the urn to deposit it ourselves in the souvenir garden, near our parents because unfortunately, they live in L. [name of the region], so we brought it back to the souvenir garden to be closer thereafter.

*On voulait récupérer l'urne pour la déposer nous-mêmes dans le jardin du souvenir, près de parents, parce-que malheureusement ils habitent en L. [nom de la région], donc on l'a ramenée dans le jardin de souvenir pour être plus proches par la suite.*

(F., T2)

I don't talk about it in the group [on social networks], they don't know my life, it's good, it relieves a little, not much, but it relieves a little, it's like the support group, I think.

*Je n'en parle dans le groupe [sur les réseaux sociaux], ils ne connaissent pas ma vie, c'est bien, ça soulage un petit peu, pas beaucoup, mais ça soulage un peu, c'est comme le groupe de parole, je pense.*

(M.(1), T2)

It's easier, the Facebook group I turn it on when I want, but there may also be shyness or the intimacy of speaking in a support group.

*C'est plus facile, le groupe Facebook je l'allume quand je veux, mais il y a peut-être aussi de la timidité, ou de l'intimité de parler dans un groupe de parole.*

(W., T2)

We have the right to attend the ceremony, so they put small candles, they make little poems, they talk a little bit and then we can bring flowers back on the stele where the ashes are scattered.

*On a le droit d'assister à la cérémonie, donc ils mettent des petites bougies, ils font des petits poèmes, ils parlent un petit peu et après on peut ramener des fleurs sur la stèle là où les cendres sont dispersées.*

(J. (2), T1)

The fourth class and last class of first group (51.10% of the U.C.E.) includes a lexical universe that concerns the emotional and feelings aspects of loss (try - *essayer*, really - *vraiment*, moment, sad - *triste*, come - *arriver*, difficult - *difficile*, come back - *revenir*, cry - *pleurer*, think - *penser*, live - *vivre*, feeling - *sensation*, do - *faire*, horrible, etc.).

Everything is mixed at the same time. Lots of sadness and telling me it's not fair and why me.  
*Y a tout qui se mélange à la fois. Beaucoup beaucoup de tristesse et de me dire que c'est pas juste et pourquoi moi.*

(A.(1), T1)

I think it's a suffering that I've put aside exclusively, that I avoid thinking to avoid suffering. That's it, I think. It's curious because I can't forget, I can't.

*Je pense que c'est une souffrance que j'ai exclusivement mis de côté, que j'évite de penser pour éviter de souffrir. C'est là, j'y pense. On va dire, c'est curieux parce-que je peux pas oublier, je ne peux pas.*

(M.(2), T2)

I'm really listening to her [his wife]. Personally, for the moment, I really feel like I'm putting my feelings aside and that if my feelings come out, so as not to crack in front of her, I'm going out, I'm going to walk, I'm going to run.



*Je suis vraiment à son écoute [de sa femme]. Moi, personnellement, pour le moment, j'ai vraiment l'impression de mettre mes sentiments de cote et que si mes sentiments sortent, pour ne pas craquer devant elle, je pars, je vais marcher, je vais courir.*

(F., T1)

I am terribly jealous of pregnant women, so much I would like them to suffer. So that's not good.

*Je suis terriblement jalouse des femmes enceintes, au stade où je leur veux du mal. Donc ça c'est pas bien.*

(A.(1), T2)

I am devastated by the fear of never being happy again.

*Je suis dévastée de la peur de plus jamais être heureuse.*

(D.(1), T1)

At the same time, I see myself telling my children that unfortunately he is a boy but that he will not be able to live. I can see our four above his coffin, holding his tree trunk to plant it.

*En même temps je me revois annoncer à mes enfants que malheureusement c'est un garçon mais que va pas pouvoir vivre. Je me revois tous les quatre au-dessus de son cercueil, je me revois tous les quatre à tenir son tronc d'arbre pour pouvoir le planter.*

(C.(1), T1)

I have a lot of things coming back without me wanting it.

*J'ai beaucoup de choses qui reviennent toutes seules sans que je le veuille.*

(A.(1), T1)

It's less intense. I spill a tear or two, then it's better, right away. Whereas before, they were whole days. I am able to have fun for something every day.

*C'est moins intense. Ça m'arrive de verser une ou deux petits larmes, après ça va mieux, tout-de-suite. Tandis qu'avant, c'étaient des journées entières. J'arrive quand-même à avoir du plaisir au quotidien pour des choses.*

(L., T2)



*C'était la nuit du 28 au 29 juin donc c'était, je crois, le nuit de jeudi au vendredi. Et donc après ils m'ont installée dans une salle d'examen avec un truc sur le ventre là, un monitoring qu'enregistrait donc le cœur des bébés, les contractions et tout.*

(J.(5), T2)

Perhaps five minutes later, there is a lady who came to explain to us how it was going to be. The next day I came to take some pills at the maternity to change the cervix and two days later I went to the maternity for a trigger, to give birth.

*Peut-être cinq minutes après, y a une dame qui est venue nous expliquer comment ça allait se passer. Le lendemain je suis venue prendre des cachets à la maternité pour commencer à modifier le col et deux jours après je suis allée à la maternité pour un déclenchement, pour accoucher.*

(J.(4), T1)

The first death in utero was at 24 weeks and the late termination of pregnancy was at 27 plus 5, so the day of delivery.

*Le décès in utero de la première c'est à 24 semaines et l'interruption médical de grossesse c'était à 27 plus 5, donc le jour de l'accouchement.*

(J.(3), T1)

And the malformation meant that the blood did not pass, a hemorrhage in the lungs, it was the absolute emergency, they had to stop her heart to operate the second malformation again, already very delicate to operate.

*Et la malformation faisait que le sang passait pas, ça faisait une hémorragie dans les poumons, c'était l'urgence absolue, fallait tout arrêter son cœur, tout ça pour réopérer la deuxième malformation, déjà très délicat d'opérer.*

(D.(1), T3)

They realized that without the respirator she was not breathing at all and on Monday evening we were told that the lungs were compressing, so she was filling up, and she died on Tuesday morning at 10:30 am in my arms .

*Ils se sont rendu compte que sans le respirateur elle ne respirait pas du tout et le lundi soir on nous a annoncé que les poumons se comprimaient, donc elle était en train de se remplir, et elle est décédée le mardi matin à 10h30 dans mes bras.*

(P., T1)

Then on the fifth-month ultrasound we noticed that there was an abnormality in the size of his head. Then we had approximately every two weeks additional examinations with doctors specializing in risky pregnancies.

*Ensuite à l'échographie du cinquième mois on a remarqué qu'il y avait une anomalie sur la taille de sa tête. Ensuite on a eu toutes les deux semaines environ de examens supplémentaires avec des médecins spécialisés dans le grossesses à risque.*

(N.(2), T1)

I was waiting for it to pass and it did not, so I called the emergency number and there I had a doctor who told me that I had to see a midwife all right now.

*J'attendais que ça passe et ça passait pas, donc j'ai appelé le numéro d'appel d'urgence et là j'ai eu un médecin qui m'a dit qu'il fallait que je vois une sage-femme tout de suite.*

(W., T3)

The second class (59.36% of the U.C.E.) concerns the feelings and emotional perceptions of grief and the difficulties perceived by the parent (thinking - *penser*, sads - *triste*, feel - *ressentir*, moving forward - *avancer*, need - *besoin*), social support (talk - *parler*, say - *dire*, - friend – *ami*, etc.), psychological support, that is the psychologist and support group, and IT groups (desire - *envie*, people - *gens*, group, support - *parole*, parent, go - *aller*).

Anyway it is sad but life goes on, so you still have to live, even with that. After today there are people with whom we can talk about it, I can say, more easily, with others it is a little more delicate.

*De tout façon c'est-ce qu'on disait, la vie continue, donc il faut quand-même continuer à vivre, même avec ça. Après aujourd'hui il y a des gens avec qui on peut en parler, on va dire, plus facilement, d'autres c'est un peu plus délicat.*

(S., T2)

I want to have another meaning in my life than to think about what happened. So I try to, even if sometimes I think about it, I try to force myself, to put this aside, still thinking of them, but I try to be here more for J. [the wife] than for me.

[...] I put it in my head and now it makes me move forward, that's why I'm not going to the [support] group. If I need to talk about it, I talk about it with J. [the wife], I talk about it with my friends, I even talk about it with strangers, even at work, there is a colleague, she knows what happened to me, she discuss about it with me, she speaks".

*J'ai envie d'avoir un autre sens à ma vie que de penser à ce-qui l'est arrive. Alors j'essaie de, même si des fois j'y pense, j'essaie de me forcer, de mettre ça un peu de côté, tout en pensant encore à eux, mais j'essaie pour être là pour J. [la femme] que pour moi.*

[...] *Moi, je me suis mis ça dans la tête et maintenant ça me fait avancer, c'est pour ça que je vais pas au groupe [de parole]. Si j'ai besoin d'en parler, j'en parle avec J. [la femme], j'en parle avec mes amis, j'en parle même avec des inconnus, même au travail, il y a une collègue, elle sait ce qui m'est arrivé, elle vient en discuter avec moi, elle parle.*

(M., T2)

I talk to other bereaved mothers because I have some in my family, I have some in my immediate circle too. So it's true that we discuss how we were progressing.

*J'échange avec d'autres maman qui sont aussi dans le deuil périnatal parce-que j'en ai dans ma famille, j'en ai dans mon entourage proche aussi. Donc c'est vrai que ça nous est arrivé d'échanger sur comment on avançait.*

(C.(1), T2)

We just had to talk, explain the same thing every time. In fact, I felt like I was going around in circles so I said: "well, I prefer to move forward for my own with sport, friends, things, talking about their experience if this happen to them".

*On devait juste parler, expliquer chaque fois la même chose. En fait j'avais l'impression de tourner en rond alors j'ai dit « ben, je préfère avancer de mon cote avec le sport, les amis, les choses-là, qui soit me parler de leur expérience si c'était déjà arrive ».*

(F., T3)

My friends C., he understands. He lives it with me. He's really great and also my brothers, my sisters in law...

*Mon amis C., il comprend. Il vit la chose avec moi. Il est vraiment super et mes frères, mes belles-sœurs...*

(A., T3)

We don't talk about it a lot and many times I feel like I'm moving forward faster than him because, precisely, I'm going to the support group, to the psychologist, because I'm talking about it quite simply.

*On en parle pas beaucoup et plus des fois j'ai l'impression que moi j'avance plus vite que lui parce-que, justement, je vais au groupe de paroles, je vais chez la psychologue, parce-que j'en parle tout simplement.*

(J.(5), T3)

They have been useful [social networks] because at the beginning when you are in grief, you feel like you are alone in the world and see that there are other women and other people who understand and live the exact same thing, they really helped me.

*Ils sont été utiles [sur les réseaux sociaux] parce que au début quand on est dans le chagrin, on a l'impression d'être seul au monde et de voir qu'il y a d'autres femmes et d'autres gens qui ne comprennent et qui vivent exactement la même chose, ça m'a vraiment aidé.*

(A.(1), T3)

I like to go there [to the support groups]! I do not know if it is useful for my grief but I feel a little useful to the parents to whom it just happened.

*J'aime bien y aller [aux groupe de parole] ! Je sais pas si c'est utile pour mon deuil mais je me sens un peu utile aux parents a qui ça vient d'arriver.*

(D.(1), T2)

The psychologist is neutral, she finds the words, she calms the anxieties a little.

*La psychologue est neutre, elle trouve les mots, elle arrive à calmer un petit peu les angoisses.*

(J.(1), T3)

Our next children will know they have a big sister who is not here but who will look after them from above. Today we continue our life. We wouldn't like her to see us sad.

*Nos prochains enfants sauront qu'ils ont une grande sœur, qui n'est pas là mais qui veillera sur eux d'en-haut. Aujourd'hui on continue notre vie. On aimerait pas qu'elle nous voit tristes.*

(S., T1)

I'm not well. I try every day to tell myself that I have to move forward, that I have to be fine, that I have to help my wife, that I have to help my self as well, but it's not easy.

*Je vais pas bien. J'essaie tous les jours de me dire qu'il faut que j'avance, qu'il faut que j'aille bien, qu'il faut que j'aide ma femme, qu'il faut que je m'aide moi aussi, mais ce n'est pas facile.*

(D.(3), T3)

There was a friend of mine who said to me: "if we don't see you too much it is because we don't know what to say to you, we are unhappy for you".

*Y en a un ami qui m'a dit : « si on vous voit pas trop c'est parce qu'on sait pas trop quoi vous dire, on est malheureux pour vous ».*

(J., T2)

Into the support group is a lot of exchanges, everyone talks and etc., and about the psychologist ... I was waiting for advice to move forward, a lot of things like that but unfortunately I didn't have those answers.

*Le groupe de parole c'est beaucoup d'échanges, c'est vraiment tout le monde parle et tout ça, et pour moi la psychologue...j'attendais des conseils pour avancer, beaucoup des choses comme ça mais malheureusement je n'avais pas ces réponses-là.*

(F., T3)

We are both on the same boat, we are both in the same grief, we are experiencing the same thing, suffering and really living it together.

*On est tous les deux dans la même galère, on est tous les deux dans le même deuil, on vit la même chose, autant souffrir et puis vraiment le vivre ensemble.*

(J. (1)., T3)

I can speak today without crying. I'm not saying I'm okay, but I'm stronger.

*Je peux parler aujourd'hui sans pleurer. Je ne dis pas que j'ai pas de mal, mais je suis plus forte.*

(M.(2), T3)

I have friends who are pregnant and I can't see them.

*J'ai des amis qui sont enceintes et que je n'arrive pas à voir.*

(C.(2), T3)

I have to live with that, I have to learn to live with it because life goes on.

*Il faut que je vive avec ça, il faut que j'apprenne à vivre avec parce-que la vie continue.*

(J.(5), T2)

I see my entourage, everyone who becomes a parent, it makes me a little weird, I feel different. It doesn't stop me from living but sometimes it makes me sad.

*Je vois mon entourage, tout le monde qui devient parents, ça me fait un peu bizarre, je me sent différent. Ça m'empêche pas de vivre, mais de temps en temps ça me rend triste.*

(M., T3)

I feel like there was a lot of support at the beginning, and now people have moved on.

*J'ai l'impression que le soutien y en avait beaucoup au début, et que maintenant les gens sont passés à autre chose.*

(N.(2), T1)

There's still a lot of anger, a lot of pain, so if I were pregnant, I don't know if I would have been happy, I don't know if I'm ready to be pregnant again, I don't know.

*Il y a encore beaucoup de colère, de douleur, donc si je venais à être enceinte, je ne sais pas si je serais contente, je ne sais pas si je ne suis pas forcément prête à être de nouveau enceinte, je ne sais pas.*

(J.(1), T3)



The third and last class of this second groups (12.50% of the U.C.E.) contains semantic categories that can be classified as: the home and in particular the child's room (bedroom - *chambre*, thing-*affaire*, bed - *lit*, decorative - *décoratif*, home - *maison*, buy - *acheter*, furniture – *meuble*, move – *demenager*, etc.), the child's objects (photo, box - *boite*, clothing - *vetament*, bracelet, blanket - *doudou*, drawing – *dessin*, etc.) and ritual practices performed by the parents (candle - *bougie*, angel - *ange*, flower - *fleur*, cemetery - *cimetiere*, ash - *cendre*, godfather - *parrain*).

I have the box of memories at the foot of my bed and I know that inside I have his pyjamas, his footprints in the clay, his bracelet, his pictures, his blanket, his cap, all that is in the box.  
*J'ai la boite de souvenirs au pied de mon lit et je sais que dedans j'ai son pyjama, ses empreintes dans l'argile, son bracelet, ses photos, sa couverture, son bonnet, tout ça c'est dedans.*

(C.(1) T3)

We put in it [in the memory box] the text that we both wrote for the ceremony. It is in our room.

*On a mis dedans [dans la boite de souvenirs] le texte qu'on avait écrit tous les deux pour la cérémonie. Elle est dans notre chambre.*

(P., T1)

We did not do a ceremony, we gathered before the departure of the coffin in the crematorium, so in the morgue, but no, we did not do a ceremony in the cemetery.

*On n'a pas fait de cérémonie, on s'est recueillis avant le départ du cercueil eu crematorium, donc à la morgue, mais non, on n'a pas fait de cérémonie au cimetière.*

(B.(2), T1)

I put it away [the memory box]. I haven't opened it yet, I don't have the courage because in it there is hair, hands and footprint, there is his cuddly toy and there are pictures when he dies.

*Je l'ai rangée [la boite de souvenirs]. Je ne l'ai pas encore ouverte, je n'ai pas le courage parce-que dedans il y a les cheveux, les mains et le pieds, il y a son doudou et y a des photos quand il est décède.*

(M.(1), T3)

I had bought a bouquet of flowers for the table and the cat kept trying to eat it, so I put it next to her photo and I said to myself: "Well, flowers for S. [the deceased daughter]!".

*J'avais acheté un bouquet de fleurs pour la table et le chat n'arrêtait pas d'essayer de le manger, donc je l'ai mis à côté de sa photo et je me suis dit : « tiens, des fleurs pour S. [la fille décédée] ! ».*

(O., T2)

It's in the living room, and I have a little picture of him next to me in the bedroom, and the hat is under the pillow of B. [the husband].

*C'est au salon, et moi j'ai à côté dans la chambre une petite photo de lui, et le bonnet est sous le coussin de B. [le mari].*

(E., T1)

There is a little teddy bear in the dining room that we looking at, we know what reminds us.

*Il y a une petite peluche à elle qui est dans la salle à manger qu'on regarde, on sais ce-que à nous rappelle.*

(D.(1), T2)

I'm going to find out what we can put, something that we could put in the garden of memories.

I had bought a small paper lantern, we put a candle in it and it flies away like that.

*Je vais aller me renseigner ce-qui peut se faire une espace, un truc qu'on pourrait mettre dans le jardin de souvenirs et sinon j'avais acheté une petite lanterne en papier, on met une bougie dedans et elle s'envole comme ça.*

(D.(1), T3)

I tried, I managed to remove some decorations that were put on the arrival of T. [the first child to die]. Do you know about decorations we hang on the wall? I managed to remove the little angels, I removed some decorations.

*J'ai essayé, j'ai réussi à enlever quelque décorations qu'on avait mises à l'arrivée de T. [le première enfant décédée]. Vous savez les décorations qu'on accroche au mur ? J'ai réussi à enlever les petits anges, enlever quelques décorations.*

(C.(2), T3)

We made a shelf in the other room with everything, everything that our loved ones gave us: little angels, candles, flowers, things like that...

*On a fait une étagère dans l'autre chambre avec tout ce-que, tout ce-que nos proches nous ont donné : des petits anges, des bougies, des fleurs, des choses comme ça...*

(J.(2), T3)

I couldn't see myself leaving without something of her. It's like I've abandoned her. So I took some cuddly toys, and I slept with them.

*Je me voyais pas partir sans quelque chose à elle. C'est comme si je l'avais abandonnée. Donc j'ai emmené les doudous, et j'ai dormi avec.*

(P., T2)

It [the child's room] is filled with cat toys and we keep our cat in it. It's a cat room! So we don't do anything in it, we don't actually use it.

*Elle [la chambre de l'enfant] est rempli de jouets pour le chat et on garde notre chat dedans. C'est une pièce à chat ! Donc, on fait rien dedans, on l'utilise pas vraiment en fait.*

(D.(2), T3)

We did the cremation in the afternoon when we scattered the ashes in the cemetery, there is an express place.

*On a fait une crémation l'après-midi, quand on a dispersé les cendres dans le cimetière, y a un endroit express.*

(J.(3), T1)

The III and last Group of this first analysis of Alceste, i.e. interviews of participants who have lost their baby for more than 12 months (>12 months), is constituted by a high relevance of treatment (78%). The program analyzed 5,692 text units, divided into five classes (Figure 83).

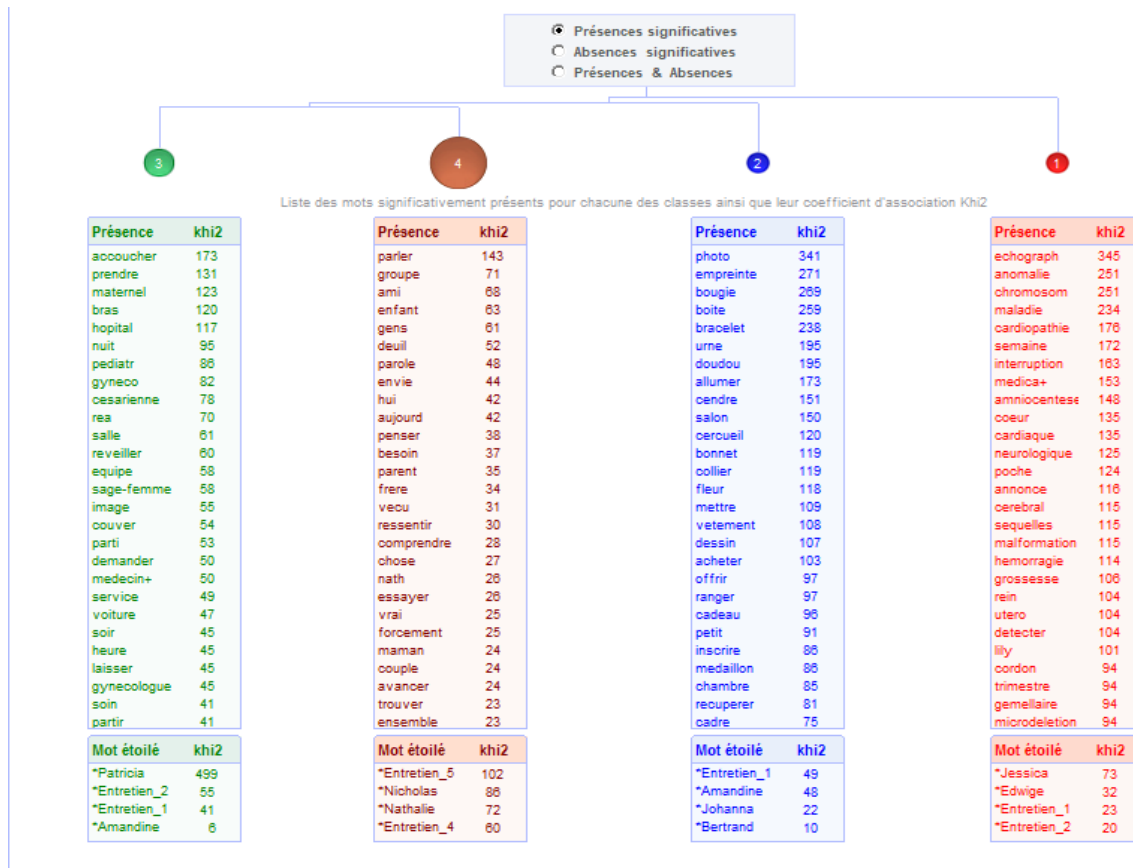


Figure 81 Word Classes of Group III (>12 months).

The first class (30.96% of the U.C.E.) concerns in particular the description of the event (ultrasound - *echograph*, week - *semaine*, amniocentesis - *amniocentèse*, announcement - *annonce*, hospital - *hôpital*, deliver - *accoucher*, result - *resultat*, meeting - *rendez-vous*, announcement - *annonce*, decision, urgent, risky - *risque*, January - *janvier*, etc.) and the cause of loss (late - *médical*, termination - *interruption*, pregnancy – *grossesse*, disease - *maladie*, etc).

We did this amniocentesis and we got the results, I think ... on ... Friday, Saturday Sunday, Monday, Tuesday ... We had it four days later. The nurses told us that there was a chromosomal abnormality, so they told us what the disease was, what the risks were for our child, and therefore what decision we wanted to make.

[...] We, anyway, said to ourselves that if ever there was a chromosomal abnormality, we ended the pregnancy. So suddenly, having had this answer, a week later we planned the late termination of pregnancy with the hospital and so we came back on January 25th in the evening.

[...] It was the longest day in my life, in our whole life, because in the uncertainty we hoped it was heart disease and not the chromosomal abnormality. So it was a very, very long wait and we were just waiting to have the result to be delivered.

*On a fait cette amniocentèse et on a eu les résultats, je crois...le...vendredi, samedi dimanche, lundi, mardi...On a eu quatre jours après. L'aide-soignant nous a annoncé qu'il y avait bien une anomalie chromosomique, donc on nous a expliqué ce qu'il en était la maladie, quels étaient des risques pour notre enfant et donc du coup que la décision que on voulait prendre.*

*[...] Nous, de toute façon, on s'est dit que si jamais il y avait une anomalie chromosomique, on mettait fin à la grossesse. Donc du coup, ayant eu cette réponse, un semaine plus tard on a planifié l'interruption médicale de grossesse avec l'hôpital et donc on est rentré le 25 janvier eu soir.*

*[...] C'était les jours les plus long de toute ma vie, de toute notre vie, parce que être dans l'incertitude, on a espère que ce soit que la cardiopathie et pas l'anomalie chromosomique. Donc ça a été une très très longue attente et on attendait justement d'avoir le résultat pour être délivré.*

(E., T3)

On November 11 at 6:00 p.m. we are admitted to the maternity unit for loss of blood, rupture of the water pocket. 6.10 p.m., first ultrasound. Everything was fine for now. He settled me in delivery clothes. Second ultrasound at 6:20 pm, everything was going very wrong, red code. I was in cesarean mode, general anesthesia. I woke up around 8:00 p.m., she was born at 6:49 p.m. I woke up around 8:00 p.m. in a room, in a surgical treatment unit.

*Le 11 novembre à 18h00 on est admis à la maternité pour perte de sang, rupture de la poche des eaux. 18h10, première échographie. Tout va bien pour l'instant. Il m'installe en tenue d'accouchement. Deuxième échographie à 18h20, tout se passe très mal, code rouge. Je suis en mode césarienne, anesthésie générale. Je me réveille vers les 20h00, elle est née à 18h49. Je me réveille vers 20h00 en chambre, en unité de soins chirurgicaux.*

(P., T4)

[...] That the brainstem was completely affected. So suddenly the care was stopped because she could not live.

*[...] Que le tronc cérébral était complètement atteint. Donc du coup les soins ont été arrêtés parce qu'elle pouvait pas vivre.*

(A.(2), T3)

There were investigative exams, so amniocentesis and more ultrasounds. Once it was finished, we didn't have the results yet, we were still in the office with the doctor, we said that in any case, if the results were bad, we would have done a late termination of pregnancy. We didn't wait for the doctors to suggest it to us.

*Il y a eu les examens d'investigation, donc l'amniocentèse et l'échographie. Une fois que ça a été terminé, on avait pas encore les résultats, on était encore dans le bureau avec le médecin, on a dit que de toute façon si les résultats étaient mauvais on demandait une interruption médicale de grossesse. On a pas attendu que ce soit le médecin qui nous le propose.*

(M-F., T4)

[...] To check if there was a problem and the protein results were positive, we went to the emergency room, we didn't wait very long, we were taken in charge quickly enough and a midwife came with a monitor to hear the heart. We couldn't hear the heartbeat. She went to get the doctor, the gynecologist.

*[...] pour vérifier si il n'y avait pas un problème et le résultats des protéines était positive, on est allé aux urgences, on n'a pas attendu très longtemps, on a été pris assez vite et une sage-femme est venue avec un monitoring pour entendre le rythme cardiaque. On entendait pas le rythme cardiaque. Elle est allée chercher le docteur, la gynécologue.*

(B.(1), T5)

The second class (10.33% of the U.C.E.) is characterized by lexical forms that refer to the child's objects (photo, bracelet, track - *empreinte*, blanket - *doudou*, box - *boite* clothing - *vetement*, etc.), to the ritual practices executed by parents (candle - *bugie*, urn - *urne*, coffin - *cercueil*, ash - *endre*, turn on - *allumer*, flower - *fleur*, cemetery - *cimetiere*, angel - *ange*, etc.), to the child's bedroom and to the house, where the child's objects are on display (living room - *salon*, put - *mettre*, buy - *acheter*, tidy - *ranger*, room - *chambre*, etc.).

We bought a transparent ball with a white feather inside. We hung it on the tree and put flowers in the cemetery.

*On a acheté une boule transparente avec une plume blanche à l'intérieur. On l'a accroché au sapin et on lui a mis des fleurs au cimetière.*

(A.(2), T2)

We dumped the ashes and kept the ballot box at home.

*On a vidé les cendres dans un coin et on a gardé l'urne à la maison.*

(J.(4), T5)

In the living room, there is a small... there is a shelf for him where there is always a candle that burns every day with a photo, the small plate with his surname, first name which was on the coffin.

*Dans le salon il a fait une petite... il y a une étagère pour lui où il y a toujours une bougie qui brûle tous les jours avec une photo, la petite plaque avec son nom, prénom qui était sur le cercueil.*

(B.(2), T3)

The photos I don't look at them very often, they are handy, I made an album, I glued photos, I put postcards that we had received. I don't watch them often but I know they're there.

*Les photos je les regarde pas très souvent, elles sont à porte de main, j'ai fait un album, j'ai collé des photos, j'ai mis des cartes postales qu'on avait reçu. Je les regarde pas souvent mais je sais qu'elles sont là.*

(W., T4)

We are looking for a pretty box that we are going to dress up, we are going to put his first name and we are going to put all his stuff in it.

*On est en train de chercher une jolie boîte qu'on va costumer, on va mettre son prénom et on va mettre toutes ses affaires dedans.*

(J.(4), T3)

I think for him [the husband] it could be a bed for another baby, while for me it is U.'s bed [the deceased child]. It's in a room, in a room we don't use, in a room where we store things.

*Je pense que pour lui [le mari] c'est plutôt que ça pourrait être un lit pour un autre bébé, tandis que pour moi c'est plutôt le lit d'U. [l'enfant décédé]. Il est dans une pièce, dans une chambre qu'on utilise pas, dans une chambre où on stocke des affaires.*

(W., T4)

The stroller was sold and then the things in the room were put away in a room, I could not sell them.

*La poussette on l'a vendue et puis les affaires de la chambre sont rangées dans une chambre, j'ai pas réussi à les vendre.*

(J.(3), T5)

We kept the furniture but we put another bed, it's a guest bedroom now, it has another function.

*Les meubles les a gardé dedans mais on a mis un autre lit, c'est une chambre d'amis maintenant, ça a une autre fonction.*

(L., T5)

The third class (8.15% of the U.C.E.) includes the categories of IT groups (Facebook, network - *reseaux*, social, page, forum, site, internet, ) and support groups (group - *groupe*, support - *parole*, organize - *organizer*, participate - *participer*, meet - *rencontre*).

What helps me is the people I met at the support groups.

*Ce qui m'aide, c'est les personnes que j'ai rencontrées dans les groupes de parole.*

(N.(2), T3)

On National Perinatal Loss Remembrance Day and there was a Facebook event where at 7 p.m. each mom and dad had to post a photo of a candle for a tribute in memory of their deceased child.



*La journée nationale de sensibilisation au deuil périnatal et il y a eu un évènement sur Facebook où à 19 heures chaque maman et chaque papa devaient poster une photo d'une bougie pour un hommage en mémoire de son enfant décède.*

(E., T4)

Because I wanted to have my [support] group on the 49 [French region] and I did not find too much. It happened when it was the National Perinatal Loss Remembrance Day, October 15. I was trying to see if there was something set up near my home and there was nothing.

*Parce-que je cherchais à avoir mon groupe [de parole] sur le 49 [région française] et je ne trouvais pas trop. Ça s'est passé quand c'était la journée national du deuil périnatal, le 15 octobre. J'essayais de voir s'il y avait quelque-chose de mis en place près de chez moi e il y a avait rien.*

(C.(1), T5)

In the way that we already meet other parents [in the support groups] who were faced with perinatal loss, there is just that kind of people there, and that ultimately the experiences of others can help us to move forward, they enrich us.

*Dans la façon où déjà on rencontre d'autres parents [dans les groupes de parole] qui ont été confrontés à un deuil périnatal, qu'on est vraiment que ce genre de personnes là, et que finalement les expériences des autres peuvent nous aider nous à avancer, elles nous enrichissent.*

(J.(5), T5)

I met moms but on the forum. I befriended another mom. They don't live here, they don't live in the north. She is pregnant with her second baby too and in fact, we are in contact almost every day.

*J'ai rencontré des mamans mais sur le forum. J'ai lie d'amitié avec une autre maman. Ils habitent pas ici, ils n'habitent pas dans le nord. Elle est enceinte de son deuxième bébé aussi et en fait on est en contact quasiment tous les jours.*

(A.(2), T3)

I participated by initiatives of N. [the woman], I did not go to seek the support groups.

*J'ai participé par initiatives de N. [la femme], je suis pas allé chercher les groupes de parole.*

(N.(1), T4)

When I was in the hospital I typed "perinatal loss" on Google and I read some discussions on a forum. I never went, I'm not in a group like that because I had enough people around me, I had the psychologist, the support group, my husband who was great, my family who was great, I had no need it.

*Quand j'étais à l'hôpital j'avais taper « deuil périnatal » sur Google et j'avais lu quelques discussions sur un forum. Je ne suis jamais allée, je ne suis pas dans un groupe comme ça parce que j'avais suffisamment de monde autour de moi, j'avais la psychologue, le groupe de parole, mon conjoint qui était formidable, ma famille qui était formidable, j'ai pas eu de besoin.*

(L., T4)

Groups of Facebook, support group, I have never loved them but I do not want to tell my life to people I do not know and hear their lives knowing that we have experienced something that could be considered as similar.

*Des groupes de Facebook, de groupe de parole, j'ai jamais fait mais j'ai pas envie de raconter ma vie à des personnes que je ne connais pas et d'entendre leur vie sachant qu'on a peu près vécu les mêmes choses.*

(J., T4)

It's often late at night and we don't live near P. [city name] either, so it's a bit complicated and we don't necessarily feel the need [for support groups].

*C'est souvent le soir tard et on n'habite pas non plus jusqu'à cote de P. [nom de ville], donc c'est un peu compliqué et on ressent pas forcément le besoin [de groupes de parole].*

(J.(1), T4)

The fourth class (41.32% of the U.C.E.) includes the categories that refer to social support (talk - *parler*, people - *gens*, friends - *ami*, couple) and to the needs and the emotional aspects of grief (sad - *triste*, desire - *envie*, cry - *pleurer*, think - *penser*, need - *besoin*, feel - *ressentir*, moving forward - *avancer*, different, impression, listen - *écouter*, lived - *véçu*, try - *essayer*, etc.).

I was always advised to eliminate the people who were not making me move forward, and the others were there. I felt they were more of a drag than helping me move forward in life. I prefer to cut the bridges and since then I am much better.

*On m'a toujours conseille d'éliminer les gens qui ne me faisaient pas avancer et les autres étaient là. Je les ai plus senti comme un frein que m'aider a avancer dans la vie. J'ai préfère couper les ponts et depuis je vais beaucoup mieux.*

(F., T5)

I felt alone with my sadness to be so sad but I felt supported too, it's not because people are there around that they understand, they still don't live the same thing, so at the same time I still felt alone and I was surrounded very well.

*Je me sentais seule avec ma tristesse d'être aussi triste mais je me sentais soutenue aussi, c'est juste que il y a des choses que c'est pas parce que les gens sont là autour que ils comprennent, il vivent quand même pas la même chose, donc à la fois je me sentais quand même seul, pourtant j'ai été très bien entourée.*

(W., T4)

From the beginning I have made my son as something positive. I'm sure, all this is not just something of negative. He made me stronger.

*Depuis le début je fais de mon fils quelque chose de positif. Je suis sûre, y a pas que du négatif dans tout ça. Il m'a rendu plus forte.*

(C.(1), T5)

I accept it better because he understood me but in my life, I don't want to appear weak, that's it. So I avoid talking about it. I prefer to keep it to myself and share my pain with J. [the wife] and I don't really internalize a lot, I'm not the kind of person who talks about it too much.

*Je l'accepte mieux parce que il m'a compris mais après dans ma vie j'ai pas envie de paraître faible, c'est ça. Donc j'évite d'en parler. Je préfère mieux le garder pour moi et partager ma peine avec J. [la femme] et j'aime pas trop intériorise beaucoup de choses, je suis pas trop pour parler.*

(M., T4)

It brought us even closer, it didn't take us away We experienced grief in two different ways, B. [the husband] is not someone who communicates, whereas I absolutely communicate. And we still managed to try to understand the other, when sometimes I really needed to talk, to communicate with him, to talk to him, he made this effort to communicate with me. And when I saw that he didn't need to talk, he didn't want to talk, well, I took it upon myself not to rush

him. Afterwards, sometimes, when it was a little complicated, as he doesn't communicate much... And when he isn't well, he has a little grumpy and tired side and sometimes I understand, well, I don't understand... but... That... it creates some tensions, but overall it has brought us closer.

*Ça nous a rapproché encore plus, ça nous a pas éloigné. On a vécu le deuil de deux façons différentes, après B. [le mari] ce n'est pas quelqu'un qui va être entré dans la communication alors que moi je suis complètement dans la communication. Et on a malgré tout réussi à essayer de comprendre l'autre, comme des fois quand moi j'avais besoin vraiment de discuter, de communiquer avec lui, de parler avec lui, il faisait cet effort ben de communiquer avec moi.*

In fact, it is the look of people that hurts.

*En fait c'est le regard des gens qui fait mal.*

(L., T4)

I like to talk a little bit about V. [the deceased daughter] with him [the husband]. I think it's with him that it's important to talk about it. If other people who are further away... I don't necessarily talk about it, it's less easy. If I know that he and I know that she exists for us...it is the most important.

*J'aime bien parler un peu de V. [la fille décède] avec lui [le mari]. Je pense que c'est avec lui que c'est important d'en parler. Après si d'autres gens plus éloignées...j'en parle pas forcément, c'est moins facile. Si je sais que lui et moi on sait qu'elle existe pour nous c'est le plus importante.*

(D.(1), T4)

There was my best friend, L., who was there and who helped me a lot too. He's someone I love, he's not someone who how to say... "It's going to be okay, don't worry, it's going to be okay", he is someone who says things, even if they hurt.

*Il y a eu mon meilleur ami, L., qui a été là et qui m'a beaucoup aidée aussi. C'est quelque un que j'aime, ce n'est pas quelqu'un qui comment dire... « ça va aller, ne t'inquiéter pas, ça va aller », c'est quelque'un qui dit les choses, même des fois si ça blesse.*

(J.(2), T5)

Give support to bereaved new parents only for our own need because we missed it so much when it happened to us that we don't want new parents to find themselves alone without anyone who has gone through the same thing to talk to.

*Donner du soutien aux nouveaux parents endeuillés que pour notre propre besoin, en fait, parce que ça nous a tellement manqué au moment où ça nous est arrivé qu'on veut pas que des nouveaux parents se retrouvent à nouveau seuls sans personne qui a vécu la même chose à qui parler.*

(N.(2), T5)

Because, for example, I don't speak necessarily to my friends because they do not understand what I live, and even if they try to understand they are always off beam.

[...] I am angry with God. [...] There is anger against my friends who did not know how to support me, sometimes against B. [the husband], because he does not speak.

*Parce que, par exemple, je parle plus forcément à mes amies parce que elles comprennent pas ce que je vis, et même si elles essaient de comprendre elles sont toujours un peu côté de la plaque. [...] Je suis en colère envers Dieu. [...] Il y a une colère contre mes amis qui n'ont pas suent me soutenir, des fois en colère contre B. [le mari] parce que il parle pas.*

(E., T5)

In the fifth and final class of this first analysis (9.24% of the U.C.E.) there are references to the categories of the dates considered as more difficult by the parents (anniversary - *anniversaire*, celebration - *fête*, Christmas - *noël*), and to the social recognition, or bureaucracy (family - *famille*, record book - *livret*, mother - *mère*, aunt - *tante*, sister - *sœur*, father - *père*, godmother - *marraine*, godfather - *parraine*, baptism - *baptême*).

And we was wondering who we would put as godfather, godmother uh ... Even if we will not make a religious celebration, we also asked the question of how the civil baptism was. And above all we asked the question of whether we could do the civil baptism for a deceased child. We were told no, we could not do a baptism for someone who had died.

*Et on s'est posé la question de savoir euh, qui on mettrait parrain, marraine euh... Même si on fera pas de fête religieuse, on s'est posé aussi la question de savoir comment se passait le baptême civil. Et on a surtout posé la question de savoir si on pouvait faire le baptême civil*

*pour un enfant défunt. On nous a dit que non, on pouvait pas faire un baptême pour quelqu'un qui était décédé.*

(C.(1), T5)

Because ... mother's day, I miss a child, at Christmas as well.

*Parce que...fête de mère, il me manque un enfant, Noël pareil.*

(E., T5)

Having another child, I think it removes, even more, the existence of the one who is no here anymore.

*Le fait d'avoir eu un autre enfant, je pense que ça supprime encore davantage l'existence aussi de celui qui n'est plus là.*

(C.(1), T5)

When someone asks me how many children I have, I always say, "I have two children." I don't know how to say that I only have a child.

N. [the living child] had to fill a notebook for the school by presenting mom, dad, brothers, and sisters, grandparents, well... we put a picture of A. [the deceased child] there.

*Quand on me demande combien j'ai d'enfant, je dis toujours : « j'ai deux enfants ». Je ne sais pas dire que j'ai qu'un enfant. N. [l'enfant vivant] a du remplir un cahier pour l'école en présentant maman, papa, les frères et sœurs, les grands-parents, bah... on a mis une photo d'A. [l'enfant décédé].*

(J.(2), T4)

Christmas, children's birthdays, father's day, mother's day, my birthday, I haven't had a celebration since we lost T. [the dead child].

*Noël, les anniversaires des enfants, fête des pères, fête des mères, mon anniversaire, je , 'ai plus fête depuis qu'on a perdu T. [l'enfant décédé].*

(C.(2), T5)

"The day of his birth and also of his death, and every day of the year when I am sorry you do not send me a message", and my mother replied that: "I had not too many dates ". When, for example, my sister, who has her children, or when it's the first day of school, I'm sure she sends a message to find out how the first day went.

*« Le jour de sa naissance et aussi de sa mort, et tous les jours de l'année où j'ai de la peine vous m'envoyez pas de message », et ma mère m'a répondu que : « j'avais pas trop de dates ». Alors que par exemple ma sœur, qui a ses enfants, ou quand c'est la rentrée des classes, je suis sûre qu'elle envoie un message pour savoir comment s'est passée la rentrée des classes.*  
(N.(2), T5)

It's going to be difficult concerning the six months, for example, a year and a half, two years and a half, it's difficult because in general for children these are important dates.

*Ça va être difficile les six mois, par exemple un an et demi, deux an et demi, c'est difficile parce qu'en général pour les enfants ce sont des dates importantes.*

(E., T5)

In my family record book, it is written that I have a child. I am a mom without my child.

*Sur mon livret de famille il y a marqué que j'ai un enfant. Je suis une maman sans mon enfant.*

(P., T4)

Table 33 (below) shows the categories and the comparison of the classes of each group.

Within the first class of Group I (<6) there are the categories of the objects related to the child, including the bedroom that had been designed for him and the scattered memories distributed within the home. Groups II (6-11) and III (>12), or those who have lost their child for more than six and twelve months, share the categories of the cause of loss and the description of the event (in particular, with respect to the announcement of the diagnosis and death, and to the physical and traumatic experience). These aspects correspond to the second class of Group I (<6), while in Group II (6-11) there are references to emotional aspects and needs related to grief perceived by the parent; the social support (specifically, partner, family and the most external entourage, such as friends, colleagues, etc.) and psychological support (namely, psychotherapy, support groups, and, confirming the representation and confusion of the parent, the IT groups). It is important to emphasize that psychotherapy is present exclusively in Group II.

In Group III (>12), there are references to objects and memories of the child, as well as the home and the rites implemented by the parents.

In the third class, Groups I and III share the categories of support groups and online groups. These are the only categories of Group III, while in Group I there are also the categories of social support and rites.

In Group II there are rites, objects related to the memory of the child and the home. For this group, the third is also the last class.

Subsequently, Group I and III share another category in the fourth class, that of emotions and feelings. Social support is also present in Group III.

Finally, Group III is the only one that presents the fifth class of words, which includes the categories of dates considered as more difficult by the parent, such as holidays and birthdays, and bureaucracy, concerning the ceremonial practices not always recognized on a social level as well, such as the request to baptize a deceased child. Furthermore, both categories are present exclusively in this group. Following the standard analysis carried out by the Alceste program, Group III is the only group that has shown 5 classes. The study of the other groups has outlined exclusively 3 classes of words grouped according to their co-occurrences for Group I and 4 classes for Group II.

	Group I (<6)	Group II (6-11)	Group III (>12)
First class	Object		
	Home		
		Cause of loss	Cause of loss
		Description of the event	Description of the event
Second class	Cause of loss		
	Description of the event		
		Emotions and feelings	
		Social support	
		Psychotherapy	
		Support group	
		IT Groups	
			Objects
			Home
			Rites
Third class	Social support		
	Support group		Support group
	IT Groups		IT Groups
	Rites	Rites	
		Objects	
		Home	
Fourth class	Emotions and feelings		Emotions and feelings
			Social support
Fifth class			Dates
			Bureaucracy

Table 32 Categories of Alceste for the three groups of the first analysis.



### *Second analysis*

The second analysis includes three different groups and the distinctive criterion is the professional therapeutic support.

In the first group (Group A), there are parents who did not receive any support, in the second those (Group B) who were followed by a therapist or who participated in support groups (for a minimum duration of ten sessions) and in the third (Group C) those who actively participated in IT groups (that is, a daily connection, frequent publication of photos, comments, and comparisons with other users), for at least six months. Since participation in IT groups does not present any physical or time restrictions, six months of active participation is considered a reasonable time criterion to highlight possible differences, such as depressive references and a sense of isolation.

As we can see in the summary table below (Tab. 34), Group A participants, i.e. those who have never been seen any professional or been to one for less than 10 sessions (both with respect to personal and group psychotherapy), are 15 parents (9 women and 6 men), for a total of 75 interviews [15 x (T1 + T2 +T3 +T4 +T5)].

In the Groups B there are 14 parents (12 women and 2 men), with a total of 70 interviews, while in the Group C there are 9 women, for a total of 45 interviews. Of these 9, 5 are also in Group B (that one of psychological support) and 4 in Group A (no support).

<b>Group A NO PSYCHOTHERAPY</b>	<b>Group B PSYCHOLOGICAL SUPPORT</b>	<b>Group C IT GROUPS</b>
F.	L.	C.(1)
A. (3)	A.(1)	C.(2)
Y.	A.(2)	D.(1)
D. (2)	C.(1)	E.
B.(1)	C.(2)	J.(2)
B. (2)	D.(1)	J.(3)
D.(3)	E.	J.S.
J.(2)	J.(1)	M.(1)
J.(3)	J.(4)	N.(1)
M.	J.(5)	
M.-F..	P.	
M.(1)	N. (2)	
M.(2)	O.	
N.(1)	S.	
W.		
Tot.= 15	Tot.= 14	Tot.= 9

Table 33 List of participants grouped with respect to psychological support.

Group A of the second analysis of Alceste selected 5,664 text units, analyzed and classified with a very high data processing relevance (equal to 80%) in five different classes (Figure 84).

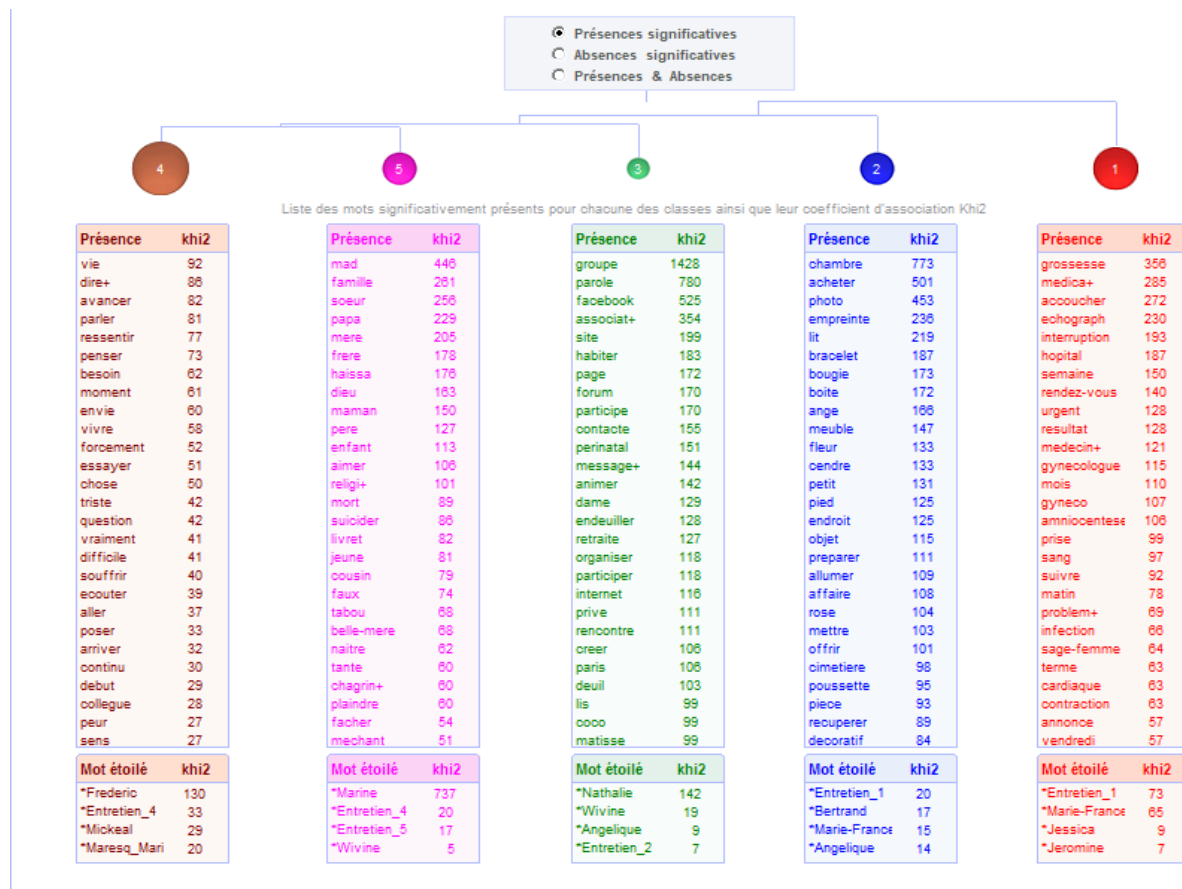


Figure 82 Word Classes of Group A (No psychological support).

The first class (25.48% of the U.C.E.) includes a lexicon that refers particularly to the cause of the child's loss (late - *interruption*, termination - *medical*, pregnancy - *grossesse*, infection, problem, cardiac - *cardiaque*), to the medical aspects (ultrasound - *echograph*, hospital - *hôpital*, taking - *prise*, blood - *sang*, amniocentesis - *amniocentèse*, gynecologist - *gynécologue*, midwife - *sage-femme*) and to the description of the event, i.e. the moment of the time of diagnosis, of the birth, etc. (birth - *acchoucher*, week - *semaine*, result - *resultat*, meeting - *rendez-vous*, urgent, room - *salle*, contraction, month - *mois*, end - *terme*, announcement - *annonce*, etc.).

In fact, I got pregnant in May, everything was fine, everything went well when after an ultrasound they detected a problem in the brain, a malformation in the brain.

*En fait je suis tombée enceinte au mois de mai, donc tout allait bien, tout allait bien quand après une échographie ils ont décelé un problème au niveau du cerveau, donc une malformation au niveau du cerveau.*

(J.(2), T2)

I gave birth at 23 weeks and 6 days following a late termination of pregnancy that we decided with my partner because of a trisomy 21.

*J'ai accouché à 23 semaine et 6 jours suite à une interruption médicale de grossesse que nous avons décidé avec mon conjoint à cause d'une trisomie 21.*

(M.-F., T3)

On the third-trimester ultrasound, almost in the eighth month of pregnancy, they discovered a heart malformation, the Guy Georges syndrome, and they made an amniocentesis to find out if there was something else.

[...] That means that there was a cardiac malformation and the chromosomal problem was added to it, so we made the decision to stop the pregnancy".

*à l'échographie du troisième trimestre, quasiment au huitième mois de grossesse, ils ont découvert une malformation cardiaque, le syndrome de Guy Georges, et heu ils ont lancé une amniocentèse pour savoir s'il n'y avait pas d'autre.*

[...] Ça veut dire qu'il y avait une malformation cardiaque et se rajoutait à ça le problème chromosomique, donc ce qui fait qu'on a pris la décision d'arrêter le grossesse.

(B.(2), T5)

In the evening she [the midwife] came at 7 pm, we did an ultrasound and she understood that the cervix was deformed and suddenly, the next day, they told us that she [the wife] would risk giving birth and that it was imminent, there was no other choice.

*Le soir elle [la sage-femme] est venue à 19h, on a fait un écho et elle s'est rendu compte que le col s'était bien déformé et du coup, le lendemain on nous a dit qu'elle [la femme] risquerait d'accoucher et que c'était imminent, que, voilà, qu'il n'y avait pas d'autre choix, quoi.*

(M., T5)

The loss of L. [one of the two deceased twins] was at 24 weeks, then we had several exams and, at 27 weeks, they discovered that L. [the second twin] had severe neurological sequelae, so we did the late termination of pregnancy.

*C'était à 24 semaines le décès de L. [l'un des deux jumeaux décédés] et ensuite donc, on a eu plusieurs examens et à 27 semaines on a découvert que L. [le second jumeau] avait de grosses séquelles neurologique, donc on a fait l'interruption médicale de grossesse.*

(J.(3), T4)

So, there were a lot of other ultrasounds and also fetal MRI, and then finally an amniocentesis that found that there was the genetic anomaly and that was at 31 weeks, the amniocentesis, and then we had the results a week later and we did the late termination of pregnancy the next week.

*Donc y a eu beaucoup d'autres échographies et aussi IRM fœtal, et puis finalement une amniocentèse qui a trouvé qu'il y avait l'anomalie génétique et ça c'était à 31 semaines, l'amniocentèse, et puis on a eu les résultats une semaine après et on a fait l'interruption médical de grossesse encore une semaine après.*

(N.(2), T1)

The second class (13.40% of the U.C.E.) presents semantic categories concerning the objects and the memories of the child (track - *empreinte*, photo, box - *boite*, bracelet, feet - *pied*, stroller - *poussette*, object - *objet*, etc.), the house – in particular with relation to the bedroom that was designed to accommodate the child and the places where the child's memories were placed (bedroom - *chambre*, buy- *acheter*, bed- *lit*, furniture - *meuble*, place - *endroit*, prepare - *préparer*, room - *piece*, decorative - *decoratif*, etc.) – the rites, i.e. rituals put in place by the parent and those related to cultural and religious traditions (candle - *bougie*, ash - *cendre*, flower - *fleur*, rose, turn on - *allumer*, case - *affaire*, cimiterly - *cimitiere*, get back - *recuperer*, offer - *offrir*).

I have a lot of pictures, so when I want to look at them, I watch my pictures and they are on the desktop of my phone, I have the two little ones.

*J'ai plein de photos, donc quand j'ai envie de regarder, je regarde mes photos et elles sont en fond d'écran de mon téléphone, j'ai les deux petits.*

(Y, T1)

Before we knew all that, I had prepared a lot of stuff, I made over all the room for her [the child], insulation, painting, the only point to make furniture.

*Avant qu'on sache tout ça, j'avais préparé plein de trucs, j'ai refait tout la chambre pour elle [l'enfant], l'isolation, la peinture, le seul point fabriquer des meubles.*

(D.(3), T3)

Sometimes I look at her bracelet, I think of her [the child].

[...] They make a ceremony on November 4th, so a week later. We have the right to attend the ceremony, so they put some small candles, they read some poems, they talk a little bit, and then we can bring flowers on the stele, where the ashes are scattered ".

*Des fois je regarde son bracelet, je pense à elle [l'enfant].*

*[...] Ils font une cérémonie le 4 novembre, donc une semaine après. Ça on a le droit d'assister à la cérémonie, donc ils mettent des petites bougies, ils font des petits poèmes, ils parlent un petit peu, et après on peut ramener des fleurs sur la stèle, là où les cendres sont dispersées.*

(J.(2), T1)

I kept, we kept the little hat that is stored in our room.

*J'ai garde, on a gardé le petit bonnet de naissance qu'on garde dans notre chambre.*

(B.(2), T3)

The stroller was sold and the stuff of the room, they are always stored in a tidy room, I was not able to sell them.

*La poussette on l'a vendu et puis les affaires de la chambre, elles sont toujours rangées dans une chambre rangée, j'ai pas réussi à les vendre.*

(J.(3), T5)

The third class (41.61% of the U.C.E.) mentions instead references concerning support groups (group - *groupe*, support - *parole*, association, live - *habiter*, take part - *participer*, run - *animer*, organize - *organiser*, meet up - *rencontre*, etc.) and the groups available on social networks (Facebook, site, page, forum, perinatal, message, internet, private - *prive*, create - *creer*, etc.).

Many parents mention the matter of the lack of associations that organize support groups near their home area. Others instead highlight their opposition and the thought that such groups are not useful. By confusing therapeutic groups with online groups present on social networks, forums and blogs, many declare that the latter can be a useful substitute.

I did not want to [go to the support group], I did not want to.

*Je n'en pas avais envie [d'aller au groupe de parole], j'en avais pas envie.*

(A.(3), T4)

I'm looking for it desperately [the support group].

*Je le cherche désespérément [le groupe de parole].*

(N.(2), T1)

For me this [the support group] is useless, I think it's more a turn of the knife in the wound than anything else. Then there is a group, I do not know the name, there is a march around March the 15th, there is a march for the loss.

[...] Groups of Facebook, support group, I have never loved them but I do not want to tell my life to people I do not know and hear their lives knowing that we have experienced something that could be considered as similar.

*Pour moi ça [le groupe de parole] sert à rien, je trouve c'est plus remuer le couteau dans la plaie qu'autre chose, après il y a un groupe, je sais pas comment on appelle ça, il y a une marche vers le 15 octobre, il y a une marche pour le deuil.*

[...] *Des groupes de Facebook, de groupe de parole, j'ai jamais fait mais j'ai pas envie de raconter ma vie à des personnes que je ne connais pas et d'entendre leur vie sachant qu'on a peu près vécu les mêmes choses.*

(Y., T4)

A lot with the support groups on the internet, it's true that the support groups were beneficial. They are websites set up by parents who lived the same thing, we could share. Being with people who have experienced the same thing and not feeling judged and understood, especially.

*Beaucoup avec des groupes de paroles sur Internet, c'est vrai les groupes de paroles c'était bénéfique. C'était des sites qui ont été mis en place par des parents qui ont vécu la même chose, on pouvait échanger. Le fait d'être avec des personnes qui ont vécu la même chose et de ne pas se sentir pas jugés et se sentir compris, surtout.*

(J.(3), T5)

[I do not participate in the] support group but they do a march for the loss or something like that, I think that this is good, I find.

*[Je ne participe pas au] groupe de parole mais ils font des marches sur le deuil ou des choses comme ça, je trouve que c'est bien, je trouve.*

(D.(2), T3)

There is none at A. [name of the city] and at the CHU, where they follow me for the MAR [Medically Assisted Reproduction]. There is some group for the MAR but there is no group for the perinatal loss, but it is something that I find pity, regrettable.

*Il n'y en a pas à A. [nom de la ville] et au CHU, qui me suit pour la PMA. Autant il y a un groupe de parole pour les PMA mais il n'y a pas pour le deuil périnatal, mais c'est des choses que je trouve dommage, regrettable.*

(M.-F., T3)

The fourth class of Group A (41.61% of the U.C.E.), or those who have no psychological support, regards the feelings perceived by the parent (moving forward - *avancer*, say - *dire*, talk - *parler*, feel - *ressentir*, live - *vivre*, try - *essayer*, sad - *triste*, suffer - *souffrir*, etc.), the social support (question, difficult - *difficile*, ask - *poser*, colleague, etc.) and the couple relationship (need - *besoin*, desire - *envie*, listen - *écouter*, etc.).

It's something that she [the wife] lived that I did not, physically. So I help her the best that I can, to support her and I know very well that sometimes, as it happens to me, when sometimes I'm not really good, but it's my way of reacting.

*C'est quelque chose qu'elle [la femme] a eu à vivre que je n'ai pas vécu physiquement. Donc je l'aide du mieux que je peux pour l'épauler et ben je sais très bien qui il y a des fois, à moi aussi, quand des fois vraiment je vais pas bien, mais moi c'est ma façon de réagir.*

(D.(3), T3)

Even if we did not talk about it [with family and friends], they were still trying to find out how I felt in general, we know each other, they did not need to ask questions directly to know if I was fine or not.

*Même si on n'en parlait pas ils [famille and amis] cherchaient quand même à savoir comment je me sentais en général, on se connaît, ils n'avaient pas besoin de poser de questions directement pour savoir si je n'allais vraiment bien ou pas.*

(M.(2), T5)

I had some colleagues at work. Today I am very close to some colleagues, very, very close, with whom I am all the time and they can see immediately if I was not fine.

*J'avais des collègues au boulot. Aujourd'hui je me suis beaucoup rapproché des certains collègues vraiment, vraiment très proche, avec qui je suis tout le temps et ils voient tout de suite si je n'allais pas bien.*

(F., T4)

Because I do not want that she sees me weak [the wife], but I do not want that she sees me strong either. After all, I'm like her, I think about it, that's it, except that it's because she feels more the need to talk about it than me, that I have advanced more or less than her.

*Parce que j'ai pas envie qu'elle me voit faible [la femme], mais j'ai pas envie qu'elle me voit fort non plus. Après je suis comme elle, j'y pense, voilà, sauf que c'est parce que elle ressent le besoin d'en parler que moi je ressens moins le besoin d'en parler que j'ai plus ou moins avance qu'elle.*

(M., T3)

There are many feelings when you ask yourself this question. On one side we want to know, to know what happened, if we want to try again, if we can, if we can avoid this drama again.

*Y a plusieurs sentiments quand on se pose la question. D'un côté on a envie de savoir, pour savoir est ce que, si jamais on veut retenter, si on peut, si on peut éviter à nouveau ce drame.*

(F., T2)

We really have more complicity, our couple is even better than before, I think.

*On a vraiment encore plus de complicité, notre couple va encore mieux qu'avant, je pense.*

(F., T5)

Let's say that I interpret it like that, it means that there are some gestures, words, but there will be nothing as concrete, nothing direct. It is difficult to bring the subject, also for us it is difficult.

*Disons que je l'interprète comme ça, c'est... on va dire, ça va être des gestes, des paroles, mais il n'y aura rien de concret, rien de direct. Le sujet est difficile à être amène, nous-même on n'arrive pas à le lancer.*

(B.(1), T4)



Now I want to have another meaning in my life than to think about what happened. So I try to, even if sometimes I think about it, I try to force myself, to put this aside, still thinking of them, but I try to be here more for J. [the wife] than for me.

*Et maintenant j'ai envie de, d'avoir un autre sens à ma vie que de penser à ce qui m'est arrivé. Alors j'essaie de, même si des fois j'y pense, j'essaie de me forcer, de mettre ça un peu de côté, tout en pensant encore à eux, mais j'essaie de, voilà, pour être la plus pour J. [la femme] que pour moi.*

(M., T2)

After all it is not necessarily, we did not experience the same things, the emotions were not necessarily the same, so after all he [the husband] listens to me, there are no worries, finally, that's it, I can talk to him when I want.

*Après on est pas forcément, on a pas vécu les mêmes choses, enfin les émotions n'étaient pas forcément les mêmes, alors après il [le mari] m'écoute, il n'y a pas de soucis, enfin, voilà, je peux lui parler quand je veux.*

(J.(3), T4)

I felt misunderstanding, anger, about what happened to me. Today I have to live with it, it's less painful but the anger is much less present.

*J'avais de l'incompréhension, de la colère, vis à vis de ce qui m'est arrivé. Aujourd'hui je dois vivre avec ça. C'est pas moins douloureux mais la colère est beaucoup moins présente.*

(A.(3), T5)

He [the husband] is not the type to express himself, he is more like the type who keeps everything for himself and then manages as he can, all by himself, so it's not the same as me.

*Il [le mari] n'est pas trop du genre à s'exprimer, il est plutôt du genre à garder tout pour lui et puis il gère comme il peut, tout seul, donc, c'est pas pareil que moi.*

(J.(2), T1)

I felt guilty at the beginning.

*Je me suis senti coupable au début.*

(W., T3)

At first it was difficult, now it's better. At first, I had a little trouble with myself, I could not have pleasant moments.

*Au début c'était difficile, maintenant ça va mieux. Au début j'avais un peu de mal avec moi-même, j'arrivais pas à avoir des moments agréables.*

(J.(3), T5)

The fifth and last class of Group A of the second analysis performed with Alceste (12.91%) presents references to the family (sister - *soeur*, dad - *papa*, mother - *mere*, child - *enfant*, cousin, aunt - *tante*, etc.), to religion (religion, suicide - *suicider*) and to bureaucracy (record book - *livret*, family - *famille*).

We made a family record book with her first name because she had to have my surname, but since she was born, she was not born alive, it is not allowed to, for the state, she has not the right to have my surname.

*On a fait un livret de famille avec son prénom parce qu'elle devait porter mon nom mais vu qu'elle est morte née, elle est pas née vivante, elle a pas le droit de, pour l'état, elle a pas le droit de porter mon nom de famille.*

(D(3), T2)

In my case, I consider religion like a charm. I think we need to hang on to something to be able to manage it. [...]. Finally, if I call the Virgin Mary, or my grandmothers, my aunts who are in heaven, or my daughter ... for me it will be the same call.

*Je considère, dans mon cas, la religion comme un grigri. Je pense que l'on a besoin de se raccrocher à quelque chose pour pouvoir y arriver. [...]. Enfin que je fasse appelle à Marie en tant que Vierge et donc à la religion, ou que je fasse appel à mes grand-mères, à mes tantes qui sont au ciel, ou à ma fille... pour moi ce sera les mêmes appels.*

(M.-F., T4)

I spoke with my son [the living child]. I already talked about it before and he is also more and more aware, at the time of the death of U. [the deceased child] he was two years old, now he is three years old and he understands better.

*J'avais parlé avec mon fils [l'enfant vivant]. J'en avais déjà parlé avant et il est aussi de plus en plus conscient, au moment de la mort de U. [l'enfant décédé] il avait deux ans, maintenant il a trois ans et il comprend mieux.*

(W. T4)

If suicide would not be a sin for religion I would have been dead since a long time and I say to myself, will another child help me? I think so.

*Si le suicide se serait pas un péché pour la religion je serais déjà morte depuis longtemps et je me dis, est-ce qu'un autre enfant va m'aider ? Je pense que oui.*

(M.(1), T2)

The next day we went to make all the documents to recognize her, because for us she is our little girl. So we had to have a family record book where she can appear in it, so we cannot say she was not, well, no, she was there, she is our first child.

*Le lendemain on est allé faire les papiers pour la reconnaître, parce que pour nous c'est notre petite fille. Donc il fallait qu'on ait un livret de famille à nous et qu'elle apparaisse dedans, donc on ne peut pas dire qu'elle n'était pas, non, elle a bien été là et pis, nous, c'est notre première enfant.*

(F., T1)

If I need support I know where to go, I have my brother, my sister, I have my mother ...

*Si j'ai besoin de soutien je sais où aller, j'ai mon frère, ma sœur, j'ai ma mère...*

(M., T3)

I know that my mother is ashamed that I had a disabled child and that she thinks that there was no possibility of keeping this child and that there was no other solution, that it had to be done.

*Je sais que ma mère a honte que j'ai eu un enfant handicapé et qu'elle considère qu'il y avait pas possibilité de garder cet enfant et que y avait pas d'autre solution, qu'il fallait le faire.*

(N.(2), T4)

The second analysis of Alceste with respect to Group B, i.e. those who went to personal psychotherapy or participated in support groups, includes 5,519 text units, with a high relevance of 76% and ranked into six classes (Figure 85).



Figure 83 Word Classes of Group B (personal psychotherapy and/or support groups).

The first class (12.34% of the U.C.E.) refers to somatic references for objects and memories of the child (photo, box - *boite*, track - *empreinte*, bracelet, blanket - *doudou*, plush - *peluche*, drawing - *dessin*, necklace - *collier*, clothes - *vêtement*), the house, namely the child's bedroom and the places of the house where the child's memories are exposed (buy - *acheter*, room - *chambre*, bed - *lit*, furniture - *meuble*, case - *affaire*, living room - *salon*, put - *mettre*, decorative - *decoratif*, tidy - *ranger*, keep - *garde*, object - *objet*) and the rites (candle - *bougie*, ash - *cedre*, necklace - *medaillon*, turn on - *allumer*, flower - *fleur*).

We emptied the ashes in a corner and kept the urn at home.

*On a vidé les cendres dans un coin et on a gardé l'urne à la maison.*

(D.(1), T2)

Since they [the deceased twins] were born on the first of July, the first of every month I go to the florist and in fact I bought two white roses and I put them on the furniture at the entrance and close to them I turn on two candles.

*Comme ils [les jumeaux décédés] sont nés le premier juillet, le premier de chaque mois je vais chez le fleuriste et en fait j'acheté deux roses blanches et je les mets sur le meuble de l'entrée et à côté j'allume deux bougies.*

(J(5), T1)

I said: "I'd really like to put the emotional memories here and that this is his pretty memory box". So we did that, so we emptied all the clothes, the objects. And in fact, in the room, there are just the empty furniture.

*J'avais dit : « J'aimerais bien qu'on mette vraiment les souvenirs affectifs ici et ce soit sa jolie caisse de souvenirs ». Donc on a fait ça, donc on a vidé tous les vêtements, les objets. Et en fait dans la chambre, il reste les meubles vides.*

(D.(1), T2)

We have given another function to the room, we put our clothes on, we removed the decorations, we just left the furniture.

*On lui a donné une autre fonction à la chambre, on y met nos vêtements, on a enlevé les décorations, on a juste laissé les meubles.*

(L., T2)

As a rule, we light a candle because he gets a small place, finally we made a small place, a small corner for him, there is his urn, a little blanket, some little objects, and we turn on a candle there, and this was very useful for us.

*En règle général on allume une bougie parce qu'il a un petit endroit, enfin on a fait un petit endroit, un petit coin à lui, il y a son urne, un petit doudou, des petites choses à lui, et on allume une bougie là et à nous fait du bien.*

(J.(4), T4)

The second class (29.12% of the U.C.E.) presents a lexical universe that concerns the aspects of psychological support, above all the support group (group - *groupe*, support - *parole*, talk - *parler*, support - *soutien*, know - *conneitre*) and the illusory support given by social networks that parents tend to consider as much as a psychotherapy (facebook, contact, perinatal, network - *reseau*, social), as well as social support (friends - *ami*, peolple - *gens*, parent, family - *famille*, close - *proche*, colleague, godmother - *marraine*, godfather - *parraine*).

Women speak much more together, more easily than men, we are always a little behind, and there may be an initiative to make a support group just for fathers.

*Les femmes parlent beaucoup plus ensemble, plus facilement que les hommes, on est toujours un peu en retrait, et y a peut-être une initiative de faire une espace de groupe de paroles juste pour les pères.*

(N.(1), T2)

I have a, I have a network of very close friends. We have unwavering support. We can ... and we can talk about Z. [the child] freely and people talk to us about Z. [the child], even now, still now.

*J'ai un, un réseau d'amis très proches. On a un soutien sans faille. On peut...et on peut parler de Z. [l'enfant] librement et les gens nous parle de Z. [l'enfant], même maintenant, encore maintenant.*

(A.(2), T1)

At first, social networks are good because we find other parents who lived the same thing, we discuss there.

*Les réseaux sociaux au début ça fait du bien parce qu'on retrouve d'autres parents avec qui on a vécu la même chose, on discute la.*

(E., T5)

I have a lot of support, from my partner, from my family, from the psychologist, from the friend I met at the support group, from some friends as well. I feel well surrounded.

*J'ai beaucoup de soutien, de mon conjoint, de ma famille, de la psychologue, de l'amie que j'ai rencontrée au groupe de parole, de quelques amis aussi. Je me sens bien entourée.*

(L., T3)

Of course, I did not go to look for the support groups, I'm not on Facebook. Finding the forums about the perinatal grief, I don't look for these kinds of things, but after every time I went with N. [the wife], it was interesting to meet other people who have experienced this, at different stages of their lives and see how they are going today.

*Moi, naturellement, je ne suis pas allé chercher les groupes de paroles, je ne suis pas sur Facebook. Retrouver les forums de périnataux, moi, je ne vais pas tellement aller chercher ce genre d'histoires mais après chaque fois que je suis allé avec N. [la femme], ça a été quand même intéressant de rencontrer d'autres personnes qui ont vécu ça, à différents stades de leur vie et voir comment ils ont, comment ils ont aujourd'hui.*

(N.(1), T3)

The support group is the best support I could have, really. We understand each other, we do not judge ourselves, we are not alone, this doesn't just happen to us, we can share it.

*Le groupe de parole c'est le meilleur soutien qu'on puisse avoir selon moi, vraiment. On se comprend, on ne se juge pas, on est pas seul, c'est pas à nous seul que ça arrive, on peut le partager.*

(O., T5)

The third class (22.38% of the U.C.E.) refers particularly to the emotional aspects and feelings perceived by the parent (sad - *triste*, cry - *pleurer*, anger - *colere*, moving forward - *arriver*, try - *essayer*, accept - *accepter*, lack - *manque*, painful - *douloureux*, difficult - *difficile*, reality - *réalité*, need - *besoin*, etc.).

I feel it more or less strong, it depends. From time to time I have tears that come to my eyes, other times it's just a sense of sadness, but I can contain myself .

*Je me sens plus ou moins fort, ça dépend. De temps en temps j'ai les larmes qui m'arrivent aux yeux, d'autres fois c'est juste une tristesse, mais j'arrive à me contenir.*

(N.(1), T5)

There are a lot of things, all that stuff in the head, at the same time I do not allow myself, sometimes I allow to feel it in my heart and to accept that it's ok like that.

*Il y a pleins de chose, tout ça qui s'embrouille dans la tête, en même temps je me n'autorise pas, des fois je l'autorise à la sentir dans mon cœur et à accepter que c'est bien comme ça.*

(D.(1), T4)

Sometimes I think back to that day where T. [the child] is deceased and I'm out of my mind, I'm very angry, I cry and all that, but, between these big crisis, it's getting a bit softer.

*Des fois je repense à cette journée ou T. [l'enfant] est mort et je suis hors de moi, je suis très en colère, je pleure et tout ça, mais, entre ces grosses crises, c'est un peu plus doux.*

(C.(2), T5)

It's very heavy, it's painful. I kept thinking about it every day, but it's less painful because I can focus more on the good times, in quotes.

*C'est très pesant, c'est douloureux. Maintenant j'y pense encore, tous les jours, mais c'est moins douloureux parce que j'arrive plus à me focaliser sur les bons moments, entre guillemets.*

(O., T5)

There are always ups and downs, sometimes I am very well, then there are little things every day that remind me, I'm a little sad, after I'm fine again. It's ups and downs, but it's less intense than it was at the beginning.

*Il y a toujours des hauts et des bas, des fois ça va très bien, après il y a des petites choses au quotidien qui me rappellent, je suis un peu triste, après je suis de nouveau bien. C'est des hauts et des bas, mais c'est moins intense qu'au début.*

(L., T2)

All my life she will accompany me. I accompanied her all her life, now she will accompany me. There are times when I can even feel happiness by thinking back to all the moments shared with her.

*Toute ma vie elle m'accompagnera. Moi je l'ai accompagné tout sa vie, maintenant c'est elle qui va m'accompagner. Il y a des fois ou j'arrive même à ressentir du bonheur en repensant à tous les moments partagés avec elle.*

(D.(2), T1)

I'm not all the time in the sadness, there are days where actually I'm sad but I don't cry necessarily, little by little I tell me that it happened and little by little I am in the phase of acceptance.



*Je ne suis plus tout le temps dans la tristesse, il y a des jours où effectivement je suis triste mais je pleure pas forcément, j'arrive petit à petit à me dire que c'est arrivé et petit à petit dans la phase d'acceptation.*

(E., T5)

We smile anyway, we laugh about a lot of other things, but there is always this effect like a boomerang. I have the impression that every time it returns as a slap, in fact.

*On sourit quand même, on arrive à rigoler sur plein d'autres choses, mais voilà. Il y a toujours cet effet un peu boomerang. J'ai l'impression qu'à chaque fois ça revient comme une claque, en fait.*

(C.(1), T4)

This whole period is very difficult and I often think about it and I see the three days, those days and I see the head of D. [the husband] when they told us that it was over.

*Tout cette période-là est très difficile et souvent j'y repense et je revis les trois jours, ces jours-là et je revois la tête de D. [le mari] quand on nous a dit que c'était fini.*

(J.(1), T1)

I am still angry and feeling unfair. So why did it happen to me? Why did this happen to us? In fact, a feeling of injustice, a feeling of anger. Why did it happen to us?

*Je suis toujours en colère et un sentiment d'injustice. Donc pourquoi ça m'est arrivé ? Pourquoi ça nous est arrivé ? En fait un sentiment d'injustice, un sentiment de colère. Pourquoi ça nous est arrivé?*

(E., T5)

The fourth class (8.23% of the U.C.E.) concerns lexical elements that can be categorized above all in relation to the subsequent child and to the relationship with the deceased child (place, sister - *soeur*, brother - *frere*, built - *construire*, existence, transfert, relationship - *relation*, face - *visage*, wish - *desiderer*, realize - *realiser*, forget - *oblire*, look like - *ressembler*, etc.).

For me, it's very important to build this place and really, and she is still part of my life.

*Pour moi c'est très important de lui construire cette place et de vraiment, et qu'elle fasse encore partie de ma vie.*

(D.(1), T4)

When her little sister does funny things or looks like things that V. [the deceased child] did, it's like a little wink between her and me and then, anyway, there are photos of V. [the deceased child] almost everywhere, so we added the photos of E. [the next child] side by side.

*Quand sa petite sœur fait des trucs rigolos ou qui ressemble à des choses que V. [l'enfant décédé] faisait du coup, c'est comme un petit clin d'œil entre elle et moi et puis, toutes façons, il y a des photos de V. [l'enfant décédé] un petit partout, alors on a rajoute les photo d'E. [l'enfant suivant] à côté.*

(D(1)., T4)

He [the deceased child] has his place, so our sweetie [the next child], she can never be a replacement child.

*Il [l'enfant décédé] a sa place, donc notre puce [l'enfant suivant], elle ne pourra jamais être un enfant de remplacement.*

(C.(1), T3)

I think that A. [the next child], she is not born in the shadow of her sister, it' will not be "you, you're here because your sister is not here and we're counting on you to get better". No, it's very different. We had time to evolve, she will really be a second child, different.

*Je pense qu'A. [l'enfant suivant], elle ne va pas naître dans l'ombre de sa sœur, ça ne va pas être toi, t'es là parce que ta sœur n'est pas là et on compte sur toi pour aller mieux, non. C'est très différent. On a eu le temps d'évoluer, ça va vraiment être un deuxième enfant, différent.*

(A.(1), T5)

We thought that the only thing that could save us was to have a new one, to have the little brother or sister as soon as possible because we are made for that, in fact.

*On s'est dit que la seule chose qui pouvait nous sauver c'était d'avoir un nouveau, d'avoir le petit frère ou sœur le plus vite possible parce-que on est fait pour ça, en fait.*

(O., T2)

There is a lot of resemblance between N. [the deceased child] and Y. [the next child], physically. There are facial features that are very representative. So there is this question of "what would he look like" that comes up very often. It is also the fact that well, there are the

first smiles, there are the first "I discover my hands", there is all her evolution in Y. [the next child] that suddenly, I will never have with N. [the deceased child].

*Il y a beaucoup de ressemblance entre N. [l'enfant décédé] et Y. [l'enfant suivant], physiquement. Il y a des traits de visage qui sont très représentatifs. Donc il y a cette question de à quoi il aurait ressemblé qui revient très souvent. Y a le fait aussi que ben du coup, on a les premiers sourires, on a les premières je découvre mes mains, il y a toute son évolution chez Y. [l'enfant suivant] que du coup, je n'aurais jamais avec N. [l'enfant décédé].*

(C.(1), T4)

The fifth class, constituted by 18.59% of the U.C.E. presents the categories of medical aspects (ultrasound - *échographie*, end - *terme*, dossier, follow - *suivre*, result - *resultat*, treatment - *traitement*) and of the causes of loss (late - *interruption*, termination - *medical*, pregnancy - *grossesse*, disease - *maladie*, handicap, malformation, chromosom, brain - *cerveau*, etc.).

The late termination of pregnancy was decided because at the third ultrasound, at the third ultrasound of the third trimester there was a heart disease that was discovered, and following this heart disease they did an amniocentesis to see if it was isolated or due to a chromosomal abnormality, and it turns out that it was due to a chromosomal abnormality, the microdeletion 22 Q Syndrome de Guy Georges. So there was already this heart disease but there could also be other symptoms including the brain, motor skills.

*L'interruption médicale de grossesse elle était décidée parce que à la troisième échographie, à l'échographie du troisième trimestre il y a une cardiopathie qui a été découvert et suite à cette cardiopathie ils ont fait une amniocentèse pour voir si elle était isolée ou due à une anomalie chromosomique et il s'avère qu'elle était due à une anomalie chromosomique. La micro délétion date 22 Q Syndrome de Guy Georges du coup il y avait donc déjà cette cardiopathie mais il pouvait y avoir aussi d'autres symptômes notamment au niveau du cerveau, de la motricité.*

(E., T3)

We had a late termination of pregnancy in the seventh month almost, after an amniocentesis where we learned a micro deletion that was going to be very disabling. So the doctors told us that they were in favor of a late termination of pregnancy, us as well, so we followed this advice.

*On a fait une interruption médicale de grossesse au septième mois presque, après une amniocentèse où on a appris une micro délétion qui allait être très handicapante. Donc les médecins nous ont dit qu'ils étaient favorables à une interruption médicale de grossesse, nous aussi, on a suivi ce conseil.*

(N.(1), T3)

The reasons that led us to make a late termination of pregnancy is that N. [the deceased child] had three brain malformations. He had a ventriculomegaly of the severe stage at 15 - 16, that is, a corpus callosum which was thick and discontinuous, which prevented the communication between his two hemispheres.

*Les raisons qui nous ont amené à faire une interruption médicale de grossesse c'est que N. [l'enfant décédé] avait trois malformation cérébrale. Il avait une ventriculomegalie de stade sévère à 15 – 16, voilà, un corps calleux qui était épais et discontinu, qui empêchait la communication entre ses deux hémisphères.*

(C.(1), T3)

The sixth and final class of the Group B (9.34% of the U.C.E.) speaks of the terms concerning the description of the event, in particular of the birth and death (hour - *heure*, night - *nuit*, birth - *accoucher*, urgent, transfer - *transférer*, caesarean - *césarienne*, Sunday - *dimanche*, contraction, thuesday - *mardi*, hospital - *hôpital*, wake up - *veiller*, fight - *battre*, respirator - *respirateur*, worried - *inquiéter*, etc.).

Perhaps five minutes later, there is a lady who came to explain to us how it was going to be. The next day I came to take pills at the maternity to change the cervix and two days later I went to the maternity for a trigger, to give birth.

*Peut-être cinq minutes après il y a une dame qui est venue nous expliquer comment ça allait se passer. Le lendemain je suis venue prendre des cachets à la maternité pour commencer à modifier le col et deux jours après je suis allé à la maternité pour un déclenchement pour accoucher.*

(J(4)., T1)

I have been transferred to eleven o'clock, I see the pediatrician who explains that the situation is not great, the liver and kidney do not work, the tension is not good, so they give drugs to

regulate her tension. She does not breathe alone. On Saturday night they told me my daughter would die very soon and then that she will not survive in the night from Saturday to Sunday. *Je suis transférée à onze heures, je vois la pédiatre qui m'explique que c'est pas génial, le foie et le rein ne fonctionnent pas, la tension n'est pas bonne, donc ils donnent des médicaments pour réguler sa tension. Elle ne respire pas toute seule. Le samedi soir on m'annonce que ma fille va mourir presque d'une minute à l'autre, enfin on nous dit qu'elle ne survivra pas dans la nuit de samedi à dimanche.*

(P., T4)

In the night from Thursday to Friday she had already changed a lot, she did not even awake to eat, so she was fed by a tube and in the morning she was very tired and when the cardiologist examined her, I think that even before to do the ultrasound, he saw that her condition was deteriorating and he did his sonography, he said "we can't wait, we operate". So everything went pretty fast because two days before she was fine.

*Dans la nuit de jeudi au vendredi elle avait déjà beaucoup changé, même pas réveillée pour manger, donc on l'a nourri par sonde et le matin elle était toute fatiguée et quand le cardiologue l'a examinée, je pense que même avant de faire l'échographie, il a vu que son état était en train de se dégrader et il lui a fait son échographie, il a dit on attend pas, on l'opère. Donc ça a été assez précipité parce que deux jours avant elle allait bien.*

(D.(1), T3)

Or if it could wait for the next day that I stomach it a bit and nothing was urgent, so I gave birth two days later, the time they ... They started to trigger childbirth on Monday morning and I gave birth on Tuesday at noon.

*Ou si ça pouvait encore attendre le lendemain que je digère un peu la chose et finalement il n'y avait rien d'urgent, donc j'ai accouché deux jours après, enfin le temps qu'ils, ils ont commencé à me déclencher l'accouchement le lundi matin et j'ai accouché le mardi à midi.*

(L., T2)

During Saturday I had not so many contractions anymore, but it was ok and then, on Sunday, I felt no movements, and this upset us. We went to the hospital in the evening and there they did exams, checked the urine, took the ultrasound (just the probe), the midwife did not hear the heart, the midwife did not hear the heart.

*Après le samedi passe, je n'avais plus trop de contractions, ça ça allait et le dimanche je la sentais pas bouger, et tout ça a commencé à bien nous inquiéter. On n'y a été, on a été à l'hôpital le soir et là ils sont nous ont fait, ils sont faits des examens et l'analyse d'urine, l'échographie juste la sonde, la sagefemme n'entendait pas, elle n'entendait pas le cœur.*

(J.(1), T3)

It was one of the pediatric emergencies and there a pediatrician comes to see me, asking me to understand a bit what happened, that he receives a baby who is not very colorful, who does not react very much.

*C'était des urgences pédiatriques et là le pédiatre qui vient me voir, qui me demande un peu de comprendre ce qui s'est passé, lui il reçoit un bébé effectivement qui n'est pas très coloré, qui réagit pas beaucoup.*

(S., T1)

I had contractions and I was alone at home, they did not pass, so I called the UAS and I was transported to the hospital and when I was in the hospital, they tried to treat me, to put me on infusions, to let me rest the day after, to do some examinations. And in fact, as the days went by, contractions did not stop and at the end, I gave birth on Saturday morning, the first of July, our two little boys.

*J'avais des contractions et j'étais seule à la maison, ça passait pas, donc j'ai appelé le SAMU et j'ai été transportée à l'hôpital et quand j'étais à l'hôpital, ils sont quand même essayé de me soigner, de me mettre des perfusions, de me mettre au repos, de me faire des examens. Et en fait, au fur et à mesure des jours, des contractions ne s'arrêtait pas et jusqu'à ce que j'accouche le samedi matin, le premier juillet, nos deux petits garçons.*

(J.(5), T3)

The C and last Group of this second analysis of Alceste, i.e. those who participated in the groups present within the social networks, is characterized by 5,313 text units, equal to 80% and therefore with a very high relevance of treatment, classified into five classes (Figure 86).

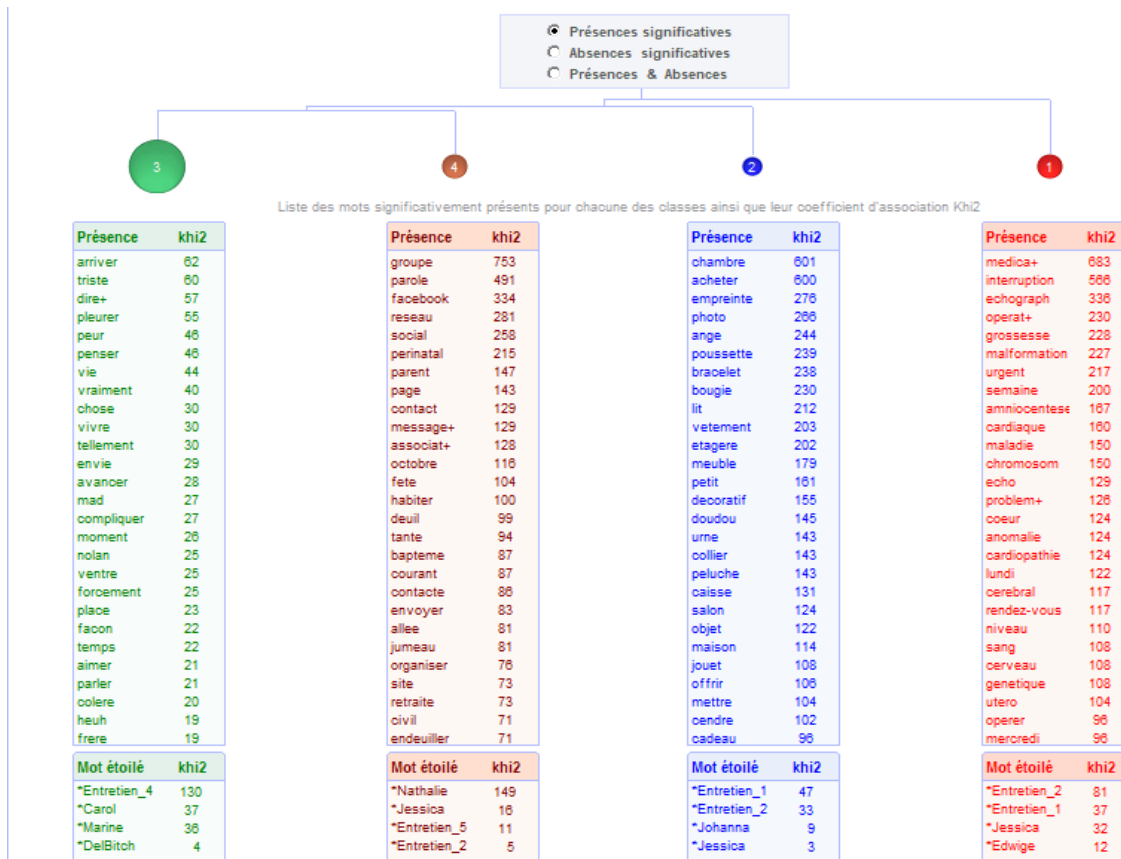


Figure 84 Word Classes of Group C (active participation on IT Groups).

The first class (13.36% of the U.C.E.) includes references to the cause of the child's loss (late - *interruption*, termination - *medical*, pregnancy - *grossesse*, heart - *coeur*, disease - *maladie*, chromosomique, problem, cerebral, cardiopathy - *cardiopathie*, anomaly - *anomalie*, brain malformation - *malformationn cerveau*, genetics - *genetique*, etc.), more generic medical aspects (ultrasound - *echographie*, amniocentesis - *amniocentèse*, blood - *sang*, utero, echo, etc.) and to the description of the event and in particular to the birth (operation, urgent, wednesday - *mecredi*, meeting - *rendez-vous*, operete - *operer*, etc.).

The late termination of pregnancy was decided because at the third ultrasound, at the third ultrasound of the third trimester there was a heart disease that was discovered and following this heart disease they did an amniocentesis to see if it was isolated or due to a chromosomal

abnormality and it turns out that it was due to a chromosomal abnormality. I did not expect that someone could tell me about this heart disease and therefore, the person explained to me that he had a problem with the heart and I had to make another appointment tomorrow with a specialist in fetal cardio ultrasound.

*L'interruption médicale de grossesse e été décidée parce que à la troisième échographie, à l'échographie du troisième trimestre il y a une cardiopathie qui a été découverte et suite à cette cardiopathie ils ont fait une amniocentèse pour voir si elle était isolée ou due à une anomalie chromosomique et il s'avère qu'elle était due à une anomalie chromosomique. [...] Je ne m'attendais pas à ce qu'on m'annonce cette cardiopathie et donc, du coup, la personne m'a expliqué qu'il avait un problème avec le cœur et il fallait que je prenne un autre rendez-vous le lendemain avec un spécialiste en échographie cardio fœtale.*

(E., T3)

Two very rare and serious genetic diseases. So he would not have survived, he would have suffered. So we did a late termination of pregnancy and they told us that this could happen again.

*Deux maladies génétique très rares et très graves. Donc il n'aurait pas survécu, il aurait souffert. Donc on a fait une première interruption médicale de grossesse et on nous a dit que ça pouvait se refaire.*

(C.(2), T2)

She died because there was a complication during the operation, she had to have an operation of the heart because she had a heart defect. It is normally a malformation that was operable and curable.

*Elle est décédée parce que qu'il y a eu une complication lors de l'opération, elle a dû se faire opérer du cœur parce qu'elle avait une malformation cardiaque. C'est normalement une malformation qui était opérable et guérissable.*

(D.(1), T2)

During the ultrasound, they said to me: "Madam, something very serious has been detected in your child, there is a big problem in the brain. The problem is that we do not know exactly what it is, we must make an appointment with some experts to examine in depth this problem".  
*à l'échographie ils m'ont dit : « Madame, on a décelé quelque chose de très grave chez votre enfant, il y a un gros problème au niveau du cerveau. Le problème c'est qu'on ne sait pas*



*exactement ce que c'est, il faut prendre rendez-vous avec des professionnels pour approfondir ce problème-là ».*

(J.(2), T5)

The second class (7.74% of the U.C.E.) refers to the objects and memories of the child (photo, track - *empreinte*, bracelet, necklace - *collier*, blanket - *doudou*, plush - *peluche*, clothes - *vetement*, stroller - *poussette*), to the house, especially compared with the bedroom and the living room where objects are usually exposed (room - *chambre*, buy - *acheter*, bed - *lit*, furniture - *meuble*, shelf - *étagère*, decorative - *decoratif*, living room - *salon*, home - *maison*, appartement) and to rites (angel - *ange*, candle - *bougie*, urn - *urne*, ash - *endre*, offer - *offrir*).

In fact, we emptied the ashes in a corner, and we kept the urn at home.

*En fait on a vidé les cendres dans un coin, et on a gardé l'urne à la maison.*

(J.(4), T5)

The little shelf that we put on the side of the bed. We put her little things, gifts that we had from friends, we put her birth bracelet, flowers, we made a small corner, in fact, for her.

*"La petite étagère qu'on a mise à côté du lit. On a mis des petites choses qui sont à elle, en fait, des cadeaux qu'on a eu par des amis, on a mis son bracelet de naissance, on a mis des fleurs, on a fait un petit coin, en fait, pour elle.*

(J.(2), T5)

I think it is useless. But there is the box there and then my personal box that I still keep very selfishly with ... footprints, a hat, his cover and his pajamas. I am unable to put it in the collective box for the moment because... because it is too difficult to detach.

*Là je pense qu'il s'en sert plus. Mais voilà y a cette boîte là et j'ai ma boîte que je garde encore très égoïstement avec heu...les empreintes, un bonnet, sa couverture et son pyjama.*

*Là je suis incapable pour le moment de mettre heu dans la boîte collective parce-que... parce-que c'est trop difficile de se détacher. Voilà".*

(C.(1), T1)

We visit him regularly in the cemetery, we bring him flowers, candles.

*On va le voir régulièrement au cimetière, on lui apporte des fleurs, des bougies.*

(J.(4), T3)

The stroller was sold and then the stuff of the room, they are always stored in a tidy room, I was not able to sell them.

*La poussette on l'a vendue et puis les affaires de la chambre, elles sont toujours rangées dans une chambre rangée, j'ai pas réussi à les vendre.*

(J.(3), T5)

Every 26 we light a candle for him and we give him back, we bring him a bouquet of flowers at the cemetery.

*Tous les 26 on allume une bougie pour lui et on lui rend, on lui amène un bouquet de fleurs au cimetière.*

(A.(2), T2)

The third class (66.76% of the U.C.E.) is about support groups, those present on the Internet (group - *groupe*, support - *parole*, facebook, network - *reseau*, contact, send - *envoyer*, messenger, page, site, association, perinatale, organize - *organiser*, etc.) and references to social support (live - *habiter*, social, parent, aunt - *tante*, etc.).

We really have good support from our friends, family, and friends. I put the support of my parents away because I do not find it too much as a support, I have never been too much close to them.

*On a vraiment un bon soutien de nos amis, de l'entourage, de la famille. Moi le soutien de mes parents je le mets un peu à distance parce que je ne trouve pas qu'il soient vraiment un soutien, j'ai jamais trop été proche d'eux.*

(D.(1), T1)

I bring my point of view, and it can be useful. Then, the Facebook group that I created it is useless for the moment because there are no participating parents.

*Donc là, moi, j'apporte mon point de vue, et ça peut être utile. Après le groupe Facebook que moi j'ai créé pour l'instant il sert à rien parce que y a pas de parents participants.*

(N.(2), T2)

Because I had created a Facebook page to find local parents and there are new parents who contact me once per month or once per two months.

*Parce que donc j'avais créé une page Facebook pour trouver des parents endeuillés localement et j'ai une fois par mois ou une fois tous les deux mois des nouveaux parents qui me contactent.*

(N.(2), T5)

There is none here, I have not found it [support group], I would have liked.

*Il n'y en a pas ici, j'ai pas trouvé [groupe de parole], j'aurais bien aimé.*

(C.(2), T3)

But for the moment, I still have not, I have not resumed any contact with all of my friends, for now.

*Mais pour l'instant, j'ai toujours pas, je n'ai pas repris contact avec l'ensemble de mes amis, pour l'instant.*

(E., T1)

I cut the bridges with everyone, especially people who were pregnant. I got back in touch when I was ready, a few months after the birth of the twins [the subsequent children] and with the people who remained benevolent despite everything.

*J'ai coupé les ponts avec tout le monde, en particulier les personnes qui étaient enceintes.*

*J'ai repris contact quand j'étais prête, quoi, quelques mois après la naissance des jumeaux [les enfants suivants] et avec les personnes qui sont restées bienveillantes malgré tout.*

(N.(2), T5)

I have some cousins with whom I am very close. After [with some] the uncles and aunts, I took a lot of distance.

*J'ai des cousins avec qui je suis très proche. Après les oncles et tantes j'ai pris énormément de distances.*

(C.(1), T3)

Many with support groups on the internet, it's true that the support groups were beneficial.

*Beaucoup avec des groupes de paroles sur internet, c'est vrai les groupes de paroles c'était bénéfique.*

(J.(3), T5)

I have a friend who has lived something similar, who has lost twins, and now I'm talking to her mainly, it's better for me than going on the social network.

*J'ai une amie qui il est arrivé un peu une chose similaire, qui a perdu des jumeaux, et maintenant je discute principalement avec elle et ça me fait du bien plus que d'aller sur les réseaux sociaux maintenant.*

(J.(3), T4)

But what I really appreciated in the support group was that there were parents who had other children after and especially I recognized myself in them because since I got pregnant everyone told me [...].

*Mais ce que j'ai apprécié justement dans le groupe de parole c'est qu'il y avait des parents qui avaient d'autres enfants après et surtout je me suis reconnue en eux parce que tout le monde me disait quand je suis tombée enceinte [...].*

(E., T3)

The fourth and final class of Group C (12.14% of the U.C.E presents instead a lexical universe that refers in particular to the emotional aspects of the parent (moving forward - *arriver*, cry - *pleurer*, so much - *tellement*, think - *penser*, live - *vivre*, desire - *envie*, anger - *colere*, feel - *ressentir*, etc.) and to subsequent child (complicate - *compliquer*, necessarily - *forcément*, belly - *ventre*, debut, desire - *envie*, fear - *peur*, way - *façon*, arm - *bras*, etc.).

I think that this will have consequences for the relationship I have with C. [the subsequent child], but I do not think I'm going to make a transfer because L. [the deceased child] is L., C [the subsequent child] is C.

*Je pense que ça aura des conséquences sur la relation que je vais avoir avec C. [l'enfant suivant], mais je pense pas que je vais faire un transfert parce que L. [l'enfant décédé] c'est L., C. [l'enfant suivant] est C.*

(E., T3)

We were happy, we were happy. Afterwards, when we decided to make a second one, at the beginning, when the time that the idea of the second child made its way, I really imagined only a girl, and as long as I imagined only a girl, I thought I should not be quite ready yet, I told me: "I must project myself as much with a girl as with a boy, for me it was a little sign that I was not completely ready".

*On était content, on était content. Après quand on a décidé d'en faire un deuxième, au début, quand le temps que l'idée du deuxième enfant fasse son chemin, je n'imaginai vraiment qu'une fille et tant que je n'imaginai qu'une fille je me disais que je ne devais pas être tout à fait prête encore, je me dis : « il faut que je puisse me projeter autant avec une fille qu'avec un garçon pour moi c'était un peu le signe que je n'étais pas tout à fait prête ».*

(D.(1), T4)

I feel less broken, in fact. At first, in the beginning, I really had no strength, no energy, no desire to do anything. Now I can come out, do something else, get my mind up, do other things, and I can do something else without feeling of guilt.

*Je me sens moins brisée en fait. Au début, au début j'avais vraiment plus de force, plus d'énergie, plus envie de rien faire. J'arrive euh, à sortir, à faire autre chose, à m'aérer l'esprit, à faire autres choses en fait, j'arrive à, un peu à faire autre chose sans forcément culpabiliser.*

(E., T2)

I was so sorry, I wanted to tell her "I'm sorry I couldn't do you well.

[...] That makes me feel good and then makes her exist too, and I think that having other children, it will make her exist even more because that will give her a real role as big sister and we will talk to them about her ".

*J'étais tellement désolée, j'avais envie de lui dire « je suis désolée de pas avoir réussi à te faire bien ».*

*[...] Ça qui me font du bien et puis qui la font exister aussi et je pense qu'après le fait d'avoir d'autres enfants, ça la fera encore plus exister en fait parce-que ça lui donnera une vraie place de grande sœur et puis que qu'on leur parlera d'elle.*

(D.(1), T1)

It is super stressful, it' is super complicated to manage, we are afraid that it will be the same thing.

*ça va être super stressant, ça va être super compliqué à gérer, on va avoir peur qu'il se repasse la même chose.*

(J.(2), T4)

It was difficult to invest completely because with the anxiety that it starts again, there are things difficult to live.

*ça a été difficile de l'investir complètement parce que ben avec l'angoisse que ça recommence, euh qu'il y ait des choses difficiles à vivre.*

(J.(3), T3)

Table 35 shows the categories of each class.

In this second analysis of Alceste only Group B, i.e. those who have followed a therapy, presents six classes, while Group A presents five classes, and Group C four.

Groups A and C, made up of those who have not had any psychological support and who have used the groups present on social networks, often have categories of words in common in each class.

The categories present in the first class of these two groups refer in particular to more rational aspects of grief, such as the cause of loss, the medical aspects and the description of the event. On the contrary, Group B's categories are elements that concern the objects linked to the child, the house – in particular the specific places where these objects are exposed and the child's bedroom – and rituals or the bond with the cemetery, funeral rites, treats and the practices put in place by the parent (such as lighting candles, offering flowers in the child's memory, etc.).

These categories are also the same as those of the second class in Group A (NO) and in Group C (IT Groups). In Group B (Psychotherapy) there are references to psychological support given by participation in support groups, IT groups (categories often present in the same class as confirmation of the parent's confusion) and social support, such as that friends, family, colleagues, etc.

As in the second class, as well as in the third class, Groups A and C have the same categories as the previous class of the Group B. In all three groups reference support and IT groups. It is important to underline that psychotherapy is absent in both in Groups A and C.

Furthermore, in Group C (IT Groups) social support is also present; while there is only one category in Group B (Psychotherapy): emotions and feelings of the parent. This also corresponds to the category of the fourth class of the Groups A and C.

In Group A (NO), there is also social support (already present in the second class of the Group B and in the third one of C) and the couple, or references to the partner, to the different experiences and expressions of pain.

Groups B and C instead report the category of the subsequent child, or the relationship and the role of the deceased child. It is, for the second time, the only category present within the Group B classes (Psychotherapy).

There is also a fifth class for Groups A and B. There are references in Group A to the family (or to the role of the child and to family relationships), the aspects linked to bureaucracy and religion, in

this case intended as a support. It is important to emphasize that these last two categories, i.e. bureaucracy and religion, are also present exclusively in Group A (NO).

For the fifth and sixth classes of Group B (Psychotherapy) the categories of the cause of loss and of the medical aspects (in the fifth) and of the description of the event (in the sixth) are present in particular with respect to birth, death and the announcement.

The three categories that we find here in the last two classes of Group B were in the first class of the other two groups.

	<b>Group A (NO)</b>	<b>Group B (PSYCHOTHERAPY)</b>	<b>Group C (IT GROUPS)</b>
<b>First class</b>	Cause of loss		Cause of loss
	Medical aspects		Medical aspects
	Description of the event		Description of the event
		Rites	
		Home	
		Objects	
<b>Second class</b>	Objects		Objects
	Home		Home
	Rites		Rites
		Psychological support (psychotherapy, support groups, IT groups)	
		Social support	
<b>Third class</b>	Support groups		Support groups
	IT groups		IT groups
		Emotions and feelings	
			Social support
<b>Fourth class</b>	Emotions and feelings		Emotions and feelings
	Social support		
	Couple		
		Subsequent child	Subsequent child
<b>Fifth class</b>	Family		
	Religion		
	Bureaucracy		
		Medical aspects	
		Cause of loss	
<b>Sixth class</b>		Description of the event	

Table 34 Categories of the second analysis of Alceste.

## 11.2 Interpretative Phenomenological Analysis

The purpose of the IPA is to be able to understand how participants make sense of the world around them and their lived experiences. The analyst immerses himself into the world of the participants. He tries to interpret their mental and emotional states. The analyst's work is therefore an active interpretation process, which is one of the fundamental elements that distinguish this specific method of analysis from others.

Our goal is to understand how parents experienced their grief, as well as understanding professional support.

Initially, a preliminary study was conducted with the first three interviews of each participant.

According to the literature (Collins & Nicolson, 2002; Eatought & Smith, 2017; J. A. Smith, 2004; J. A. Smith & Osborn, 2003), to be able to carry out a valid and solid analysis through the use of the IPA, it is necessary to consider a limited number of participants. Therefore, in order to maintain a high level of methodological quality, it was subsequently decided to select and analyze the semi-direct interviews of four parents.

Two women and two men were selected as representative of the parents' experience to the loss of a child in the perinatal period.

Two women and two men (whose names were replaced with invented names) were selected as representatives of the parents' experience with respect to the loss of a child in the perinatal period.

The two women are Cindy and Susan. Cindy is a 37-year-old married woman and a businesswoman who lost her child at 26 weeks of amenorrhea after deciding to carry out a Late Termination of Pregnancy (LTP) following the diagnosis of a severe motor and cerebral handicap. The child was born alive and he lived three minutes.

The loss took place about 5 months before the start of the study (T1). Prior to the loss, Cindy already had become the mother of two other children, a boy and a girl, who at the time of the death were 11 and 8 years old. During the study, another child was born, about a year and a half after the loss of the child. In addition, for the entire duration of the study, i.e. 18 months, Cindy has undertaken a path of personal psychotherapy and participated in the IT groups.

Susan, on the other hand, is a 31-year-old woman, linked in a civil partnership with her partner. She is also an employee and mother of a child that died at eighth months of pregnancy, about 10 months before our first meeting. Susan and her husband have decided to carry out an LTP because the doctors had diagnosed the child with a serious cardiac malformation. About a year and a half away from the loss, another baby was born. With respect to therapeutic support, Susan was followed by a therapist all 18 months of the study and at the same time participated in support and IT groups.



The two men are Tim and Thomas. Tim is a 36 years old man, linked in a civil partnership with his partner, employee and father of a child that died about nine months before T1. The child died on the 36th week of amenorrhea, following the decision to carry out an LTP after the diagnosis of a chromosomal disease. Tim and his partner immediately tried to have another child after his death. The couple had fertility problems, the child was conceived after a 3-year journey of Medically assisted procreation (MAP). About 2 years after the loss, he and his wife had a pair of twins. Tim was followed by a therapist for about six months, but he never felt the need to participate in support groups (not present in his area) or in groups available on the internet.

Thomas is a 31-year-old male who lives with his partner and is the father of a child who died during the ninth month of pregnancy without any initial medical explanation. The autopsy results arrived six months after loss, showing that the death was due to a placental defect. The first meeting with Tim took place about a month after the loss.

Thomas has fertility problems. The child was conceived after seven years of MAP. Currently, he and his partner have resumed treatments to try and have another child.

Thomas has never received nor has he requested any professional therapeutic support and does not participate in Social Networks groups.

Out of respect for the privacy of participants, the phrases and parts of interviews that determined the categorization will not be shown.

Compared with the analysis of the five interviews carried out with these four participants, the Interpretative Phenomenological Analysis highlighted five general categories:

1. The description of the event;
2. A continuing bond;
3. Social support;
4. Subsequent child;
5. Psychological support.

As explained above, the IPA is a process that takes place from the bottom up. The summary of sentences and paragraphs of the interviews led to an unlimited number of notes, which are subsequently resumed and summarized in the main and subordinated themes listed in the table below (Table 36). After having started working exclusively on the paragraphs' summaries of the interviews, the work of categorization took place in different steps.

Before this final version, for example, the previous one consisted of nine and not five categories. To make the issues more understandable and inclusive, it was subsequently decided to reduce the number of categories. The previous categories were more general. For example, there was a category called "child", which contained the themes of symbolic objects and experiences with him or her, or there

was a category just for the partner and hospital. They were subsequently reorganized and associated with other similar themes to make the analysis more valid and complete. The final categories were considered the most inclusive, comprehensive and clear to present the themes encountered during the IPA.

<i>Categories</i>	<i>Themes</i>	<i>Keywords</i>
<b>1. DESCRIPTION OF THE EVENT</b>	1.1 Emotions and feelings	Anger, sense of guilt, difficult dates, acceptance, loneliness
	1.2 Experiences with child	Proximity, body, memories
	1.3 Cause of loss	LTP, unknown cause, decision, diagnosis
<b>2. CONTINUING BOND</b>	2.1 Linking objects	Memories, memory box, home, baby's room
	2.2. Symbolic and religious representations	Rites, cemetery, spirituality, religion, tattoos
	2.3 Bureaucracy	Legal rights, recognition
<b>3. SOCIAL SUPPORT</b>	3.1 Partner	Support, communication, sex
	3.2. Family	Living children, grandparents, support
	3.3 Friends	Communication, recognition
	3.4 Hospital	Health professionals, reactions, need
<b>4.SUBSEQUENT CHILD</b>	4.1 Desire	Spontaneous or artificial project (Assisted Reproductive Technology - ART, adoption), fertility
	4.2 Subsequent pregnancy	Fears, emotional investment, dates, replaced child, support
	4.3 Subsequent child	Relationship with deceased and subsequent child, investment
<b>5. PSYCHOLOGICAL SUPPORT</b>	5.1 Psychotherapy	Help, considerations, usefull
	5.2 Support group	Support, comparison, logistical difficulties
	5.3 IT groups	Isolation, necessity, support, comparison

Table 35 Categories and themes of IPA

## 1. Description of the event

In the description of the event there are three different themes: emotions and feelings of parents, experiences with the child and cause of loss.

This was often experienced as a traumatic event that conditioned and determined important and different reactions in the parent.

We can see how there are ambivalent perceptions, with respect to grief in general, to the child and also according to gender.

The different experiences between men and women are evident and with a common sense of suffering and difficulty.

### 1.1. Emotions and feelings

Numerous and different are the feelings and perceptions extrapolated from the interviews carried out with the parents. Longitudinal research was useful in following their path and how, progressively, the intensity of their pain has changed, accompanied by a sense of constant sadness.

Cindy declares that over time she was able to make sense of the loss, as well as speak and associate the child's memories, not only with a strong sense of sadness, but also with happiness.

Furthermore, Cindy perceives the role of the one who must claim the existence of the child. The acceptance of death coincided with the awareness of the difficulty and uniqueness of perinatal loss, poor in memories to be shared.

Susan initially associated the child's loss with her own death, as if there had been another person since.

Anger, jealousy and a sense of injustice are some of the emotions that Susan describes about her grief. She then perceived a vortex of different feelings up to the difficult acceptance of the loss.

The loss of the child was therefore totally destabilizing, making her aware of unusual aspects of herself.

In our last meeting, Susan said she had a miscarriage. Despite the perception of progression with respect to the emotional phases that follow grief, this event was experienced with a return of a similar strong sense of anger and injustice.

Susan is aware of having to continue working on these feelings, which are obviously still very present. Furthermore, she does not seem to have experienced abortion in a painful way, probably because during the study a healthy and living child was born, which could be understood as a confirmation and narcissistic reparation to be able to have a healthy child.

The expressions used by Tim and Thomas are different.

They suffer and feel sadness and pain for the loss of the child, perceiving a sense of emptiness and difficulty in accepting it.

But for men it seems more difficult to verbalise their feelings. Tim declares that it is difficult to "*put it into words*".

Perinatal loss is experienced as a traumatic and shocking event, "*nothing will ever be the same again*". Eighteen months later, Tim also recognizes the need to remember the child's existence on a social level.

The pain of loss was also linked to the narcissistic wound inflicted by the difficulty of being able to conceive a child. The birth of twins, the subsequent children, is considered as a source of hope, as a change, and a reparation of the consequences of grief, in particular with respect to the isolation and recovery of social and family contacts.

Men also tend to avoid talking and showing their pain by hiding and masking it. Thomas also uses the term "combat", a typically masculine association, meaning the inner struggle to succeed in overcoming sadness.

Furthermore, they often perceive their grief as secondary and dependent on that of their partner.

Compared with the possible differences between the experiences of mothers and fathers, women present more feelings of anger, guilt and a greater ambivalence than the cause of the child's death.

Loss is perceived as a failure with respect to the biological role of women, understood socially and culturally as a creator of life.

Cindy feels the guilt of "*not having made a child with a brain*."

By rationalizing, she realizes that she made the best choice for the child based on the diagnosis; However the sense of guilt, perceived as pain in the heart and therefore assuming a somatic connotation, is always present.

For Susan the sense of guilt takes on a more social connotation, or rather the prejudice of being the woman who failed to give birth to a child and who killed him in her womb.

Cindy also expresses feelings of regret and the fear of having made the wrong decision, asking her husband, probably considered more lucid and detached, to remind her of the seriousness of the illness and the reasons that led to their decision.

Men instead, perceive a secondary role in grief, above all on a physiological level. They tend to feel less guilty and have less of a sense of responsibility than mothers. They are perhaps more easily accepting of the event and show more confidence to doctors' advice.

Furthermore, parents also perceive specific dates as more difficult. They do not concern themselves exclusively with the anniversary of the birth or death of the child, but also holidays.

For Tim it was important to let people around him know which dates were more "delicate".

He therefore perceives the importance of the child being remembered, not only by him and his partner, but also by all the dearest to him.

The recognition of their pain and the existence of the child on a social level is seen as fundamental. Furthermore, these dates are perceived with fear, in particular with respect to the emotions and the reactions that may emerge. At the same time, as yet further confirmation of the progress of grief, it is important for parents to make sense of these dates, taking the opportunity to commemorate the child and celebrate his existence, as in the case of Cindy.

Following the loss, parents often perceive themselves as changed, more empathetic, more attentive and as having different priorities.

They give importance to other things, relate differently and are more attentive to some dynamics.

The child's loss is perceived as an inner change.

## 1.2 Experiences with child

Parents often consider experiences shared with the child in the hospital or in the mortuary as limited but fundamental.

These moments, despite the passing of the months, remain vivid and lucid in the parent's memory, and is probably idealized. The encounter with the real child is perceived as the only family moment in which the parents had the opportunity to know him or her.

Cindy talks about the importance of seeing and meeting the child, as well as memorizing his physicality.

Following birth, Cindy's baby remained alive for three minutes before passing.

She considers this birth as a gift from the child and as a confirmation of having succeeded in giving birth to a living child. She describes the child in terms of generosity ("gift") and strength ("to have right").

Within the experiences with the child, kinesthetic descriptions of mothers are also included. The pregnancy period is probably idealized, emphasizing the symbiotic relationship between the mother and her child.

There is the image of Cindy waking up in the middle of the night, talking and sharing moments with her child. Thinking that probably a limited investment in the course of pregnancy would have produced minor suffering, she declares that she has no remorse and is grateful for those months of pregnancy.

Fathers' experiences may be different. First of all, Tim underlines how the child was first placed in the mother's arms.

While women declare a more kinaesthetic relationship and a connection started with the child during pregnancy, one of Tim's most important memories is dressing his child, a gesture of care, protection and a unique moment between father and daughter.

Like Susan, Tim also expresses the importance of having spent time with his child and the partner, as well as collecting memories like photos.

Furthermore, once again Tim refers to the possible male role in the perinatal loss and the need to remain lucid and organize the funeral alone (probably because it was too difficult for his partner).

There are also parents like Thomas who instead decide not to see the child. He states that he was not strong enough.

The fear of trauma and the effect of a deceased child's body can therefore frighten the parent. The parent instead prefers to keep the fantasies of the imaginary child.

Furthermore, Thomas also perceived a change in his personal vision of perinatal loss. If in the beginning he considered the death of a living child more difficult, with time and the evolution of emotions and consequences related to loss, the sadness of not having been able to have and share moments with the child is now greater for him. This emphasizes the importance of memories (absent in perinatal loss and especially if occurred during pregnancy).

### 1.3 Cause of loss

The parents' experiences with respect to the child's loss, the announcement of the diagnosis and the decision to carry out an LTP are collected within this category.

We can see how Cindy and her husband made the LTP's decision following the diagnosis of severe motor and cerebral disability.

She thought of the child (who would not be able to recognize her) and of the living children, even on a social level.

This category therefore shows how in LTP's circumstances parents experience a "double choice", characterized by the rational and emotional aspects of parenting.

For Tim, the event was not totally unexpected. The child's pregnancy was at risk from the very beginning. Despite this, he did not expect such a serious diagnosis, which led him and his partner to decide to carry out an LTP.

He speaks of the "worst imaginable end"; he was probably ready for an abortion but not having to make such a decision.

Moreover, he expresses the pain of waiting between the diagnosis and the operation. He reports some references to the suffering and kinesthetic sensation of the partner who carried the child for those seven days, which he describes as "a parallel world".

Tim then perceived the diagnosis and the following moments as surreal, difficult to realize and at the same time distant. He also speaks of not being the physical protagonist of the story.

Thomas recounts the shock, the totally unexpected event of the diagnosis and of the child's death that occurred during the pregnancy. For him, the pregnancy was seen as perfect and serene, and everyone was happy.

Also in this case, there is the kinesthetic aspect of the partner. The concerns about the child's health arose because her partner did not feel her kicking.

He also speaks of traumatic reference, given by probable intrusive images (*"I can see the 48 hours I saw my wife suffer"*).

Thomas's perception of the child's death and of the announcement are linked above all to the experience of the partner and his feeling of powerlessness to see her suffer.

The cause of the death of Thomas's child is unknown. Understanding what happened seems like an obsession. In particular, he designs and imagines the next pregnancy. This is characterized by great anxiety and stress. Not knowing the cause therefore seems to affect his grief and the images of his future.

Susan reports on how she and her partner found out about the disease.

Susan's experience is very precise and detailed, even at the temporal level. Her perception seems very mechanical, taking up and probably underlining the rational aspect that led to her decision to carry out an LTP.

## 2. Continuing bond



Within the categories of continuing bond we find the themes of linking objects, symbolic representations and bureaucracy. For the bereaved parent it is important in trying to maintain a bond with the child, be it through the objects or specific practices or the legal and social recognition of his or her existence (for example, through his or her registration in the family record book).

### 2.1. Linking objects

For parents, keeping memories of the child, such as items bought for him or her during pregnancy or those in the memory box and photos, is essential.

As often happens after loss, a psychological mechanism is to the symbolization of objects, which assumes the meaning of the emotional bond with the deceased, as well as a sign of his existence and emotional closeness. These objects are referred to as symbolic objects.

Even in the case of perinatal loss, parents manifest the need to project the child's memory onto an object.

For example, Cindy talks about the need to touch/hug her son's cuddle toy at night. She associates this object with the child, "*Who I had with me all the time*," aware that it is a metaphor for this lack. Furthermore, in the hospital, nurses generally give parents the memory box, a box with photographs, documents and objects belonging to the child, such as clothes, bracelets, etc.

It seems that Susan does not have many objects related to the child, except however for the hat, which remains very important for her. It retains the smell of the child.

The object is therefore associated not only with memory but also with the sensory aspect, in this case olfactory.

Thomas instead tells of his ambivalent relationship with an armchair he had designed but not finished for the child, where he imagined he would rock her during the night.

Thomas fails either to touch or throw away the object that reminds him of the child, his work and the paternal image. He doesn't know what to do, he's confused, he can't make a decision.

The objects related to the child can therefore be perceived not only as a source of joy but also of sadness, determining feelings of conflict and avoidance.

The objects related to the child, however, are often kept by parents in specific places. For example, many of them, like Susan, place memories in a corner of the living room to remember the child and show his or her existence.

Susan describes exactly what she has placed in this small space dedicated to him, without expressing feelings of sadness or anger. She describes the objects that remind her most of the child, including a

candle that remains lit all the time and gifts bought for his birthday, continuing then the bond with the child and acting on specific dates as if he were alive (buying presents for his birthday).

The connection with the child is not given only by objects that remind the parents of his existence, but also by some specific places, such as the child's bedroom or the whole apartment.

Parents often project their pain and grief onto the bedroom designed for the child. It is often difficult for them to change the room or give this place another function. It can often remain intact or avoided, causing a sense of inhibition.

For example, Cindy describes how aware she is of the fact that the baby has never been there or used the furniture and objects. It is very difficult and painful for her to empty the bedroom. She describes it as a "*very complicated*" room.

Cindy had already organized the bedroom and is now finding it difficult to empty it. Susan had not yet finished organizing the bedroom for the baby's arrival, but at the same time the room remained empty, thus perceiving a difficulty in giving it another role.

Additionally, Susan did not perceive any difficulty in donating the room previously designed for the child to the next sibling. To finally consider that room as the bedroom of a living child was for her a sort of "revenge", a restorative fantasy.

As mentioned above, not only can the room be seen in an ambivalent manner and linked to the memory of the child, but the whole apartment as well.

For example, Tim describes the difficulty of living in the same house where, above all, his wife, experienced the pregnancy. This has led to the decision to move.

## 2.2. Symbolic and religious representations

Within this theme there are the references with respect to rituals, to burial sites, spirituality and tattoos, as the child's metaphor.

For example, Cindy recounts the initial visceral need to go near the tree where the baby's ashes were spread during the night.

This tree is therefore considered as the resting place of the child, where the child is present, thus determining an obsessive attachment and the difficulty in letting him go.

Furthermore, declaring herself as laic, Cindy was interested in baptizing the child through a civil ceremony. Not being allowed to baptize someone who is deceased, she thought of organizing a birth party and of identifying a godfather and a godmother for the deceased child.

She realizes that she is asking for "*something special*", not common or recognized at a social level, and having to look for someone "*with an open mind*". She sees and understands the difficulty of the

social recognition of her request but, in spite of this, she highlights the need to celebrate and remember the birth of the child.

Parents also tend to implement rituals, "home" practices and symbolic representations of the child, such as lighting a candle in his memory on specific days.

For example, Tim lights a candle every 10<sup>th</sup> of the month, the anniversary of the child's birth and death.

Furthermore, the memory of the child also resurfaces thanks to the symbol of a small bird, a natural living element linked to an image of freedom.

Tim shows no hesitation in talking about such actions and associations, they are instinctive and in response to the need for bonding and attachment with the child.

Cindy perceives the need to believe that there is something after death, particularly with respect to the memory of the deceased child. She associates the memory of her child, or more generally, the image of an angel with that of the feathers. Believing that a feather means the passage of an angel is a comfort to her.

As mentioned above, in addition to religious rituals and symbols related to nature, a modern metaphor is often that of the tattoo.

Thomas tattooed a stylized image dedicated to the child on his back.

Thomas says that washing the tattoo is like clean the child, thus indicating a symbolic connection with him.

He then perceives the need to affirm his role, to continue taking care of his baby.

On a spiritual and religious level, not all parents recognize the cemetery as the reference point for the child's rest.

For example, Thomas rationally describes how there are no ashes for a child who died too early. The memory, the connection with the child is therefore not given by the cemetery but totally internalized, in the heart and in the head, on a cognitive, emotional and affective level.

Furthermore, linked to the concept of spirituality is the concept of religion.

As a believer, Susan experienced a moment of anger and incomprehension related to her faith, which was not considered as a support.

She also perceived a sense of abandonment and injustice, professing religious teachings in her daily life and having, despite this, experienced such a tragedy.

### 2.3 Bureaucracy

Bureaucracy is a further source of suffering for many parents. The lack of legal and bureaucratic recognition of the child defined according to medical and legal criteria does not correspond to the parent's experience and feelings. Being denied the child's existence can sharpen the sense of incomprehension and isolation.

For example, Cindy holds the administrative system responsible for making her progress and mourning (associated with the metaphor of a scar) even more difficult.

An administration considered totally unsuitable reminds her that the birth and death of her child are events considered out of the ordinary, which the bureaucracy is not prepared to handle.

Furthermore, Cindy perceives a sense of anger with respect to a bureaucratic system that does not allow her to recognize the existence of her child through a civil baptism. It is a forbidden and unrecognized practice for a deceased child.

Compared with the recognition in the family record book, not registering the child with his last name or that of his partner created great anger in Thomas. This was especially true in the beginning, and then followed by intense disappointment.

He perceives a sense of injustice given by the legal and bureaucratic non-recognition of his child, only because she was born lifeless.

### 3. Social support

Social support includes the categories of partner, family and friends, from the most intimate entourage to the most extensive.

Furthermore, there are also references to the parent's experiences in the hospital and the perception and judgment of professionals, such as doctors, midwives, nurses, etc., whose work and support are fundamental for the grief of the parent.

#### 3.1 Partner

The interviews conducted with the mothers and fathers who participated in the research emphasized the social roles with respect to the expression of grief.

Since the mother was the one who carried the child in her womb and underwent surgery, maternal grief is considered a priority, while the father takes on the role of protector of the woman's psychological and emotional condition.

For example, Thomas considers himself in a subordinate position, in which his duty is to support and help his partner, assuming the burden of hiding his pain so as not to influence or overload her with his sadness.

For Thomas, the loss of the child meant not only pain and suffering but also an element of sharing and solidification of the couple.

He considers his partner the only real and present support, the only person who can truly understand the painful situation. He uses the metaphor of a boat. In the beginning, those who understand and support each other are Thomas and his partner. Only afterwards and in different grades is there the support given by the social entourage.

Furthermore, there are several dynamics that can be created within the couple following the loss. For example, Cindy and Susan perceive how the different conception and expression of grief influenced their relationships with their respective partners.

Immediately after the death of the child, they both perceived the relationship with their partner as stronger and more solid.

Subsequently, Cindy began to see her husband as distant and herself as alone and misunderstood, also declaring that the progress of each one occurs at different times.

With time and greater acceptance, the perception of the partner's support and experience also changed in Cindy.

Over the months, she began to accept the partner's expression of pain, realizing that love and recognition of the child's existence are not questioned. Furthermore, she recognises that they each

have their moments of weakness, not wanting therefore to impose her modality of expression on her partner or to consider him exclusively as a support, ignoring his necessities.

Susan instead perceives difficulty in terms of communication. She expresses her need to talk about her child, especially with her partner. She is unable to explain and understand his behavior, and above all his minimal need for expression and sharing.

As we have seen, grief is often perceived especially by women as a tragic event that has produced not only an intrapersonal upheaval, but also at the level of couple.

Tim also experienced loss as a source of change in the balance of the couple's dynamics.

The feeling between "two" is always the same and very strong but the child's death was experienced as a breakdown in their stability.

Compared with the relationship with the partner, there are also references to the sexual life, often experienced differently by men and women.

For example, Cindy showed some initial difficulties. In particular, the first reports were experienced as a shock, linked to the kinesthetic memory of the child's birth.

Sex has been associated with childbirth and perceived with fear, for having to relive this feeling and not be the same person again.

For Susan, it was difficult to live peacefully and resume sexual relations with her partner especially in the beginning. Sex was linked to the inability to be able to feel pleasure without feeling guilty about the child, as if "we had no right".

Thomas, on the other hand, perceives sex as a way of being closer to his partner. After the initial difficulties, probably more on a physiological level due to the operation, the sexual relationship is considered as improved and more frequent. Thomas lives and considers the increase in sexual intensity and quality as the only advantage derived from the loss of the child.

For others, the desire for a new child can influence sexual relationship, as in the case of Tim.

### 3.2. Family

Compared with the family, there are the references both of the family of origin and of the living children, those who were born before the loss.

Parents often define their children as a support. For example, Cindy perceives how the living children were able to understand her pain and need to mourn the deceased child.

Compared with the family of origin, parents are not always perceived as a source of help.

Cindy speaks in particular about her mother, who despite the death of her grandchild, is perceived as a nefarious person and without empathy,.

Cindy says that it's already been two years since she has taken a distance from her, meaning that the relationship with her mother was already difficult and complicated before the loss of the child.

Furthermore, especially following the birth of the subsequent child, Cindy perceives the need to remember the child's existence. The fact that he is not brought up during family conversations is experienced as something frustrating, incoherent to her needs and feelings for which commemorating and remembering the child is fundamental.

Susan sees that the only important aspect for her parents is to see her advancing in her grief, without trying to help her or understand her or talking about the deceased grandchild.

Susan instead declares that she can't hide what happened or move on and return to her previous life. She perceives the need to be sad and to cry over the child, and the only person with whom she shares all of this exclusively is her partner.

For others, the loss of the child has made the relationship with the family more complicated.

In Tim's case, he understands that it is not easy, even for family members. They try to be close to him but sometimes they can take actions that can be considered as insensitive.

Even if there is no sharing and communication, Thomas instead is aware of family support.

He knows that his parents suffer and that they do not express their suffering, not because they are insensitive but because they do not want to add their pain to that of their child. He understands this dynamic because it is the same that he puts in place with his partner.

### 3.3 Friends

Compared with their larger entourage, some parents explain that they are grateful and supported by friends and colleagues.

For example, Cindy sees friends as essential, able to help her. Not all friends react or support her in the same way, and for her this is very useful. She speaks of "good friends" and "pure friends".

Cindy realizes that conversations about the child are decreasing more and more. Friends are more focused on the birth of the subsequent child.

She understands the reasons for this, but for her the need to remember and talk about the child remains essential.

On the other hand, other parents do not perceive the support of friends, but rather the need to isolate themselves.

In Susan's case, she perceived the social pressure of having to move forward, forgetting what happened. She has maintained relationships exclusively with two friends, the only ones who probably tried to talk about the child, to ask how she was, without forcing her or minimizing her grief.

Furthermore, she also perceives a sense of anger towards some friends who proved to be totally insensitive. In addition to self-isolation, she felt abandoned and unsupported.

Tim instead experiences a difficult situation with his friends. He does not perceive them as support, but he realizes that this feeling does not depend on friends, but rather on the isolation that he and his partner created and need. He then realizes the difficult situation in which his friends are, "*walking on eggshells*".

Thomas shows how people close to him often do not realize the pain and suffering that could be felt following the loss of a child.

He, as seen above, is a person who does not express his feelings and needs.

Despite this, the fact that people show themselves to be a little insensitive means that he is not treated differently.

He associates the loss with a handicap, he lives the death of the child as a deficit, and for this reason, he does not want to be reminded of what happened through others' behavior.

Parents emphasize attachment and affection towards the child begin during pregnancy.

In general, the parent can perceive how, on a social level, perinatal loss is considered as a non-event, a non-grief. The parent may feel misunderstood because the people believe that the pain of a child's death should disappear after a certain period of time, especially in light of a new pregnancy.

Cindy perceives this devaluation of the child's existence with disdain, sensing the need for her, as well as her close friends, to recognize her pain.

Some parents report how difficult it is to answer the question of how many children there are in the family.

As perinatal loss is very rarely used in everyday conversations and seen in the collective imagination, it is often difficult to understand how much this question, considered as simple and banal, is painful for a bereaved parent.

Often, the parent does not want to make others feel uneasy or simply does not want to open up with a stranger, but at the same time does not want to betray the child's memory by denying or minimizing his or her existence. The parent suffers from the responsibility of having an active role in keeping the child's memory alive, remembered only through the conversations and stories of parents or close persons.



This is the case for Cindy, mother of 3 other children, 2 born before and 1 after loss. She declares that this question is complicated and after the answer people "decompose", not able to react to such a situation.

### 3.4 Hospital

Another category is that of hospital professionals. The analysis revealed the need for perceived support from the parents in the hospital. It is essential for parents that the professionals be patient, as well as provide all the information and respect the needs of the parent.

It is necessary that the hospital is able to accept and manage perinatal loss and give the parent the possibility to choose how to relate to the child and the time needed to spend with him.

For example, Cindy reports how most professionals were understanding and supportive, suggesting that they see the living child and the possibility of spending time with him.

At the same time, she perceives anger and stupidity compared with professionals who instead treated the child exclusively as a fetus, minimizing its his existence and importance.

Susan also perceived hospital professionals as a support. Despite the diagnosis, they never tried to influence the parents' decision and did not "abandon" them even after the loss.

It was therefore very important for her to be able to choose independently and not feel judged, but rather supported.

Thomas's experience was different. According to him, the hospital was too rigid, too focused on protocols that only considered the medical aspect of the person, and not the psychological and emotional aspects.

He would have preferred to be able to have a c-section immediately instead of waiting 48 hours. Those 48h were evidently the hours of labor before birth, which he perceived as a common suffering, and therefore not only felt by his partner.

Furthermore, the professionals of the hospital had forgotten to call him and his partner to explain the results of the analysis as to the cause of the child's death. He then perceives a sense of frustration and possible anger, considering this gesture as further confirmation of the trivialization of loss.

Some parents, mindful of the support perceived in the hospital, also decide to be followed by the same professionals even for the next pregnancy. Although these professionals are a constant reference to the death of the child, they remember that they felt supported, understood and treated medically in the best possible way.

Susan considers that being followed by the same gynecologist from the previous pregnancy is helpful. The latter knows the clinical history and has shown, according to Susan, human and empathic facets, which she considered as fundamental.

#### 4. Subsequent child

As previously expressed, the time between the death of the child and the beginning of participation in the study by the parents is variable, characterized by a maximum time frame of about 10 months and a minimum of 22 days.

Within the category of the subsequent child there are the themes of desire, i.e. the project and wish to have a new child, and how the parent experienced the subsequent pregnancy and birth.

#### 4.1 Desire

At different times compared with the date of loss, parents often start thinking about and planning a new pregnancy.

Cindy perceives the importance of having finished the work of mourning, of being physically and psychologically ready to have a new baby. She is afraid that by doing things too quickly, she may risk developing the replacement child syndrome.

She is already thinking, projecting herself into the future of the next child. She wants to protect him, in order to not make him believe that he was born exclusively to fill a gap, because she knows that the deceased child will always be present.

The project of a new child is therefore lived with anxiety and concern, both for the deceased child and for the future one.

Susan also felt the need to wait. Furthermore, she was afraid of the dates of her new pregnancy and previous one coinciding.

The dates therefore represent a traumatic stimulus, a possible confusion and an element of difficulty in being able to mentalize and separate the two pregnancies.

Furthermore, over time and following the birth of the subsequent child, Susan perceives the need and desire to have other children. This desire depended on the traumatic aspect and the fear of reliving another loss. The child assumes a reparatory function. By declaring that she is aware that she is not replacing any of the children, in the event of further death she declares that the greatest support is the presence of other children.

Some parents reported their difficulties in not being able to have a new baby.

Due to the risk of genetic diseases and fertility problems, many have tried to have a child through assisted reproduction, in vitro, adoption, etc.

For Tim, the desire to have a new child and the difficulty in conceiving is a doubly painful, a double suffering that is added to that of having lost the child.

Even Thomas experiences some fertility difficulties. Furthermore, he is aware that fertility problems depend on him and he therefore feels responsible to request that his partner undergo physical suffering and stress. For this reason, he considers the desires and times of his partner as priority to his own, placing himself and experiencing his grief and the desire to have another child in a secondary and lateral position compared with that of his partner.

He therefore perceives the desire to have a child with feelings of guilt, responsibility and passivity.

#### 4.2 Subsequent pregnancy

Subsequent pregnancy is often described as an event experienced with great anxiety and fear of reliving another loss.

For example, Cindy perceives the difficulty of investing in the new child, of developing an emotional attachment. She is afraid of suffering another loss. The traumatic event of the death of the previous child caused a feeling of loss of control and safety, perceiving a sense of instability and unpredictability.

She perceives the pressure and the difficulty of investing in the baby associated with the growth of the belly, a mental and physiological symbol of the progression of pregnancy.

She therefore probably perceives social pressure given by the expectations of others with respect to the new pregnancy and maternal attachment (identified by not being able to hide her belly from others any more), but contrasted with her feelings of anxiety and fear.

Susan also perceives the difficulty of living and investing in this new pregnancy. She realizes that her attitude and expectations are different. She doesn't want to talk about the child, rejoice and share that moment with other people. She also perceives a sense of misunderstanding due to the common claims that the new pregnancy is the same as forgetting the deceased child or that this pregnancy will surely be successful. She feels insecure and sad. She does not perceive this pregnancy with serenity and prefers to isolate herself.

Moreover, Cindy explains that other difficult moments of the next pregnancy are also linked to stimuli given by hospital situations. She has chosen to be followed by the same professionals and for the check-ups, she must go to the same medical offices or to the same hospital. At certain times, being in those places is very painful, which denotes a further aspect of difficulty encountered during the new pregnancy.

Tim also finds it difficult to experience the new pregnancy in a serene and joyful way. The fear of reliving a loss is always constant.

Furthermore he perceives the difficulty of hiding the new pregnancy from all over the world, thus supporting the desire and needs of his partner and, in the meanwhile, he would not like to receive a lot of questions about the new pregnancy as well, but also not push his family and his closest friends away.

#### 4.3 Subsequent child

After the birth of the subsequent living and healthy child, some parents continued to perceive a concern of losing the child again.

For example, Cindy fails to separate from the child for fear that she may die during sleep. She is very agitated, she perceives a sense of insecurity and fear that something could happen at any moment. For this reason, she prefers not to leave the child alone.

In addition, she sees the deceased child in the subsequent child, notable in the facial features. She therefore wonders how the deceased child would have been if he had survived.

Owing to the constant reference to the child and the fear of suffering another loss, the death of the child can influence the relationship with the next child.

Furthermore, Cindy also perceives the difficulty of explaining his role to the subsequent child with respect to the loss. Cindy is especially afraid that the child may see herself as a substitute.

She states that she also felt guilty about the deceased child for having had the subsequent sibling "*too soon*".

This birth was therefore experienced in an anxious manner, not only with respect to the fear of suffering another loss, but also considering the role and the link with respect to the next and the deceased child.

## 5. Psychological support

Within this category are found the themes of psychotherapy, support groups and, based on the confusion and illusion of the parents who consider them therapeutic, the groups on perinatal loss available on various social networks, such as Facebook, blogs, forums, etc.

### 5.1 Psychotherapy

Compared with personal psychotherapy, those who are sought professional help often define this support as fundamental.

For example, Cindy perceives psychological support as a great help, both with respect to grief and in relation to the subsequent pregnancy.

She realizes that she is experiencing the new pregnancy with anxiety and fear, and has difficulties in investing in it.

She considers therapy as a safe place where she can express her suffering and reveal her feelings that often unrecognized and heard by her entourage (her husband, friends, etc.).

The progression of mourning is also found in the perception of psychological support and in the change in therapeutic demand.

With time, Cindy perceives therapy as useful, not only with respect to grief – a subject that has now become almost secondary – but above all to other topics, such as the relationship with parents, etc.

Susan also sees psychotherapy as a support to fill a gap. She considers the help of her family and friends useless. Professional support is therefore seen as a space for intimate listening, even if not completely understood since only a person who has experienced such a loss can actually understand.

Tim experiences the therapeutic support as useful in understanding how to manage his grief and the relationship with his partner, whom he believes is in more difficulty and whom he would like to help. Psychotherapy is therefore perceived for him as an accompaniment to reflection and to understanding how to help himself and his partner.

As often happens, not all parents perceive the need to contact a professional. Thomas says that instead of going to a therapist, he prefers to suppress his suffering. He is afraid that therapy could open his "inner bottle" and that he would not be able to manage his emotions and reactions.

Therapy is therefore perceived as a profound and probably painful process.

## 5.2 Support group

Most participants say that they are interested in participating in support groups; however there are logistical difficulties that render this impossible. The associations of support groups are often exclusively in the big cities, and therefore not easily accessible, and with time schedules they are often considered inconvenient.

In the imagination of those who would like to have the opportunity to go, support groups are considered a place of meeting and exchange.

Cindy often points out that for her, it would not only be a place where people could mourn deceased children, but also where to find hope and comfort and to meet parents that have overcome this pain and that have had a subsequent child.

For Susan, support groups are perceived as the only place where the child's existence is recognized. She perceives the social pressure of having to move forward because she is pregnant again. However, despite the new child, she needs a place to remember and mourn the memory of the deceased child. The comparison with other parents who can understand is seen as very useful.

Furthermore, many parents do not consider support groups to be a useful tool for grief. Many, especially men, declare the difficulty and/or uselessness of opening up and sharing their experience with unknown people, "*of being influenced by their sadness and not concentrating exclusively on their own experience,*" as is Tim's case.

## 5.3 IT groups

IT groups are the groups that we can find on Facebook. They consist of the various blogs and forums created with the sole purpose of discussing perinatal loss.

They are used mainly by mothers and are often associated and confused with therapeutic groups.

Fathers regard these groups as useless, and prefer discussing their pain with people they know or live, as in the case of Thomas.

For Thomas, human contact and direct interaction are very important.

For mothers, however, these groups are very useful as a source of support, understanding, closeness and exchange of information.

Cindy perceives a sense of support and common respect, of protection and a place where to express and ask any kind of questions, even those considered less acceptable on a social level (like jealousy and inability to see babies or pregnant women).

Furthermore, Cindy recognizes that with the advancement of mourning the need to participate in such groups has become marginal. At the same time, however, she perceives strong anger and frustration because, based on the comparison with the experience of others, she realizes that these groups exist above all to fill a social and bureaucratic gap with respect to perinatal loss. According to her, parents are not sufficiently supported and informed about this event and above all the following period.

For Susan, two of the most important support factors of these groups is availability and accessibility, without geographical and organizational limits, where people can activate conversations at any time. For her, these groups are also useful for meeting people who have been through the same experience ; those that can therefore understand her completely and with whom she can have conversations and exchange private messages with more intimate connotations.



To conclude, those presented in the previous chapters are therefore the results obtained during the qualitative and quantitative analyses.

In summary, the qualitative analysis includes two different tools: Alceste, a qualitative statistical program and the Interpretative Phenomenological Analysis.

Two different analyses were carried out with respect to Alceste.

The first one was to follow the evolution of the participant's speech, also trying to identify aspects related to the complicated grief disorder.

For this reason, since the time elapsed from the loss of the child to the first meeting was not the same for all participants (the minimum time between death and the first meeting was 22 days and the maximum was about 10 months), three different groups were created based on the moment of loss.

Group I (<6) (consisting of 19 participants, including 14 women and 5 men, and 30 interviews) was made up of those who had lost their child for less than 6 months.

The parents of Group II (6-11) (made up of the total number of participants, that is 29 parents, including 21 women and 8 men, with a total of 41 interviews) had lost the child from 6 to 11 months.

The third and final group (of 29 participants and 74 interviews) has lost the baby for over a year.

The total number of classes was 5: 4 for Group I (<6), 3 for Group II (6-11) and 5 classes for Group III (> 12).

The categories that emerged concerned: the causes of death, the description of the event, objects related to the child, home, emotional and psychological support (psychotherapy, support groups, and online groups), rituals, dates, and bureaucracy.

According to the results, a change in the topics of the discussion was highlighted. The categories for each group were almost always the same but appeared in different classes.

This result demonstrates how parents' speech has changed over the months.

Furthermore, exclusively in Group III (6-11) was present the category of psychotherapy, while in group III (> 12) those of dates and bureaucracy.

Finally, it is possible to see that there are no abrupt changes in the categories' position of the three groups. This comparison highlighted the linear and gradual change of the parents' discourse and needs, indicated by an initial need to maintain the bond of the child (first class of Group I) to end with the importance of his social recognition (last class of Group III).

The second analysis of Alceste concerned therapeutic support. The participants were in fact divided into three groups: those who did not demand any support (Group A - No); those who were followed by a professional and / or participated in support groups (Group B - Psychotherapy) for a minimum of ten sessions; and those who participated in online groups for a minimum of six months (Group C - IT groups).

The first group (Group A) consisted of 15 parents (9 women and 6 men), the second one (Group B) of 14 (12 women and 2 men) and the third one (Group C) of 9 women.

In total the classes were 6: 5 for Group A (NO), 6 for Group B (Psychotherapy) and 4 for Group C (IT Groups).

Specifically, we have seen a similarity of classes between Group A (NO) and Group C (IT groups).

Furthermore, in Group A (NO) the categories of partner, family, religion and bureaucracy were present only in this group, while the category of the subsequent child was absent.

The category of personal psychotherapy was present only in Group B (Psychotherapy).

In general, it emerged that Groups A and C presented fewer references to the emotional aspects of grief and to psychological and social support, compared to Group B (Psychotherapy).

Finally, with respect to the comparison between the two analyses of Alceste, they almost always presented the same categories, but with some differences. In the first analysis there were no references to the specific categories of couple, family, religion and subsequent child. While in the second analysis the category of the dates considered as difficult was missing.

The second qualitative analysis concerns the Interpretative Phenomenological Analysis (IPA).

It is a process of understanding the interpretation of the event by the subject, through the active role of the researcher who must try to make sense of the vision of the other person's world.

To achieve the best possible results, the IPA was used to analyze the five interviews of four participants, two men and two women. The researcher selected these participants as representatives of the categories that had emerged from a first general analysis with all the participants.

The four parents are: Cindy, Susan, Tim and Thomas.

Cindy decided to terminate her pregnancy at the 26th week of pregnancy following the diagnosis of a severe brain and motor malformation. The child was born alive and survived three minutes. She was followed by a therapist and participated in online groups.

Susan decided to make an LTP at the eighth month of pregnancy following a diagnosis of cardiac malformation. She was followed by a therapist and she participated in support and online groups.

Tim carried out an LTP at the 36th week of pregnancy for the diagnosis of a brain malformation and he was followed by a therapist.

Finally, Thomas had lost his child in the ninth month of pregnancy. Only after about six months he and his partner discovered the reason of the death, that is a defect in the placenta. He had not requested any psychological support.

During the eighteen months that characterized the study, Cindy, Susan and Tim had a new baby while Thomas started an assisted reproductive program.

The IPA has highlighted five different categories. Although they are the same as those of Alceste, the IPA categories are subdivided into sub-categories that cover more specific topics. For example, the category of the subsequent child includes the themes of desire, the subsequent pregnancy and the subsequent child.

The IPA was useful to better understand the parent's experience and possible psychological consequences. Interesting issues were highlighted, as well as a clear distinction in the expression and defense mechanisms implemented by women and men.

## Chapter 12: Analyses of results

The quantitative and qualitative data from the previous chapter have made possible the following evaluation/analysis.

The aim was therefore to present them by summarizing and correlating the analyses carried out with a mixed methodology.

To facilitate a more fluid reading and a detailed explanation, the results were grouped by main concepts, namely:

- The risk of developing complicated grief disorder and possible comorbidities;
- Social support (partner, family and friends);
- Psychological support (psychotherapy, support and IT groups);
- Living siblings and subsequent children;
- Cause of loss and description of the event;
- Rites, linking objects and home;
- Hospital professionals and bureaucracy.

These categories were selected and named not only according to the aims of the research (i.e., risk assessment of developing the CG and psychological support), but also to the variables and categories highlighted during the qualitative and quantitative examinations.

After the reading and presentation of the analysis of the results, the general discussion of the study will be debated in the following part, part D.

### *The risk of developing complicated grief disorder and possible comorbidities*

It seems that after more than a year and half the parents have advanced in their grief.

On a qualitative level, and in particular with respect to the analysis of the IPA, we were able to observe how there actually was an evolution, a progression of the emotional states linked to the loss.

We could see how perinatal loss strongly shook parents and how women especially verbalize their feelings and emotions.

Both have expressed that they perceived, especially in the beginning, a strong sense of anger, sadness and injustice, which are typical expressed in signs of grief.

For example, Susan associated the loss of her child with her own death, highlighting how this loss threatened and affected her own identity, seeing and perceiving herself only as a mother.

As the months passed, parents gradually changed their conception of grief, highlighting less pain and sadness and probably greater acceptance.

At quantitative level, both questionnaires (ICG and GHQ-28) registered an improvement and lower risk of getting a diagnosis of complicated grief disorder, anxiety and insomnia, depression, somatic problems and social dysfunction (Table 8).

Compared with the ICG, in T1 the average was around 45, reaching instead in T5, or 18 months later, the value of 23.2. This result, although not enormously below the reference cut-off of the questionnaire (i.e. > 25), underlined the parents' progress and the achievement of the uncomplicated grief's threshold and confirmed by the repeated measures ANOVA which showed that this decrease was significant, constant and linear over the months.

Generally speaking, there were no significant differences with respect to the gender of the parents: they always reported almost the same results of ICG. Mothers recorded slightly higher values than the fathers in T1, T4 and T5, while the fathers achieved a higher average in T2 and T3.

Variance analysis showed that the decrease in ICG averages was significant for both men and women (Table 9).

Specifically, in women there was a significant difference between the result obtained in T1 and the values of T2, T3, T4 and T5, with a decrease of the average of about 26 points from T1 to T5.

These data are also confirmed by the cut-off frequencies, where we can see that 18 women in T1, 13 in T2, 12 in T3, 11 in T4 obtained a majority above 25 to end up in T5 with 13 women with a value lower than 15 (Figure 15).

The significant difference for men was in particular compared to T1, T4 and T5 (with an average score of 44.8 in T1 and 25.6 and 21.5 in T4 and T5) (Table 9).

Data also confirmed by the frequencies, since in T1 it was the totality of men who had presented results superior to the reference cut-off, while in T4 and T5 they were only 4 and 3 men. This means that after a year and half, the men obtained a score approximately 24 points less than in the beginning. Considering the qualitative analysis, a lot of men also said that seeing their partner/wife "improve" allowed them to feel free to live and get in touch with their pain. The higher value of the ICG's average of men in T2 and T3 could be a confirmation of what was expressed by the fathers.

According to GHQ-28, for both men and women, starting from the second interview the results obtained in the four subscales showed considerable changes. Apart from the subscale of somatic disorders and depression (which recorded scores of <4 already in T1) (Table 8), the improvement and lowering of the other three subscales' average appeared clearly starting from T2.

All the subscales underwent a marked change, evidenced by the significant differences that emerged in the analysis of the variance between the results of every T.

Except for the subscale of the Somatic Symptoms, the specific comparison between the results obtained in the different times and the gender of the participants showed a significant and linear improvement (Table 9).

Even with respect to the cut-off frequencies, in the Somatic symptoms subscale (Figure 9), mothers showed a minimum frequency of values greater than 4: out of 24, only 3 mothers in T1, T2 and T3 and 1 in T4.

Compared to the other subscales, however, the frequency was higher, especially in that of Anxiety and Insomnia, where there were 14 mothers with a result greater than the cut-off in T1, 9 in T2 and T3, 6 in T4 and 2 in T5 (Figure 10).

Although not significantly, generally up to T3, fathers presented slightly higher values in the subdivision of Somatic Symptoms, while mothers in those of Anxiety and Insomnia, Social dysfunction and Severe depression. In the last interviews and in particular in T5, the mothers showed slightly higher values in all four subscales of the GHQ-28 (Tables 27, 28, 29 and 30) (where in fact all men have recorded results lower than the cut-off) (Figures 9, 10, 11 and 12).

The only significant differences emerged between the values of mothers in T1 and those of fathers in T4 and T5 compared to the subscales Anxiety and Insomnia and Social dysfunction (Table 31). This comparison showed that men's averages were significantly reduced with respect to the very first values of women

Carrying on, on a quantitative level, concerning the time since the date of the child's death, we have seen that most of the parents presented results superior to the reference cut-off of the ICG questionnaire up to the first 21 months of grief (Figure 15). This means that -always considering the cut-off frequencies-, although at the beginning the risk of developing a CG is more evident, a possible improvement does not occur in the first months following the death, but more than a year and a half later.

The progress of mourning over time emerged also in qualitative terms, in particular with respect to the first analysis of Alceste, whose purpose was to detect possible changes on a temporal level, highlighting modifications with respect to discourse and the possible risk of CG (Table 33). This analysis was based on the distribution of the participants' interviews in three different groups (according to the time of death) and the comparison between the semantic categories present in the classes of words selected by the program. The three groups consisted of parents' interviews based on the time of death, i.e. interviews of those who lost their child from 0 to 5 months (Group I), from 6 to 11 months (Group II) and from 12 months (Group III).

In addition, the semantic categories within the different classes follow a linear evolution. None of the class' categories of a group are positioned diametrically opposite in the other two but with a maximum

distance of one or two classes. For example, the references to social support that are present in the third class of Group I (<6) are found in the second class of Group II (6-11) and in the fourth class of Group III (> 12).

Rather than dwelling on the differences between the classes of the three groups, it is important to evaluate the course of speech for each group.

In Group I (<6) the aspects considered most important (as first class) are those that refer to the emotional and symbolic link with the child, that is, his memory and the testimony of his existence, then move on to the reasons for his death and the description of the event (second class), social support and participation in support groups and online (third class), and finally the emotional aspect (perhaps as an indication of a possible avoidance mechanism).

Compared to Group II (6-11), the first class corresponds to the more rational aspects, i.e. to the description of the event and the cause of death, and then to the second class in which the main categories are contained (feelings, emotions and the needs of the parent, including emotional and psychological support), ending in the third class, with symbolic objects and rites related to the memory of the child.

In Group III, as for Group II, the rational aspects of the event initially emerge, followed by: the relationship with the objects associated with his memory often exhibited in the home and the practices implemented by the parents (second class); psychological support (that is, online and support groups); social support and the expression of one's feelings and emotions (fourth class); finally ending with the importance of the social recognition of the existence of the child, expressed through the categories of the dates considered as more difficult and bureaucracy.

This first analysis demonstrates the linear path of the parent and the most important semantic references during the grief.

Considering the possible aspects of the CG, it is possible to highlight through a more in-depth reading of the same categories in the different groups, how the risk and the elements associated with this disorder have changed and reduced over time.

For example, in the category of emotions and feelings of Group I (<6) (which corresponds to the fourth class), there are clear and important references to intrusive images and thoughts (an aspect that distinguishes complicated grief and traumatic experience). It is important, however, to underline how these references are not present in the other groups, thus emphasizing the progression of work of mourning.

Furthermore, it is possible to highlight how the category of psychotherapy is present exclusively in Group II, that is, in the interviews of those who have lost the child from a period of time between six and twelve months.

Just in the third group, there are the categories of dates considered more difficult and that one of bureaucracy, associated with the social and legal recognition of the child's existence, probably because only with the passage of time the parents have faced these specific recurrences that have fueled or rekindled the pain of the loss, such as Christmas, birthdays, etc., a hypothesis also confirmed by the IPA. We could see that with the passing of months, it was important for the parent to be able to dedicate a specific moment to the child's memory, celebrating him or her with family members and loved ones, and not only perceiving a strong sense of sadness but also of joy.

This is probably because it is not a priority, nor is it homogeneous and frequent (i.e., according to the selection and analysis criteria of Alceste). The category of difficult dates is instead absent in the second analysis of the program (Table 35), this being based on psychological support and on where the participants are grouped according to who was seen by a professional (personal or group therapy) (Group B), to those who did not request any help (Group A) and who participated in the social networks groups (Group C).

Furthermore, a variable that emerged exclusively on the quantitative level is that of the consumption of medicine. Only 10.3% and 6.9% (Table 30) declared that they were taking drugs, showing that these parents present a more significant risk of complicated grief disorder, somatic symptoms and anxiety. Their difficulty in overcoming the obstacles of loss therefore translated into a request for pharmacological support.

#### *Social support: partner, family and friends*

Emotional support is fundamental after the loss of a child.

Compared to the partner, most of the participants initially perceived the other person as present and helping. This support was perceived in 89.7% of the cases in T1 and in 86.2% in T2 and T3 (Table 23), and then reduced significantly with the passing of months and reaching 55% in T5 (35% less compared with the beginning).

Furthermore, the quantitative results (Anova and Cohen's  $d$ ) showed that lack of partner support might be a risk of complicated grief and somatic disorders in T3 and T4 (Tables 23 and 24), anxiety and insomnia in T3, T4 and T5 (Table 25), social dysfunction in T2 (Table 23) and depression in T2, T3, T4 and T5 (Table 25).

We can, therefore, affirm that this support is an important factor in protection, particularly with respect to disorders related to anxiety, sleep and depression (i.e. the two constant diagnoses starting from T3).

Over time, the support perceived by men with respect to their partners/wives was always more or less constant. Only 2 men out of 8 did not feel supported in T4 and T5 (i.e., 25%) (Table 23).



The reduction therefore concerned principally women. In T1 there were 18 mothers that received their partner's support. This concerned only 10 women out of 21 in T5 (about 47%).

With respect to what emerged from the IPA, women underlined how men live their grief differently. For this reason, they sometimes feel inhibited in sharing their pain and seeking their partners' comfort.

According to them, fathers advance faster in their grief and they tend not to verbalize and show their pain.

Men therefore highlighted a greater difficulty in verbalizing their pain. Many of them declared and confirmed that they are aware that they are very introverted, and do not feel the need to share their feelings, even with their partner. Moreover, in addition to trying to avoid or have difficulty showing their pain, they often feel obliged to be strong and to prioritize the women's needs and suffering. This attitude could be interpreted as a defense mechanism in the removal of pain, displacing and projecting their feelings and needs on their partner.

This is also confirmed by the greater frequency of interjections of men, associated therefore with a possible intellectualization (one of the highest defense mechanisms), thus trying to block and control the emotional stress linked to the loss.

Furthermore, in Thomas it is also possible to see the presence of a false self, "*showing to others only the smile, the beautiful facade*", thus avoiding confronting his anguishes by lying.

Many women declared that by advancing in their grief, they began to accept the different expression of their partner's pain, an awareness that didn't influence or diminish their sense of isolation and solitude (as in Cindy's case).

However, the period after loss does not necessarily have to be difficult for the couple. Most of the participants have always perceived the support of the partner and many of them declared that this terrible experience brought them closer to their partner, the only person able to understand the moments of sadness, having also been through the same drama. Grief is therefore shared within the couple, despite the different modes of expression. For example, Thomas uses the boat metaphor: Only he and his partner are in a small boat that represents pain.

Considering Alceste's analysis, in the first analysis (Table 33), there is no specific category for the couple. The relationship with the partner is included in a more general discourse, inserted within the social support's category.

Compared to the second analysis carried out with Alceste (Table 35), the category of the couple is present exclusively in the group of those who were not followed by a professional (Group A).

It is therefore possible that the reflections regarding the relationship, the support and the partner have emerged during the semi-direct interviews, hypothesizing that the other participants use personal,

group sessions or the posts and messages via the internet as a way of expressing their experience and the couple's dynamics (Group B and C).

Furthermore, on a quantitative level, not only that of the partner, but also the support perceived by the family decreased over time, passing from 58.6% in T1 to 31% in T4 (Table 26), 27% less from the beginning. In T5, the support received by the family of origin is increased compared to T4, by about 22%.

After eighteen months, the perception of this support changed drastically, bringing those who felt supported to a 52% majority. This data also confirms what was expressed in the interviews, from which it emerged that, with the passage of time and in particular advancing in one's grief and perceiving a lower sense of anger, some parents felt ready to lower their defenses and reduce the self-isolation, letting people get closer.

Other parents said that for personal reasons they already had difficult relationships with their families of origin prior to death (for example, see Cindy). Others avoid talking about the child so as not to make their own parents suffer or give others the impression that they themselves are strong and resolute. This was done to coincide with the expectations of the entourage.

Others declared that they perceive the their parents' support and share their grief with them. For them, it is fundamental that all members of the family recognize the child's identity.

Compared to Alceste, in the first analysis, the family category is present in all three groups within that of social support. In the second one (Table 35), based on the comparison with psychological support, the specific category concerning the family is only present in those who do not see a professional (Group A), i.e., by those who probably perceive a greater need for help from their family and received neither professional nor "virtual" support.

As for the partner, the analysis of variance shows that such support was a protective factor, particularly according to the results of ICG in T4 (Table 26) and of all the GHQ-28 subscales in T5 (Table 27), emphasizing its role with respect to the general mental health of the person (i.e., to possible somatic, anxiety, sleep, depression and social disorders).

Furthermore, with respect to social support, even that perceived by friends showed a linear decrease during the first year, going from 62% in T1 to 52% in T4, to then increase, not so drastically as the family variable, by 3% from T4 to T5 (Table 28).

Over the months, even compared with friends, the progression of the work of mourning and the lower sense of anger may have influenced a possible opening towards others and an improvement in social relations, also confirming that the experience of the parent emerged from the study of the semi-directive interviews, as in the case of Tim.

In general, qualitative analyses have shown that the support of friends has always been very important (for example, this variable is remained constant in the Alceste analysis).

Some parents, however, declared their disappointment towards some friends that they considered unable to demonstrate their support or recognition of the child's existence. Such is the case of Susan, who perceived the lack of recognition of her pain and child's existence, as well as the social pressure of having to move forward, thus causing a strong sense of anger and isolation.

In the second analysis of Alceste (Table 35) and in particular in the group of those who used social networks (Group C), there were specific references to the sense of isolation and the breakdown of numerous social relationships.

Compared to the results of two questionnaires, significant differences between the variable of friends' support and the severe depression's subscale of GHQ-28 in T1 (Table 28) and with respect to the results of the ICG in T3 were recorded, data also confirmed by the majority of results above the reference cut-off (Figures 67 and 63). This support can therefore be considered as a protective factor, especially at the beginning.

#### *Psychological support: psychotherapy, support groups and IT groups*

The need for normalization and confrontation of one's feelings, within a therapeutic setting such as support groups, are an important protective factor, especially in the period following the loss.

There is a significant difference between participation in support groups and the results of the ICG questionnaire in the beginning: those who participate in such groups presented a lower level of complicated grief's risk (Figure 41), data also confirmed by the total majority of results above the reference cut-off for all non-participants (Figure 36).

Because the ICG results showed a considerable decrease, one can posit that support groups help the recession of the complicated grief or that their effect is more effective in the beginning and when the risk or the level of the disturbance is high.

Furthermore, women who participate in support groups are generally also see a psychologist (Table 19). They could therefore perceive the group as an additional support to psychotherapy. Notwithstanding the above, not all those who would have liked personal psychotherapy actually participated in support groups. A number of parents said they were interested in support groups but unable to participate for logistical and practical reasons. In many cases, groups or associations are exclusively in big cities, forcing people to drive for at least an hour and with uncompromising schedules. In some cases, when pregnant again, some mothers interrupted their participation in the group, both for the physical discomfort given by the pregnancy and to not disturb the other members.

Based on the data collected in the five interviews, 24.1%, 27.6%, 24%, 21% and 17% of bereaved parents participated in support groups organized by associations (Table 19).

Furthermore, at least 1 or 2 out of 8 men admitted to taking part in them (2 in T2 e T3 e 1 in T1, T4 e T5). The total number of men is not representative but it means that between 12% and 25% of them participated in support groups. The only constant male participant said that he initially started to please his partner, but he became aware of the benefit and importance of group therapy over time.

Compared with therapy, for which specific approaches were different and difficult to compare (such as psychoanalysis, Eriksonian hypnosis, EMDR, etc.), more than half of the participants (72.4%) said that they were seen by a psychotherapist in the beginning (Table 15).

There was one woman for whom this was an exception. She had been previously been diagnosed with depression, and had therefore started the treatment before. The rest of the participants – especially the mothers – felt the need to request support after the child's loss. Many of them decided on their own, whereas others were advised and directed by the hospital staff. Furthermore, all the participants stated that they carried had individual i.e., without being accompanied by the partner.

Over the months, more and more people decided to quit, reaching 72.4% in T4 and T5 (just 8 women said to continue it).

With respect to men, 4 fathers were seen by a psychologist in T1, to get to 1 in T2, 2 in T3 and 0 in T4 and T5.

The decrease in the individual therapeutic path was therefore remarkable. Those who decided to leave the therapy explained that they no longer feel the need or, in some cases, of not having really felt accepted and approved by the professional. Others said that "*friends are better than a psychologist.*"

With respect to the analysis of variance, a significant difference emerged with respect to lower risk of developing anxiety and sleep disorders for those who were not seen by any practitioner in T5 (Table 17). Furthermore, up to T3, all parents showed a majority of values higher than the ICG cut-off, data subsequently highlighted only in those who continued to request professional support (Figure 31).

Among other things, those who saw a therapist in T5 were also the same ones who started the therapeutic path from T1, without any interruptions.

This variable was also analyzed in relation to other possible aspects (such as the birth of a child before or after loss, perceived social support, etc.), however no significant differences emerged, thus confirming the uniqueness of this correlation between the risk of anxiety disorders and psychological support.

This information can be interpreted as a confirmation of the psychotherapeutic work: those who continued to receive psychological support were also the same ones who kept psychic work active,

faced painful situations and complications and reduced the defenses of avoidance, as opposed to those who did not request any help.

Furthermore, this above hypothesis was confirmed by the second analysis in Alceste (Table 35). Different categories emerged with respect to the variable taken into consideration, namely psychological support. In this second analysis, all the participants who had personal therapy or participated in support groups for at least 10 sessions, before or during the study (according to the interviews), were grouped in Group B.

The categories that emerged from the parents of Group B highlighted a greater expression of their feelings, difficulties and needs, as well as recognizing the importance of psychotherapeutic and social support. The other groups (those who did not receive any professional support and those who participated in the social networks groups) instead showed a greater propensity for possible avoidance. As a result of situations that are difficult to accept, such as the grief of a child, being able to make sense of loss is one of the most complicated processing tasks.

The participants of Group A (those who had no professional support) explicitly stated that in order to advance avoiding thinking about the child, they also avoided using exclusively the term birth and never that one of death. Moreover, it is important to note that Group B (Psychotherapy) is also the only one in which the category of psychotherapy is present and in which there are six classes, compared with the five of Group A (NO) and to the four classes of Group C (IT Groups), as well as presenting classes consisting of a single thematic category (i.e., that of feelings, the next child and the description of the event).

Since the classes represent the dominant ideas and themes of the body of text, these aspects are particularly significant. It is therefore also interesting to note the "poverty" of the classes of the other groups.

Furthermore, compared with the analysis carried out with the IPA, those who saw a professional explained that psychological support was fundamental and a safe place to express freely their own pain. As often reported in the interviews, personal therapy was not centered just on grief: within this pathway, the patient and therapist also addressed other issues. For example, Cindy and Tim expressed how therapy was useful, not only with respect to their personal pain, but also to understand how to relate to the partner and the next child (especially in the case of Cindy).

Compared instead with support groups, they are recognized as the main space in which the child can be remembered, thanks to the comparison and exchange of information with the other parents.

Participants report that for people who have not lived through such experiences, total understanding and empathy are impossible. Moreover, some of them declare how after an initial and considerable effort, hints about the child, his death and the pain of the parents become slowly more marginal and

secondary, close to disappearing. Many parents are often isolated, with an insufficient support network.

This is one of the main reasons that lead the parent to look for other types of support, such as groups available and accessible on the Internet.

Many parents have stated that the impossibility to participate in support meetings is one of the reasons why some participants have signed up and actively participate in the groups that are on Facebook or on the various blogs and forums.

As a research variable, only "active participation" on the Internet was considered, namely: regular access, the exchange of public and private messages and comments on one's own experience and that of others.

According to the mothers (the only participants), these groups were very useful especially in the beginning. Cindy and Susan perceive these groups as a space for listening and freedom of expression, far from the judgment of others. The fathers' vision is different. Thomas and Tim always explained that they needed to know the person and have an emotional contact. This was to be done in person.

According to the mothers, they could also decide when and how to participate in these groups, as well as be protected by anonymity and select the most appropriate and interesting topic (such as, for example, the causes of death, the hospital, bureaucratic information, the subsequent child, etc.). Cindy considers the groups as important to obtain important information, above all at the bureaucratic level, which highlights the recognition of this loss. Although perinatal loss is very frequent, the support to the parents is seen as too limited.

Nevertheless, after several months, many women decided to abandon them: 58.6% up to 17.2% in T5 (Table 21) participated in the beginning.

Many of them explained that with the passage of time, the continuous vision of photos of deceased children and reading the painful experiences of other people was no longer a source of support, but one of suffering. These visual stimuli were now negative and determined the return of pain and discomfort, even in the moments when they believed that they were advancing in their grief.

Furthermore, this risk of rumination was also recorded on the statistical level. Although the values of severe depression generally decreased, the mothers who went on to write, comment and share on social media reported higher and significant values of severe depression in T4 (Table 21).

With time and constant participation, the situation evolved and possibly worsened, highlighting in T5 a risk of complicated grief (Table 21), of somatization, anxiety and sleep disorders and, as in T4, depression (Table 22).

The diseases taken into consideration through the administration of the two questionnaires therefore revealed significant differences both with respect to the CG (data also confirmed by the majority of

results above the reference cut-off, Fig.) and to all subscales of the GHQ-28, with the exception of that of social dysfunction.

Although this participation does not determine or imply difficulties or pathological deficits at a relational and social level, Table 37 shows that among those who continued to participate in these groups in T5, most of them did not receive adequate social support.

In addition to a lack of professional support (such as the difficulty in joining support groups), many mothers also perceived unsatisfactory social support even with those closest to them, notably family and friends.

**Frequencies of Participation on online groups T5**

		Perception of partner support T5	
Participation on online groups T5		YES	NO
		NO	14
YES		2	3

		Perception of family support T5	
Participation on online groups T5		YES	NO
		NO	15
YES		0	5

		Perception of social support T5	
Participation on online groups T5		YES	NO
		NO	15
YES		1	4

Table 36 Frequencies table about the social support and participation in IT groups in T5

Moreover, as seen in Table 28, those who participated in these groups were also mothers who were saw a therapist, particularly in the beginning. This data could therefore confirm the additional need to dedicate a specific space to the memory of the child, but above all to have a comparison with other bereaved parents.

Further analyses were then carried out to understand if the pathological risks highlighted with respect to the variable of participation in IT groups also depended on therapeutic support. However, these additional analyses did not show any correlation, indicating and confirming that the risk depended specifically on the prolonged participation in the groups available on the Internet.

Furthermore, even if this participation was not directly related to a risk of pathology of social dysfunction, references to social support were more connected to a sense of isolation, disappointment and the breakdown of numerous social relationships (Table 35) in Group C of the second analysis of Alceste (those who used IT groups).

This group also had a lower number of classes than the other two, which was characterized by five classes in Group A (those without psychological support) and six classes in Group B (those who go to therapy or participate in support groups).

Moreover, considering specifically psychological support, which corresponds to the main variable that determined the structure of the three different groups, there are references to the help provided by the support and IT groups in all three. They are always simultaneously present in the same class, confirming the confusion and mental association carried out by the parents.

Compared to the first analysis of Alceste, references to support and online groups were always present together, that is in the same classes, and in all three groups.

The psychotherapy category was present exclusively in Group II (6-11), or in the interviews of those who lost the baby from 6 to 11 months (Table 33).

The presence within this group of a specific category aimed at psychotherapy could be determined by the percentage of participation.

We remember that not all parents lost the child in the same period. Many parents conducted their first interview about six months after the child's loss, whose interviews were included in Group II (6-11). As we have seen from the statistical percentages, many parents, especially during T1 and T2, said they had requested personal professional support, probably explaining the presence of this category within Group II (6-11).

Compared to participation in support groups and online groups, although their participation percentage also decreased over time, many parents continued to make comparisons or to underline the importance of being able to access these services.

### *Living siblings and subsequent children*

Continuing to analyze the results of the subsequent variables, another aspect that has been taken in consideration is the case of having already become/been a parent before the loss.



On the quantitative level, no significant data emerged, while compared to the IPA, however, it seems that parents perceive the presence of living children as fundamental. Cindy perceives them as "*the only reason that helped to move forward*," to continue her daily routine. Furthermore, a sense of guilt may be felt for focusing too much on one's own grief and leaving children "alone".

Depending on the age of the children and therefore on their cognitive ability to understand the event, there are several reactions that can emerge. Often bereaved siblings perceive the need to protect their parents. For example, in the case of Cindy, the older child tends to hide his emotions and difficulties while the second shows protective behavior towards the mother and the next child.

Moreover, the results of our study have shown that having another child after a perinatal loss does not correspond to either a protective or a risk factor for the parent but, also if it is not significant, this population have obtained a majority of values higher than the ICG cut-off up to T4 (Figure 25). This data is confirmed on qualitative analysis, where the parents describe the moment following pregnancy as not only a source of happiness, but also of deep anxiety.

Since the child died towards the end of the pregnancy or after birth, many of them are waiting for the birth of the child to decide to buy back indispensable items, such as cribs, clothes, etc. once again.

As Cindy and Susan have shown, mothers especially perceive the difficulty of affectionately attaching themselves to the child during pregnancy because of fear of reliving another loss and suffering again. Furthermore, the desire to hide the pregnancy (as is the case of Cindy or Susan) may emerge. This denial can be interpreted as a defense mechanism, both with respect to one's own psychic experience and social expectations, perceiving a strong fear of reliving loss and disappointing one's entourage. For this reason, women especially tend to live the next pregnancy alone.

Furthermore, there is a possible split between the desire to have a new baby and the desire to have a new pregnancy. As in the case of Susan, she states that subsequent pregnancy is a confirmation with respect to the functioning of her body and ability to procreate (Soubieux, 2013).

Furthermore, particularly with respect to the IPA, we can see how the lowering of defenses could lead to the gradual investment and attachment to the subsequent child. The initial ambivalent relationship with the child – during pregnancy and after childbirth – showed possible references or risks to the syndromes of the replacement and vulnerable child, especially in women. In some cases, such as for Susan and Cindy, women are more prone to express that they reviewed the image of the deceased child projected this onto the subsequent one, emphasizing physical similarities. Further investigation should be made with other modalities and timing, but compared to what emerged from the IPA, it seems that the gradual work of mourning also coincided with the acceptance and differentiation of children and the decrease in state of anxiety and nervousness towards the born child. The new pregnancy does not therefore correspond to the end of the work of mourning.

Many parents also perceive the child's place within the family (as an older brother or sister) and themselves as custodians of child's memory (as in the case of Cindy).

Furthermore, in the Alceste analysis, the “subsequent child” category concerns specifically the relationship between the successive child and the role of the deceased child.

In the second analysis of Alceste (Table 35), this variable is present in Groups B (Psychological support) and C (IT groups). Compared with the latter one, there are instead more frequent and specific references to the anxieties and fears given by the subsequent pregnancy, thus confirming the role of social networks as place to look for exchange and support (not perceived in “real” life).

In Group A, for those who did not follow either therapy or participated in support groups, this category is not mentioned. This is probably due to a possible defense mechanism implemented towards the acceptance of the loss and the subsequent investment.

With respect to the first analysis, in none of the three groups, the reference to the subsequent pregnancy and child appears specifically.

For this reason, we can think the classification by co-occurrence of the word has identified priority and more general semantic categories that do not include that one of "subsequent child".

This fact does not diminish the difficulties or the aspects linked with the next child but determines that during the interviews the relationship with the deceased child has proved to be the main topic, confirming the parents' need to express their experiences and difficulties.

Another aspect to consider that emerged from the IPA, is the desire and difficulty of having a child that reached almost possible obsessional aspects. The need to have another child is perceived as fundamental, encompassing every aspect of a person's life, including social and couple life.

Furthermore, as we can see in Table 15, compared to the data collected in T3, 7 parents, including Susan, experienced a miscarriage. With respect to this event, no significant quantitative differences emerged. On a qualitative level, the parents described this further loss without pain. They claim not to have had the time to realize or invest in this pregnancy.

Compared to the IPA, we can see from the perception of Susan the anger and the sense of injustice to continue to suffer further losses, which is more so than anything related to the previous loss.

Failure to invest in and project oneself in a pregnancy terminated with an abortion can be interpreted as an avoidance mechanism and denial implemented by parents, which represents an Ego that is still too weak to accept further loss.

### *Cause of loss and description of the event*

Going on, with respect to the variable of the causes of death, the data changed over time.

In T1, 28% of parents did not know the reason for the child's death. 27.5% of the children died of medical problems and 34% of the parents decided to carry out a Late Termination of Pregnancy (LTP). The latter figure was obviously unchanged, while starting from T4 those who lost the child for medical reasons became 50% and those who did not know the cause about 16% (Table 9). As the months passed, two participants discovered the reason for the child's death, which they came to understand as being because of medical complications.

At the epidemiological level, the quantitative values for the cause of the child's death are normal. In addition to bibliographic research, a doctor from the gynecology and obstetrics department and an expert in epidemiology at the CMCO hospital in Strasbourg made herself available to check the data, confirming the compliance of the results with the diagnoses, the percentage of deaths of the children's gender and the closeness of parents to housing centers (thus excluding possible risks due to the long distance from hospitals).

On the basis of this data, an analysis was performed with respect to the results of the ICG and GHQ-28 questionnaires and knowing the reason for death.

Thus, at the beginning a significant effect was found between those who lost the child for medical reasons, those who didn't know the cause of the child's death and the ICG. In T1, those who did not know the reason for the child's death showed a greater risk of developing a complicated grief disorder. This data was also confirmed by the qualitative data, as well as from the IPA analysis, where the initial difficulty of not knowing the causes of death emerged. For example, in the case of Thomas, the reason for the child's death was discovered only a few months later. At the beginning, there was a strong sense of misunderstanding, of injustice but above all of destabilization and anxiety with respect to his partner's health and the possible sense of guilt.

In the Alceste analysis, the category of the cause of death is always present. From the analysis, it is possible to highlight how the parents often faithfully reported the technical terms and the medical aspects that surrounded the reasons for the death. In the comparison between the different groups, the descriptions reported and the placement of this category within the classes of the two analyses has been interpreted and associated with greater rationalization and possible avoidance by the parents.

Furthermore, considering the quantitative analysis compared to those who decided to carry out an LTP, we have seen that these parents have consistently obtained a very raised average and higher than the reference cut-off of the ICG. The risks and difficulties of these parents were also confirmed at qualitative level: compared to the IPA, important references have emerged as to the difficulty of the decision, to the sense of guilt, responsibility and regrets.

Mothers, in particular, expressed strong feelings of guilt and remorse for not being able to conceive a healthy child and having taken the decision to interrupt his life, thus witnessing an inner battle between rationality and emotion.

Furthermore, according to the results of the two questionnaires, analysis of the comparison between those who lost a living child or during pregnancy showed that there was an improvement, a lowering of the risk of developing possible psychological disorders in all participants. In particular, compared to the ICG values (Table 11), in addition to a general reduction in the average and a majority of the final frequency lower than the cut-off, the only constant data was that of the parents who lost a child after a few months: out of 2 participants, 1 parent consistently maintained the result above 25, thus highlighting the possible risk. Those who lost the baby after a few months are also the parents who have registered a general average higher than the other variables (mean = 37, therefore also higher than 25), in T5.

Additionally, the GHQ-28 results of all participants showed that the Anxiety and insomnia subscale (Table 13) was the one with the highest scores and frequencies. This data was also confirmed by Cohen's *d*, which showed that those who lost a child after a few months had a larger effect size than the others ( $d=0.8096$ ), underlining and confirming that the bereaved parents of a living child are more at risk.

Compared to the description of the event, the announcement was a shock, a surreal moment in which the parent was not able to understand. It was a sort of emotional and cognitive anesthesia (as in the case for Susan and Tim).

For Thomas, the moment between the announcement and the birth was perceived as too long. Parents tend to want to give birth as soon as possible, and not have the feeling of carrying a deceased or sick child into their womb. Unlike the parents' opinion, this period can be beneficial for the work of mourning. It is important for parents to have time to carry out the event and memorize the last days with the child (especially the bodily sensations for the mother) (Soubieux, 2013).

Following birth or death, for someone seeing the child was too difficult. They were unable to meet a real child that differed too much from parenting expectations and fantasies.

Those who saw and touched the child never expressed any regret about having made this decision. From the parents' narrative, it is also possible to highlight the possible idealization of the child and the moments spent with him, during pregnancy or in the hospital (for example, in Cindy's case).

Furthermore, parents often remember, even months afterwards, with precision all the details of the loss of the child, specifying the days and the hours. The trauma of loss and repetitive thinking can protect the parent from psychic pain that is too strong and unmanageable, but also helps in maintaining the bond with the child.

This link is also maintained at the body level. It is not uncommon, especially in the beginning, for women to experience somatic pain (at the level of the scar or as a phantom pregnancy). The body is in fact the place where the woman's traumatic experience is memorized (Soubieux, 2013).

Furthermore, during the interviews a few references to possible involuntary images and thoughts emerged (see Thomas). Furthermore, it is important to underline that during the interviews a few symptoms and aspects related to the post-traumatic disorder were highlighted.

For example, except for those who have moved, parents tend not to avoid places and situations related to the child. With time, the difficulty of modifying or giving a new role to the child's room also decreased.

### *Rites, linking objects and home*

In 75% of cases the child was cremated (Table 18) and, in spite of the cremation, 53% of the children were in a cemetery where a memorial plaque or stele was placed for their commemoration (Table 7). The rest of parents instead made the decision to disperse the ashes or to give full responsibility to the hospital. At the quantitative level, there is not any difference between those who decided to bury the body or the ashes of the child and those who did not. Compared to the qualitative analysis, both in the IPA and in Alceste, more details emerged that we can consider and insert within the category of rituals.

In addition to the rituals related to the funeral and the cemetery, they concern the habits put into practice, the ritualized and habitual gestures through which the parent keeps the memory of the child alive and the link with him or her. In some cases, the need to practice a non-socially recognized ritual, such as the baptism of a deceased child (for example, in the case of Cindy), also emerged.

Furthermore, as expressed above, in complicated grief, the person's life is entirely dedicated to the deceased: thoughts, speeches and actions are projected towards the memory of the missing person, considering that the present life is useless and insignificant. Going to the cemetery every day, keeping the bedroom intact, constantly manipulating objects and reorganizing the clothes of the deceased are other forms of this hyper-investment (Lombardo et al., 2014).

During the months, the participants also explained that they would go less assiduously to the place where the child rests (the cemetery or where the ashes were dispersed). This aspect, recognized as a possible symptom of complicated grief, can be considered as a further confirmation of the parent's progress.

A clear example is Cindy, who expressed and described the initial need to go to the place where the child's ashes were scattered every night, denying his death and projecting his existence onto the tree planted on that spot.

Furthermore, references to religion and spirituality were also highlighted within the category of rituals. Most parents saw themselves as non-believers, perceiving above all a sense of anger towards a God they consider unjust. For the few believers, the relationship with one's faith was complicated, as for Susan for example.

A probable reason for this, the category of religion is present exclusively in the first group of the second analysis of Alceste. It is understood as a source of another type of support and sense making compared with those that see a professional (Group B) or participate on Internet (Group C) (Table 35).

Even in those who profess to be laic are there recurring spiritual references, probably linked to aspects that are now more cultural than religious, such as thinking about the child in paradise or associating him with an angel. Furthermore, parents reconnect the image and memory of the child to specific spiritual situations, such as the sunset, the starry sky, flowers, feathers, etc.

From the results of the first analysis in Alceste (Table 33), however, it emerged that the category of rituals -that is present all of three groups - appears immediately after the loss, perhaps to indicate how symbolization sharpens during the work of mourning and probably to fill a lack of social recognition (Group I).

Furthermore, compared to the procedure implemented by the parent, such as lighting a candle or offering flowers in memory of the child, they are often practiced at home, where the child's memories and objects are placed, such as in his bedroom or living room.

In particular, the parent often describes the difficulty in modifying the bedroom that was designed for the child, especially in the beginning.

Furthermore, the symbolic objects related to the child often include photos, clothes, stuffed toys, bracelets, medallions, objects related to birth or pregnancy, tattoos, etc.

Since the relationship with the child is projected onto these objects, through the attachment of the parent to these objects, it is possible to understand the degree of progression and acceptance of the loss.

For example, it was difficult for Cindy to accept losing the baby's smell kept in the memory box. Thomas instead expressed an ambivalent relationship with the rocking chair he had built for the child, a symbol of his denial and difficulty in realizing the loss.

Furthermore, the tattoo, which emerged in particular from the IPA rather than in the analysis in Alceste (i.e. in the case of Thomas and Susan), is a recurrent modern metaphor with which the parent marks his own body with the eternal memory of the child.

Compared to Thomas, his tattoo represents a clear example of how men, with greater difficulty in verbalizing, express their grief and pain in other ways.

With respect to the position of the tattoo (behind the back), it is also possible to highlight the ambitious reaction of Thomas's grief: present but hidden.

Furthermore, if the “home” category was present within the qualitative analysis, both in the IPA and in Alceste, it also corresponds to a quantitative variable, more specifically associated with the concept of the move. 34.4% of parents decided to move house and, some of them, even the city.

The image of a child who has never physically lived in that house becomes difficult to bear for the parents, a place on which the desires, the projects and the pains of loss are projected.

In T4, more than a year after the loss, those who moved showed a greater risk of developing a severe depression disorder. The possible avoidance of the house where the parents carried on the pregnancy could therefore be considered as a risk.

However, this difference did not emerge in T5. Evidently, it is possible to hypothesize that in the following six months other factors could influence the risk of depression linked to the move, such as greater acceptance and therefore less avoidance and denial, social support, a subsequent pregnancy, etc.

### *Hospital professionals*

Finally, an aspect that is not present in the quantitative variables but emerged in the qualitative analysis is the appearance of the hospital professionals and their accompaniment, in particular, through the IPA.

In the Alceste analysis, the specific category of the parent's experience in the hospital emerged in a more general discourse within the category of the description of the event, while in the IPA analysis, the experience of the announcement of the child's illness or death and the professionals' attitude were more specific.

Parents memorize the reactions of the professionals and perceive a greater need for understanding and respect.

They often highlight – especially at the outset – a strong sense of anger, in particular towards doctors, on whom pain and blame for the death of the child are often projected.

In most cases, fathers share their wives' opinions. They consider the woman as the main user of the hospital service, perceiving a strong sense of powerlessness.

Furthermore, many parents decided to use the same professionals for the subsequent pregnancy, although this meant that they would have to go to the hospital where the child was born and/or died. It was important for them that the professional knew the whole medical history thoroughly, as well as have a more humane and attentive attitude given the situation.

### *Bureaucracy*

A final aspect highlighted exclusively during the qualitative analysis is bureaucracy. In the first analysis in Alceste (Table 33), it is present exclusively in Groups III (>12), a result that shows how important it is for parents to obtain legal and social recognition of the child over time.

On the other hand, in the second analysis, references to bureaucracy were identified exclusively in Group A, or in those who had no psychological support and therefore risked denying and projecting their pain onto the administration.

As also evidenced by the IPA, in particular in the beginning, the feelings addressed to the administration were characterized by a sense of anger and injustice.

Parents therefore often stated that they were forced to deal with bureaucratic situations that they considered inappropriate or illogical. A first example is given by the impossibility of being able to record the surname of the child in the family booklet if the child was not born alive (“Circulaire no 2009-182 du 19 juin 2009 relative à l’enregistrement à l’état civil des enfants décédés avant la déclaration de naissance et de ceux pouvant donner lieu à un acte d’enfant sans vie, à la délivrance du livret de famille, à la prise en charge des corps des enfants décédés, des enfants sans vie et des fœtus,” 2016). Furthermore, there are other bureaucratic practices that require the parent's attention and patience, such as parental leave, the dispersion of ashes, etc.

The parents often claim to have therefore met unprepared operators and a system unable to accompany and facilitate this difficult moment.



In summary, both at quantitative and qualitative level, at the end of the eighteen months that characterized the study there was a lower risk of psychological distress.

Only in T5 parents reach the threshold of uncomplicated grief compared to the ICG values (and after twenty one months following the loss, according to the frequency values of cut-off). These data were also confirmed with respect to qualitative analyses, also highlighted with respect to the first analysis of Alceste, in which the parents presented different classes based on the time of loss.

Furthermore, if at the quantitative level there were no differences between the values of men and women, the different expressions of grief emerged at qualitative level. In particular, the different defense mechanisms were highlighted, influencing the relationship and the perception of the partner's support.

Compared to the cause of death, at the quantitative level the only differences were recorded in T1, where those who did not know the reason for the loss showed a greater risk of developing a CG. On a qualitative level, however, feelings of guilt and greater difficulty in accepting the loss emerged in the parents who decided to carry out an LTP (data confirmed by the frequency of the results above and below the reference cut-off and the values of the general average).

Moreover, in particular, at qualitative level, the presence of living children was perceived as fundamental. On the other hand, there were no differences compared to those who had (55%) or did not have a subsequent child but the latter ones showed a frequency of values higher than the ICG cut-off up to T4. From the analysis of the interviews, for those who could not have a child due to problems related to fertility, possible obsessive aspects were highlighted.

For both methods, the emotional support perceived by the partner, family and friends was confirmed as a support factor.

Compared to psychological support those who were followed by a therapist showed a greater risk of anxiety disorders in T5. Those who requested a professional help radically decreased over time, going from 72% to 28%. Furthermore, those who participated in support groups recorded a lower risk of CG in T1. Even for those who participated in these groups, attendance decreased from 24% to 17%. Furthermore, mothers who continued to participate assiduously in online groups showed a risk of CG (in T4 and T5), somatic disorders, anxiety and depression (in T5).

Many mothers have stopped participating over the months (passing from 59% to 17%), claiming that these groups made the progression and acceptance of the loss even more difficult.

Furthermore, at a quantitative level, it emerged that those who took medicines (about 7%) had a greater risk of complicated grief (in T2, T4 and T5), anxiety (T4 and T5) and somatic disorders (T2 and T4).

Finally, some categories emerged only at qualitative level.

They are the categories of the continuing bond (which includes the objects, the symbolic representations of the child and the bureaucracy), and the support received in the hospital (present in the category of emotional support).

After the presentation of the results' analysis, it is important to underline how the use of a mixed methodology has been confirmed as the most useful and suitable for the study of perinatal loss experiences and consequences.

The decision to use Alceste proved to be effective and consistent with the research objectives. The categories that emerged from the statistical qualitative analysis were also the same as those highlighted by the IPA.

Therefore, in the next chapter the general discussions related to the study and reflections will be presented with respect to the initial hypotheses and the parent's experience following a traumatic event such as the death of a child in the perinatal period.

## **PART D. GENERAL DISCUSSION**

The following part concerns the general discussion of the results, in particular their elaboration and reflection on the main hypotheses and aims that moved the interest of this study.

We are therefore approaching the last part of the research: the next part will be indeed dedicated to the conclusions.

### **Chapter 13: Discussion**

Mourning is not only equivalent to the loss of a loved one, but also to the loss of one's role, one's identity. Overcoming this pain means being able to carry out a complex mental process that leads to the acceptance and transformation of mental images of oneself and of the lost object.

To succeed in overcoming the loss, it is fundamental that the person has achieved a complete psychic structuring and overtaken the separation anxiety (inherent in the development process), as a basic intrapsychic tool for the work of mourning.

The characteristics of perinatal loss, however, cannot be included in a general discourse; this is a unique form of grief.

Parents who lost a child during pregnancy or in his first months of life have not had the possibility to create enough memories and imprint the child's memory within the community (Alexandre & Gaugue, 2016).

In general, the loss of a young child, especially during pregnancy, is often minimized and, after some time, socially forgotten, contrary to what happens in the parent (Cacciatore, 2013; Sani et al., 2019).

In addition to the loss of the child himself and of the love's object, this also corresponds to a symbolic loss. The child's loss is the non-realization of the best part of one's self, a narcissistic wound inflicted on one's role and on identifying processes experienced during the pregnancy (with respect to one's own parents and with oneself as an infant) (Leon, 1986).

Perinatal loss is a traumatic event (*deuil traumatogène*), in which numerous elements intertwine: the threat of death for a loved one, the threat of death for oneself (that is, for the woman who carries the child) and the separation from the object of love (Bacqué, 2003).

The coincidence of death with birth is a link that is impossible to conceive. They are the representatives of two opposite poles, two independent events that require a psychic reorganization within the diachronic dimension (Ugo, 2012).

According to Freud (1915/1976), the individual denies the concept of death, "*No one believes in his own death, or, to put the same thing another way, that, in the unconscious, everyone is convinced of his own immortality*" (Freud, 1976). The reigning sense of omnipotence and control is injured following the perinatal loss, which is considered as illogical and unnatural.

Birth recalls experiences and magical fantasies of being able to create something from nothing. Death, on the other hand, corresponds to the dissolution of something that has lived, but how can we then manage the loss of a person who has not had enough time to "exist"? (Ugo, 2012).

Contrary to social expectations, which tend to underestimate the perinatal loss, often not recognizing the child's existence and the parent's pain, this death can determine a psychological distress.

The work of mourning that the parent must do is a slow and gradual psychic process.

An important aspect to consider is the risk of pathologizing and stigmatizing the reactions of parents following this loss. It is essential to remember that everyone experiences mourning and detachment from a loved one in a completely personal way and with possible aspects and reactions related to the culture of belonging and contextual variables (Frances et al, 2010; Wakefield, 2013).

The introduction of a possible disease linked to grief within the DSM 5th has therefore led to a double effect: a recognition and greater attention and awareness of issues related to loss and, on the other hand, to a generalization and medicalization of one of the most personal aspects that distinguish the person.

This means that the risk is that of misdiagnosing normal grief reactions, resulting in high frequencies of false positives and unsuitable psychiatric treatment (Lacasse & Cacciatore, 2014; Wakefield, 2013).

Our studies confirm the results of several studies that have shown that bereaved parents have higher scores than other populations (Thieleman & Cacciatore, 2014). Using quantitative results as guidelines and possible food for thought, it is therefore important to remember the impossibility of generalizing and labeling the mourning process of the parents and their need to maintain a bond with the child as pathological.

Longitudinal research allowed us to follow the evolution of parents during this process. Particularly highlighted thanks to the qualitative analysis, it was possible to observe the reactions of the participants, who experienced the strong desire to be reunited with the child, the sense of guilt, anger, the difficulty in accepting death and a sense of apathy, all typical features of complicated grief, whose intensity has progressively reduced, returning to a functional and uncomplicated mental state after more than eighteen months following the loss of the child.

Pain, anger and guilt, as well as identification with the child, can therefore act as a form of protection, maintaining a bond with the child according to the needs of the parent's Ego (Soubieux, 2013).

Although at an advanced stage in the work of mourning, at quantitative level the risk of developing diseases such as complicated grief disorder was still present several months after the loss of the child (T4).

The results of the ICG in T5 showed that the parent reached the uncomplicated grief threshold exclusively after more than a year and a half after the loss (Table 8).

The improvement was also evident with respect to the GHQ-28 questionnaire (Table 8), whose subscales (Somatic symptoms, Anxiety and Insomnia, Social dysfunction and Severe depression) corresponded to further possible disorders that bereaved parents could develop (Christiansen et al., 2013; Prigerson et al., 1996).

Furthermore, contrary to what is expressed in the literature (Bornstein & Clayton, 1972; Musaph, 1990), some anniversary reactions were not highlighted in our study.

One of the main purposes of carrying out an 18-month longitudinal study was to try to identify if the parents' difficulties and symptoms became acute around the twelfth month of grief. Parents perceived several specific dates as more complicated, such as monthly anniversaries, anniversaries, holidays, etc. Over time, however, these difficulties also diminished. Parents tried to give meaning and purpose to these dates considered more difficult, remembering and commemorating the child and perceiving not only anger and suffering but also serenity and gratitude.

Overcoming the loss of a child therefore requires a set of specific fundamental tasks and aids, including social and professional support.

The initial shock (or *sidération psychique* in French) of the parent can be reduced thanks to therapeutic work, in particular with respect to participation in support groups.

As demonstrated by our research and confirming the literature (Bacqué & Merg, 2015; Cacciatore, 2007; Côté-Arsenault & Freije, 2004; Dyregrov et al., 2013; Stirtzinger & Robinson, 1989; Umphrey & Cacciatore, 2011), participating and sharing their experiences and the perception of emotional recognition of parent's pain, produce some positive and supportive effects on the levels of complication, on the acceptance of the loss and psychological consequences, especially in the beginning.

Parents consider support groups as essential. Unfortunately, there are very few French cities there are associations that provide this service, confirming that perinatal loss is still too little recognized and validated at a cultural and social level today.

Furthermore, between 12 and 25% of the fathers participated in support groups (Table 19), thus confirming the literature according to which their participation in support groups has increased in the last twenty years (Bacqué & Merg, 2015).

It is important to underline that when asked if they would participate in support groups, many mothers answered with the following statement: “*Not in person, but to those on Facebook yes, I do.*” The IT groups were associated and confused with the therapeutic ones.

Many of them describe Facebook groups and various forums as very advantageous tools, someone even preferring them to support groups: those on the Internet are available hourly, they do not have timetables or physical spaces that prevent participation and they are accessible without obstacles.

They are considered a place where everyone can communicate, exchange information and share their experiences. One is far from the judgments or the sense of piety that limit participants in sharing their grief, even with the closest. Moreover, these groups guarantee anonymity, another factor that parents consider fundamental.

A further element that is in favour of support groups is the sense of altruism that emerges from the feeling of helping other parents (Cacciatore, 2007). This was also perceived with respect to groups available on the social networks (as in the case of Cindy and Susan), thus highlighting a further possible association between therapeutic and IT groups.

One of the key processes in the development of grief is the capacity for mentalization, a process that develops and maintains itself from childhood through interpersonal relationships. It is therefore possible that in our society, increasingly governed by technology, that there is the fantasy that social networks are a form of help, communication, and relationship to be able to mentalize the difficult situation, as a possible replacement for introspection (Bortolotti, 2017).

The phenomenon of impulsive sharing is often a reaction of feelings of anxiety and confusion perceived following the loss, but it is essential to remember that there is no knowledge, control and professional support behind online communication. Our study has confirmed that constant participation on these web sites can influence the development of psychopathological disorders such as anxiety and somatic diseases, depression and CG, favored by rumination and isolation.

From this it is possible to believe that with the passing of time the effect of online social sharing of emotions may not be supportive but harmful to the bereaved person.

So, while support groups have shown an initial beneficial effect, the possibility to share and talk about the child's death at any moment, the anonymity and the lack of physical perception of the other, are just some of the many aspects that can jeopardize psychological evolution, contrary to what these mothers thought (the only users).

According to the literature, those who actively participate in such groups are Caucasian women, adults under 50 years old, with a high level of education, a decent income and with a minimum knowledge of how to use the Internet (Gold, et al., 2016; Swartwood et al., 2011). Our research has therefore confirmed that it is mainly women who are part of it but of different social classes. Unlike a thought that could arise spontaneously, it is not just unemployed women and those who have more time to participate in such groups: the age range, status, job and education are quite varied.

One possible interpretation, confirmed by our results, is that those who use and seek comfort on the Internet do not perceive adequate emotional support in their "real" world. In addition to a lack of professional help (such as the difficulty in joining the associations of group therapy), some mothers also perceive unsatisfactory social support, even with respect to the closest people (partners, friends, family members, etc.).

It is therefore essential to consider isolation as one of the main problems of loss.

The social recognition of grief, pain and the existence of the child, accompanied by constant support over time (therefore present not only in the first days or months following the loss) are central and main aspects of the work of mourning.

Compared to psychotherapy, it is considered fundamental by the parents who requested and continued to receive such support.

Research suggests that only those who are at risk for complicated grief can actually benefit from professional support and not all bereaved people need specialized help (Endo et al., 2015; Gold et al., 2016; Schut & Stroebe, 2005; Steiner, 2006).

Nevertheless, those who declare that they do not need to contact a professional (especially the fathers) could put in place resistance, in order to avoid their own pain and the unconscious contents of consciousness, confirming the quantitative and qualitative data.

Psychotherapeutic work helps the person to access suppressed memories, experiences and feelings, thus causing functional anxiety for the person (Marty, 2017). According to Lecours (2005), "*the work of therapy then focuses on the search for hidden content: to fill the gaps in memory, to undo the disguise work of censorship, to flesh out preconscious scenarios by translating manifestations of the unconscious, to enlarge the realm of Ego.*"<sup>3</sup> (Lecours, 2005).

Therapeutic support is therefore confirmed as essential to accompany parents in their work of mourning, considering the need to be followed by both a professional in the setting of a personal therapy and group therapy.

Furthermore, considering specifically the results obtained with respect to social support, the perception of the support of primary entourage is a priority, in particular with respect to people considered more intimate (i.e., partners and family members).

In T5, eighteen months after the start of our study, the support of the partner and the family turned out to be significant protective factors with respect to possible pathological disorders (anxiety, somatization, depression and social dysfunction) (Tables 23, 25 and 27).

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<sup>3</sup> « *Le travail de la thérapie porte alors essentiellement sur la recherche de contenus cachés : compléter les lacunes de la mémoire, défaire le travail de déguisement effectué par la censure, étoffer les scénarios préconscients par la traduction des manifestations de l'inconscient, agrandir le domaine du moi* ».

Furthermore, parents state that the most important support is that of the partner, the only person who can actually understand the pain and suffering of having lost the child.

Many parents (especially mothers) however have difficulty in perceiving their partner as a support. With respect to the distinction between mothers and fathers, sex seems to play a fundamental role in the experience of grief. While identity is something that one possesses (given by the correlation between representations and the experience of the self), gender roles develop and depend also on interpersonal relationships, social expectations and the historical-cultural context. It corresponds to the syntonic relationship between behavioral style and biological-sexual identity (Attorre, 2016).

Scientific research shows that women are more available to request psychological support than men and to show a greater need for sharing (Ware & Raval, 2007; Wijngaards-de Meij et al., 2008; Wing et al., 2001). Furthermore, according to Vance and collaborators, mothers tend to express their emotional distress for about two or three years after the loss, as opposed to eight months for fathers (Vance et al., 2002).

This data was also confirmed in our study. First of all, more women than men consented to participate in this research. In addition, even if in a smaller and not representative number, of the 8 men just a few of them have "tried" to go to a psychologist, mainly because they were pushed by their partners. This changed in T5 where a male participation equal to 0 (Table 26) was found.

Furthermore, confirming the literature (Ware & Raval, 2007), male participants feel the social pressure of having to be strong and to respect the social stereotype for which their grief is secondary. They deny, project and "mask" their pain to support and comfort the mother who is considered as more in need of attention and in difficulty.

Moreover, men can use sexual relations as a way of comfort and intimacy, while in some cases women are not yet ready to consider sex as a pleasant or intimate act but as a child's betrayal (Hunter et al., 2017).

Despite the remarkable influence of the role imposed by social conventions and the different defense mechanisms between men and women, which regulate and influence the expression of mourning and probably the couple's relationship, the quantitative scores confirm that both bereaved parents have the same levels and risks of complications following the loss of the child. Based on our results, we can therefore state that the attachment to the child and the consequences for his loss are the same both in men and women.

Furthermore, our research has shown that the loss of a child does not mechanically determine the separation of the couple. Out of the 29 couples, only 1 separated after the child's death. Many participants declared that they were afraid of divorce or separation but also that the gradual acceptance



of the loss favored the understanding of the partner's expression of pain and the perception of an even more united and solid couple.

Furthermore, besides the shared memory with the partner and the loved ones, it is important for the parent to have the possibility of recognizing the child at the bureaucratic level and to inscribe him officially in the family tree.

In a society where the recognition of the child is determined by the impositions linked to medicine, it is the biological and physiological aspects of the child at the time of birth or death that condition the social perception of mourning.

In this perspective, the role and need of the rite emerges energetically, confirming the specificity and uniqueness of the perinatal loss.

First of all, it is important to remember that from the cremation of stillbirth babies or fetuses, it is not possible to obtain the ashes because the calcium of the bones of children younger than one year is not yet sufficiently consolidated. In cemeteries there is generally a common place to remember all children and some crematoria provide a symbol, such as a medallion (Rocle, 2012).

It is probably for these reasons that the bereaved parent seems not to recognize the cemetery as the resting place of the child, and perceives the need to carry out memorial practices inside the home.

The parent's house is the place where there is no taboo and where the child's symbolic objects are collected and displayed in a specific corner, like a sort of small altar, where the parent can remember the child and perform practices usually limited to cemetery or religious places (like lighting a candle or offering flowers, gifts, etc.).

The parent perceives the need to remember the child at least within the home, through actions and symbolic elements and, in some cases, to evade and suppress this taboo, affirming the existence of the child either through the publication of photos, videos and comments on social networks (like videos posted on YouTube), which reduces the sense of alienation (Sani et al, 2019).

Furthermore confirming the literature, the participants present greater sensitivity linked to spiritual aspects (as the contact with nature, music, etc.) and an initial conflictual relationship with faith (for those who were believers), coming to recognize their belief as a support (Arnold et al., 2008; Greeff et al., 2011; Nuzum et al., 2017).

It is also interesting to note that in a typically secular state like France, some aspects related to religion have taken on a cultural rather than religious connotation, such as the association of the child with the figure of the angel, with paradise, and in some cases requesting a civil baptism for a deceased child (not recognized and allowed on a legal and social level).

In general, any form of support – professional, social and religious – is essential to accompany the parent. Following difficult situations such as the loss of a child, sense making is indeed one of the most complicated tasks of processing.

Parents are faced with the realization of the worst fantasies, wondering if at an unconscious level the ambivalence present during pregnancy has prevailed and induced real destructive forces.

The parent perceives a sense of guilt and failure in not being able to save the child and to finalize the reproductive act, intended as biological, mechanical and natural, determining the image of a destructive and non-functioning self (especially in the mother). This is especially true if it was the first child.

In the most difficult cases, the sterile parent or the parent who has some difficulty to conceive can develop obsessive thoughts, perceiving a visceral need to have a new child, which can take on a repairing function of the narcissistic wound inflicted after the loss.

Furthermore, the subsequent child is simultaneously a source of joy and frustration, unconsciously projecting the fantasies and experiences of the previous one to the new pregnancy.

The traumatizing event leads the parent to live a state of anticipatory anxiety and the need to pass the dates of diagnosis and death, and to meet the child, appeasing his fears only through reality testing, that is holding and touching a healthy child.

The worries and fantasies of reliving another loss could influence the parent's lack of emotional investment in the new child. In many cases, this lack of investment is a clear form of denial, a defense of an Ego that is too weak to face another painful event.

In the most serious cases, the parent can develop the syndrome of the replaced child or of the vulnerable child, characterized by a hyper-protection (Burden et al., 2016; Cacciatore, 2013; Franche & Bulow, 1999; Gaudet et al., 2010; Hunter et al., 2017; O'Leary, 2004). Furthermore, having a baby within a year would implicate a higher level of anxiety, depression and PTSD and the prolongation of symptoms until the first year of a healthy baby's life (Hughes et al., 1999; Hunter et al., 2017; Rousseau, 1999; Turton et al., 2001; Zeanah, 1989).

Contrary to these observations, the results of the study showed instead that the subsequent pregnancy did not affect the possible psychopathological risks of the parent or compared to the next child (including the replacement and vulnerable syndrome), despite the conception taking place starting from the six months after the loss.

Compared with the causes of death, there was clear advancement even for those who did not know the reasons (that is 15.6%) over time. This means that, contrary to the literature, knowing the causes of death did not significantly affect a minor risk of developing the complicated grief disorder (Keese et al., 2008; Lichtenthal et al., 2013; Song et al., 2010).

Other factors, such as psychic and external, probably influenced the lowering of values and their work of mourning, allowing them to make sense of death.

Many participants decided to carry out an LTP (Late Termination of Pregnancy), a sort of fetal euthanasia that leads the parent to consider his pain as secondary. Paradoxically, the parent chooses to protect the child's life by depriving him of it. For many of them, especially mothers, the sense of guilt is lacerating and in the worst cases, the parents are faced with a regret, punishing and obsessing themselves.

It is also interesting to note that the choice of the parent to carry out an LTP also influences the decision of the name. Many participants have assigned the child a name, which is a further symbolic connotation connected to his destiny. The names were chosen on the basis of meaning, as an image of strength, of courage, or linked to the spiritual image of the child in paradise.

Furthermore, comparing those who lost a child during pregnancy with those who lost a living child, our study confirms the theory that the consequences of the parents who have known the child (even if in a minority) are deeper (such as complicated grief and depression disorders) (Wijngaards-de Meij et al., 2005).

Pregnancy corresponds to a period in which the parent's sentimental investment and the imaginary child's creation are activated. His death (be it an abortion or a LTP) is therefore a real loss of an invested object with expectations and parental identifications in a phantasmatic and symbolic way.

The moment of birth is instead an interruption of this investment and its introduction into the real sphere. The fantasies and representations nurtured during the pregnancy are modified, activated by the meeting with the real child, of which the parent begins to memorize the characteristics, the movements, the smell, etc.

The death of a child who has lived therefore determines not only the loss of the imaginary object, but also the real one. Furthermore, the aspect of everyday life also comes into play: the mother takes care of the child every day, responding to his needs (according to Winnicott's primary maternal preoccupation) and increasing the degree of investment, experiences and real memories with him.

Following a death that occurred too early, in which the only memories are imprinted in the memory of the parents, the symbolic object assumes an even more profound connotation than the other deaths. It is the testimony of the child's existence.

In addition to the photos and to the objects that belonged to the child or imagined for him, there are many parents who decided to get a child's tattoo (the imprint, the date of birth and death, etc.).

It corresponds to a new memorial practice that is very frequent within our society and is also highlighted during our study.

In a cultural context in which the tattoo is increasingly accepted and linked to aesthetic reasons, the tattoo for the child is an ancestral return, a bodily and eternal metaphor, whose symbol lies in the meaning and location, imprinted on the parent's body.

Finally, the priority role and function of professionals within the hospital is confirmed. The fatherly role, which is seen as authoritative, and the motherly role, which is seen as welcoming; are projected onto the hospital structure.

Parents need constant support that should be able to accompany them emotionally, to provide all the information and detailed medical and bureaucratic explanations. The defense mechanisms put in place by the professionals are often experienced as distant and devaluing attitudes with respect to the parent's requests. However, no criticisms have emerged regarding how professionals have handled the parents' decision to see or not see the child. Considering also the possibility of taking photos and obtaining the memory box, it is clear that in French hospitals there is an awareness of perinatal loss, an awareness that has certainly started but that is still not sufficient.

In summary, the work of mourning following the loss of a child in the perinatal period is unique and not comparable to other grief. It includes the acceptance of the loss of the imaginary and real child, the role of self as a parent and the ability to heal the narcissistic wound of not having given birth a healthy child. Birth and death merge, requiring a parent's psychic organization.

Compared to our results, only more than eighteen months after loss parents reached what is called the uncomplicated grief threshold, with an average lower than the ICG cut-off.

These data were also demonstrated by the qualitative analysis, which allowed us to highlight the work of mourning and the gradual acceptance of the loss.

Moreover, over the months the need of the parent to have the possibility of remembering and commemorating the child remained constant, especially on specific dates considered as the most important and difficult (such as anniversaries, holidays, Mother's and Father's Day, etc.).

The sense of isolation and misunderstanding of the parents is fundamental to consider. It is indeed a risk factor for possible psychopathological consequences such as complicated grief disorder and depression. Perceiving to be able to express pain and recognizing the child's existence openly is essential, above all compared to primary entourage (partner and family).

The absence of such support and the impossibility of meeting other bereaved parents during support groups is likely to lead many women to seek this support through other means, such as participation in online groups dedicated to perinatal loss.

The active and prolonged participation in these groups has however proved as very dangerous and harmful for the parent, increasing the risk of developing complicated grief, anxiety, somatic disorders and depression.

For those who feel the need, therapeutic support and participation in support groups were useful. Unfortunately the latter are generally very difficult to reach, being present only in the main cities.

Furthermore, significant differences have emerged between the verbal expression of grief between women and men. If at a quantitative level there were no differences, on a qualitative level it was possible to verify and confirm the need and greater openness of women in verbalizing and requesting emotional and professional support. On the contrary, men tend to deny and project their sadness, not verbalizing their suffering and focusing exclusively on women.

These ways can create initial difficulties in the couple. The gradual work of mourning accompanies the acceptance of loss's expression of the other. Despite these difficulties, many parents have declared the person perceived to be closer following this event is the partner, the only one who can truly understand.

The uniqueness of perinatal loss and its lack of recognition at social level is also highlighted by the parent's need to commemorate the child through rituals and symbolic representations.

The difficulties were also expressed during the subsequent pregnancy. The trauma of reliving a loss has translated into an initial denial and lack of attachment to the subsequent child.

Furthermore, the sense of guilt, above all maternal, is an aspect that returned cyclically during the interviews, especially if the death had occurred following the decision to carry out an LTP.

## **PART E. CONCLUSIONS**

Chapter 14 presents the conclusions we arrived after analyzing our results.

Furthermore, possible ideas for future research will be presented below, besides some limitations whose awareness fueled reflections and interpretation.

### **Chapter 14: Conclusions and future perspectives**

Our study wanted to highlight the possible psychological consequences of the bereaved parent and the efficacy of therapeutic support.

Our study was a longitudinal research. 29 French parents, 21 women and 8 men were met for a total of five times distributed over eighteen months.

The time elapsed between the loss and the first meeting was not the same for everyone. The minimum time was 22 days, while the maximum time was about ten months.

In particular, our aim was to study the risk of developing a complicated grief (CG) disorder following the loss of a child in the perinatal period.

As therapeutic support, we wanted to analyze the possible efficacy given by personal therapy and participation in support groups. A third therapeutic variable that was added during the research was the role of online groups dedicated to perinatal loss.

We have chosen to analyze this participation after understanding the confusion and mental association of the parents: they believed that such groups had the same function as therapeutic groups.

Our methodology was mixed. Each meeting was characterized by a semi-directive interview and the administration of the Inventory of Complicated Grief (Prigerson et al, 1995) and General Health Questionnaire-28 (Goldberg, 1978). At qualitative level, the interviews were analyzed through the French statistical program Alceste and the Interpretative Phenomenological Analysis (Smith, 1996). Through our research we confirm that the loss of a child in the perinatal period is a difficult and risky event.

As expressed by Leon (1996) in his multidimensional model, following a perinatal loss, the development, pulsional, relational and narcissistic axes of the parent are touched and, in some cases, damaged (Leon, 1996; Shulz et al., 2015). The loss of the real and imaginary child, the role of parent and the narcissistic injury of the ego have therefore invalidated the parent's self. The work of perinatal mourning has therefore required several months for its complete fulfillment.

Only more than a year and a half after loss, the parents reached what is called the uncomplicated grief threshold, a result confirmed by both qualitative and quantitative analyses.

Our quantitative data confirmed the prolonged parents' difficulties and psychological distress present in the following months after the loss. At the same time, the qualitative analysis has underlined the evolution and psychic functioning of the work of mourning.

Furthermore, although it was not the main disorder we wanted to investigate, no elements emerged that led to a possible diagnosis of Post-Traumatic Stress Disorder.

Moreover, even if not underscored in quantitative terms but only with respect to qualitative values, reactions of grief and difficulties may re-emerge on special occasions, such as the anniversary of birth and death, holidays, etc.

An important aspect to underline is the pain of both parents, mothers and fathers. We obviously cannot quantify the grief, but it is possible to highlight how the emotional and affective aspects are the same (Bennett et al., 2005; Schaap et al., 1997; Turton et al., 2006). What is different are their manifestations. The social role and cultural impositions of gender influence the expression of grief, in fact: men tend not to verbalize their sadness and needs, denying and projecting them on women (Stroebe et al., 2013); women probably have a greater need but also less resistance in verbalizing their sadness and suffering, more frequently seeking professional and social help (Cacciatore, 2013; Schaap et al., 1997; Zeanah, 1989).

Not surprisingly, 65% of the participants are mothers, the same who made themselves available to participate in the study after having read the recruitment notice published on the social network groups, where women participate more assiduously and actively.

These groups are a response to the lack of social recognition of perinatal loss. Parents often feel themselves abandoned and isolated, both emotionally and practically (for example, with respect to medical and / or bureaucratic and legal information).

Therefore, if these groups play the classic role of social networks, based on exchange of information and contacts, at the same time they do not correspond to an emotional support and must not be absolutely confused with professional help.

Our study has shown that thinking that online groups and therapeutic ones are equivalent is an illusion, a risk in developing diseases related to grief, such as complicated grief, depression, anxiety and somatic disorders. Furthermore, this result confirms that talking and expressing the feelings only does not amount to facilitating the experience of grief (Stroebe et al., 2005), especially in an uncontrolled context that risks feeding rumination and keeping the parent in the acute phase of grief. With respect to psychological support, the opportunity to participate in support groups would therefore seem useful. Meeting and comparing with other bereaved parents within a professional and therapeutic setting is very important, especially at the beginning.



Compared to personal therapy, only with respect to the last meeting and therefore eighteen months after the start of the research, significant data emerged, probably highlighting the psychic work and the lack of denial in those who requested this support.

The results could therefore confirm that psychotherapy can actually be useful only for those who feel the need. Considering also the experiences expressed by the parents during the interviews, the singularity that characterizes each grief must be very clear for the therapists.

They must accompany the parents considering their needs, specific difficulties and the motivations that lead the person to request support and respecting their choices and their culture (Zech et al., 2010).

Regarding the emotional support, the closeness and help of the partner and family are very important. Remembering and commemorating the child despite the passing of time and subsequent pregnancies are fundamental.

Obviously this recognition does not only concern the more intimate entourage but also the more extended one. Parents must in fact be given the opportunity to express their grief and get information about all the aspects that surround the loss.

It is therefore necessary to highlight the need to make society aware of this issue, starting with the administration and all the professionals dealing with perinatal loss (doctors, midwives and nurses, including psychologists).

It would be useful to carry out specific professional training on this topic, in order to understand the parent's experience, the risks, their needs and how support them.

We have seen that the support groups are fundamental. Unfortunately, professional associations that offer this opportunity are not always present. It could therefore be useful to concentrate the energies and resources on trying to create or extend these associations throughout the territory and not only in the main cities.

Furthermore, with respect to our methodology, we can also conclude that the use of a mixed methodology has been useful to achieve our goals and to fully highlight the psychic functioning of the bereaved parent.

Our results also confirmed the validity of the use of Alceste associated with the Interpretative Phenomenological Analysis. Alceste has therefore demonstrated its validity with respect to the study of semi-direct interviews about perinatal loss.

## Limitations

This research has also brought some limitations out. Our concentration has focused above all on certain disorders, such as complicated grief. Possible research could therefore also consider other problems that may arise after a perinatal loss, such as Post-Traumatic Stress Disorder.

A further limitation to underscore is the role of only one researcher in this study. For subsequent work it would be useful to have the possibility of having a co-researcher to obtain greater validity beside qualitative results.

Furthermore, it was not possible to create a homogeneous group that would allow a real comparison, in particular in relation to the gender of the participants (of which about one third are women), to the time of the child's death (whether during pregnancy or after delivery) and to those who have requested a therapeutic support.

These limitations were due to the initial difficulty of being able to recruit the number of participants in a limited period of time.

It is important to underline that most of the participants were recruited on social networks' groups about perinatal loss. As also shown by our data, most of the users are women and parents who lost a child during pregnancy (or they are the ones who showed more availability). It is therefore possible to interpret these limitations as a greater need for those who present these characteristics in wanting to express their pain and seek support.

## Scientific contributions

During these three years of work, starting from this research, the researchers carried out further studies related to the topic of perinatal loss.

One of these was an important and extensive research on the rituals related to the loss of the child throughout History (Bacqué et al, 2018a; Bacqué et al, 2018b). This research has highlighted the role of the child and the expression of the suffering of parents from the Neanderthal era to the present day. The various testimonies concerned in particular the territory of current Europe. Through a bibliographic search in psychology, history and sociology, the expressions of parents' needs based on different social and cultural rules were analysed and presented.

A further study was carried out to highlight the new contemporary practices. Today, in addition to groups on social networks, it is increasingly common for parents to publish videos dedicated to the memory of children on YouTube. These videos represent a sort of social baptism of the child and an immortal testimony of his existence (Sani et al, 2019).

Furthermore, a study was also conducted on the comparison between the legal recognition of parent's rights in France and Italy (Sani & Bacqué, 2019). This article highlighted the many differences between these two countries and the social and legal gaps linked to this loss in Italy.

### Perspectives

It is important to continue to carry out studies on perinatal loss to be able to know the psychological consequences on the parents and to support them.

In particular, longitudinal research could be suggested to highlight specific and possible comorbidities following a traumatic loss, such as the post traumatic stress disorder.

Furthermore, possible consequences could be assessed with respect to living children, grandparents and the subsequent child.

It is also important to continue to analyze the role of the internet in such loss and the possible outcomes that it can determine.

Furthermore, currently the practice of conducting psychotherapy sessions with Skype is spreading. These have begun to model according to the needs and restrictions of the patients, such as for those who live abroad, or cannot move for medical reasons, or for those who suffer from agoraphobia, etc. (Bouchard et al., 2004; Cipolletta, 2015; Edirippulige et al., 2013; Freeman et al., 2013). Following this example, some associations have started promoting support group meetings via Skype (ecoute-psy.com, 2016; "Online Support Groups - Aware NI," 2019).

Their effectiveness has not yet been demonstrated but this could be an interesting subject for future research. It is necessary to find a solution for people with geographical limitations and restrictions, to let them reach the association of support groups if they feel the need.

Furthermore, as previously expressed, our research has demonstrated the validity and effectiveness of the comparison between the categories emerged through the IPA and the French statistical program Alceste.

It could therefore, for methodological purposes, be useful to continue to analyze this association and possibly use Alceste also for international studies.

## Bibliography

- Agapa. (2017). S'informer. Retrieved May 1, 2019, from agapa website: <https://association-agapa.fr/sinformer/>
- Aho, A. L., Inki, M., & Kaunonen, M. (2018). Grandmothers' grief after the loss of a grandchild. *Mental Health and Family Medicine, 14*(1), 676–680.
- Aho, A. L., Paavilainen, E., & Kaunonen, M. (2012). Mothers' experiences of peer support via an Internet discussion forum after the death of a child. *Scandinavian Journal of Caring Sciences, 26*(3), 417–426. <https://doi.org/10.1111/j.1471-6712.2011.00929.x>
- Albuquerque, S., Buyukcan-Tetik, A., Stroebe, M. S., Schut, H. A. W., Narciso, I., Pereira, M., & Finkenauer, C. (2017). Meaning and coping orientation of bereaved parents: Individual and dyadic processes. *PLOS ONE, 12*(6), e0178861. <https://doi.org/10.1371/journal.pone.0178861>
- Alexandre, M., & Gaugue, J. (2016). Le deuil périnatal : la question de la reconnaissance sociale et juridique des bébés mort-nés. *Devenir, Vol. 28*(1), 5–20.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: DSM-5* (5 edition). Washington, D.C: American Psychiatric Publishing.
- Anisfeld, L., & Richards, A. D. (2000). The Replacement Child. *The Psychoanalytic Study of the Child, 55*(1), 301–318. <https://doi.org/10.1080/00797308.2000.11822527>
- Antonio, L. (2014). *Il gruppo terapeutico: Bion* (Università degli Studi della Campania Luigi Vanvitelli). Retrieved from <https://www.docsity.com/it/il-gruppo-terapeutico-bion/491325/>
- Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. *Social Science & Medicine, 36*(6), 725–733. [https://doi.org/10.1016/0277-9536\(93\)90033-Z](https://doi.org/10.1016/0277-9536(93)90033-Z)
- Aoyama, M., Sakaguchi, Y., Morita, T., Ogawa, A., Fujisawa, D., Kizawa, Y., ... Miyashita, M. (2018). Factors associated with possible complicated grief and major depressive disorders. *Psycho-Oncology, 27*(3), 915–921. <https://doi.org/10.1002/pon.4610>

- Armstrong, D. S. (2002). Emotional Distress and Prenatal Attachment in Pregnancy After Perinatal Loss. *Journal of Nursing Scholarship*, 34(4), 339–345. <https://doi.org/10.1111/j.1547-5069.2002.00339.x>
- Armstrong, D. S., Hutti, M. H., & Myers, J. (2009). The Influence of Prior Perinatal Loss on Parents' Psychological Distress After the Birth of a Subsequent Healthy Infant. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 38(6), 654–666. <https://doi.org/10.1111/j.1552-6909.2009.01069.x>
- Arnold, J., & Buschman Gemma, P. (2008). The Continuing Process of Parental Grief. *Death Studies*, 32(7), 658–673. <https://doi.org/10.1080/07481180802215718>
- Attorre, F. (2016). *Saggi di Psicoanalisi del male e del dolore: Un viaggio nei meandri della Psiche alla ricerca della verità*. Edizioni Accademiche Italiane.
- Aubert-Lotarski, A., & Capdevielle-Mougnibas, V. (2002). *Dialogue méthodologique autour de l'utilisation du logiciel Alceste en sciences humaines et sociales: "lisibilité du corpus et interprétation des résultats*. Presented at the JADT 2002: 6es Journées internationales d'Analyse statistique des Données Textuelles, Saint-Malo. Retrieved from [https://www.researchgate.net/publication/312233106\\_Dialogue\\_methodologique\\_autour\\_de\\_l'utilisation\\_du\\_logiciel\\_Alceste\\_en\\_sciences\\_humaines\\_et\\_sociales\\_lisibilite\\_d\\_corpus\\_e\\_t\\_interpretation\\_des\\_resultats](https://www.researchgate.net/publication/312233106_Dialogue_methodologique_autour_de_l'utilisation_du_logiciel_Alceste_en_sciences_humaines_et_sociales_lisibilite_d_corpus_e_t_interpretation_des_resultats)
- Avelin, P., Erlandsson, K., Hildingsson, I., & Rådestad, I. (2011). Swedish Parents' Experiences of Parenthood and the Need for Support to Siblings When a Baby is Stillborn. *Birth*, 38(2), 150–158. <https://doi.org/10.1111/j.1523-536X.2010.00457.x>
- Avelin, P., Gyllenswärd, G., Erlandsson, K., & Rådestad, I. (2014). Adolescents' Experiences of Having a Stillborn Half-Sibling. *Death Studies*, 38(9), 557–562. <https://doi.org/10.1080/07481187.2013.809034>

- Azogh, M., Shakiba, M., & Navidian, A. (2018). The Effect of Psychoeducation on Anxiety in Subsequent Pregnancy Following Stillbirth: A Quasi-Experimental Study. *Journal of Family and Reproductive Health*, 42–50.
- Bacchetta, E. (2014). *Il suicidio e l'elaborazione del lutto*. Università degli Studi di Milano Bicocca. Facoltà di Psicologia Corso di Laurea in Scienze e Tecniche Psicologiche, Alternativa-A.
- Bacqué, M.-F. (1990). Il processo del lutto. Un modello di adattamento alla perdita. In G. Morasso & G. Invernizzi, *Di fronte all'esperienza di morte: il paziente e i suoi terapeuti*. Milano: Elsevier.
- Bacqué, M.-F. (1997). *Mourir aujourd'hui: Les nouveaux rites funéraires*. Paris: Odile Jacob.
- Bacqué, M.-F. (2003a). Abord et psychothérapie individuelle d'adultes et d'enfants présentant un deuil post-traumatique. *Études sur la mort*, no 123(1), 131–141. <https://doi.org/10.3917/eslm.123.0131>
- Bacqué, M.-F. (2003b). Deuil post-traumatique et catastrophes naturelles, Summary. *Études sur la mort*, no 123(1), 111–130. <https://doi.org/10.3917/eslm.123.0111>
- Bacqué, M.-F. (2006). Deuils et traumatismes. *Annales Médico-Psychologiques, Revue Psychiatrique*, 164(4), 357–363. <https://doi.org/10.1016/j.amp.2006.02.006>
- Bacqué, M.-F., & Hanus, M. (2014). L'accompagnement des personnes en deuil. *Que sais-je?*, 6e éd.(3558), 74–79.
- Bacqué, M.-F., & Hanus, M. (2016). *Le deuil* (7e édition). Presses Universitaires de France - PUF.
- Bacqué, M.-F., & Merg, D. (2013). Des corps immémoriaux... Devenir du corps de l'enfant mort autour de la naissance. Deuils social et psychologique des parents. *Corps*, 11, 57–68.
- Bacqué, M.-F., & Merg, D. (2015). Animer un groupe de parents en deuil de leur enfant. La coanimation d'un groupe par un professionnel et des parents endeuillés formés. In Accompanying the grief in traumatic situation. In H. Romano, *Accompagner le deuil en situation traumatique - 10 contextes cliniques* (pp. 116–131). Arcueil: Dunod.

- Bacqué, M.-F., Sani, L., Rauner, A., Losson, A., Merg, D., & Guillou, P. (2018). Mort périnatale et d'un jeune enfant. Histoire des rites et des pratiques funéraires en Europe issus de l'expression affective et sociale du deuil. Première partie : de la Préhistoire aux Lumières. *Neuropsychiatrie de l'Enfance et de l'Adolescence*, 66(4), 240–247. <https://doi.org/10.1016/j.neurenf.2018.03.001>
- Bacqué, M.-F., Sani, L., Rauner, A., Losson, A., Merg-Essadi, D., & Guillou, P. (2018). Mort périnatale et d'un jeune enfant. Histoire des rites et des pratiques funéraires en Europe issus de l'expression affective et sociale du deuil. Deuxième partie : des Lumières à aujourd'hui. *Neuropsychiatrie de l'Enfance et de l'Adolescence*, 66(4), 248–255. <https://doi.org/10.1016/j.neurenf.2018.04.005>
- Badenhorst, W., & Hughes, P. (2007). Psychological aspects of perinatal loss. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 21(2), 249–259. <https://doi.org/10.1016/j.bpobgyn.2006.11.004>
- Baker, D. A., & Perez Algorta, G. (2016). The Relationship Between Online Social Networking and Depression: A Systematic Review of Quantitative Studies. *CyberPsychology, Behavior & Social Networking*, 19(11), 638–648. <https://doi.org/10.1089/cyber.2016.0206>
- Banjanin, N., Banjanin, N., Dimitrijevic, I., & Pantic, I. (2015). Relationship between internet use and depression: Focus on physiological mood oscillations, social networking and online addictive behavior. *Computers in Human Behavior*, 43, 308–312. <https://doi.org/10.1016/j.chb.2014.11.013>
- Barr, P., & Cacciatore, J. (2008). Problematic Emotions and Maternal Grief. *OMEGA - Journal of Death and Dying*, 56(4), 331–348. <https://doi.org/10.2190/OM.56.4.b>
- Bart, D. (2011). L'analyse de données textuelles avec le logiciel ALCESTE. *Recherches en didactiques*, N° 12(2), 173–184.
- Bell, D. (1976). *The Coming of Post-Industrial Society: A Venture in Social Forecasting* (Reissue edition). New York: Basic Books.

- Bellini, B., Cescut, A., Caravale, B., Galli, F., Paravicini, V., Lucchese, F., & Guidetti, V. (2013). Sudden Infant Dead: Reaction to Bereavement in Siblings and Mothers. *Journal of Palliative Care & Medicine*, 03(05). <https://doi.org/10.4172/2165-7386.1000159>
- Bennett, N., & Chichester, M. (2015). Ripples in the pond: caring for extended family members after a perinatal loss. *BMC Pregnancy and Childbirth*, 15(1), A17. <https://doi.org/10.1186/1471-2393-15-S1-A17>
- Bennett, S. M., Litz, B. T., Lee, B. S., & Maguen, S. (2005). The Scope and Impact of Perinatal Loss: Current Status and Future Directions. *Professional Psychology: Research and Practice*, 36(2), 180–187. <https://doi.org/10.1037/0735-7028.36.2.180>
- Bennett, S. M., Litz, B. T., Maguen, S., & Ehrenreich, J. T. (2008). An Exploratory Study of the Psychological Impact and Clinical Care of Perinatal Loss. *Journal of Loss and Trauma*, 13(6), 485–510. <https://doi.org/10.1080/15325020802171268>
- Besanceney, J.-C. (1997). Evolution des rites catholiques du deuil et nouvelles pratiques rituelles. In M.-F. Bacqué, *Mourir aujourd'hui: Les nouveaux rites funéraires* (pp. 167–195). Paris: Odile Jacob.
- Beutel, M., Willner, H., Deckardt, R., Rad, M. V., & Weiner, H. (1996). Similarities and differences in couples' grief reactions following a miscarriage: Results from a longitudinal study. *Journal of Psychosomatic Research*, 40(3), 245–253. [https://doi.org/10.1016/0022-3999\(95\)00520-X](https://doi.org/10.1016/0022-3999(95)00520-X)
- Bion, W. R. (1991). *Experiences in Groups* (1 edition). London: Routledge.
- Blackmore, E. R., Côté-Arsenault, D., Tang, W., Glover, V., Evans, J., Golding, J., & O'Connor, T. G. (2011). Previous prenatal loss as a predictor of perinatal depression and anxiety. *The British Journal of Psychiatry*, 198(5), 373–378. <https://doi.org/10.1192/bjp.bp.110.083105>
- Blood, C., & Cacciatore, J. (2014). Parental Grief and Memento Mori Photography: Narrative, Meaning, Culture, and Context. *Death Studies*, 38(4), 224–233. <https://doi.org/10.1080/07481187.2013.788584>



- Boccalon, R. (1999). La terapia di gruppo. In O. Codispoti & C. Clementel, *Psicologia clinica. Modelli, metodi, trattamenti*. Roma: Carocci.
- Boelen, P. A., & Prigerson, H. G. (2007). The influence of symptoms of prolonged grief disorder, depression, and anxiety on quality of life among bereaved adults. *European Archives of Psychiatry & Clinical Neuroscience*, 257(8), 444–452. <https://doi.org/10.1007/s00406-007-0744-0>
- Boelen, P. A., & Prigerson, H. G. (2012). Commentary on the Inclusion of Persistent Complex Bereavement-Related Disorder in DSM-5. *Death Studies*, 36(9), 771–794. <https://doi.org/10.1080/07481187.2012.706982>
- Boelen, P. A., & Smid, G. E. (2017). Disturbed grief: prolonged grief disorder and persistent complex bereavement disorder. *BMJ*, 357, j2016. <https://doi.org/10.1136/bmj.j2016>
- Boelen, P. A., van den Bout, J., & de Keijser, J. (2003). Traumatic Grief as a Disorder Distinct From Bereavement-Related Depression and Anxiety: A Replication Study With Bereaved Mental Health Care Patients. *American Journal of Psychiatry*, 160(7), 1339–1341. <https://doi.org/10.1176/appi.ajp.160.7.1339>
- Bogensperger, J., & Lueger-Schuster, B. (2014). Losing a child: finding meaning in bereavement. *European Journal of Psychotraumatology*, 5(1). <https://doi.org/10.3402/ejpt.v5.22910>
- Bonanno, G. A., & Kaltman, S. (1999). Toward an integrative perspective on bereavement. *Psychological Bulletin*, 125(6), 760–776.
- Bonanno, G. A., & Malgaroli, M. (2019). Trajectories of grief: Comparing symptoms from the DSM-5 and ICD-11 diagnoses. *Depression and Anxiety*, 0(0). <https://doi.org/10.1002/da.22902>
- Bortolotti, T. (2017, July 18). Vivere il lutto su facebook: social network e mentalizzazione. *Kalporz*. Retrieved from <http://www.kalporz.com/2017/07/mdc-vivere-il-lutto-su-facebook-social-network-e-mentalizzazione/>
- Bouchard, S., Paquin, B., Payeur, R., Allard, M., Rivard, V., Fournier, T., ... Lapierre, J. (2004). Delivering Cognitive-Behavior Therapy for Panic Disorder with Agoraphobia in

Videoconference. *Telemedicine Journal and E-Health*, 10(1), 13–25.  
<https://doi.org/10.1089/153056204773644535>

- Bowlby, J. (1980). *Attachment and loss. Volume 3, Loss : sadness and depression*. New York: Basic Books.
- Bowlby, J. (1983). *Attachment: Attachment and Loss Volume One (1969)* (2nd edition). New York: Basic Books.
- Bowlby, J. (1988). *A Secure Base: Parent-Child Attachment and Healthy Human Development* (Reprint edition). New York: Basic Books.
- Bowlby, J. (1998). *Attachment and loss. Volume Two: Separation - Anxiety and Anger (1973)* (New Ed edition). Pimlico.
- Bowlby, J., & Parkes, C. M. (1970). Separation and loss within the family. In E. J. Anthony & C. Koupernik, *The Child in His Family, Children at Psychiatric Risk* (pp. 197–2016). New York: Wiley.
- Boyle, F. M., Vance, J. C., Najman, J. M., & Thearle, M. J. (1996). The mental health impact of stillbirth, neonatal death or SIDS: Prevalence and patterns of distress among mothers. *Social Science & Medicine*, 43(8), 1273–1282. [https://doi.org/10.1016/0277-9536\(96\)00039-1](https://doi.org/10.1016/0277-9536(96)00039-1)
- Boyras, G., Horne, S. G., & Sayger, T. V. (2012). Finding Meaning in Loss: The Mediating Role of Social Support Between Personality and Two Construals of Meaning. *Death Studies*, 36(6), 519–540. <https://doi.org/10.1080/07481187.2011.553331>
- Braun, M. J., & Berg, D. H. (1994). Meaning reconstruction in the experience of parental bereavement. *Death Studies*, 18(2), 105–129. <https://doi.org/10.1080/07481189408252647>
- Brier, N. (2008). Grief Following Miscarriage: A Comprehensive Review of the Literature. *Journal of Women's Health*, 17(3), 451–464. <https://doi.org/10.1089/jwh.2007.0505>
- Büchi, S., Mörgeli, H., Schnyder, U., Jenewein, J., Glaser, A., Fauchère, J.-C., ... Sensky, T. (2009). Shared or Discordant Grief in Couples 2–6 Years After the Death of Their Premature Baby:

- Effects on Suffering and Posttraumatic Growth. *Psychosomatics*, 50(2), 123–130.  
<https://doi.org/10.1176/appi.psy.50.2.123>
- Büchi, S., Mörgeli, H., Schnyder, U., Jenewein, J., Hepp, U., Jina, E., ... Sensky, T. (2007). Grief and Post-Traumatic Growth in Parents 2–6 Years after the Death of Their Extremely Premature Baby. *Psychotherapy and Psychosomatics*, 76(2), 106–114.  
<https://doi.org/10.1159/000097969>
- Burden, C., Bradley, S., Storey, C., Ellis, A., Heazell, A. E. P., Downe, S., ... Siassakos, D. (2016). From grief, guilt pain and stigma to hope and pride – a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BMC Pregnancy and Childbirth*, 16, 9. <https://doi.org/10.1186/s12884-016-0800-8>
- Cacciatore, J. (2007). Effects of Support Groups on Post Traumatic Stress Responses in Women Experiencing Stillbirth. *OMEGA - Journal of Death and Dying*, 55(1), 71–90.  
<https://doi.org/10.2190/M447-1X11-6566-8042>
- Cacciatore, J. (2010). Stillbirth: Patient-centered Psychosocial Care. *Clinical Obstetrics and Gynecology*, 53(3), 691. <https://doi.org/10.1097/GRF.0b013e3181eba1c6>
- Cacciatore, J. (2013). Psychological effects of stillbirth. *Seminars in Fetal and Neonatal Medicine*, 18(2), 76–82. <https://doi.org/10.1016/j.siny.2012.09.001>
- Cacciatore, J., & Bushfield, S. (2007). Stillbirth: The Mother's Experience and Implications for Improving Care. *Journal of Social Work in End-of-Life & Palliative Care*, 3(3), 59–79.  
[https://doi.org/10.1300/J457v03n03\\_06](https://doi.org/10.1300/J457v03n03_06)
- Cacciatore, J., & Flint, M. (2012). Mediating Grief: Postmortem Ritualization After Child Death. *Journal of Loss & Trauma*, 17(2), 158–172. <https://doi.org/10.1080/15325024.2011.595299>
- Cacciatore, J., Rådestad, I., & Frøen, J. F. (2008). Effects of Contact with Stillborn Babies on Maternal Anxiety and Depression. *Birth*, 35(4), 313–320. <https://doi.org/10.1111/j.1523-536X.2008.00258.x>

- Cacciatore, J., Schnebly, S., & Froen, J. F. (2009). The effects of social support on maternal anxiety and depression after stillbirth. *Health & Social Care in the Community*, *17*(2), 167–176. <https://doi.org/10.1111/j.1365-2524.2008.00814.x>
- Caglar Nazali, H. P., & Yildirim, E. A. (2017). The relationship between grief process and attachment styles in the cases with the treatment of complicated grief: A prospective study. *European Psychiatry*, *41*, S354. <https://doi.org/10.1016/j.eurpsy.2017.02.337>
- Callister, L. C. (2006). Perinatal loss: a family perspective. *The Journal of Perinatal & Neonatal Nursing*, *20*(3), 227-34; quiz 235-6. <https://doi.org/10.1097/00005237-200607000-00009>
- Campbell-Jackson, L., Bezance, J., & Horsch, A. (2014). “A renewed sense of purpose”: Mothers’ and fathers’ experience of having a child following a recent stillbirth. *BMC Pregnancy and Childbirth*, *14*(1), 423. <https://doi.org/10.1186/s12884-014-0423-x>
- Campbell-Jackson, L., & Horsch, A. (2014). The Psychological Impact of Stillbirth on Women: A Systematic Review. *Illness, Crisis & Loss*, *22*(3), 237–256. <https://doi.org/10.2190/IL.22.3.d>
- Carlson, J. A. (1993). The psychologic effects of sudden infant death syndrome on parents. *Journal of Pediatric Health Care*, *7*(2), 77–81. [https://doi.org/10.1016/0891-5245\(93\)90077-U](https://doi.org/10.1016/0891-5245(93)90077-U)
- Carlson, R., Lammert, C., & O’Leary, J. M. (2012). The Evolution of Group and Online Support for Families Who Have Experienced Perinatal or Neonatal Loss. *Illness, Crisis & Loss*, *20*(3), 275–293. <https://doi.org/10.2190/IL.20.3.e>
- Carmassi, C., Conversano, C., Pinori, M., Bertelloni, C. A., Luche, R. D., Gesi, C., & Dell’Osso, L. (2016). Il lutto complicato nell’era del DSM-5. *Rivista Di Psichiatria*, *51*(6), 231–237.
- Carter, D., Misri, S., & Tomfohr, L. (2007). Psychologic aspects of early pregnancy loss. *Clinical Obstetrics and Gynecology*, *50*(1), 154–165. <https://doi.org/10.1097/GRF.0b013e31802f1d28>
- Chambers, P. L., Mahabee-gittens, E. M., & Leonard, A. C. (2011). Vulnerable Child Syndrome, Parental Perception of Child Vulnerability, and Emergency Department Usage. *Pediatric Emergency Care*, *27*(11), 1009–1013. <https://doi.org/10.1097/PEC.0b013e318235bb4f>

- Chan, A. (2011). Décès et deuil périnatal [Institut national de santé publique Québec]. Retrieved August 23, 2019, from Le Portail d'information prénatale website: <http://infoprenatale.inspq.qc.ca/deces-et-deuilperinatal.aspx>
- Charlier, P., & Clavandier, G. (2015). Petites dépouilles: le sort des foetus et des mort-nés. *Le Seuil*, (97), 117–129.
- Christiansen, D. M., Elklit, A., & Olf, M. (2013). Parents bereaved by infant death: PTSD symptoms up to 18 years after the loss. *General Hospital Psychiatry*, 35(6), 605–611. <https://doi.org/10.1016/j.genhosppsy.2013.06.006>
- Christiansen, D. M., Olf, M., & Elklit, A. (2014). Parents bereaved by infant death: sex differences and moderation in PTSD, attachment, coping and social support. *General Hospital Psychiatry*, 36(6), 655–661. <https://doi.org/10.1016/j.genhosppsy.2014.07.012>
- Cipolletta, S. (2015). When therapeutic relationship is online: Some reflections on skype sessions. *Costruttivismi*, 2, 88–97.
- Circulaire 2001-576 du 30 Novembre 2001.*, 576 § (2001).
- Circulaire no 2009-182 du 19 juin 2009 relative à l'enregistrement à l'état civil des enfants décédés avant la déclaration de naissance et de ceux pouvant donner lieu à un acte d'enfant sans vie, à la délivrance du livret de famille, à la prise en charge des corps des enfants décédés, des enfants sans vie et des foetus. (2016, June 28). Retrieved March 16, 2018, from Légibase État civil & Cimetières website: <http://etat-civil.legibase.fr/base-de-connaissances/deces/circulaire-no-2009-182-du-19-juin-2009-relative-45120>
- Civilstāvokļa aktu reģistrācijas likums. (2017). Retrieved May 1, 2019, from likumi.lv website: <https://likumi.lv/doc.php?id=253442>
- Coffey, H. (2016). *Parents' experience of the care they received following a stillbirth: a literature review*. 14(1), 16–21.

- Collins, K., & Nicolson, P. (2002). The Meaning of 'Satisfaction' for People with Dermatological Problems: Reassessing Approaches to Qualitative Health Psychology Research. *Journal of Health Psychology, 7*(5), 615–629. <https://doi.org/10.1177/1359105302007005681>
- Cook, A. S., & Oltjenbruns, K. A. (1998). The bereaved family. In *Dying and Grieving: Lifespan and Family Perspectives* (2nd edition). Fort Worth: Wadsworth Pub Co.
- Cook, J. A. (1983). A Death in the Family: Parental Bereavement in the First Year. *Suicide and Life-Threatening Behavior, 13*(1), 42–61. <https://doi.org/10.1111/j.1943-278X.1983.tb00004.x>
- Corsini, R. J., & Rosenberg, B. (1955). Mechanisms of group psychotherapy: Processes and dynamics. *The Journal of Abnormal and Social Psychology, 51*(3), 406–411. <https://doi.org/10.1037/h0048439>
- Côté-Arsenault, D., Bidlack, D., & Humm, A. (2001). Women's Emotions and Concerns During Pregnancy Following Perinatal Loss. *MCN: The American Journal of Maternal/Child Nursing, 26*(3), 128.
- Côté-Arsenault, D., Brody, D., & Dombeck, M.-T. (2009). Pregnancy as a Rite of Passage: Liminality, Rituals & Communitas. *Journal of Prenatal & Perinatal Psychology & Health, 24*(2), 69.
- Côté-Arsenault, D., & Freije, M. M. (2004). Support Groups Helping Women Through Pregnancies after Loss. *Western Journal of Nursing Research, 26*(6), 650–670. <https://doi.org/10.1177/0193945904265817>
- Cour de cassation, civile, Chambre civile 1, 6 février 2008, 06-16.498, Publié au bulletin. , Publié au bulletin (Cour de cassation 2008).
- Crawley, R., Lomax, S., & Ayers, S. (2013). Recovering from stillbirth: the effects of making and sharing memories on maternal mental health. *Journal of Reproductive and Infant Psychology, 31*(2), 195–207. <https://doi.org/10.1080/02646838.2013.795216>
- Crehan, G. (2004). The Surviving Sibling: The Effects of Sibling Death in Childhood. *Psychoanalytic Psychotherapy, 18*(2), 202–219. <https://doi.org/10.1080/14749730410001700723>

- Currier, J. M., Holland, J. M., & Neimeyer, R. A. (2006). Sense-Making, Grief, and the Experience of Violent Loss: Toward a Mediational Model. *Death Studies, 30*(5), 403–428. <https://doi.org/10.1080/07481180600614351>
- Damageux, F. (2014). Les groupes de parole et de soutien pour parents endeuillés. *Vocation Sage-femme, 13*(110), 19–22.
- Davidson, D., & Letherby, G. (2014). Griefwork online: Perinatal loss, lifecourse disruption and online support. *Human Fertility, 17*(3), 214–217. <https://doi.org/10.3109/14647273.2014.945498>
- Davies, R. (2004). New understandings of parental grief: literature review. *Journal of Advanced Nursing, 46*(5), 506–513. <https://doi.org/10.1111/j.1365-2648.2004.03024.x>
- Davila, J., Hershenberg, R., Feinstein, B. A., Gorman, K., Bhatia, V., & Starr, L. R. (2012). Frequency and Quality of Social Networking Among Young Adults: Associations With Depressive Symptoms, Rumination, and Corumination. *Psychology of Popular Media Culture, 1*(2), 72–86. <https://doi.org/10.1037/a0027512>
- Davis, D. L., Stewart, M., & Harmon, R. J. (1988). Perinatal Loss: Providing Emotional Support for Bereaved Parents. *Birth, 15*(4), 242–246. <https://doi.org/10.1111/j.1523-536X.1988.tb01118.x>
- Davis, D. L., Stewart, M., & Harmon, R. J. (1989). Postponing Pregnancy after Perinatal Death: Perspectives on Doctor Advice. *Journal of the American Academy of Child & Adolescent Psychiatry, 28*(4), 481–487. <https://doi.org/10.1097/00004583-198907000-00002>
- De Frain, J. D., Jakub, D. K., & Mendoza, B. L. (1992). The Psychological Effects of Sudden Infant Death on Grandmothers and Grandfathers. *OMEGA - Journal of Death and Dying, 24*(3), 165–182. <https://doi.org/10.2190/CBXP-UQFV-JDYT-2D6Q>
- Debra, A. (2005). Le deuil de la fratrie. In Michel Hanus, Elisabeth Baron, Emmanuel De Becker, Alain de Broca, & Collectif, *La mort d'un enfant : Approches de l'accompagnement et du deuil*. Paris: Vuibert.

- Décret n° 2008-800 du 20 août 2008 relatif à l'application du second alinéa de l'article 79-1 du code civil. , 2008-800 § (2008).
- Delavigne, V. (2003). *Alceste, un logiciel d'analyse textuelle*. Retrieved from <https://hal.archives-ouvertes.fr/hal-00924168>
- Dell'Osso, L., Carmassi, C., Musetti, L., Socci, C., Shear, M. K., Conversano, C., ... Perugi, G. (2012). Lifetime mood symptoms and adult separation anxiety in patients with complicated grief and/or post-traumatic stress disorder: A preliminary report. *Psychiatry Research, 198*(3), 436–440. <https://doi.org/10.1016/j.psychres.2011.12.020>
- Deutsch, H. (1945). *The psychology of women. Vol. 2. Motherhood*. Oxford, England: Grune & Stratton.
- Deutsch, H. (2005). Absence de douleur (1937). In *L'affect* (pp. 79–87). Retrieved from <https://www.cairn.info/l-affect%20--9782130548652-p-79.htm>
- Deutsch, H. (2007). *Omission du travail de deuil (1936)*. Retrieved from [http://bsf.spp.asso.fr/index.php?lvl=notice\\_display&id=100583](http://bsf.spp.asso.fr/index.php?lvl=notice_display&id=100583)
- Diamond, D., & Diamond, M. (2017). Parenthood After Reproductive Loss. *Psychotherapy, Publish Ahead of Print*. <https://doi.org/10.1037/pst0000127>
- Dierik, P., & Lietaer, G. (1990). Member and Therapist Perceptions of Therapeutic Factors in Therapy and Growth Groups: Comments on a Category System. In G. Lietaer, J. Rombauts, & V. R. Balen, *Client-Centered and Experiential Psychotherapy in the Nineties* (01 ed.). Leuven, Belgium: Leuven University Press.
- DiMarco, M., Menke, E., & McNamara, T. (2001). Evaluating a Support Group for Perinatal Loss. *MCN, The American Journal of Maternal/Child Nursing, 26*(3), 135–140.
- Doering, B. K., & Eisma, M. C. (2016, September). Treatment for complicated grief: state of the science and ways forward [Text]. <https://doi.org/info:doi/10.1097/YCO.0000000000000263>



- Döveling, K. (2015). Emotion regulation in bereavement: searching for and finding emotional support in social network sites. *New Review of Hypermedia and Multimedia*, 21(1–2), 106–122. <https://doi.org/10.1080/13614568.2014.983558>
- Due, C., Chiarolli, S., & Riggs, D. W. (2017). The impact of pregnancy loss on men's health and wellbeing: a systematic review. *BMC Pregnancy and Childbirth*, 17(1), 380. <https://doi.org/10.1186/s12884-017-1560-9>
- Dumoulin, M., & Valat, A.-S. (2001). Morts en maternité : devenir des corps, deuil des familles. *Etudes sur la mort*, no 119(1), 77–99.
- Dyregrov, A., & Dyregrov, K. (1999). Long-Term Impact of Sudden Infant Death: A 12- to 15-Year Follow-Up. *Death Studies*, 23(7), 635–661. <https://doi.org/10.1080/074811899200812>
- Dyregrov, A., & Gjestad, R. (2011). Sexuality Following the Loss of a Child. *Death Studies*, 35(4), 289–315. <https://doi.org/10.1080/07481187.2010.527753>
- Dyregrov, A., & Matthiesen, S. B. (1987a). Anxiety and vulnerability in parents following the death of an infant. *Scandinavian Journal of Psychology*, 28(1), 16–25. <https://doi.org/10.1111/j.1467-9450.1987.tb00901.x>
- Dyregrov, A., & Matthiesen, S. B. (1987b). Similarities and differences in mothers' and fathers' grief following the death of an infant. *Scandinavian Journal of Psychology*, 28(1), 1–15. <https://doi.org/10.1111/j.1467-9450.1987.tb00900.x>
- Dyregrov, K., Dyregrov, A., & Johnsen, I. (2013). Positive and Negative Experiences from Grief Group Participation: A Qualitative Study. *Omega: Journal of Death & Dying*, 68(1), 45–62. <https://doi.org/10.2190/OM.68.1.c>
- Dyregrov, K., Nordanger, D., & Dyregrov, A. (2003). Predictors of Psychosocial Distress After Suicide, Sids and Accidents. *Death Studies*, 27(2), 143–165. <https://doi.org/10.1080/07481180302892>
- Earle, S., Komaromy, C., Foley, P., & Lloyd, C. (2017). The social dimensions of reproductive loss. *Practising Midwife*, 10(6), 28–34.

- Earle, S., Komaromy, C., & Layne, L. (Eds.). (2012). *Understanding Reproductive Loss: Perspectives on Life, Death and Fertility*. Retrieved from [https://www.amazon.fr/Understanding-Reproductive-Loss-Perspectives-Fertility-ebook/dp/B01C677HTG/ref=sr\\_1\\_fkmr0\\_1?ie=UTF8&qid=1553269640&sr=8-1-fkmr0&keywords=Understanding+Reproductive+Loss%3A+Perspectives+on+Life%2C+Death+and+Fertility+.+Farnham%2C+Surrey%3A+Ashgate+](https://www.amazon.fr/Understanding-Reproductive-Loss-Perspectives-Fertility-ebook/dp/B01C677HTG/ref=sr_1_fkmr0_1?ie=UTF8&qid=1553269640&sr=8-1-fkmr0&keywords=Understanding+Reproductive+Loss%3A+Perspectives+on+Life%2C+Death+and+Fertility+.+Farnham%2C+Surrey%3A+Ashgate+).
- Eatought, V., & Smith, J. (2017). Interpretative phenomenological analysis. In C. Willig & W. S. Rogers, *The SAGE Handbook of Qualitative Research in Psychology*. London: SAGE.
- ecoute-psy.com. (2016, January 31). Therapie de groupe : se voir au travers des autres. Retrieved September 30, 2019, from ecoute-psy.com website: <https://www.ecoute-psy.com/therapies/therapies-de-groupe/>
- Edirippulige, S., Levandovskaya, M., & Prishutova, A. (2013). A qualitative study of the use of Skype for psychotherapy consultations in the Ukraine. *Journal of Telemedicine and Telecare*, 19(7), 376–378. <https://doi.org/10.1177/1357633X13506523>
- Ellis, A., Chebsey, C., Storey, C., Bradley, S., Jackson, S., Flenady, V., ... Siassakos, D. (2016). Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. *BMC Pregnancy and Childbirth*, 16(1), 16. <https://doi.org/10.1186/s12884-016-0806-2>
- Endo, K., Yonemoto, N., & Yamada, M. (2015). Interventions for bereaved parents following a child's death: A systematic review. *Palliative Medicine*, 29(7), 590–604. <https://doi.org/10.1177/0269216315576674>
- Erlandsson, K., Avelin, P., Säflund, K., Wredling, R., & Rådestad, I. (2010). Siblings' farewell to a stillborn sister or brother and parents' support to their older children: a questionnaire study from the parents' perspective. *Journal of Child Health Care*, 14(2), 151–160. <https://doi.org/10.1177/1367493509355621>

- Erlandsson, K., Säflund, K., Wredling, R., & Rådestad, I. (2011). Support After Stillbirth and Its Effect on Parental Grief Over Time. *Journal of Social Work in End-of-Life & Palliative Care*, 7(2–3), 139–152. <https://doi.org/10.1080/15524256.2011.593152>
- Evans, S. C., Reed, G. M., Roberts, M. C., Esparza, P., Watts, A. D., Correia, J. M., ... Saxena, S. (2013). Psychologists' perspectives on the diagnostic classification of mental disorders: Results from the WHO-IUPsyS Global Survey. *International Journal of Psychology*, 48(3), 177–193. <https://doi.org/10.1080/00207594.2013.804189>
- Ezechi, O., & Odberg-Petterson, K. (2012). *Perinatal Mortality* (Oliver Ezechi). InTech.
- Fellous, M. (2006). Autour de l'enfant mort-né, créer un espace rituel pour les parents. *L'Autre*, Volume 7(3), 383–398.
- Fernández-Alcántara, M., & Zech, E. (2017). One or Multiple Complicated Grief(s)? The Role of Kinship on Grief Reactions. *Clinical Psychological Science*, 5(5), 851–857. <https://doi.org/10.1177/2167702617707291>
- Ferret, J.-P. (2018, January 16). Le Pacs, une question d'âge 32. *Insee Flash Nouvelle-Aquitaine*, 32. Retrieved from <https://www.insee.fr/fr/statistiques/3306514#consulter>
- Fidanza, P. (1990). Lutto e perdita del soggetto. *Atque*, 1, 117–128.
- Field, A., Miles, J., & Field, Z. (2012). *Discovering Statistics Using R*. Thousand Oaks, Calif: SAGE Publications Ltd.
- Field, N. P., & Sundin, E. C. (2001). Attachment Style in Adjustment to Conjugal Bereavement. *Journal of Social and Personal Relationships*, 18(3), 347–361. <https://doi.org/10.1177/0265407501183003>
- Flenady, V., Koopmans, L., Middleton, P., Frøen, J. F., Smith, G. C., Gibbons, K., ... Ezzati, M. (2011). Major risk factors for stillbirth in high-income countries: a systematic review and meta-analysis. *The Lancet*, 377(9774), 1331–1340. [https://doi.org/10.1016/S0140-6736\(10\)62233-7](https://doi.org/10.1016/S0140-6736(10)62233-7)

- Folkman, S., & Lazarus, R. S. (1980). An Analysis of Coping in a Middle-Aged Community Sample. *Journal of Health and Social Behavior*, 21(3), 219–239. <https://doi.org/10.2307/2136617>
- Fonagy, P., Gergely, G., Jurist, E., & Target, M. (2010). *Affect Regulation, Mentalization, and the Development of the Self* (1 edition). Other Press Professional.
- Forstmeier, S., & Maercker, A. (2007). Comparison of two diagnostic systems for Complicated Grief. *Journal of Affective Disorders*, 99(1), 203–211. <https://doi.org/10.1016/j.jad.2006.09.013>
- Foulkes, S. H. (1984). *Therapeutic Group Analysis*. London: Routledge.
- Frances A., Pies R. & Zisook S. (2010). DSM5 and the medicalization of grief: two perspectives. *Psychiatric Times*, 27(5).
- Franche, R. E. -louis., & Bulow, C. (1999). The Impact of a Subsequent Pregnancy on Grief and Emotional Adjustment. *Infant Mental Health Journal*, 20(2), 175–187.
- Franche, R.-L., & Mikail, S. F. (1999). The impact of perinatal loss on adjustment to subsequent pregnancy. *Social Science & Medicine*, 48(11), 1613–1623. [https://doi.org/10.1016/S0277-9536\(98\)00438-9](https://doi.org/10.1016/S0277-9536(98)00438-9)
- Freeman, K. A., Duke, D. C., & Harris, M. A. (2013). Behavioral Health Care for Adolescents with Poorly Controlled Diabetes via Skype: Does Working Alliance Remain Intact? *Journal of Diabetes Science and Technology*, 7(3), 727–735. <https://doi.org/10.1177/193229681300700318>
- Freud, S. (1917). *Mourning and Melancholia*. Merck, Sharp & Dohme.
- Freud, S. (1976). *Considerazioni attuali sulla guerra e sulla morte e scritti 1915/1918*. Roma, Newton.
- Freud, S., & Breuer, J. (1966). *Studies on Hysteria*. Avon Books.
- Friedman, R., & James, J. W. (2008). The Myth of the Stages of Dying, Death and Grief. (cover story). *Skeptic*, 14(2), 37–41.

- Frøen, J. F., Cacciatore, J., McClure, E. M., Kuti, O., Jokhio, A. H., Islam, M., & Shiffman, J. (2011). Stillbirths: why they matter. *The Lancet*, 377(9774), 1353–1366. [https://doi.org/10.1016/S0140-6736\(10\)62232-5](https://doi.org/10.1016/S0140-6736(10)62232-5)
- Frost, M., & Condon, J. T. (1996). The psychological sequelae of miscarriage: a critical review of the literature. *Australian and New Zealand Journal of Psychiatry*, 30(1), 54–62.
- G. Ney, P., Ball, K., & Sheils, C. (2010). Results of Group Psychotherapy for Abuse, Neglect and Pregnancy Loss. *Current Women's Health Reviews*, 6(4), 332–340. <https://doi.org/info:doi/10.2174/157340410793362177>
- Galinsky, N. (2001). *When a Grandchild Dies: What To Do, What To Say, How To Cope*. Retrieved from <https://eric.ed.gov/?id=ED451464>
- Gamba, F. (2007). Rituels postmodernes d'immortalité : les cimetières virtuels comme technologie de la mémoire vivante. *Societes*, n° 97(3), 109–123.
- Gamba, F. (2015). Vaincre la mort : reproduction et immortalité à l'ère du numérique. *Études sur la mort*, (147), 169–179.
- Gaudet, C., Séjourné, N., Camborieux, L., Rogers, R., & Chabrol, H. (2010). Pregnancy after perinatal loss: association of grief, anxiety and attachment. *Journal of Reproductive and Infant Psychology*, 28(3), 240–251. <https://doi.org/10.1080/02646830903487342>
- Geka, M., & Dargentas, M. (2010). L'apport du logiciel Alceste à l'analyse des représentations sociales : l'exemple de deux études diachroniques. *Les Cahiers Internationaux de Psychologie Sociale, Numéro 85*(1), 111–135.
- Gemigani, S. (2013). *Validazione della versione italiana dell'Inventory of Complicated Grief (ICG): uno studio sul profilo sintomatologico del Lutto Complicato*. (Università di Pisa). Retrieved from <https://etd.adm.unipi.it/t/etd-07042013-102632/>
- Germain, A., Caroff, K., Buysse, D. J., & Shear, M. K. (2005). Sleep quality in complicated grief. *Journal of Traumatic Stress*, 18(4), 343–346. <https://doi.org/10.1002/jts.20035>

- Gesi, C., Carmassi, C., Shear, K. M., Schwartz, T., Ghesquiere, A., Khaler, J., & Dell'Osso, L. (2017). Adult separation anxiety disorder in complicated grief: an exploratory study on frequency and correlates. *Comprehensive Psychiatry*, *72*, 6–12. <https://doi.org/10.1016/j.comppsy.2016.09.002>
- Gibb, J. R. (2013). The Effects of Human Relations Training. In M. J. Lambert (Ed.), *Handbook of Psychotherapy and Behavior Change* (6 edition; By A. Bergin & S. Garfield). Hoboken, N.J: Wiley.
- Gilrane-McGarry, U., & O'Grady, T. (2011). Forgotten grievers: an exploration of the grief experiences of bereaved grandparents. *International Journal of Palliative Nursing*, *17*(4), 170–176. <https://doi.org/10.12968/ijpn.2011.17.4.170>
- Gold, K. J., Boggs, M. E., Mugisha, E., & Palladino, C. L. (2012). Internet Message Boards for Pregnancy Loss: Who's On-Line and Why? *Women's Health Issues*, *22*(1), e67–e72. <https://doi.org/10.1016/j.whi.2011.07.006>
- Gold, K. J., Normandin, M. M., & Boggs, M. E. (2016). Are participants in face-to-face and internet support groups the same? Comparison of demographics and depression levels among women bereaved by stillbirth. *Archives of Women's Mental Health*, *19*(6), 1073–1078. <https://doi.org/10.1007/s00737-016-0657-x>
- Gold, K. J., Sen, A., & Leon, I. (2018). Whose Fault Is It Anyway? Guilt, Blame, and Death Attribution by Mothers After Stillbirth or Infant Death. *Illness, Crisis & Loss*, *26*(1), 40–57. <https://doi.org/10.1177/1054137317740800>
- Goldberg, D. (1972). *Detection of Psychiatric Illness by Questionnaire*. London, New York: Oxford University Press.
- Goldberg, D. (1986). Use of the general health questionnaire in clinical work. *British Medical Journal (Clinical Research Ed.)*, *293*(6556), 1188–1189.
- Goldberg, D. P. (1978). *Manual of the general health questionnaire*. Retrieved from <https://trove.nla.gov.au/version/11878284>

- Goldberg, D. P., & Hillier, V. F. (1979). A scaled version of the General Health Questionnaire. *Psychological Medicine*, 9(1), 139–145. <https://doi.org/10.1017/S0033291700021644>
- Gonin, A. (2008). *L'aide à autrui dans le champ de l'intervention sociale. Une approche psychosociale des représentations professionnelles : historicité, ancrages et fonctions*. (Université Lumière Lyon 2). Retrieved from [https://scholar.googleusercontent.com/scholar?q=cache:PWa7rIZeJYJ:scholar.google.com/+Gonin,+2008+alceste&hl=fr&as\\_sdt=0,5&as\\_ylo=2008&as\\_yhi=2008](https://scholar.googleusercontent.com/scholar?q=cache:PWa7rIZeJYJ:scholar.google.com/+Gonin,+2008+alceste&hl=fr&as_sdt=0,5&as_ylo=2008&as_yhi=2008)
- Gourbin, C., & Masuy-Stroobant, G. (1994). *Are live and stillbirths comparable all over Europe? Legal definitions and vital registration data processing (late foetal death, legal definition, perinatal mortality, quality of vital records, stillbirth)*. Retrieved from <https://unstats.un.org/unsd/vitalstatkb/KnowledgebaseArticle50505.aspx>
- Gourbin, C., & Masuy-Stroobant, G. (1995). Registration of vital data: are live births and stillbirths comparable all over Europe? *Bulletin of the World Health Organization*, 73(4), 449–460.
- Granet, F. (2001). Les droits européens et le décès périnatal. *Etudes sur la mort*, no 119(1), 163–169.
- Gravensteen, I. K., Jacobsen, E.-M., Sandset, P. M., Helgadottir, L. B., Rådestad, I., Sandvik, L., & Ekeberg, Ø. (2018). Anxiety, depression and relationship satisfaction in the pregnancy following stillbirth and after the birth of a live-born baby: a prospective study. *BMC Pregnancy and Childbirth*, 18(1), 41. <https://doi.org/10.1186/s12884-018-1666-8>
- Greeff, A. P., Vansteenwegen, A., & Herbiest, T. (2011). Indicators of Family Resilience after the Death of a Child. *OMEGA - Journal of Death and Dying*, 63(4), 343–358. <https://doi.org/10.2190/OM.63.4.c>
- Green, M., & Solnit, A. J. (1964). Reactions to the threatened loss of a child: a vulnerable child syndrome. *Pediatrics*, 34, 58–66.
- Grout, L. A., & Romanoff, B. D. (2000). The Myth of the Replacement Child: Parents' Stories and Practices After Perinatal Death. *Death Studies*, 24(2), 93–113. <https://doi.org/10.1080/074811800200595>

- Guyard-Boileau, B. (1999). Un groupe de parole et de soutien dans le deuil perinatal. In A. Cadoret, G. Delaisi de Parseval, C. Haussaire-Niquet, & D. Lett, *L'euthanasie foetale* (L'esprit du temps). Retrieved from <http://ecla.aquitaine.fr/Ecrit-et-livre/Catalogues-des-oeuvres/Etudes-sur-la-mort-L-euthanasie-foetale>
- Hada, K., Kuse, E., & Nakatsuka, M. (2018). Women with Recurrent Pregnancy Loss : Their Psychology During Late Pregnancy and the Supportive Behavior of Their Partners. *Acta Medica Okayama*, 72(4), 387–394. <https://doi.org/10.18926/AMO/56176>
- Hale, B. (2007). Culpability and blame after pregnancy loss. *Journal of Medical Ethics*, 33(1), 24–27. <https://doi.org/10.1136/jme.2005.015560>
- Hanus, M. (2001). Le deuil de ces tout-petits enfants. *Études sur la mort*, no 119(1), 7–15. <https://doi.org/10.3917/eslm.119.0007>
- Hanus, M. (2006). Deuils normaux, deuils difficiles, deuils compliqués et deuils pathologiques. *Annales Médico-Psychologiques, Revue Psychiatrique*, 164(4), 349–356. <https://doi.org/10.1016/j.amp.2006.02.003>
- Harpel, T. S., & Hertzog, J. (2010). “I Thought My Heart Would Burst”: The Role of Ultrasound Technology on Expectant Grandmotherhood. *Journal of Family Issues*, 31(2), 257–274. <https://doi.org/10.1177/0192513X09348491>
- Harper, M., O'Connor, R. C., & O'Carroll, R. E. (2011). Increased mortality in parents bereaved in the first year of their child's life. *BMJ Supportive & Palliative Care*, 1(3), 306–309. <https://doi.org/10.1136/bmjspcare-2011-000025>
- Haussaire-Niquet, C. (2003). *Accompagner le deuil périnatal du fil-de-soi perdu au fil-du-soi tissé* (Centre Source - Ecole Française de Psychosynthèse). Retrieved from <https://docplayer.fr/21070239-Accompagner-le-deuil-perinatal.html>
- Hazard, A., Weston, J., & Gutterres, C. (1992). After a child's death: Factors related to parental bereavement. *Journal of Developmental and Behavioral Pediatrics*, 13(1), 24–30. <https://doi.org/10.1097/00004703-199202000-00006>



- Heller, S. S., & Zeanah, C. H. (1999). Attachment disturbances in infants born subsequent to perinatal loss: A pilot study. *Infant Mental Health Journal*, 20(2), 188–199. [https://doi.org/10.1002/\(SICI\)1097-0355\(199922\)20:2<188::AID-IMHJ6>3.0.CO;2-H](https://doi.org/10.1002/(SICI)1097-0355(199922)20:2<188::AID-IMHJ6>3.0.CO;2-H)
- Hennegan, J. M., Henderson, J., & Redshaw, M. (2018). Is partners' mental health and well-being affected by holding the baby after stillbirth? Mothers' accounts from a national survey. *Journal of Reproductive and Infant Psychology*, 36(2), 120–131. <https://doi.org/10.1080/02646838.2018.1424325>
- Hogue, C. J. R., Parker, C. B., Willinger, M., Temple, J. R., Bann, C. M., Silver, R. M., ... Goldenberg, R. L. (2015). The Association of Stillbirth with Depressive Symptoms 6–36 Months Post-Delivery. *Paediatric and Perinatal Epidemiology*, 29(2), 131–143. <https://doi.org/10.1111/ppe.12176>
- Horowitz, M. (2001). *Stress Response Syndromes: Personality Styles and Interventions* (Fourth Edition edition). Northvale, N.J: Jason Aronson, Inc.
- Horowitz, M. J., Siegel, B., Holen, A., Bonanno, G. A., Milbrath, C., & Stinson, C. H. (1997). Diagnostic criteria for complicated grief disorder. *American Journal of Psychiatry*, 154(7), 904–910. <https://doi.org/10.1176/ajp.154.7.904>
- Hughes, C. B., & Page-lieberman, J. (1989). Fathers experiencing a perinatal loss. *Death Studies*, 13(6), 537–556. <https://doi.org/10.1080/07481188908252331>
- Hughes, P., & Riches, S. (2003). Psychological aspects of perinatal loss. *Current Opinion in Obstetrics and Gynecology*, 15(2), 107.
- Hughes, P., Turton, P., & Evans, J. (1999). Stillbirth as risk factor for depression and anxiety in the subsequent pregnancy: cohort study. *BMJ*, 318(7200), 1721–1724. <https://doi.org/10.1136/bmj.318.7200.1721>
- Hunter, A., Tussis, L., & MacBeth, A. (2017). The presence of anxiety, depression and stress in women and their partners during pregnancies following perinatal loss: A meta-analysis. *Journal of Affective Disorders*, 223, 153–164. <https://doi.org/10.1016/j.jad.2017.07.004>

- Hutton, C. J., & Bradley, B. S. (1994). Effects of Sudden Infant Death on Bereaved Siblings; a Comparative Study. *Journal of Child Psychology and Psychiatry*, 35(4), 723–732. <https://doi.org/10.1111/j.1469-7610.1994.tb01217.x>
- ICD-11 - Mortality and Morbidity Statistics. (n.d.). Retrieved October 13, 2018, from <https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/1183832314>
- Insee. (2016). Définition - Enfant sans vie ou mort-né. Retrieved May 1, 2019, from Insee - Institut national de la statistique et des études économiques website: <https://www.insee.fr/fr/metadonnees/definition/c1394>
- Insee. (2018a). La mortalité infantile est stable depuis dix ans après des décennies de baisse. Retrieved May 1, 2019, from <https://www.insee.fr/fr/statistiques/3560308#tableau-Figure5>
- Insee. (2018b). Taux de mortalité infantile en 2018. Retrieved March 26, 2019, from Insee - Institut national de la statistique et des études économiques website: <https://www.insee.fr/fr/statistiques/2383444>
- Jaffe, J. (2017). Reproductive trauma: Psychotherapy for pregnancy loss and infertility clients from a reproductive story perspective. *Psychotherapy*, 54(4), 380–385. <https://doi.org/10.1037/pst0000125>
- Jenewein, J., Moergeli, H., Fauchère, J.-C., Bucher, H. U., Kraemer, B., Wittmann, L., ... Büchi, S. (2008). Parents' mental health after the birth of an extremely preterm child: A comparison between bereaved and non-bereaved parents. *Journal of Psychosomatic Obstetrics & Gynecology*, 29(1), 53–60. <https://doi.org/10.1080/01674820701640181>
- Johnson, M. P., & Puddifoot, J. E. (1998). Miscarriage: Is vividness of visual imagery a factor in the grief reaction of the partner? *British Journal of Health Psychology*, 3(2), 137–146. <https://doi.org/10.1111/j.2044-8287.1998.tb00562.x>
- Kalampalikis, N. (2005). L'apport de la méthode Alceste dans l'étude des représentations sociales. In J.-C. Abric (Ed.), *Méthodes d'étude des représentations sociales*. (pp. 147–163). Retrieved from <https://halshs.archives-ouvertes.fr/halshs-00532849>

- Keesee, N. J., Currier, J. M., & Neimeyer, R. A. (2008). Predictors of grief following the death of one's child: the contribution of finding meaning. *Journal of Clinical Psychology, 64*(10), 1145–1163. <https://doi.org/10.1002/jclp.20502>
- Kemp, S. (2018). Digital in 2018: World's internet users pass the 4 billion mark. Retrieved March 22, 2019, from We Are Social website: <https://wearesocial.com/blog/2018/01/global-digital-report-2018>
- Kentish-Barnes, N., Chaize, M., Seegers, V., Legriél, S., Cariou, A., Jaber, S., ... Azoulay, É. (2015). Complicated grief after death of a relative in the intensive care unit. *European Respiratory Journal, 45*(5), 1341–1352. <https://doi.org/10.1183/09031936.00160014>
- Kersting, A., Brähler, E., Glaesmer, H., & Wagner, B. (2011). Prevalence of complicated grief in a representative population-based sample. *Journal of Affective Disorders, 131*(1), 339–343. <https://doi.org/10.1016/j.jad.2010.11.032>
- Kersting, A., & Wagner, B. (2012). Complicated grief after perinatal loss. *Dialogues in Clinical Neuroscience, 14*(2), 187–194.
- Killikelly, C., & Maercker, A. (2017). Prolonged grief disorder for ICD-11: the primacy of clinical utility and international applicability. *European Journal of Psychotraumatology, 8*(sup6), 1476441. <https://doi.org/10.1080/20008198.2018.1476441>
- Kingdon, C., Givens, J. L., O'Donnell, E., & Turner, M. (2015). Seeing and Holding Baby: Systematic Review of Clinical Management and Parental Outcomes After Stillbirth. *Birth, 42*(3), 206–218. <https://doi.org/10.1111/birt.12176>
- Klass, D. (1987). Marriage and Divorce among Bereaved Parents in a Self-Help Group. *OMEGA - Journal of Death and Dying, 17*(3), 237–249. <https://doi.org/10.2190/T8L3-UVD8-J2RD-TLLB>
- Klein, M. (1940). Mourning and its relation to manic-depressive states. *The International Journal of Psychoanalysis, 21*, 125–153.

- Klein, M. (1950). On the criteria for the termination of a psycho-analysis. *International Journal of Psychoanalysis*, 31, 78–80.
- Klemm, P., & Hardie, T. (2002). Depression in Internet and Face-to-Face Cancer Support Groups: A Pilot Study. *Oncology Nursing Forum*, 29(4), 641–641. <https://doi.org/10.1188/02.ONF.E45-E51>
- Klier, C. M., Geller, P. A., & Ritsher, J. B. (2002). Affective disorders in the aftermath of miscarriage: A comprehensive review. *Archives of Women's Mental Health*, 5(4), 129–149. <https://doi.org/10.1007/s00737-002-0146-2>
- Kokotos, F. (2009). The vulnerable child syndrome. *Pediatrics in Review*, 30(5), 193–194. <https://doi.org/10.1542/pir.30-5-193>
- Koopmans, L., Wilson, T., Cacciatore, J., & Flenady, V. (2013). Support for mothers, fathers and families after perinatal death. *Cochrane Database of Systematic Reviews*, (6). <https://doi.org/10.1002/14651858.CD000452.pub3>
- Kübler-Ross, E. (1996). *Les derniers instants de la vie*. Genève: Labor et Fides.
- Kubler-Ross, E., & Kessler, D. (2011). *Sur le chagrin et sur le deuil*. Pocket.
- Lacasse, J. R., & Cacciatore, J. (2014). Prescribing of Psychiatric Medication to Bereaved Parents Following Perinatal/Neonatal Death: An Observational Study. *Death Studies*, 38(9), 589–596. <https://doi.org/10.1080/07481187.2013.820229>
- Lagache, D. (1977). Le travail du deuil : ethnologie et psychanalyse (1938). In D. Lagache, E. Roseblum, & D. Anzieu, *Les hallucinations verbales et travaux cliniques : Oeuvres I (1932-1946)*. Retrieved from [http://bsf.spp.asso.fr/index.php?lvl=notice\\_display&id=84487](http://bsf.spp.asso.fr/index.php?lvl=notice_display&id=84487)
- Lagache, D. (1982). Deuil pathologique (1956). In D. Lagache & E. Roseblum, *Agressivité structure de la personnalité et autres travaux*. Paris: Presses Universitaires de France - PUF.
- Lahlou, S. (1998). *Penser manger*. <https://doi.org/10.3917/puf.insti.1998.01>

- Lamb, E. H. (2002). The Impact of Previous Perinatal Loss on Subsequent Pregnancy and Parenting. *The Journal of Perinatal Education*, 11(2), 33–40. <https://doi.org/10.1624/105812402X88696>
- Langner, R., & Maercker, A. (2005). Complicated grief as a stress response disorder: evaluating diagnostic criteria in a German sample. *Journal of Psychosomatic Research*, 58(3), 235–242. <https://doi.org/10.1016/j.jpsychores.2004.09.012>
- Lannen, P. K., Wolfe, J., Prigerson, H. G., Onelov, E., & Kreicbergs, U. C. (2008). Unresolved Grief in a National Sample of Bereaved Parents: Impaired Mental and Physical Health 4 to 9 Years Later. *Journal of Clinical Oncology*, 26(36), 5870–5876. <https://doi.org/10.1200/JCO.2007.14.6738>
- Larkin, M., & Thompson, A. R. (2011). Interpretative phenomenological analysis. In D. Harper & A. R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (1 edition, pp. 99–106). Chichester, West Sussex: Wiley-Blackwell.
- Lasker, J. N., & Toedter, L. J. (1991). Acute Versus Chronic Grief. *American Journal of Orthopsychiatry*, 61(4), 510–522. <https://doi.org/10.1037/h0079288>
- Latham, A. E., & Prigerson, H. G. (2004). Suicidality and Bereavement: Complicated Grief as Psychiatric Disorder Presenting Greatest Risk for Suicidality. *Suicide and Life-Threatening Behavior*, 34(4), 350–362. <https://doi.org/10.1521/suli.34.4.350.53737>
- Lawn, J. E., Blencowe, H., Waiswa, P., Amouzou, A., Mathers, C., Hogan, D., ... Cousens, S. (2016). Stillbirths: rates, risk factors, and acceleration towards 2030. *The Lancet*, 387(10018), 587–603. [https://doi.org/10.1016/S0140-6736\(15\)00837-5](https://doi.org/10.1016/S0140-6736(15)00837-5)
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping* (1 edition). New York: Springer Publishing Company.
- Le Mazou Hafner, S.-A. (2018). Tant que mon corps n’aura pas disparu... Pour un art du tatouage comme aide au travail de deuil. *Études sur la mort*, (151), 107–126.

- Lecours, S. (2005). Niveaux de fonctionnement mental et psychothérapie psychanalytique. *Psychotherapies, Vol. 25(2)*, 91–100.
- Lee, L., McKenzie-McHarg, K., & Horsch, A. (2013). Women's Decision Making and Experience of Subsequent Pregnancy Following Stillbirth. *Journal of Midwifery & Women's Health, 58(4)*, 431–439. <https://doi.org/10.1111/jmwh.12011>
- Leon, I. (1987). Short-term psychotherapy for perinatal loss. *Psychotherapy: Theory/Research/Practice/Training, 24(2)*, 186–195.
- Leon, I. (2008). Helping Families Cope with Perinatal Loss. *The Global Library Of Women's Medicine, 6*. <https://doi.org/10.3843/GLOWM.10418>
- Leon, I. G. (1986a). Intrapsychic and family dynamics in perinatal sibling loss. *Infant Mental Health Journal, 7(3)*, 200–213. [https://doi.org/10.1002/1097-0355\(198623\)7:3<200::AID-IMHJ2280070304>3.0.CO;2-M](https://doi.org/10.1002/1097-0355(198623)7:3<200::AID-IMHJ2280070304>3.0.CO;2-M)
- Leon, I. G. (1986b). Psychodynamics of Perinatal Loss. *Psychiatry, 49(4)*, 312–324. <https://doi.org/10.1080/00332747.1986.11024331>
- Leon, I. G. (1986c). The Invisible Loss: the Impact of Perinatal Death on Siblings. *Journal of Psychosomatic Obstetrics & Gynecology, 5(1)*, 1–14. <https://doi.org/10.3109/01674828609016738>
- Leon, I. G. (1987). Short-term psychotherapy for perinatal loss. *Psychotherapy: Theory, Research, Practice, Training, 24(2)*, 186–195. <https://doi.org/10.1037/h0085703>
- Leon, I. G. (1996a). Reproductive Loss: Barriers to Psychoanalytic Treatment. *Journal of the American Academy of Psychoanalysis, 24(2)*, 341–352. <https://doi.org/10.1521/jaap.1.1996.24.2.341>
- Leon, I. G. (1996b). Revising psychoanalytic understandings of perinatal loss. *Psychoanalytic Psychology, 13(2)*, 161–176. <https://doi.org/10.1037/h0079646>
- Leon, I. G. (2017). Empathic psychotherapy for pregnancy termination for fetal anomaly. *Psychotherapy, 54(4)*, 394–399. <https://doi.org/10.1037/pst0000124>

- Li, J., Laursen, T. M., Precht, D. H., Olsen, J., & Mortensen, P. B. (2005). Hospitalization for Mental Illness among Parents after the Death of a Child. *New England Journal of Medicine*, 352(12), 1190–1196. <https://doi.org/10.1056/NEJMoa033160>
- Li, J., Precht, D. H., Mortensen, P. B., & Olsen, J. (2003). Mortality in parents after death of a child in Denmark: a nationwide follow-up study. *The Lancet*, 361(9355), 363–367. [https://doi.org/10.1016/S0140-6736\(03\)12387-2](https://doi.org/10.1016/S0140-6736(03)12387-2)
- Li, J., Tendeiro, J. N., & Stroebe, M. (2018). Guilt in bereavement: Its relationship with complicated grief and depression. *International Journal of Psychology*, 0(0). <https://doi.org/10.1002/ijop.12483>
- Lichtenthal, W. G., Cruess, D. G., & Prigerson, H. G. (2004). A case for establishing complicated grief as a distinct mental disorder in DSM-V. *Clinical Psychology Review*, 24(6), 637–662. <https://doi.org/10.1016/j.cpr.2004.07.002>
- Lichtenthal, W. G., Neimeyer, R. A., Currier, J. M., Roberts, K., & Jordan, N. (2013). Cause of Death and the Quest for Meaning After the Loss of a Child. *Death Studies*, 37(4), 311–342. <https://doi.org/10.1080/07481187.2012.673533>
- Lieberman, M. A. (1993). Bereavement self-help groups: A review of conceptual and methodological issues. In M. S. Stroebe, W. Stroebe, & R. O. Hansson (Eds.), *Handbook of Bereavement: Theory, Research, and Intervention* (1 edition). Cambridge England ; New York, NY, USA: Cambridge University Press.
- Lin, S. X., & Lasker, J. N. (1996). Patterns of grief reaction after pregnancy loss. *American Journal of Orthopsychiatry*, 66(2), 262–271.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101(2), 141–148. <https://doi.org/10.1176/ajp.101.2.141>
- Lithuania Family Law (Civil Code)*. , Pub. L. No. 65, XI (2008).
- Livret de famille. (2018). In *Wikipédia*. Retrieved from [https://fr.wikipedia.org/w/index.php?title=Livret\\_de\\_famille&oldid=146807936](https://fr.wikipedia.org/w/index.php?title=Livret_de_famille&oldid=146807936)

- Lohan, J. A., & Murphy, S. A. (2007). Bereaved Mothers' Marital Status and Family Functioning After a Child's Sudden, Violent Death: A Preliminary Study. *Journal of Loss and Trauma, 12*(4), 333–347. <https://doi.org/10.1080/15325020701296794>
- Lombardo, L., Lai, C., Luciani, M., Morelli, E., Buttinelli, E., Aceto, P., ... Penco, I. (2014). Eventi di perdita e lutto complicato: verso una definizione di disturbo da sofferenza prolungata per il DSM-5. *Rivista Di Psichiatria, 49*(3), 106–114.
- Lowe, P., Powell, J., Griffiths, F., Thorogood, M., & Locock, L. (2009). “Making it All Normal”: The Role of the Internet in Problematic Pregnancy. *Qualitative Health Research, 19*(10), 1476–1484. <https://doi.org/10.1177/1049732309348368>
- Maciejewski, P. K., Maercker, A., Boelen, P. A., & Prigerson, H. G. (2016). “Prolonged grief disorder” and “persistent complex bereavement disorder”, but not “complicated grief”, are one and the same diagnostic entity: an analysis of data from the Yale Bereavement Study. *World Psychiatry, 15*(3), 266–275. <https://doi.org/10.1002/wps.20348>
- Maciejewski, P. K., & Prigerson, H. G. (2017). Prolonged, but not complicated, grief is a mental disorder. *The British Journal of Psychiatry, 211*(4), 189–191. <https://doi.org/10.1192/bjp.bp.116.196238>
- Main, M., & Goldwyn, R. (1984). Predicting rejection of her infant from mother's representation of her own experience: Implications for the abused-abusing intergenerational cycle. *Child Abuse & Neglect, 8*(2), 203–217. [https://doi.org/10.1016/0145-2134\(84\)90009-7](https://doi.org/10.1016/0145-2134(84)90009-7)
- Malacrida, C. (1999). Complicating Mourning: The Social Economy of Perinatal Death. *Qualitative Health Research, 9*(4), 504–519. <https://doi.org/10.1177/104973299129122036>
- Mancini, A. D., & Bonanno, G. A. (2009). Predictors and Parameters of Resilience to Loss: Toward an Individual Differences Model. *Journal of Personality, 77*(6), 1805–1832. <https://doi.org/10.1111/j.1467-6494.2009.00601.x>



- Markin, R. D. (2017). An introduction to the special section on psychotherapy for pregnancy loss: Review of issues, clinical applications, and future research direction. *Psychotherapy, 54*(4), 367–372. <https://doi.org/10.1037/pst0000134>
- Markin, R. D. (2018). “Ghosts” in the womb: A mentalizing approach to understanding and treating prenatal attachment disturbances during pregnancies after loss. *Psychotherapy (Chicago, Ill.), 55*(3), 275–288. <https://doi.org/10.1037/pst0000186>
- Markin, R. D., & Zilcha-Mano, S. (2018). Cultural processes in psychotherapy for perinatal loss: Breaking the cultural taboo against perinatal grief. *Psychotherapy (Chicago, Ill.), 55*(1), 20–26. <https://doi.org/10.1037/pst0000122>
- Marrone, A. (2001). Incontrare per incontrarsi. I fattori facilitanti la crescita e il cambiamento nei gruppi d’incontro. *Rivista di Studi Rogersiani*. Retrieved from <http://www.acp-italia.it/>
- Marty, F. (2017). *Les grands concepts de la psychologie clinique - 3e éd.* Dunod.
- Mathiesen, A., Frost, C. J., Dent, K., & Feldkamp, M. (2012). Parental Needs among Children with Birth Defects: Defining a Parent-to-Parent Support Network. *Journal of Genetic Counseling, 21*(6), 862–872. <https://doi.org/10.1007/s10897-012-9518-6>
- McCreight, B. S. (2007). Narratives of Pregnancy Loss: the role of self-help groups in supporting parents. *Medical Sociology Online, 2*, 3–16.
- McDermott, O. D., Prigerson, H. G., Reynolds, C. F., Houck, P. R., Dew, M. A., Hall, M., ... Kupfer, D. J. (1997). Sleep in the wake of complicated grief symptoms: An exploratory study. *Biological Psychiatry, 41*(6), 710–716. [https://doi.org/10.1016/S0006-3223\(96\)00118-7](https://doi.org/10.1016/S0006-3223(96)00118-7)
- McSpedden, M., Mullan, B., Sharpe, L., Breen, L. J., & Lobb, E. A. (2017). The presence and predictors of complicated grief symptoms in perinatally bereaved mothers from a bereavement support organization. *Death Studies, 41*(2), 112–117. <https://doi.org/10.1080/07481187.2016.1210696>

- Meaney, S., Everard, C. M., Gallagher, S., & O'Donoghue, K. (2017). Parents' concerns about future pregnancy after stillbirth: a qualitative study. *Health Expectations*, 20(4), 555–562. <https://doi.org/10.1111/hex.12480>
- Meert, K. L., Donaldson, A. E., Newth, C. J. L., Harrison, R., Berger, J., Zimmerman, J., ... Shear, K. (2010). Complicated Grief and Associated Risk Factors Among Parents Following a Child's Death in the Pediatric Intensive Care Unit. *Archives of Pediatrics & Adolescent Medicine*, 164(11), 1045–1051. <https://doi.org/10.1001/archpediatrics.2010.187>
- Meert, K. L., Templin, T. N., Michelson, K. N., Morrison, W. E., Hackbarth, R., Custer, J. R., ... Thurston, C. S. (2012). The Bereaved Parent Needs Assessment: A new instrument to assess the needs of parents whose children died in the pediatric intensive care unit. *Critical Care Medicine*, 40(11). <https://doi.org/10.1097/CCM.0b013e31825fe164>
- Metz, C., Calmet, J., & Thevenot, A. (2019). Women subjected to domestic violence: The impossibility of separation. *Psychoanalytic Psychology*, 36(1), 36–43. <https://doi.org/10.1037/pap0000186>
- Ministère de la justice. (2008). Enfants sans vie et état civil. Retrieved May 1, 2019, from justice.gouv.fr website: <http://www.justice.gouv.fr/europe-et-international-10045/etudes-de-droit-compare-10285/enfants-sans-vie-et-etat-civil-15927.html>
- Ministère du travail, de l'emploi et de la santé, & Secrétariat d'Etat à la santé. (2011, October 26). Instruction ministérielle du 26 octobre 2011. Retrieved August 21, 2019, from Circulaires.gouv.fr website: <http://circulaire.legifrance.gouv.fr/index.php?action=afficherCirculaire&hit=1&r=34067>
- Molinié, M., & Hureauux, S. (2012). La vie tangible des bébés morts. *Études sur la mort*, (142), 109–123. <https://doi.org/10.3917/eslm.142.0109>
- Moretti, M. (2011). *La perdita di una figura di attaccamento nell'infanzia: fattori di rischio e vulnerabilità nell'elaborazione del lutto* (Tesi di dottorato). Retrieved from <http://paduaresearch.cab.unipd.it/3986/>

- Murphy, S. A., Clark Johnson, L., & Lohan, J. (2003). Finding Meaning in a Child's Violent Death: A Five-Year Prospective Analysis of Parents' Personal Narratives and Empirical Data. *Death Studies, 27*(5), 381.
- Murphy, S., & Cacciatore, J. (2017). The psychological, social, and economic impact of stillbirth on families. *Seminars in Fetal and Neonatal Medicine, 22*(3), 129–134. <https://doi.org/10.1016/j.siny.2017.02.002>
- Murphy, S., & Jones, K. S. (2014). By the way knowledge: Grandparents, stillbirth and neonatal death. *Human Fertility, 17*(3), 210–213. <https://doi.org/10.3109/14647273.2014.930190>
- Murphy, S., Shevlin, M., & Elklit, A. (2014). Psychological Consequences of Pregnancy Loss and Infant Death in a Sample of Bereaved Parents. *Journal of Loss and Trauma, 19*(1), 56–69. <https://doi.org/10.1080/15325024.2012.735531>
- Murray, J. A., Terry, D., Vance, J. C., Battistutta, D., & Connolly, Y. (2000). Effects of a Program of Intervention on Parental Distress Following Infant Death. *Death Studies, 24*(4), 275–305. <https://doi.org/10.1080/074811800200469>
- Najman, J. M., Vance, J. C., Boyle, F., Embleton, G., Foster, B., & Thearle, J. (1993). The impact of a child death on marital adjustment. *Social Science & Medicine, 37*(8), 1005–1010. [https://doi.org/10.1016/0277-9536\(93\)90435-7](https://doi.org/10.1016/0277-9536(93)90435-7)
- Nakajima, S. (2018). Complicated grief: recent developments in diagnostic criteria and treatment. *Phil. Trans. R. Soc. B, 373*(1754), 20170273. <https://doi.org/10.1098/rstb.2017.0273>
- Neimeyer, R., Botella, L., Herrero, O., Figueras, S., Pacheco, M., & Werner-Wildner, L. A. (2002). The meaning of your absence: Traumatic loss and narrative reconstruction. In J. Kauffman, *Loss of the Assumptive World: A Theory of Traumatic Loss* (1 edition). London: Routledge.
- Neri, C. (2017). *Gruppo*. Milano: Cortina Raffaello.
- Neria, Y., & Litz, B. T. (2004). Bereavement by Traumatic Means: The Complex Synergy of Trauma and Grief. *Journal of Loss and Trauma, 9*(1), 73–87. <https://doi.org/10.1080/15325020490255322>

- Newson, R. S., Boelen, P. A., Hek, K., Hofman, A., & Tiemeier, H. (2011). The prevalence and characteristics of complicated grief in older adults. *Journal of Affective Disorders, 132*(1), 231–238. <https://doi.org/10.1016/j.jad.2011.02.021>
- Niela-Vilén, H., Axelin, A., Salanterä, S., & Melender, H.-L. (2014). Internet-based peer support for parents: A systematic integrative review. *International Journal of Nursing Studies, 51*(11), 1524–1537. <https://doi.org/10.1016/j.ijnurstu.2014.06.009>
- Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Vedsted, P., Bro, F., & Guldin, M.-B. (2017). Predictors of Complicated Grief and Depression in Bereaved Caregivers: A Nationwide Prospective Cohort Study. *Journal of Pain and Symptom Management, 53*(3), 540–550. <https://doi.org/10.1016/j.jpainsymman.2016.09.013>
- Nolen-Hoeksema, S., Larson, J., & Grayson, C. (1999). Explaining the gender difference in depressive symptoms. *Journal of Personality and Social Psychology, 77*(5), 1061–1072.
- Nucleus accumbens. (2018). In *Wikipedia*. Retrieved from [https://en.wikipedia.org/w/index.php?title=Nucleus\\_accumbens&oldid=849065538](https://en.wikipedia.org/w/index.php?title=Nucleus_accumbens&oldid=849065538)
- Nuzum, D., Meaney, S., & O'Donoghue, K. (2017). The Spiritual and Theological Challenges of Stillbirth for Bereaved Parents. *Journal of Religion and Health, 56*(3), 1081–1095. <https://doi.org/10.1007/s10943-017-0365-5>
- O'Connor, M.-F., Wellisch, D. K., Stanton, A. L., Eisenberger, N. I., Irwin, M. R., & Lieberman, M. D. (2008). Craving love? Enduring grief activates brain's reward center. *NeuroImage, 42*(2), 969–972. <https://doi.org/10.1016/j.neuroimage.2008.04.256>
- Oikonen, J., & Brownlee, K. (2002). Family Therapy Following Perinatal Bereavement. *Family Therapy: The Journal of the California Graduate School of Family Psychology, 29*(3), 125–140.
- O'Leary, J. (2004). Grief and its impact on prenatal attachment in the subsequent pregnancy. *Archives of Women's Mental Health, 7*(1), 7–18. <https://doi.org/10.1007/s00737-003-0037-1>

- O'Leary, J., & Thorwick, C. (2008). Attachment to the Unborn Child and Parental Mental Representations of Pregnancy following Perinatal Loss. *Att: New Dir. in Psychother. Relat. Psychoanal.*, 292–320.
- O'Leary, J., Warland, J., & Parker, L. (2011). Bereaved Parents' Perception of the Grandparents' Reactions to Perinatal Loss and the Pregnancy That Follows. *Journal of Family Nursing*, 17(3), 330–356. <https://doi.org/10.1177/1074840711414908>
- Olson-Garriott, A. N., Gamino, L. A., Davies, E. B., & Gudmundsdottir, M. (2015). Having or adopting another child: Perspectives from bereaved fathers. *Professional Psychology: Research and Practice*, 46(5), 317–324. <https://doi.org/10.1037/pro0000026>
- Online Support Groups - Aware NI. (2019). Retrieved September 30, 2019, from Aware website: <https://www.aware-ni.org/how-we-can-help-you/aware-ni-online-support-groups>
- Onofri, A., & La Rosa, C. (2016). *Il lutto. Psicoterapia cognitivo-evoluzionista e EMDR*. Roma: Giovanni Fioriti Editore.
- Oxford. (2013). *Oxford Dictionary of English* (3 edizione). New York, NY: Oxford.
- Oza, S., Cousens, S. N., & Lawn, J. E. (2014). Estimation of daily risk of neonatal death, including the day of birth, in 186 countries in 2013: a vital-registration and modelling-based study. *The Lancet Global Health*, 2(11), e635–e644. [https://doi.org/10.1016/S2214-109X\(14\)70309-2](https://doi.org/10.1016/S2214-109X(14)70309-2)
- Parat, H. (2005). À propos d'absence de douleur (1937) d'Hélène Deutsch. In *L'affect* (pp. 77–78). Retrieved from <https://www.cairn.info/l-affect%20--9782130548652-page-77.htm>
- Pariente, P., Challita, H., Mesbah, M., & Guelfi, J. (1992). The GHQ-28 questionnaire in French: A validation survey in a panel of 158 general psychiatric patients. *European Psychiatry*, 7, 15–20.
- Parkes, C. M. (1972). *Bereavement; studies of grief in adult life*. International Universities Press.
- Parkes, C. M. (1990). Risk Factors in Bereavement: Implications for the Prevention and Treatment of Pathologic Grief. *Psychiatric Annals*, 20(6), 308–313. <https://doi.org/10.3928/0048-5713-19900601-07>

- Parkes, C. M. (2002). Grief: Lessons from the Past,visions for the Future. *Death Studies*, 26(5), 367–385. <https://doi.org/10.1080/07481180290087366>
- Parkes, C. M., & Prigerson, H. G. (2009). *Bereavement: Studies of Grief in Adult Life, Fourth Edition* (2 edition). Hove, East Sussex, UK ; New York: Routledge.
- Parkes, C. M., & Weiss, R. S. (1983). *Recovery from bereavement*. Basic Books.
- Peppers, L. G., & Knapp, R. J. (1980). *Motherhood and Mourning: Perinatal Death*. New York, N.Y: Praeger Publishers Inc.
- Perini, M. (2013). Balint. Il metodo. In *SPIPEDIA*. Retrieved from <https://www.spiweb.it/spipedia/balint-il-metodo/>
- Petrov, V. D. (2017). Birth Certificate of Stillbirth and Succession. *International Conference KNOWLEDGE-BASED ORGANIZATION*, 23(2), 197–200. <https://doi.org/10.1515/kbo-2017-0113>
- Phipps, S. (1986). The Subsequent Pregnancy after Stillbirth: Anticipatory Parenthood in the Face of Uncertainty. *The International Journal of Psychiatry in Medicine*, 15(3), 243–264. <https://doi.org/10.2190/GDC5-KA60-JPNH-PND2>
- Pietkiewicz, I., & Smith, J. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Czasopismo Psychologiczne Psychological Journal*, 20(1). <https://doi.org/10.14691/CPPIJ.20.1.7>
- Ponzetti, J., & Johnson, M. A. (1991). The forgotten grievers: Grandparents’ reactions to the death of grandchildren. *Death Studies*, 15(2), 157–167. <https://doi.org/10.1080/07481189108252420>
- Porot, M. (1996). *L’enfant de remplacement* (Retirage). Paris: Editions Frison-Roche.
- Poznanski, E. O. (1972). The “replacement child”: A saga of unresolved parental grief. *The Journal of Pediatrics*, 81(6), 1190–1193. [https://doi.org/10.1016/S0022-3476\(72\)80261-0](https://doi.org/10.1016/S0022-3476(72)80261-0)

- Prigerson, H., Bierhals, A. J., Kasl, S. V., Reynolds, C. F., Newsom, J. T., & Jacobs, S. (1997). Traumatic grief as a risk factor for mental and physical morbidity. *American Journal of Psychiatry*, *154*(5), 616–623. <https://doi.org/10.1176/ajp.154.5.616>
- Prigerson, H., Frank, E., Kasl, S. V., Reynolds, C. F., Anderson, B., Zubenko, G. S., ... Kupfer, D. J. (1995). Complicated grief and bereavement-related depression as distinct disorders: preliminary empirical validation in elderly bereaved spouses. *American Journal of Psychiatry*, *152*(1), 22–30. <https://doi.org/10.1176/ajp.152.1.22>
- Prigerson, H. G., Bierhals, A. J., Kasl, S. V., Reynolds, C. F., Shear, M. K., Newsom, J. T., & Jacobs, S. (1996). Complicated grief as a disorder distinct from bereavement-related depression and anxiety: a replication study. *The American Journal of Psychiatry*, *153*(11), 1484–1486. <https://doi.org/10.1176/ajp.153.11.1484>
- Prigerson, H. G., & Maciejewski, P. K. (2005). A Call for Sound Empirical Testing and Evaluation of Criteria for Complicated Grief Proposed for Dsm-V. *Omega: Journal of Death & Dying*, *52*(1), 9–19.
- Prigerson, H. G., & Maciejewski, P. K. (2008). Grief and acceptance as opposite sides of the same coin: setting a research agenda to study peaceful acceptance of loss. *The British Journal of Psychiatry*, *193*(6), 435–437. <https://doi.org/10.1192/bjp.bp.108.053157>
- Prigerson, H. G., Maciejewski, P. K., Reynolds, C. F., Bierhals, A. J., Newsom, J. T., Fasiczka, A., ... Miller, M. (1995). Inventory of complicated grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research*, *59*(1), 65–79. [https://doi.org/10.1016/0165-1781\(95\)02757-2](https://doi.org/10.1016/0165-1781(95)02757-2)
- Prigerson, H. G., Shear, K., & Jacobs, S. C. (2000). Grief and its relation to posttraumatic stress disorder. In D. J. Nutt, J. R. T. Davidson, & J. Zohar, *Post-traumatic Stress Disorder: Diagnosis, Management and Treatment* (1 edition, pp. 163–177). London: CRC Press.
- Prigerson, H., Horowitz, M. J., Jacobs, S. C., Parkes, C. M., Aslan, M., Goodkin, K., ... Maciejewski, P. K. (2009). Prolonged Grief Disorder: Psychometric Validation of Criteria Proposed for

DSM-V and ICD-11. *PLOS Medicine*, 6(8), e1000121.  
<https://doi.org/10.1371/journal.pmed.1000121>

Prigerson, H. O., & Jacobs, S. C. (2001). Traumatic grief as a distinct disorder: A rationale, consensus criteria, and a preliminary empirical test. In M. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut, *Handbook of bereavement research: Consequences, coping, and care* (pp. 613–645).  
<https://doi.org/10.1037/10436-026>

Prigerson, H., Shear, M. K., Jacobs, S. C., Reynolds, C. F., Maciejewski, P. K., Davidson, J. R. T., ... Zisook, S. (1999). Consensus criteria for traumatic grief: A preliminary empirical test. *The British Journal of Psychiatry*, 174(1), 67–73. <https://doi.org/10.1192/bjp.174.1.67>

Radestad, I., Steineck, G., Nordin, C., & Sjogren, B. (1996). Psychological complications after stillbirth—influence of memories and immediate management: population based study. *BMJ*, 312(7045), 1505–1508. <https://doi.org/10.1136/bmj.312.7045.1505>

Rando, T. A. (1983). An Investigation of Grief and Adaptation in Parents Whose Children Have Died from Cancer. *Journal of Pediatric Psychology*, 8(1), 3–20.  
<https://doi.org/10.1093/jpepsy/8.1.3>

Rando, T. A. (1986). *Parental Loss of a Child* (1 edition). Champaign, Ill: Research Pr Pub.

Rando, T. A. (1993). The Increasing Prevalence of Complicated Mourning: The Onslaught is Just Beginning. *OMEGA - Journal of Death and Dying*, 26(1), 43–59.  
<https://doi.org/10.2190/7MDL-RJTF-NA2D-NPQF>

Raphael, B., & Martinek, N. (1997). Assessing traumatic bereavement and posttraumatic stress disorder. In *Assessing psychological trauma and PTSD* (pp. 373–395). New York, NY, US: Guilford Press.

Ray-Debove, J., & Rey, A. (2000). *Le nouveau Petit Robert : dictionnaire alphabétique et analogique de la langue française*. Paris: LR.



- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience | The Psychologist. *The Psychologist*, 18(1). Retrieved from <http://thepsychologist.bps.org.uk/volume-18/edition-1/exploring-lived-experience>
- Reid, M. (2007). The loss of a baby and the birth of the next infant: The mother's experience. *Journal of Child Psychotherapy*, 33(2), 181–201. <https://doi.org/10.1080/00754170701431339>
- Reynolds, J. J. (2004). Stillbirth: To Hold or Not to Hold .... *OMEGA - Journal of Death and Dying*, 48(1), 85–88. <https://doi.org/10.2190/L7PR-3744-8GLD-W4CQ>
- Rickels, L. A. (1988). *Aberrations of Mourning*. University of Minnesota Press.
- Rifkin, J. (2013). *Third Industrial Revolution*. Basingstoke: Palgrave Macmillan.
- Rimé, B., Mesquita, B., Boca, S., & Philippot, P. (1991). Beyond the emotional event: Six studies on the social sharing of emotion. *Cognition and Emotion*, 5(5–6), 435–465. <https://doi.org/10.1080/02699939108411052>
- Robinson, G. E. (2014). Pregnancy loss. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 28(1), 169–178. <https://doi.org/10.1016/j.bpobgyn.2013.08.012>
- Robinson, M., Baker, L., & Nackerud, L. (1999). The Relationship of Attachment Theory and Perinatal Loss. *Death Studies*, 23(3), 257–270. <https://doi.org/10.1080/074811899201073>
- Rocle, J.-P. (2012). Une cérémonie pour les tout-petits. *Études sur la mort*, (140), 103–112.
- Rogers, C. H., Floyd, F. J., Seltzer, M. M., Greenberg, J., & Hong, J. (2008). Long-term effects of the death of a child on parents' adjustment in midlife. *Journal of Family Psychology*, 22(2), 203–211.
- Rogers, C. R. (1978). *I gruppi di incontro*. Roma: Astrolabio Ubaldini.
- Romano, H., Baubet, T., Rezzoug, D., & Roy, I. (2006). Prise en charge du deuil post-traumatique chez l'enfant suite à une catastrophe naturelle. *Annales Médico-Psychologiques, Revue Psychiatrique*, 164(3), 208–214. <https://doi.org/10.1016/j.amp.2006.01.010>
- Romanoff, B. D., & Terenzio, M. (1998). Rituals and the Grieving Process. *Death Studies*, 22(8), 697–711. <https://doi.org/10.1080/074811898201227>

- Roose, R. E., & Blanford, C. R. (2011). Perinatal Grief and Support Spans the Generations: Parents' and Grandparents' Evaluations of an Intergenerational Perinatal Bereavement Program. *The Journal of Perinatal & Neonatal Nursing*, 25(1), 77. <https://doi.org/10.1097/JPN.0b013e318208cb74>
- Rosen, E. J. (1989). Family Therapy in Cases of Interminable Grief for the Loss of a Child. *OMEGA - Journal of Death and Dying*, 19(3), 187–202. <https://doi.org/10.2190/L4FU-M3F3-N8YW-5M9J>
- Rousseau, P. (1999). La grossesse après une interruption médicale de grossesse. In A. Cadoret, G. D. de Parseval, C. Haussaire-Niquet, D. Lett, & S. de thanatologie, *Etudes sur la mort, numéro hors série - 1999 : Euthanasie*. Le Bouscat: L'Esprit du Temps.
- Rozalski, V., Holland, J. M., & Neimeyer, R. A. (2017). Circumstances of Death and Complicated Grief: Indirect Associations Through Meaning Made of Loss. *Journal of Loss and Trauma*, 22(1), 11–23. <https://doi.org/10.1080/15325024.2016.1161426>
- Rubin, G. (1996). Fonctions structurantes et contenantantes des rituels de deuil. *Revue française de psychanalyse*, no 60(1), 211–218.
- Rubin, S. (1981). A Two-track model of bereavement: theory and application in research. *American Journal of Orthopsychiatry*, 51(1), 101–109. <https://doi.org/10.1111/j.1939-0025.1981.tb01352.x>
- Ruellan, J. (2011). Les cérémonies « civiles » en développement et en quête de sens. *Etudes sur la mort*, n° 140(2), 55–61.
- Sabbadini, A. (1989). L'enfant de remplacement. *La psychiatrie de l'enfant*, 32(2). Retrieved from <https://search.proquest.com/openview/1303e917c769a71b74ffef05a88c68c/1?pq-origsite=gscholar&cbl=1817462>
- Sani, L., & Bacqué, M.-F. (2018). Les enfants morts autour de leur naissance ont-ils réellement disparu ? Comparaison Italie/France de l'acceptation sociale et de la reconnaissance juridique du deuil périnatal. *Études Sur La Mort*, (151).

- Sani, L., Laurenti Dimanche, A.-C., & Bacqué, M.-F. (2019). Angels in the Clouds: Stillbirth and Virtual Cemeteries on 50 YouTube Videos. *OMEGA - Journal of Death and Dying*, 0030222818824732. <https://doi.org/10.1177/0030222818824732>
- Schaap, A. H. P., Wolf, H., Bruinse, H. W., Barkhof-van de Lande, S., & Treffers, P. E. (1997). Long-term impact of perinatal bereavement: Comparison of grief reactions after intrauterine versus neonatal death. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 75(2), 161–167. [https://doi.org/10.1016/S0301-2115\(97\)00127-9](https://doi.org/10.1016/S0301-2115(97)00127-9)
- Scharnitzky, P., & Kalampalikis, N. (2007). Analyse lexicale des sources d'influence dans les jurys d'assises. *Bulletin de psychologie, Numéro 491(5)*, 425–432.
- Scheidt, C. E., Hasenburg, A., Kunze, M., Waller, E., Pfeifer, R., Zimmermann, P., ... Waller, N. (2012). Are individual differences of attachment predicting bereavement outcome after perinatal loss? A prospective cohort study. *Journal of Psychosomatic Research*, 73(5), 375–382. <https://doi.org/10.1016/j.jpsychores.2012.08.017>
- Scheidt, C. E., Waller, N., Wangler, J., Hasenburg, A., & Kersting, A. (2007). Mourning after perinatal death--prevalence symptoms and treatment--a review of the literature. *Psychotherapie, Psychosomatik, medizinische Psychologie*, 57(1), 4–11. <https://doi.org/10.1055/s-2006-951906>
- Schellinski, K. (2014). 'Who am I?' *Journal of Analytical Psychology*, 59(2), 189–210. <https://doi.org/10.1111/1468-5922.12069>
- Schut, H. A. W., Keijser, J. de, Bout, J. van D., & Dijkhuis, J. H. (1991). Post-traumatic stress symptoms in the first years of conjugal bereavement. *Anxiety Research*, 4(3), 225–234. <https://doi.org/10.1080/08917779108248776>
- Schut, H., & Stroebe, M. S. (2005). Interventions to Enhance Adaptation to Bereavement. *Journal of Palliative Medicine*, 8(supplement 1), s-140. <https://doi.org/10.1089/jpm.2005.8.s-140>
- Schwab, R. (1998). A Child's Death and Divorce: Dispelling the Myth. *Death Studies*, 22(5), 445–468. <https://doi.org/10.1080/074811898201452>

- Schwartzberg, S. S. (1993). Struggling for Meaning: How Hiv-positive Gay Men Make Sense of Aids. *Professional Psychology: Research and Practice*, 24(4), 483–490.
- Service des etudes juridique. (2018). Étude de législation comparée n° 184 - avril 2008 - Les enfants nés sans vie. Retrieved May 1, 2019, from Senat.fr website: <https://www.senat.fr/lc/lc184/lc1840.html>
- Shakespeare, C., Merriel, A., Bakhbaki, D., Baneszova, R., Barnard, K., Lynch, M., ... Siassakos, D. (2018). Parents' and healthcare professionals' experiences of care after stillbirth in low- and middle-income countries: a systematic review and meta-summary. *BJOG: An International Journal of Obstetrics & Gynaecology*, 0(0). <https://doi.org/10.1111/1471-0528.15430>
- Shear, K., Frank, E., Houck, P. R., & Reynolds, C. F. (2005). Treatment of Complicated Grief: A Randomized Controlled Trial. *JAMA*, 293(21), 2601–2608. <https://doi.org/10.1001/jama.293.21.2601>
- Shear, K., & Shair, H. (2005). Attachment, loss, and complicated grief. *Developmental Psychobiology*, 47(3), 253–267. <https://doi.org/10.1002/dev.20091>
- Shear, M. K. (2012). Grief and mourning gone awry: pathway and course of complicated grief. *Dialogues in Clinical Neuroscience*, 14(2), 119–128.
- Shear, M. K. (2015). Complicated Grief. *New England Journal of Medicine*, 372(2), 153–160. <https://doi.org/10.1056/NEJMcp1315618>
- Shear, M. K., Reynolds, C. F., Simon, N. M., Zisook, S., Wang, Y., Mauro, C., ... Skritskaya, N. (2016). Optimizing Treatment of Complicated Grief: A Randomized Clinical Trial. *JAMA Psychiatry*, 73(7), 685–694. <https://doi.org/10.1001/jamapsychiatry.2016.0892>
- Shear, M. K., Simon, N., Wall, M., Zisook, S., Neimeyer, R., Duan, N., ... Keshaviah, A. (2011). Complicated grief and related bereavement issues for DSM-5. *Depression and Anxiety*, 28(2), 103–117. <https://doi.org/10.1002/da.20780>

- Shulz, J., Beauquier-Maccotta, B., Soubieux, M.-J., Mériot, M.-E., Wailly, D. de, & Missonnier, S. (2015). Entre honte et culpabilité, stigmates de la femme enceinte après une Interruption Médicale de Grossesse. *Champ psy*, *N° 68(2)*, 67–83.
- Shulz, J., Wailly, D. de, & Missonnier, S. (2018). Deuil prénatal et rituels, entre intime et collectif. In A. Ciccone, *Handicap et mort*. Retrieved from <https://www.cairn.info/handicap-et-mort--9782749262284-page-31.htm>
- Simon, N. M., Shear, K. M., Thompson, E. H., Zalta, A. K., Perlman, C., Reynolds, C. F., ... Silowash, R. (2007). The prevalence and correlates of psychiatric comorbidity in individuals with complicated grief. *Comprehensive Psychiatry*, *48(5)*, 395–399. <https://doi.org/10.1016/j.comppsy.2007.05.002>
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, *11(2)*, 261–271. <https://doi.org/10.1080/08870449608400256>
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1(1)*, 39–54. <https://doi.org/10.1191/1478088704qp004oa>
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. Smith, *Qualitative Psychology: A Practical Guide to Research Methods*. London ; Thousand Oaks, Calif: SAGE Publications Inc.
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain*, *9(1)*, 41–42. <https://doi.org/10.1177/2049463714541642>
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research* (Vol. 6).

- Smith, J., & Osborn, M. (2008). Interpretative Phenomenological Analysis. In C. Willig, *Introducing Qualitative Research in Psychology* (2 edition, pp. 53–58). Maidenhead: Open University Press.
- Søfting, G. H., Dyregrov, A., & Dyregrov, K. (2016). Because I'm Also Part of the Family. Children's Participation in Rituals After the Loss of a Parent or Sibling: A Qualitative Study From the Children's Perspective. *OMEGA - Journal of Death and Dying*, 73(2), 141–158. <https://doi.org/10.1177/0030222815575898>
- Song, J., Floyd, F. J., Seltzer, M. M., Greenberg, J. S., & Hong, J. (2010). Long-Term Effects of Child Death on Parents' Health-Related Quality of Life: A Dyadic Analysis. *Family Relations*, 59(3), 269–282. <https://doi.org/10.1111/j.1741-3729.2010.00601.x>
- Soubieux, M.-J. (2013). *Le berceau vide*. Eres.
- Soubieux, M.-J., & Caillaud, I. (2015). Le groupe thérapeutique des mères endeuillées. *Le Carnet PSY*, N° 186(1), 27–31.
- Steiner, C. S. (2006). Grief Support Groups Used by Few. *Journal of Social Work in End-of-Life & Palliative Care*, 2(1), 29–53. [https://doi.org/10.1300/J457v02n01\\_04](https://doi.org/10.1300/J457v02n01_04)
- Stephansson, O., Petersson, K., Björk, C., Conner, P., & Wikström, A.-K. (2018). The Swedish Pregnancy Register – for quality of care improvement and research. *Acta Obstetrica et Gynecologica Scandinavica*, 97(4), 466–476. <https://doi.org/10.1111/aogs.13266>
- Sterling, M. (2011). General Health Questionnaire – 28 (GHQ-28). *Journal of Physiotherapy*, 57(4), 259. [https://doi.org/10.1016/S1836-9553\(11\)70060-1](https://doi.org/10.1016/S1836-9553(11)70060-1)
- Stiffler, D., Birch, N., Campbell, H., & Cullen, D. (2017). A Synthesis of Coping Experiences After Infant Death. *Holistic Nursing Practice*, 31(2), 118–125. <https://doi.org/info:doi/10.1097/HNP.000000000000199>
- Stinson, K. M., Lasker, J. N., Lohmann, J., & Toedter, L. J. (1992). Parents' Grief following Pregnancy Loss: A Comparison of Mothers and Fathers. *Family Relations*, 41(2), 218–223. <https://doi.org/10.2307/584836>

- Stirtzinger, R., & Robinson, G. E. (1989). The psychologic effects of spontaneous abortion. *CMAJ: Canadian Medical Association Journal*, *140*(7), 799–805.
- Stroebe, M. (1993). Coping with Bereavement: A Review of the Grief Work Hypothesis. *OMEGA - Journal of Death and Dying*, *26*(1), 19–42. <https://doi.org/10.2190/TB6U-4QQC-HR3M-V9FT>
- Stroebe, M., Finkenauer, C., Wijngaards-de Meij, L., Schut, H., van den Bout, J., & Stroebe, W. (2013). Partner-Oriented Self-Regulation Among Bereaved Parents: The Costs of Holding in Grief for the Partner's Sake. *Psychological Science*, *24*(4), 395–402. <https://doi.org/10.1177/0956797612457383>
- Stroebe, M. S., Hansson, R. O., Stroebe, W., & Schut, H. (Eds.). (2001). *Handbook of Bereavement Research: Consequences, Coping, and Care* (1st edition). American Psychological Association.
- Stroebe, M., & Schut, H. (1999). The Dual Process Model of Coping with Bereavement: Rationale and Description. *Death Studies*, *23*(3), 197–224. <https://doi.org/10.1080/074811899201046>
- Stroebe, M., & Schut, H. (2010). The Dual Process Model of Coping with Bereavement: A Decade on. *OMEGA - Journal of Death and Dying*, *61*(4), 273–289. <https://doi.org/10.2190/OM.61.4.b>
- Stroebe, M., & Schut, H. (2016). Overload: A Missing Link in the Dual Process Model? *OMEGA - Journal of Death and Dying*, *74*(1), 96–109. <https://doi.org/10.1177/0030222816666540>
- Stroebe, W., & Schut, H. (2001). Risk factors in bereavement outcome: A methodological and empirical review. In *Handbook of bereavement research: Consequences, coping, and care* (pp. 349–371). <https://doi.org/10.1037/10436-015>
- Stroebe, W., Zech, E., Stroebe, M. S., & Abakoumkin, G. (2005). Does Social Support Help in Bereavement? *Journal of Social and Clinical Psychology*, *24*(7), 1030–1050. <https://doi.org/10.1521/jscp.2005.24.7.1030>

- Swartwood, R. M., Veach, P. M., Kuhne, J., Hyun Kyung Lee, & Kangting Ji. (2011). Surviving Grief: An Analysis of the Exchange of Hope in Online Grief Communities. *Omega: Journal of Death & Dying*, 63(2), 161–181. <https://doi.org/10.2190/OM.63.2.d>
- Takahashi, Y., Uchida, C., Miyaki, K., Sakai, M., Shimbo, T., & Nakayama, T. (2009). Potential Benefits and Harms of a Peer Support Social Network Service on the Internet for People With Depressive Tendencies: Qualitative Content Analysis and Social Network Analysis. *Journal of Medical Internet Research*, 11(3). <https://doi.org/10.2196/jmir.1142>
- Tal, I., Mauro, C., III, C. F. R., Shear, M. K., Simon, N., Lebowitz, B., ... Zisook, S. (2017). Complicated grief after suicide bereavement and other causes of death. *Death Studies*, 41(5), 267–275. <https://doi.org/10.1080/07481187.2016.1265028>
- Tavares Da Silva, F., Gonik, B., McMillan, M., Keech, C., Dellicour, S., Bhange, S., ... Munoz, F. M. (2016). Stillbirth: Case definition and guidelines for data collection, analysis, and presentation of maternal immunization safety data. *Vaccine*, 34(49), 6057–6068. <https://doi.org/10.1016/j.vaccine.2016.03.044>
- Temple, C., & Denoux, P. (2008). Construction d'un outil d'identification des stratégies identitaires en psychologie interculturelle. *Les Cahiers Internationaux de Psychologie Sociale, Numéro 79(3)*, 47–56.
- Thearle, M. J., Vance, J. C., Najman, J. M., Embelton, G., & Foster, W. J. (1995). Church Attendance, Religious Affiliation and Parental Responses to Sudden Infant Death, Neonatal Death and Stillbirth. *OMEGA - Journal of Death and Dying*, 31(1), 51–58. <https://doi.org/10.2190/BAXY-48AU-PETW-4MQ3>
- Theut, S. K., Moss, H. A., Zaslow, M. J., Rabinovich, B. A., Levin, L., & Bartko, J. J. (1992). Perinatal loss and maternal attitudes toward the subsequent child. *Infant Mental Health Journal*, 13(2), 157–166. [https://doi.org/10.1002/1097-0355\(199223\)13:2<157::AID-IMHJ2280130206>3.0.CO;2-Q](https://doi.org/10.1002/1097-0355(199223)13:2<157::AID-IMHJ2280130206>3.0.CO;2-Q)



- Thieleman, K., & Cacciatore, J. (2014). When a Child Dies: A Critical Analysis of Grief-Related Controversies in DSM-5. *Research on Social Work Practice, 24*(1), 114–122.  
<https://doi.org/10.1177/1049731512474695>
- Thuen, F. (1995). Satisfaction with bereavement support groups. Evaluation of the Norwegian Bereavement Care Project. *Journal of Mental Health, 4*(5), 499–510.  
<https://doi.org/10.1080/09638239550037334>
- Toedter, L. J., Lasker, J. N., & Janssen, H. J. E. M. (2001). International Comparison of Studies Using the Perinatal Grief Scale: A Decade of Research on Pregnancy Loss. *Death Studies, 25*(3), 205–228. <https://doi.org/10.1080/074811801750073251>
- Treccani 2014 dizionario della lingua italiana.* (2013). Firenze: Giunti Scuola.
- Truc, G. (2011). Analyser un corpus illisible ? Le logiciel Alceste confronté à des registres de condoléances. *Langage et société, n° 135*(1), 29–45.
- Turner, J. A. (2017). Online Support Groups: The Good, the Bad, and the Motivated. *Journal of Consumer Health on the Internet, 21*(1), 11–25.  
<https://doi.org/10.1080/15398285.2017.1279930>
- Turton, P., Badenhorst, W., Hughes, P., Ward, J., Riches, S., & White, S. (2006). Psychological impact of stillbirth on fathers in the subsequent pregnancy and puerperium. *The British Journal of Psychiatry, 188*(2), 165–172. <https://doi.org/10.1192/bjp.188.2.165>
- Turton, P., Badenhorst, W., Pawlby, S., White, S., & Hughes, P. (2009). Psychological vulnerability in children next-born after stillbirth: a case-control follow-up study. *Journal of Child Psychology and Psychiatry, 50*(12), 1451–1458. <https://doi.org/10.1111/j.1469-7610.2009.02111.x>
- Turton, P., Hughes, P., Evans, C. D. H., & Fainman, D. (2001). Incidence, correlates and predictors of post-traumatic stress disorder in the pregnancy after stillbirth. *The British Journal of Psychiatry, 178*(6), 556–560. <https://doi.org/10.1192/bjp.178.6.556>

- Umphrey, L. R., & Cacciatore, J. (2011). *Coping with the ultimate deprivation: narrative themes in a parental bereavement support group*. Retrieved from [https://scholar.google.it/scholar?q=COPING+WITH+THE+ULTIMATE+DEPRIVATION+%3A+NARRATIVE+THEMES+IN+A+PARENTAL+BEREAVEMENT+SUPPORT+GROUP\\*&btnG=&hl=it&as\\_sdt=0%2C5](https://scholar.google.it/scholar?q=COPING+WITH+THE+ULTIMATE+DEPRIVATION+%3A+NARRATIVE+THEMES+IN+A+PARENTAL+BEREAVEMENT+SUPPORT+GROUP*&btnG=&hl=it&as_sdt=0%2C5)
- Uren, T. H., & Wastell, C. A. (2002). Attachment and Meaning-Making in Perinatal Bereavement. *Death Studies, 26*(4), 279–308. <https://doi.org/10.1080/074811802753594682>
- Üstündağ – Budak, A. M., Larkin, M., Harris, G., & Blissett, J. (2015). Mothers' accounts of their stillbirth experiences and of their subsequent relationships with their living infant: an interpretative phenomenological analysis. *BMC Pregnancy and Childbirth, 15*(1), 263. <https://doi.org/10.1186/s12884-015-0700-3>
- van der Houwen, K., Stroebe, M., Schut, H., Stroebe, W., & van den Bout, J. (2010). Online mutual support in bereavement: An empirical examination. *Computers in Human Behavior, 26*(6), 1519–1525. <https://doi.org/10.1016/j.chb.2010.05.019>
- Vance, J., Boyle, F. M., Najman, J. M., & Thearle, M. J. (2002). Couple distress after sudden infant or perinatal death: A 30-month follow up. *Journal of Paediatrics and Child Health, 38*(4), 368–372. <https://doi.org/10.1046/j.1440-1754.2002.00008.x>
- Vance, J. C., Boyle, F. M., Najman, J. M., & Thearle, M. J. (1995). Gender Differences in Parental Psychological Distress Following Perinatal Death or Sudden Infant Death Syndrome. *The British Journal of Psychiatry, 167*(6), 806–811. <https://doi.org/10.1192/bjp.167.6.806>
- Vance, J. C., Najman, J. M., Thearle, M. J., Embelton, G., Foster, W. J., & Boyle, F. M. (1995). Psychological Changes in Parents Eight Months After the Loss of an Infant From Stillbirth, Neonatal Death, or Sudden Infant Death Syndrome—A Longitudinal Study. *Pediatrics, 96*(5), 933–938.
- Verdon, C., de Montigny, F., & Vachon, É. D. (2009). Les services offerts aux familles lors d'un décès périnatal. *L'infirmière Clinicienne, 6*(2), 25–28.

- Viaud, J., Patiño, F. J. U., & Ávila, M. T. A. (2007). Représentations et lieux communs de la mondialisation. *Bulletin de psychologie, Numéro 487*(1), 21–33.
- Videka-Sherman, L. (1982). Coping with the death of a child: A study over time. *American Journal of Orthopsychiatry, 52*(4), 688–698. <https://doi.org/10.1111/j.1939-0025.1982.tb01458.x>
- Videka-Sherman, L., & Lieberman, M. (1985). The effects of self-help and psychotherapy intervention on child loss: The Limits of Recovery. *American Journal of Orthopsychiatry, 55*(1), 70–82. <https://doi.org/10.1111/j.1939-0025.1985.tb03422.x>
- Villecourt-Couchat, I. (2018). Accession à la parentalité, solitude maternelle psychique... et communauté virtuelle. *Revue de psychothérapie psychanalytique de groupe, n° 70*(1), 127–136.
- Vital Statistics Registration Act – Riigi Teataja. (2009). Retrieved May 1, 2019, from riigiteataja website: <https://www.riigiteataja.ee/en/eli/ee/504022014001/consolide>
- Vollmann, S. R. (2014). A Legacy of Loss: Stories of Replacement Dynamics and the Subsequent Child. *OMEGA - Journal of Death and Dying, 69*(3), 219–247. <https://doi.org/10.2190/OM69.3.a>
- Wagner, B., & Maercker, A. (2008). An Internet-based cognitive-behavioral preventive intervention for complicated grief: a pilot study. *Giornale Italiano Di Medicina Del Lavoro Ed Ergonomia, 30*(3 Suppl B), B47-53.
- Wagner, B., & Maercker, A. (2010). The Diagnosis of Complicated Grief as a Mental Disorder: A Critical Appraisal. *Psychologica Belgica, 50*(1–2), 27–48. <https://doi.org/10.5334/pb-50-1-2-27>
- Wakefield, J. C. (2013). DSM-5 grief scorecard: Assessment and outcomes of proposals to pathologize grief. *World Psychiatry, 12*(2), 171–173. <https://doi.org/10.1002/wps.20053>

- Walsh, K., King, M., Jones, L., Tookman, A., & Blizard, R. (2002). Spiritual beliefs may affect outcome of bereavement: prospective study. *BMJ*, *324*(7353), 1551. <https://doi.org/10.1136/bmj.324.7353.1551>
- Ware, J., & Raval, H. (2007). A Qualitative Investigation of Fathers' Experiences of Looking After a Child with a Life-limiting Illness, in Process and in Retrospect. *Clinical Child Psychology and Psychiatry*, *12*(4), 549–565. <https://doi.org/10.1177/1359104507080981>
- Warland, J., O'Leary, J., McCutcheon, H., & Williamson, V. (2011). Parenting paradox: Parenting after infant loss. *Midwifery*, *27*(5), e163–e169. <https://doi.org/10.1016/j.midw.2010.02.004>
- Wayment, H. A., & Vierthaler, J. (2002). Attachment Style and Bereavement Reactions. *Journal of Loss & Trauma*, *7*(2), 129–149. <https://doi.org/10.1080/153250202753472291>
- Weiss, R. (1974). The provisions of social relationships. In Z. Rubin, *Doing unto others: joining, molding, conforming, helping, loving*. Englewood Cliffs, N.J: Prentice-Hall.
- Wenzel, A. (2017). Cognitive behavioral therapy for pregnancy loss. *Psychotherapy*, *54*(4), 400–405. <https://doi.org/10.1037/pst0000132>
- What causes infant mortality? (n.d.). Retrieved October 3, 2017, from Eunice Kennedy Shriver National Institute of Child Health and Human Development website: <https://www.nichd.nih.gov/health/topics/infant-mortality/topicinfo/Pages/causes.aspx>
- Wheeler, I. (2001). Parental Bereavement: The Crisis of Meaning. *Death Studies*, *25*(1), 51–66. <https://doi.org/10.1080/07481180126147>
- Wijngaards-de Meij, L., Stroebe, M., Schut, H., Stroebe, W., van den Bout, J., Heijden, P. G. M., & Dijkstra, I. (2008). Parents grieving the loss of their child: Interdependence in coping. *British Journal of Clinical Psychology*, *47*(1), 31–42. <https://doi.org/10.1348/014466507X216152>
- Wijngaards-de Meij, L., Stroebe, M., Schut, H., Stroebe, W., Van den Bout, J., Van der Heijden, P., & Dijkstra, I. (2005). Couples at risk following the death of their child: predictors of grief versus depression. *Journal of Consulting and Clinical Psychology*, *73*(2), 617–623.

- Wilson, A. L., & Soule, D. J. (1981). The role of a self-help group in working with parents of a stillborn baby. *Death Education*, 5(2), 175–186. <https://doi.org/10.1080/07481188108252090>
- Wing, D. G., Burge-Callaway, K., Rose Clance, P., & Armistead, L. (2001a). Understanding gender differences in bereavement following the death of an infant: Implications of or treatment. *Psychotherapy: Theory, Research, Practice, Training*, 38(1), 60–73.
- Wittouck, C., Van Autreve, S., De Jaegere, E., Portzky, G., & van Heeringen, K. (2011). The prevention and treatment of complicated grief: A meta-analysis. *Clinical Psychology Review*, 31(1), 69–78. <https://doi.org/10.1016/j.cpr.2010.09.005>
- Wonch Hill, P., Cacciatore, J., Shreffler, K. M., & Pritchard, K. M. (2017). The loss of self: The effect of miscarriage, stillbirth, and child death on maternal self-esteem. *Death Studies*, 41(4), 226–235. <https://doi.org/10.1080/07481187.2016.1261204>
- Woolner, A. M. F., & Bhattacharya, S. (2015). Obesity and stillbirth. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 29(3), 415–426. <https://doi.org/10.1016/j.bpobgyn.2014.07.025>
- Worden, J. W. (1991). *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner* (2nd edition). New York: Springer Pub Co.
- World Health Organization. (2016). *Making every baby count: audit and review of stillbirths and neonatal deaths*. Retrieved from [http://www.who.int/maternal\\_child\\_adolescent/documents/stillbirth-neonatal-death-review/en/](http://www.who.int/maternal_child_adolescent/documents/stillbirth-neonatal-death-review/en/)
- Wright, K. B., Rosenberg, J., Egbert, N., Ploeger, N. A., Bernard, D. R., & King, S. (2013). Communication Competence, Social Support, and Depression Among College Students: A Model of Facebook and Face-to-Face Support Network Influence. *Journal of Health Communication*, 18(1), 41–57. <https://doi.org/10.1080/10810730.2012.688250>
- Wu, L., Bonanno, G., DuHamel, K., Redd, W. H., Rini, C., Austin, J., ... Manne, S. (2008). Pre-bereavement meaning and post-bereavement distress in mothers of children who underwent

haematopoietic stem cell transplantation. *British Journal of Health Psychology*, 13(3), 419–433. <https://doi.org/10.1348/135910707X204236>

Yalom, I. D. (1985). *The Theory and Practice of Group Psychotherapy* (1st edition). Basic Books, Inc.

Youngblut, J. M., Brooten, D., Blais, K., Hannan, J., & Niyonsenga, T. (2010). Grandparent's Health and Functioning After a Grandchild's Death. *Journal of Pediatric Nursing*, 25(5), 352–359. <https://doi.org/10.1016/j.pedn.2009.02.021>

Youngblut, J. M., Brooten, D., Cantwell, G. P., Moral, T. del, & Totapally, B. (2013). Parent Health and Functioning 13 Months After Infant or Child NICU/PICU Death. *Pediatrics*, peds.2013-1194. <https://doi.org/10.1542/peds.2013-1194>

Zeanah, C. H. (1989). Adaptation Following Perinatal Loss: A Critical Review. *Journal of the American Academy of Child & Adolescent Psychiatry*, 28(4), 467–480. <https://doi.org/10.1097/00004583-198907000-00001>

Zech, E. (2006). *Psychologie du deuil. Impact et processus d'adaptation au décès d'un proche*. Retrieved from <https://dial.uclouvain.be/pr/boreal/object/boreal:92736>

Zech, E., Ryckebosch, A.-S., & Delespau, E. (2010). Improving the efficacy of intervention for bereaved individuals : toward a process-focused psychotherapeutic perspective. *Psychologica Belgica*, 50(1), 103.

Zublena, P. (20002). Il lutto. *The Edinburgh Journal of Gadda Studies*. Retrieved from <https://www.gadda.ed.ac.uk/Pages/resources/walks/pge/luttozublen.php>

### Résumé

Cette recherche vise à évaluer le risque de développement d'un trouble du deuil compliqué et l'apport d'un soutien psychologique (personnel, de groupe et sur internet) à la suite d'une perte périnatale. 29 parents français ont été rencontrés au total cinq fois : une première fois, puis 3, 6, 12 et 18 mois après la première réunion.

Une méthodologie mixte a été utilisée, s'appuyant sur des entretiens qualitatifs (évalués avec l'Interpretative Phenomenological Analysis et le programme Alceste) et à l'aide de deux questionnaires (l'Inventory of Complicated Grief et le General Health Questionnaire-28).

21 femmes (72%) et 8 hommes (28%) sont les parents rencontrés avec une moyenne d'âge de 31,4 ans. Le délai maximal entre le décès de l'enfant et la première réunion était d'environ 10 mois, le délai minimum était quant à lui de 22 jours. 44% des décès étaient dus à des problèmes médicaux et 35% à une interruption médicale de grossesse. Seulement 22% des enfants étaient mort-nés (maximum 96 jours) et 79% étaient décédés in utero.

Notre recherche a confirmé que la perte périnatale est un événement difficile et risqué pour les parents. Ce n'est que 18 mois après la perte de l'enfant que les parents ont rejoint le niveau du deuil non compliqué. La participation à des groupes de parole s'est révélée utile, tandis que les groupes sur internet peuvent mener au développement de troubles psychopathologiques.

Le rôle social et les contraintes culturelles liées au genre influencent la façon dont s'exprime le chagrin des parents. Au niveau du soutien émotionnel, la proximité et l'aide du partenaire et de la famille sont très importantes. Se souvenir et commémorer l'enfant malgré le temps qui passe et les grossesses ultérieures est fondamental pour aller de l'avant.

Mot clés : deuil périnatale - Trouble de deuil compliqué - soutien thérapeutique - parents

### Abstract

This research aims to evaluate the risk of complicated grief disorder (CG) and the contribution of psychological support (professional, or personal and group, and online) following a perinatal loss. 29 bereaved French parents were met for a total of five meetings: the first one, 3, 6, 12 and 18 months after the first meeting.

A mixed methodology was used, drawing on qualitative interviews (evaluated through the Interpretative Phenomenological Analysis and the Alceste program) and two questionnaires (Inventory of Complicated Grief and General Health Questionnaire 28).

The parents were 21 women (72%) and 8 men (28%), with a mean age of 31.4 years old. The maximum time between the child's death and the first meeting is about 10 months, while the minimum is 22 days. 44% of deaths occurred due to medical problems and 35% to a Late Termination of Pregnancy. Only 22% of children lived (up to a maximum of 96 days) and 79% died in utero.

Our research confirmed that perinatal loss is a difficult and risky event. Only more than 18 months a half after the loss, the parents reached the uncomplicated grief threshold.

Participation in support groups has proved useful while online groups can influence the development of psychopathological disorders.

The social role and cultural impositions of gender influence the expression of grief. Regarding the emotional support, the closeness and help of the partner and family are very important. Remembering and commemorating the child despite the passing of time and subsequent pregnancies are fundamental to move forward.

Keywords: perinatal loss - Complicated Grief disorder - therapeutic support - parents