Grief After Pregnancy Loss, Stillbirth, and Neonatal Death

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02 Clarifications

For simplicity, the terms “child”, “parent”, and “birth” are used throughout the thesis to encompass all concepts of the result of an abortion or birth and of self-identification. We recognize that other terms such as “fetus” may be preferred by some and hope that you will bear with the chosen terminology.

03 Dansk resumé

Når vi mister en vi holder af, sørger vi. Sorg er et naturligt fænomen og en forventelig del af livet. Forskning i sorg viser at langt de fleste vil tilpasse sig til tabet, mens nogle få vil udvikle komplicerede sorgreaktioner, herunder depression, angst, forlænget sorglidelse (Prolonged Grief Disorder, PGD), posttraumatisk stress syndrom (PTSD) og i værste fald død. I denne afhandling har fokus været på to af disse sorgreaktioner, PGD og PTSD. PGD er sorgspecifik i modsætning til andre lidelser som f.eks. PTSD. PGD er kendetegnet ved længsel efter afdøde og intens følelsesmæssig smerte med fastlåsning i sorgudtrykket der varer ved i mindst seks måneder og som medfører betydelige funktionsnedsættelse. PTSD er en lidelse der kan udvikle sig som følge af en traumatisk begivenhed. Lidelsen er karakteriseret ved bl.a. genoplevelse af traumet gennem mareridt og flashbacks samt undgåelse af situationer, steder og tanker der relaterer sig til traumet.

Vi har undersøgt PGD og PTSD specifikt for forældre, der har mistet et barn i graviditeten (fra graviditetsuge 14), under fødslen eller i barnets første levemåned. Til dette formål har vi brugt data fra en stor national spørgeskemaundersøgelse kaldet Livet Efter Tabet. Denne afhandling indeholder tre studier. To af disse anvender data fra Livet Efter Tabet og undersøger sorgforløb, risikofaktorer og behandling under indlæggelse i forbindelse med fødsel og barsel. Det sidste studie undersøger om dem der deltager i Livet Efter Tabet er systematisk forskellige fra dem der ikke deltager ved at koble Livet Efter Tabet til data fra danske registre.

I det første studie kortlagde vi symptomer på PGD ved tre nedslagspunkter efter tabet: 1, 7 og 13 måneder. Vi fandt at 73,1% af forældrene havde et sorgforløb, der var kendetegnet ved vedvarende lave symptomer på PGD. Dertil havde 16.9% af forældrene høje symptomer på PGD der faldt over tid, mens 10% havde

vedvarende høje symptomer på PGD. Vi fandt også at det i højere grad var dem med dødfødsler og dem der havde mistet et barn i dets første levemåned der havde vedvarende høje symptomer på PGD set i forhold til dem der havde spontane aborter eller dem der havde fået udført en senabort på grund af misdannelser hos barnet. Vedvarende høje symptomer på sorg sås også i højere grad blandt kvinder og blandt forældre der ikke havde nogle levende børn i forvejen.

I det andet studie undersøgte vi hvordan indlæggelse på en specialafdeling for forældre der har mistet sammenlignet med standardbehandling var relateret til symptomer på PGD og PTSD samt oplevet grad af støtte fra jordemoder. Indlæggelse på specialafdeling indikerede lavere symptomer på både PGD og PTSD sammenlignet med standardbehandling, men vi kunne ikke påvise en statistisk signifikant sammenhæng. Indlæggelse på specialafdeling var relateret til en meget høj grad af oplevet støtte fra jordemoder overordnet set og for alle typer af tab, men det var særligt tydeligt for forældre, der havde oplevet dødfødsel, hvoraf 100% angav støtte i meget høj grad, mens dette kun var 77,5% i standardbehandling.

I det sidste studie undersøgte vi deltagelsesmønstre i Livet Efter Tabet. Vi fandt en deltagelsesgrad på 25,7% ved spørgeskemaet udsendt en måned efter tabet og heraf deltog 72,6% i syv-måneders spørgeskemaet og 59,7% i 13-måneders spørgeskemaet. Deltagelse ved en måned var kendetegnet ved færre mænd, færre med lav uddannelse samt færre med mentale helbredsproblemer forud for tabet. Mens mænd og dem med lav uddannelse fortsatte med at være underrepræsenteret i opfølgningsspørgeskemaerne, så udviskedes forskellen relateret til mentalt helbred sig. Vi konkluderede at man i studier fra Livet Efter Tabet skal være særligt opmærksom på disse forskelle i deltagelse, og at resultater fra sådanne studier ikke kan overføres direkte til andre grupper.

04 Summary in English

When we lose someone, we love, we grieve. Grief is a natural phenomenon and an expected part of life. Research on grief shows that the vast majority will adjust adequately to the loss, while a few will develop complicated grief reactions, including depression, anxiety, prolonged grief disorder (PGD), post-traumatic stress disorder (PTSD), and in the worst cases, death. In this thesis, the focus has been on two of these grief reactions, PGD and PTSD. PGD is a grief-specific disorder, unlike other disorders such as PTSD. PGD is characterized by longing for the deceased and intense emotional pain with a fixation on grief expressions lasting for at least six months and resulting in significant functional impairment. PTSD is a disorder that can develop as a result of a traumatic event. The disorder is characterized by, among other things, re-experiencing the trauma through nightmares and flashbacks, as well as avoiding situations, places, and thoughts related to the trauma.

We have investigated PGD and PTSD specifically for parents who have lost a child during pregnancy (from gestational week 14), during childbirth, or in the child's first month of life. For this purpose, we used data from a large national questionnaire survey called Life After Loss. This thesis contains three studies. Two of these use data from Life After Loss and examine grief trajectories, risk factors, and care during hospitalization in connection with the loss. The last study examines whether those who participate in Life After Loss are systematically different from those who do not participate by linking Life After Loss to data from Danish registries.

In the first study, we mapped symptoms of PGD at three time points after the loss: 1, 7, and 13 months. We found that 73.1% of parents had a grief trajectory characterized by persistent low symptoms of PGD. In addition, 16.9% of parents had high symptoms of PGD that decreased over time, while 10% had persistent

high symptoms of PGD. We also found that it was more likely for those with stillbirths and those who had lost a child in its first month of life to have persistent high symptoms of PGD compared to those who had spontaneous abortions or those who had undergone late abortions due to fetal abnormalities. Persistent high symptoms of grief were also more common among women and among parents who did not have any living children beforehand.

In the second study, we examined how admission to a specialized unit for bereaved parents compared to standard treatment was related to symptoms of PGD and PTSD as well as the perceived level of support from midwives. Admission to the specialized unit indicated lower symptoms of both PGD and PTSD compared to standard treatment, but we could not demonstrate a statistically significant relationship. Admission to the special unit was related to a very high degree of perceived support from midwives overall and for all types of loss, but this was particularly evident for parents who had experienced stillbirths, with 100% reporting very high support, compared to only 77.5% in standard treatment.

In the last study, we examined participation patterns in Life After Loss. We found a participation rate of 25.7% in the questionnaire sent one month after the loss. Of these, 72.6% participated in the seven-month questionnaire and 59.7% in the 13-month questionnaire. Participation at one month was characterized by fewer men, fewer with low education, and fewer with mental health problems prior to the loss. While men and those with low education continued to be underrepresented in the follow-up questionnaires, the difference related to mental health diminished. We concluded that in studies from Life After Loss, special attention should be paid to these differences in participation, and that results from such studies cannot be directly transferred to other groups.

05 List of Abbreviations

AIC - Akaike Information Criterion

BIC - Bayesian Information Criterion

CI - Confidence Interval

DAG - Directed Acyclic Graph

DSM - Diagnostic and Statistical Manual of Mental Disorders

ICD - International Classification of Diseases

IQR - Interquartile Range

ISCED - International Standard Classification of Education

LGMM - Latent Growth Mixture Modelling

LMR-LRT - Lo-Mendell-Rubin Likelihood Ratio Test

MBR - Medical Birth Registry

NPR - National Patient Register

NICU - Neonatal Intensive Care Unit

PGD - Prolonged Grief Disorder

PR - Prevalence Ratio

PTSD – Post-Traumatic Stress Disorder

SA - Spontaneous Abortion

SD - Standard Deviation

SSA-BIC - Sample-size-adjusted Bayesian Information Criterion

TOPFA - Termination of Pregnancy due to Fetal Anomalies

06 List of Papers

This thesis is based on the following three studies. Throughout, they will be referred to by their Roman numerals, as indicated below:

Study I

Sofie Mørk, Dorte Hvidtjørn, Sören Möller, Tine Brink Henriksen, Maja O'Connor, George A. Bonanno. *Grief Trajectories After Loss in Pregnancy and During the Neonatal Period: Variations by Type of Loss.* Journal of Psychiatric Research. Nov 2023. https://doi.org/10.1016/j.jpsychires.2023.10.052

Study II

Sofie Mørk, Maja O'Connor, Tine Brink Henriksen, Sören Möller, Dorte Hvidtjørn. *Specialized care or standard care after pregnancy and infant loss: A cohort study investigating symptoms of prolonged grief, post-traumatic stress, and support from midwives*. [in preparation for British Journal of Obstetrics and Gynaecology]

Study III

Sofie Mørk, Sören Möller, Maja O'Connor, Tine Brink Henriksen, Dorte Hvidtjørn. *Factors associated with non-participation and loss to follow-up in bereavement research using data from a cohort of parents with a loss in pregnancy or the neonatal period*. [submitted to European Journal of Epidemiology]

07 Introduction

In the course of a lifetime, nearly anyone will experience loss and grief. Grief is complex, particularly because it entails both love and suffering; without the former, the latter would not occur. As such, bereavement can be viewed as an expected and normal life event. At the same time, bereavement may also be a highly stressful event associated with a period of intense emotional pain, fostering cognitive, behavioral, and somatic reactions (1). Most people will adapt to the loss as the intensity of grief symptoms fade over time, and for them, the loss becomes an integrated part of life (1). However, around 10-20% of bereaved adults will experience complicated grief reactions (2, 3). Complicated grief can be seen as a general term, encompassing various aspects of grief including persistent and elevated grief symptoms, anxiety, depression, post-traumatic stress, somatic diseases (4), and even, as a potentially ultimate consequence, death (4-6); the latter is colloquially also known as dying from a broken heart. In addition, these types of complicated grief reactions often co-occur (7-9).

In this project, we focused on two of these aspects: 1) persistent and elevated grief symptoms corresponding to symptoms of Prolonged Grief Disorder, and 2) symptoms of post-traumatic stress disorder.

07.01 Prolonged Grief

Prolonged Grief Disorder (PGD) has been established as a distinct condition among various expressions of complicated grief with clear symptoms and etiology that are not better described by other diagnoses (7). PGD was recognized as a bereavement-specific disorder and implemented in the *International Classification of Diseases (ICD), 11th revision* that came into effect in 2022 (10, 11). The criteria for PGD include a) the death of someone close to the bereaved, b) a persistent and pervasive grief response characterized by intense emotional pain, a profound longing for or preoccupation with the deceased that clearly exceeds expected social, cultural, or religious norms, c) the presence of a grief reaction for a minimum of six months, and d) significant impairment in personal, family, social, educational, occupational, or other important areas of functioning (11). The prevalence of PGD has been estimated to occur in approximately 10% in a diverse population of bereaved adults (12). Factors that increase the risk of PGD symptoms include the loss of a child or partner, unexpected deaths, single relationship status, identifying as a woman, low socioeconomic status, and a history of previous losses (13-15).

In this project, the evaluation of grief symptoms was conducted within the framework of PGD by assessment of PGD symptoms. However, fulfillment of formal diagnostic criteria was not pursued, given that a PGD diagnosis requires formal psychiatric assessment, and that delving into estimating probable caseness poses potential challenges – a topic that will be further elaborated on in the discussion (see section 11.02).

07.02 Post-traumatic Stress

Post-traumatic stress disorder (PTSD) is a psychiatric condition that may develop in response to exposure to a traumatic event. The diagnostic criteria for PTSD, as outlined in ICD-11, requires all of the following: a) re-experiencing the traumatic event in the present, e.g., flashbacks, intrusive thoughts or memories, and nightmares, b) avoidance of trauma-related cues in the form of thoughts, memories, places, activities, and people, c) constant feelings of threat or danger that may present as hypervigilance, and d) significant impairment in personal, family, social, educational, occupational, or other important areas of functioning (16).

While PTSD is distinct from PGD, there are notable overlaps in symptoms, which is also evidenced by a high level of comorbidity that complicates differentiation between the two (17). Thus, some qualitative distinctions and similarities should be highlighted. PTSD is often linked to emotions of guilt, anger, fear, and shame, whereas PGD is associated with feelings of abandonment, emptiness, and longing (7). A shared feature is a sense of numbness and the experience of intrusive thoughts and images; however, the nature of these intrusive thoughts and images differs. In PTSD, fixation on the circumstances of the loss and on threatening or frightening aspects tend to dominate, whereas, in PGD, the focus often revolves around positive experiences with the deceased (18). Research suggests that PTSD related to bereavement trauma disturbs the natural course of grief and may increase the risk for subsequent PGD (19, 20).

07.03 Pregnancy and Neonatal Loss

Complicated grief reactions, including PTSD and PGD, have also been observed in response to pregnancy and neonatal loss, with neonatal loss being defined as the death of a newborn infant within the first 28 days of life (21, 22). Globally, the incidence of stillbirths and neonatal deaths is estimated at approximately 30 per 1000 births, impacting roughly 4.2 million families annually (23, 24).

Pregnancy and neonatal loss are often sudden and unexpected and may present unique challenges in the grieving process. Parents may grapple with unfulfilled expectations of parenthood, the loss of some anticipated future, and feelings of guilt or blame (25). The lack of tangible memories with the child and societal misunderstandings about the depth of grief may further exacerbate the grieving experience (26, 27). Research indicates that pregnancy and neonatal losses may be linked to heightened grief symptoms, with variations based on the specific type of loss (21, 28). These variations might be due to differences in gestational age, given that attachment to the child appears to intensify with gestational age (29). Moreover, termination of pregnancy due to fetal anomalies (TOPFA) differs significantly from spontaneous loss; for instance, parents must decide to terminate the pregnancy, and the loss may be perceived as ambiguous (30).

Given the diverse nature of pregnancy and neonatal losses, the type of loss could contribute to variations in grief response. Additionally, experiencing repeated pregnancy loss and lacking a history of a successful pregnancy prior to the loss may exacerbate levels of grief symptoms (31, 32). While the gender of the bereaved has been discussed as a potential predictor of grief patterns, results have been inconsistent, and gender has seldom been explored within dyads, such as partners within the same household (14, 33, 34).

Losing a child during pregnancy is associated with considerable direct, indirect, psychological, and social costs to the parents and society (35, 36), and some of these costs may be moderated by a development of PGD and PTSD symptoms.

In a systematic review from 2022 grief reactions in mothers who had experienced a miscarriage or stillbirth was examined, the assessment of grief spanning from a few weeks to several years post-loss revealed disparate rates of grief scores (ranging from 3.5% to 80%), surpassing the corresponding cut-offs on grief scales (21). The review was based on 13 cross-sectional studies and eight longitudinal studies, nearly half of which were considered as having a high risk of bias. The review concluded that more longitudinal studies are needed to investigate complicated grief related to pregnancy loss with a specific focus on identifying those who develop PGD. Furthermore, the authors highlighted that there is a need for studies addressing grief in subgroups of bereaved parents, i.e., parents with recurrent pregnancy loss or parents with different types of loss, including miscarriages, TOPFA, and stillbirths (21). Grief symptoms within the framework of PGD have yet to be investigated in relation to pregnancy loss.

PTSD has been observed in response to pregnancy loss with one study finding that symptoms of PTSD were seven times higher in mothers experiencing stillbirth or neonatal death as compared to mothers who gave live birth (37). In a systematic review of PTSD and PTSD symptoms after miscarriages, termination of pregnancy, stillbirths, and neonatal deaths, several risk-factors were investigated (22). This review included data from 48 studies, which, overall, were deemed to be of good methodological quality. Symptoms of PTSD were most prevalent during the first weeks after the loss and generally decreased over time. Factors including higher gestational age, identifying as a woman, low education, young age, a history of mental health problems, and current loss-related grief were all associated with higher levels of PTSD symptoms (22).

The consequences of PGD and PTSD symptoms can be severe, with studies suggesting connections to impaired interpersonal relationships, occupational dysfunction, and an increased risk of comorbid mental health disorders, such as depression and substance abuse (17, 38-41). Furthermore, parents may experience heightened anxiety, fear of recurrence, and challenges in forming a positive emotional connection with a subsequent pregnancy. This may contribute to increased stress as well as potential complications during later pregnancies (42, 43). Early intervention and comprehensive treatment approaches are crucial for mitigating the long-term impact of PGD and PTSD symptoms.

07.04 Bereavement Care

Effective care organization in hospitals and support from caregivers during and after losing a child may mitigate the consequences of pregnancy loss (35, 44, 45). Existing studies emphasize the impact of compassionate and empathetic care in supporting parents' coping mechanisms, while inadequate and inconsistent communication may intensify their sense of loss (35, 46). Existing studies have primarily explored single aspects of care and there is a lack of research focusing on the comprehensive organization of care for bereaved parents (47).

In general, parents value compassionate and patient-centered care (48). Studies show that they find it distressing to be admitted to a room in a gynecology, labor, or maternity ward, due to them being in close proximity to expectant and laboring women or parents with healthy babies (46). Spending time with the dead baby has been reported as beneficial for the parents, and one study found that mothers who were able to stay with their stillborn babies for as long as they wished developed fewer depressive symptoms (49). Given that individual midwives might go months or even years between caring for bereaved parents, they rarely develop any routine in the specific tasks related to pregnancy loss, e.g., information on and arranging autopsy and burial.

From clinical experience we know that many labor wards have a specific binder, encompassing all the guidelines related to pregnancy loss; obviously, these differ significantly from those related to regular births in terms of the administrative tasks. This organization has the potential to lead to inadequate information being provided to the parents, and the caregiver may sometimes become very preoccupied with relatively unfamiliar tasks and guidelines, which, in turn, may contribute to parental distress (36, 50, 51). Clinicians as well as parents have highlighted a need for specialized education in loss and grief to provide high quality care (36).

In Denmark, most parents are offered standard care when experiencing pregnancy or neonatal loss and in the majority of cases, the birth is attended to by a midwife. In standard care, the woman and her partner are admitted to a gynecology, labor, or maternity ward alongside other pregnant women or parents with newborn babies. A midwife on call attends the birth but, as mentioned above, due to the relatively long intervals between attending to loss events, the individual midwife rarely builds any routine in the tasks specific to these. From clinical experience we know that parents who experience loss often choose to leave the hospital within the first day after the birth despite being offered longer stays. The care for parents during and after infant death is handled by the staff at the neonatal intensive care unit (NICU) and the parents are usually discharged directly from the NICU.

Participation in grief support groups organized by the hospitals is routinely offered in The Region of Southern Denmark as well as in The Central Denmark Region where the Unit for Loss is located. In the remaining three Danish regions, a few hospitals offer similar programs.

A unit offering specialized care for bereaved parents, Unit for Loss, was established at Aarhus University Hospital in 2011 to tailor and improve the quality of care for bereaved parents (52). The Unit is run by seven midwives with special education in loss and grief, with one midwife being present daily from 7 AM to 8 PM, which is the period where most spontaneous abortions, TOPFAs, and stillbirths occur. The Unit is situated close to, but shielded from, the labor ward and has its own entrance. Bereaved parents may stay for as many days as they want, and often stay for two or more days; in cases of stillbirth, the parents sometimes stay up to eight days (52).

Parents within the uptake area of Aarhus University Hospital are admitted to the Unit for Loss if they have experienced a loss during pregnancy (from 14 weeks of gestation), TOPFA, or stillbirth. Health care professionals at the NICU handles the care for neonates and in case of infant death within the first 48 hours after birth, the parents are offered to stay at the Unit for Loss with their deceased child for as long as they wish. The Unit for Loss was the first and only of its kind in Denmark up until December 2021, with a few more having been established in subsequent years. However, specialized care remains to be offered by all Danish regions.

08 Aim

08.01 Overall Objective

The overall objective of the PhD was to describe chronic grief reactions in bereaved parents in the first year after a pregnancy or neonatal loss and to investigate associated risk factors.

08.01.01 Study I

In this study, we aimed to describe grief trajectories in the first year after a pregnancy or neonatal loss and to investigate variations by type of loss, gender, previous loss, and having living children.

08.01.02 Study II

We aimed to assess the association between care offered at Danish hospitals and symptoms of PGD and PTSD measured one month after the loos of a child in pregnancy or during the first 48 hours after birth. Furthermore, we aimed to investigate associations between care and experienced support from midwives.

08.01.03 Study III

This study aimed to investigate non-participation and loss to follow-up in a longitudinal cohort of bereaved parents, data from which Studies I and II were based.

09 Methods

To explore the aims of this PhD, we used data from the Danish National Cohort, *Life After the Loss* (29), which comprises data on and from parents who have experienced a loss during pregnancy, during birth, or in the neonatal period. We used Latent Growth Mixture Modelling (LGMM) on data collected at one, seven, and 13 months after the loss to describe grief trajectories and identify risk factors. Organization of care was explored comparing specialized to standard care using linear regression models to estimate differences in PGD and PTSD symptoms, and chi squared testing was employed to investigate perceived support from attending midwives. Lastly, non-participation and loss to follow-up in the Life After the Loss cohort were investigated by linking cohort data with data from Danish registers on sociodemographic and obstetric characteristics and computing prevalence ratios comparing non-participants and participants.

09.01 Data Source

To conduct our research, we utilized data from the Danish cohort, Life After the Loss (29). The Life After the Loss study aimed to provide a comprehensive understanding of grief, emotional well-being, and existential values following pregnancy or neonatal death within the Danish population. The study included parents who experienced loss in pregnancy (from 14 weeks of gestation), during birth, or in the neonatal period defined as the death of a child within the first 28 days after birth. The scope covered various types of losses, including spontaneous or missed abortions, termination of pregnancy due to fetal anomalies (TOPFA), stillbirth, and neonatal death.

In Denmark, spontaneous abortion is defined as fetal death before 22 weeks of gestation, while stillbirth is recognized as fetal death at 22 weeks of gestation or later. Abortion is legal until 12 weeks of gestation without requiring special permission. After 12 weeks, TOPFA can be sought, and approval may be granted by a regional council (53). Although there is no formal upper gestational age limit, TOPFA is seldom approved after 24 weeks. It should be noted that all TOPFA procedures are presumed medically induced, as surgical abortions are not performed after 14 weeks of gestation in Denmark.

Data collection for the Life After the Loss study commenced in the Region of Southern Denmark in January 2016, extending to the Central Denmark Region in January 2017 (54). By the summer of 2018, the study was expanded and became nationwide, encompassing the remaining three regions, i.e., the North Denmark Region, Region Zealand, and the Capitol Region of Denmark. Recruitment to the cohort varied due to differences in the organization of care at the Danish hospitals. In the Region of Southern Denmark and the Central Denmark Region, parents were invited to participate at discharge from the hospital or during a planned telephone call from a grief-support group leader. In the remaining three Regions, recruitment was multifaceted encompassing a) invitations at discharge, b) announcements on the homepage of the Danish patient organization "Parents and grief" (Danish: Forældre og Sorg), and c) for a period of approximately one year, direct invitations to the mother's electronic mailbox were sent out if a loss diagnosis was registered in the Danish registers. If the parents consented to participate, questionnaires were sent out at three timepoints: one, seven and 13 months after the loss. Reminders were sent out two and four weeks after the initial invitation. Parents typically joined the cohort one month following their loss. In cases where there was no response, they were extended an invitation once more during the seven- or 13-month follow-up. The questionnaire administered upon entry to the cohort encompassed baseline information concerning obstetric and sociodemographic characteristics of the pregnancy and parents, respectively. Recruitment to the Life After the Loss study is expected to continue until the end of 2024 (54).

For all studies based on data from the Life After the Loss cohort, multiple pregnancies where one child survived were excluded. From clinical experience we know that the experiences of these parents differ substantially from other types of loss and, unfortunately, there were too few in the cohort to comprise a separate subcategory.

09.02 Psychometric Measures

The Life After the Loss study's questionnaires encompass a range of psychometric measures, with scales assessing symptoms of PTSD and PGD incorporated in all three surveys.

09.02.01 Prolonged Grief

Symptoms of PGD were examined within the framework established by Prigerson et al. (2009), utilizing the PG-13 instrument (55) available in the Life After the Loss study (54). The PG-13 comprises 13 items. Items 1–11 assess separation anxiety, cognitive, emotional, and behavioral symptoms, using a 5-point Likert scale that ranges from "not at all" to "several times a day" for items 1–4 and from "not at all" to "extremely" for items 5–11. Items 12 and 13 provide information on duration and impairment, requiring responses of "yes" or "no." The scores from items 1–11 can be summed, resulting in a total score ranging from 11 to 55 (55). The PG-13 has previously been translated into Danish (56) and has been found to have high validity and reliability (57). The questions underwent modifications for the Life After the Loss study, specifically adapting the wording to address bereaved parents. For example, "your loss" was adjusted to "the loss of your child" (see Table 1).

Table 1. The Danish version of the PG-13 instrument adjusted to a population of parents bereaved in pregnancy, birth or shortly after birth [in English]. Items 1-11 was answered with respect to the parents' experiences in the last month.

Category	Symptom criteria	Item	Question
A: Event	All participants must have experienced a loss		
B: Separation anxiety	Longing for the deceased	Item 1	How often have you felt yourself longing or yearning for the child you lost?
	Emotional or physical suffering	Item 2	How often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to the child you lost?
C: Cognitive, emotional, and behavioral symptoms.	Avoidance	Item 3	How often have you tried to avoid reminders that you have lost your child, or that you are no longer pregnant?
	Shock	Item 4	How often have you felt stunned, shocked, or dazed by your loss?
	Confusion about role in life	Item 5	Do you feel confused about your role in life or feel like you don't know who you are (i.e., feeling that a part of yourself has died)?
	Difficulty accepting the loss	Item 6	Have you struggled accepting the loss?
	Difficulty trusting others	Item 7	Have you struggled trusting others since your loss?
	Bitterness	Item 8	Do you feel any bitterness towards the fact that your child has died?
	Difficulty moving on	Item 9	Do you feel that moving on (e.g., laughing, pursuing new interests) would be difficult for you now?
	Emotional numbness	Item 10	Do you feel emotionally numb since the loss of your child?
	Feeling that life is unfulfilling	Item 11	Do you feel that your life has become unfulfilling, empty, or meaningless since the loss of your child?
D: Duration.	Elevated symptoms for at least 6 months.	Item 12	In one or more of the previous questions, you have indicated that you have experienced the described scenarios to some degree. Have these experiences lasted for at least six months?
E: Impairment criterion	The disturbance causes significant impairment in personal, family, social, educational, occupational, or other important areas of functioning.	Item 13	Have you experienced a significant reduction in social, occupational, or other important areas of functioning (e.g., domestic responsibilities)?

09.02.02 Post-traumatic Stress

PTSD can be assessed using the Post-Traumatic Stress Disorder Checklist (PCL) (58). This instrument was included in the Life After the Loss questionnaires and comprises 17 items aligned with the PTSD symptom criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) 4th edition by the American Psychiatric Association. Respondents use a 5-point Likert scale, ranging from "not at all" to "extremely", to indicate the extent to which they have been disturbed by each PTSD symptom over the past month. The score for each item in the PCL can be summed to yield a continuous score of PTSD symptoms. The PCL has high internal consistency, test–retest reliability, convergent validity, and discriminant validity (59). The instrument was adapted for the Life After the Loss study leaving out item 12 “Feeling as if the future will be short” and adapting the wording to bereaved parents, e.g., changing “traumatic event” to “the loss of your child” (see Table 2).

Table 2. The Danish version of the PCL instrument adjusted to a population of parents bereaved in pregnancy, birth or shortly after birth [in English]. The parents indicated the extent to which they had experienced that issue in the past month.

Item	Response
1	Repeated, disturbing memories, thoughts, or images related to my child and the days surrounding the loss?
2	Repeated, disturbing dreams related to my child and the days surrounding the loss?
3	Suddenly acting or feeling as if the loss was happening again (as if you were reliving it)?
4	Feeling very upset when something reminded you of the loss of your child?
5	Having physical reactions (e.g., heart pounding, trouble breathing, or sweating) when something reminded you of the loss of your child and the days surrounding the loss?
6	Avoid thinking about or talking about your child and the days surrounding the loss or avoid having feelings related to it?
7	Avoid activities or situations because they remind you of your child and the days surrounding the loss?
8	Trouble remembering important parts of the circumstances and days surrounding the loss?
9	Loss of interest in things that you used to enjoy?
10	Feeling distant or cut off from other people?
11	Feeling emotionally numb or being unable to have loving feelings for those close to you?
13	Trouble falling or staying asleep?
14	Feeling irritable or having angry outbursts?
15	Having difficulty concentrating?
16	Being “super alert” or watchful on guard?
17	Feeling jumpy or easily startled?

09.03 Covariates

Aside from psychometric measures, the Life After the Loss study provides information on sociodemographic and obstetric characteristics as well as circumstances of the loss. Parental characteristics obtained from the questionnaire at entry to the cohort included: age (integer), gender (man/woman), parent (mother/partner), civil status (single/cohabitating/married), educational attainment (categories), having any living children (yes/no), previous losses in pregnancy (yes/no), gestational age at time of birth (integer) and whether the child was live- or stillborn. We categorized type of loss into four groups using information on mode of delivery, gestational age and whether the child was live- or stillborn. The four groups were defined as 1) spontaneous abortion (gestational age between 14-21 and not categorized as TOPFA), 2) TOPFA (mode of delivery specified as induced birth or abortion due to fetal anomalies or due to the mother's illness and gestational age between 14-24 weeks), 3) stillbirth (stillborn at 22 weeks or later), and 4) neonatal death (the death of a liveborn within 28 days of life and gestational age at or after 22 weeks).

09.04 Ethical Considerations

Parents who have experienced loss constitute a particularly vulnerable group. Hence, inviting them to participate in research necessitates careful ethical considerations. Nevertheless, research indicates that bereaved parents often experience their involvement in research projects as meaningful (60). This positive response is driven by a desire to contribute and assist other parents (61). The Life After the Loss questionnaires were tested by seven grief-support group leaders and 18 parents with a previous loss, and their comments and suggestions were incorporated in the final version of the questionnaires (54).

The participating parents provided written consent and participation was anonymous. The study was approved by the Region of Southern Denmark’s record for data processing activities (record no 18/15684), ensuring adherence to ethical standards for observational research.

09.05 Statistical Analyses

In general, the distribution of population characteristics and covariates are described by counts and frequencies for categorical variables. Continuous measures are presented as means with corresponding standard deviations (SD) for normally distributed data and as medians with interquartile ranges (IQR) for non-normally distributed data. As the data from the Life After the Loss cohort included mothers and partners from the same household, their answers may not be independent. Dyads were therefore identified using unique identifiers including date of birth, gestational age, and type of loss. Consequently, all analyses accounted for the non-independence of observations through clustered standard errors (62).

09.05.03 Study I

In this study, we aimed to describe PGD symptom trajectories in the first year following loss and to identify variations by type of loss. All Life After the Loss participants with a loss from January 1, 2016, to September 22, 2021, who had completed at least two of the three questionnaires were included.

To identify longitudinal patterns of grief, LGMM was applied to continuous data on PGD symptoms, utilizing the total score derived from items 1–11 of the PG-13. LGMM, recognized for its computational robustness, has the ability to categorize heterogeneous data into latent classes representing distinct longitudinal trajectories (63). This method has demonstrated efficacy in numerous studies on grief and depression, exhibiting high levels of replication and consistency (14, 64-66). The process involved identifying the best-fitting trajectories of grief symptoms across the three time points. Optimal class solution was determined by testing successive models with varying numbers of trajectories and adjustments in the estimation of intercept and slope parameters. This evaluation utilized standard fit indices including the Akaike Information Criterion (AIC), Bayesian Information Criterion (BIC), and sample-size adjusted Bayesian Information Criterion (SSA-BIC), for which lower values indicate better model fit. Entropy values range between 0-1 with higher values indicating better classification. The Lo-Mendell-Rubin likelihood ratio test (LMR-LRT) assessed whether adding a class improved model fit significantly. To enhance model convergence, additional runs were conducted with fixed slope or intercept. The selection of the optimal model considered interpretability, model parsimony, and theoretical coherence (67, 68).

Covariates evaluated within the conditional model included type of loss (spontaneous losses/TOPFA), gender (man/woman), previous losses in pregnancy (yes/no), and having any living children (yes/no). To explore the association between type of loss and grief class membership, a stratification by the four loss types was conducted outside the model using multinomial regression.

A set of sensitivity analyses were also carried out. The first was an analysis restricted to parents with complete data. The second analysis was conducted to investigate if an alternate definition of neonatal loss, using the Danish legal definition and including all liveborn children regardless of gestational age, would change the association between type of loss and grief trajectory.

Maximum likelihood estimation was employed to handle missing data. Stata 17 (StataCorp, College Station, TX, USA) and Mplus version 8.7 were used to perform all analyses.

09.05.04 Study II

In study II, our aim was to investigate if organization of care was associated with symptoms of PGD and PTSD as well as with experiences of support from midwives. We used data from Life After the Loss participants who experienced a loss from November 1, 2016, to November 30, 2021. The participants could have experienced a loss during pregnancy, during birth, or within 48 hours after birth (infant death). We included parents who had completed the first questionnaire within 90 days after the loss, given that we aimed to investigate experiences in the early aftermath of the loss.

Place of birth was used as exposure, comparing specialized to standard care. Specialized care was defined as having given birth at Aarhus University Hospital assuming that a majority of parents within the uptake area of this hospital would have been admitted to Unit for Loss. All other hospitals were categorized as standard care. The outcome measures included PGD and PTSD symptoms and the degree of experienced support from midwives. Information on the outcomes was derived from the first Life After the Loss questionnaire, which was sent out one month after the loss. Using simple and multiple linear regression, we estimated the mean differences with 95% confidence intervals (CI) in PGD and PTSD symptom scores between specialized and standard care. Covariates included in the adjusted model were chosen a priori and a Directed Acyclic Graph (DAG) was used to visualize the direction of associations and to determine the minimal set of variables to adjust for. Type of loss, previous losses, and age were thus included in the model.

As a preliminary analysis, we tested for interaction and found that type of loss modified the association between organization of care and PGD and PTSD symptoms. Consequently, all analyses were stratified by type of loss. The outcome measure, support from midwives, were derived from a single item question included in the one-month questionnaire. The parents were asked "to which degree have the following been of support to you?" and answered with regard to the midwife. The options were "not at all", "to some degree", "to a high degree", "to a very high degree", and "not relevant." This categorization was kept in the analysis. The degree of support was investigated by means of chi-squared testing.

09.05.05 Study III

In this study, we wanted to investigate non-participation and loss to follow-up in the Life After the Loss cohort. We linked data from the cohort with data from Danish registers on all parents who experienced a loss and gave birth in the Region of Southern Denmark between November 1, 2016, and December 31, 2018. Participants were identified in the cohort and linked to register data and non-participants were identified in the Medical Birth Registry (MBR) or the National

Patient Register (NPR) using the first loss in the study period as the index loss. The pattern of participation and attrition was described by sociodemographic, obstetric, and psychometric variables available in the Danish registers and in the Life After the Loss cohort. Characteristics available for all parents included parent (mother/partner), age at the time of loss, civil status (married or cohabitating/living alone), living children (yes/no), previous losses from 14 weeks of gestation (yes/no), previous losses regardless of gestational age (yes/no). Educational attainment was classified according to the International Standard Classification of Education (ISCED) (69); compulsory school (ISCED 0-2), beyond compulsory (ISCED 3-5), bachelor's (ISCED 6), master's or higher degree (ISCED 7-8). Chronic diseases and mental health conditions were defined by diagnoses in the NPR and by prescribed medicine in the Danish National Prescription Registry using an algorithm set forth by Prior et al. (70). Type of loss was categorized and defined as; spontaneous or missed abortion (gestational age between 14 and 21 weeks and loss specific ICD-10 diagnoses), termination of pregnancy (from 14 weeks of gestation and loss specific ICD-10 diagnoses), stillbirth (stillborn at or after 22 weeks of gestation), neonatal death (liveborn at or after 22 weeks of gestation who died during the first 28 days of life). We obtained information on the mothers' smoking habits recorded in the first trimester in the MBR. Symptoms of PGD and PTSD was available in the Life After the Loss cohort and was used to investigate loss to follow-up.

The pattern of participation was examined by calculating the prevalence and participation rate for each characteristic. We estimated prevalence ratios (PR) with 95% CIs, comparing the prevalence in baseline participants to that of the source population. The prevalences at the seven-month and 13-month follow-ups were compared to the prevalence at baseline.

The Region of Southern Denmark is one of five Danish regions, representing 21% of the national population. Recognizing potential variations in demographics compared to other Danish regions, we utilized data encompassing all losses in Denmark throughout the study period to describe the distribution of characteristics across all five regions.

All analyses were conducted using Stata 18 (StataCorp, College Station, TX, USA).

As this study relates to the internal and external validity of the Life After the Loss cohort, the findings will be presented and discussed in the Discussion (see section 11.01).

10 Summary of Findings

In this section, the main findings and interpretations of study I and study II are described. The results of study III are presented in the discussion. For more details, please refer to the appendix where all papers are enclosed in their full length.

10.01 Study I

With this study, we wanted to provide a general description of grief in the first year following the loss of a child in pregnancy or during the neonatal period. Our aim was to describe grief trajectories and investigate variations in these by type of loss, gender, previous loss, and having living children. We used the PGD framework to assess grief at three points in time within the first year after the loss.

We included 676 parents with a loss from January 1, 2016, to September 22, 2021 in the study. Nearly two thirds were women, and most of the parents were either married or cohabitating and had finished an education beyond secondary school. We identified three distinct patterns of grief in the population (see Figure 1). The most common trajectory was characterized by consistently low symptoms of prolonged grief with a slight decline over time. We named this trajectory *resilience* with 73.1% of participants following this pattern. The second most common trajectory was followed by 16.9% of the parents and termed *recovery,* given its characterization of high initial symptoms of prolonged grief that decreased steadily over time. The third trajectory, *chronic grief*, was characterized by elevated prolonged grief symptoms throughout the study period and was observed in 10% of participating parents.

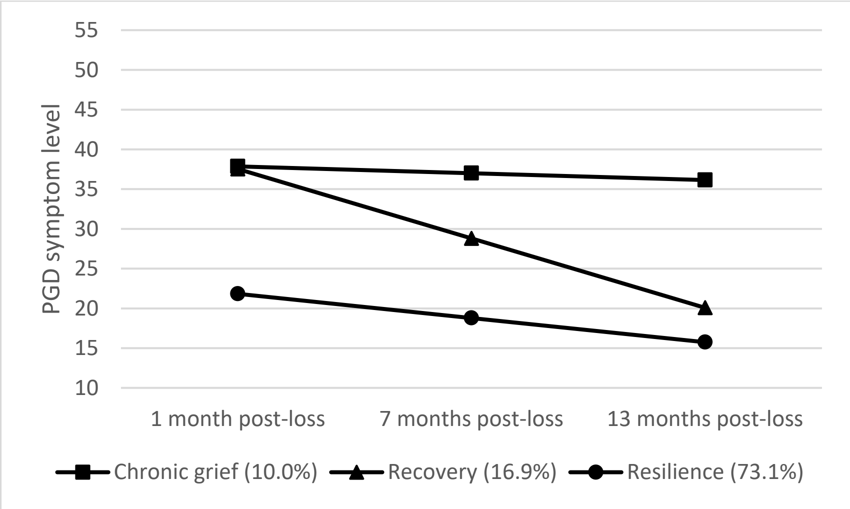


Fig 1. Grief trajectories of 676 parents bereaved during pregnancy or in the neonatal period. Abbreviations: PGD *Prolonged Grief Disorder*

These trajectories and the distributions within them were similar to those observed in other populations of bereaved (2, 14). However, the distribution of trajectories in the present study showed substantial variation based on type of loss, particularly evident in the chronic grief trajectory where stillbirths and neonatal deaths were overrepresented, accounting for approximately 16% of cases (see Table 3).

Table 3. Distribution of loss type within class membership (*n*=676).

	Resilient n (%)		*Recovery* n (%)		*Chronic* n (%)	
All	494	(73.1)	114	(16.9)	68	(10.0)
TOPFA	208	(80.3)	35	(13.5)	16	(6.2)
SA	118	(75.3)	31	(17.0)	14	(7.7)
Stillbirth	110	(63.6)	35	(20.2)	28	(16.2)
Neonatal death	58	(62.9)	13	(21.0)	10	(16.1)

Abbreviations: SA *spontaneous abortion,* TOPFA *termination of pregnancy due to fetal anomalies*

We then carried out an additional analysis in which neonatal deaths were defined regardless of gestational age as opposed to the primary analysis where neonatal deaths were restricted to losses at or after 22 weeks. The results showed a drop in frequency of neonatal deaths in the chronic group from 16.1% to 12.9%, suggesting that variations in grief by type of loss may be mediated by differences in gestational age. Other factors implicit in the construct “type of loss” may also have contributed to these variations, including whether the baby was live- or stillborn, the lifespan of the child in the case of livebirth, and the difference between spontaneous loss or termination of pregnancy. These are factors to be explored in the future.

Women and parents without living children were also more likely to follow a chronic rather than resilient trajectory (see Table 4). We discussed whether the observed gender difference was in fact due to gender or rather to differences in attachment due to the difference between carrying the child or not. Within the current study, however, we did not have enough female non-carrying partners to pursue an analysis of this idea.

Table 4. Covariate patterns within class membership (n=676 parents).

	RRR	95% CI
Resilient	reference	
Recovery		
Gender, woman	17.1	(4.7-62.1)
Previous loss, yes	2.2	(0.8-6.5)
Living children, no	3.9	(2.3-6.8)
Spontaneous loss, yes	2.3	(1.2-4.2)
Chronic		
Gender, woman	4.7	(1.9-11.4)
Previous loss, yes	1.2	(0.3-4.9)
Living children, no	2.9	(1.5-5.7)
Spontaneous loss, yes	2.8	(1.4-5.8)

Abbreviations: CI *confidence interval,* RRR *relative risk ratio*
No significant differences were found comparing the *recovery* class to the *chronic* class

We did not assess probable PGD caseness as this requires a formal psychiatric evaluation and, we therefore stressed that the 10% *chronic* class should not be misinterpreted as a PGD prevalence. This should be explored in future research.

The results highlighted the complexity of grief experiences, emphasizing the role of loss type and gender as characteristics that warrant further exploration. Furthermore, although it was reassuring that most parents followed a *resilient* or *recovery* trajectory, an exploration of the potential of early interventions to relive grief symptoms in the *chronic* class is highly warranted. Furthermore, studies using longer follow-up periods are needed to assess whether elevated symptoms continue past the initial 13 months subsequent to the loss experience.

10.02 Study II

Our aim was to investigate specialized care in comparison to standard care and its association with symptoms of PGD and PTSD as measured one month after the loss. In addition, we aimed to assess the degree of experienced support from midwives.

The study population consisted of 732 parents of whom 165 (22.5%) received specialized care. Parents who received specialized care were more likely to have completed a higher-cycle education than parents in standard care but were otherwise quite similar.

Receiving specialized care was associated with lower symptoms of PGD ($Diff_{adj}$ -0.9 [95% CI -2.5 - 0.7]) (see Table 5). This was moderated by type of loss, and the stratified analysis showed that, with the exception of those having experienced spontaneous abortions, all types of loss indicated lower PGD symptoms when specialized care was compared to standard care. Our results also indicated lower PTSD symptoms ($Diff_{adj}$ -1.9 [95% CI -4.1 – 0.3]) comparing specialized care to standard care, and although not statistically significant, all types of loss indicated lower symptoms.

Table 5. Simple and multiple linear regression estimates of PGD and PTSD symptoms comparing specialized care to standard care, overall and stratified by type of loss in 732 parents who experienced a pregnancy or infant loss between November 1, 2016, and November 30, 2021, in Denmark.

	Standard care mean(SD)		Specialized care mean(SD)		Diff.	Adj. Diff.*	95% CI
PGD symptoms							
Overall	27.3	(9.9)	26.3	(9.2)	-1.0	-0.9	(-2.5; 0.7)
SA	26.9	(9.8)	27	(9.3)	0.1	0.4	(-2.7; 3.6)
TOPFA	25.2	(9.8)	23.4	(8.4)	-1.8	-1.8	(-4.3; 0.6)
Stillbirth	29.9	(9.4)	28.8	(9.2)	-1.0	-0.9	(-4.2; 2.4)
Infant death	32.8	(9.1)	31.7	(8.6)	-1.1	-0.4	(-6.5; 5.8)
PTSD symptoms							
Overall	36.6	(13.7)	34.5	(12.0)	-2.1	-1.9	(-4.1; 0.3)
SA	36.6	(13.5)	34.8	(13.5)	-1.9	-1.4	(-6.2; 3.4)
TOPFA	34.3	(13.6)	32.1	(11.0)	-2.3	-2.2	(-5.4; 1.1)
Stillbirth	39.5	(14.2)	37.1	(12.1)	-2.5	-2.2	(-6.7; 2.3)
Infant death	40.0	(11.5)	39.1	(8.6)	-0.9	-1.0	(-8.7; 6.6)

*Adjusted estimates accounted for previous loss and age and overall adjusted estimates also accounted for type of loss.
PGD *prolonged grief disorder,* PTSD *post-traumatic stress disorder,* SA *spontaneous abortion,* SD *standard deviation,* TOPFA *termination of pregnancy due to foetal anomalies*

Support from midwives was generally experienced as high or very high, but more parents experienced a very high degree of support from midwives in specialized care (87.2%) compared to standard care (75.6%), a result which was statistically significant (see Table 6). Stratification on type of loss showed that this difference was most significant for parents with stillbirths, 100% of whom experienced a very high degree of support at the specialized care unit compared to 77.5% in standard care.

Table 6. Parents' experience of support from midwives stratified by organization of care at birthplace and by type of loss in 732 parents who experienced a pregnancy or infant loss between November 1, 2016, and November 30, 2021, in Denmark.

	Standard care n(%)		Specialized care n(%)		p
Support from midwife					
Overall					
Not at all	12	(2.2)	<3	N/A	
To some degree	40	(7.3)	6	(3.7)	
To a high degree	81	(14.9)	14	(8.5)	
To a very high degree	412	(75.6)	143	(87.2)	0.016
SA					
Not at all	6	(4.0)	0	(0.0)	
To some degree	11	(7.3)	<3	N/A	
To a high degree	23	(15.3)	3	(6.7)	
To a very high degree	110	(73.3)	40	(88.9)	0.153
TOPFA					
Not at all	<3	N/A	<3	N/A	
To some degree	13	(5.8)	4	(5.9)	
To a high degree	33	(14.8)	8	(11.8)	
To a very high degree	175	(78.5)	55	(80.9)	0.909
Stillbirth					
Not at all	<3	N/A	0	(0.0)	
To some degree	12	(8.5)	0	(0.0)	
To a high degree	18	(12.7)	0	(0.0)	
To a very high degree	110	(77.5)	39	(100)	0.014
Infant death					
Not at all	<3	N/A	0	(0.0)	
To some degree	4	(13.3)	0	(0.0)	
To a high degree	7	(23.3)	3	(25)	
To a very high degree	17	(56.7)	9	(75)	0.411

Denominators in percentages are non-missing observations

N/A *not applicable*, p *p-value,* SA *spontaneous abortion,* TOPFA *termination of pregnancy due to foetal anomalies*

In this study, specialized care was highly complex and comprised factors such as surroundings, time with the child, and specialized education and experience of the midwives. There is a lack of research investigating the combined effect of support interventions, thus hindering comparison with other studies. Our results were therefore discussed in references to single aspects of care and we found that factors such as unlimited time with the child, shielded unit, and midwives with specialized training and experience may be important explanatory factors of parents' perceived support from midwives.

While the clinical impact of the potential decrease in PGD and PTSD symptoms seen in specialized care is difficult to determine due to the relatively small numbers, our results indicate that organizing the care at a specialized unit may be beneficial to bereaved parents in the early aftermath of their loss. The potential benefit of specialized care was further supported by the increased number of parents who experienced very high degrees of support from midwives in specialized care compared to standard care.

We concluded that these findings should be elaborated on in studies designed specifically to investigate the impact of specialized bereavement care, including the outcome measures used here, and, in addition, investigating aspects such as birth experience, and the ability to cope with the loss.

11 Discussion

11.01 Methodological Considerations

11.01.01 Selection Bias, Study III

We conducted a study to investigate non-participation and loss to follow-up in the Life After the Loss cohort by linking data from the cohort to data from Danish registers and estimating prevalence ratios (PRs) for selected characteristic.

From November 1, 2016, to December 31, 2018, 725 parents experienced a loss during pregnancy or the neonatal period in the Region of Southern Denmark. Of the source population, 186 (25.7%) participated in the Life After the Loss cohort and of these 135 (72.6%) and 111 (59.7%) participated in the seven- and 13-month follow-ups, respectively. None of the initial participants were lost to follow-up due to death or emigration.

We found that baseline participants differed from the source population, particularly in terms of parental characteristics (large table, see enclosed paper for Study III). Initially, mothers exhibited a higher participation rate compared to partners (PR 1.30 [95% CI: 1.22; 1.38]). Although the initial disparities diminished during follow-up, even at the 13-month mark, mothers remained more likely to participate than partners.

The level of completed education was strongly linked to baseline participation, with lower education levels associated with decreased participation (PR 0.43 [95% CI: 0.27; 0.70]). While differences in educational attainment lessened over time, the pattern persisted. Despite not reaching statistical significance, PRs suggested substantial underrepresentation of parents with a pre-existing mental health condition, those in the upper-age category, and those living alone, with PRs ranging from 0.50 to 0.62. Although parents living alone continued to be underrepresented during follow-up, initial differences related to mental health and age did not persist.

Type of loss also played a role in participation, and this pattern varied across the three time points. Initially, parents with spontaneous abortions were underrepresented, but this discrepancy was not evident at the seven-month follow-up. Conversely, an overrepresentation of parents with stillbirths, coupled with an underrepresentation of those undergoing TOPFA, became apparent by the 13-month follow-up.

Information on PGD symptoms and PTSD symptoms was not available for the source population and we were thus unable to assess initial participation patterns based on these characteristics. However, no significant differences were found between baseline participants and those in further follow-up with regards to PGD and PTSD symptoms.

Furthermore, no significant differences were observed in terms of having living children, previous losses, chronic diseases, or smoking during pregnancy.

As we were only able to investigate participation patterns in parents from the Region of Southern Denmark, we also investigated if this subpopulation was comparable to the entire Danish population of bereaved parents. Parents from the Region of Southern Denmark closely resembled the general population on most characteristics, although a lower percentage had completed a master's degree compared to the nationwide population. Overall, regional differences were modest, with greater variation in factors such as educational attainment and type of loss, where the Capital Region of Denmark typically stood out.

Overall, the sociodemographic factors shaping participation in the Life After the Loss cohort was in alignment with studies from other cohorts of adults (71-73), which have concluded that initial disparities did not contribute with substantial selection bias (72, 73). Furthermore, engagement in follow-up was generally sustained and some of the differences at baseline diminished during follow-up, reducing the risk of attrition bias. However, studies investigating specific characteristics including education level, mother/partner, and type of loss should consider the influence of differences in participation patterns.

These findings provided a degree of reassurance regarding the internal validity of studies from the cohort. However, we advise caution when generalizing findings from the cohort and we urged that in doing so, participation patterns should be considered along with the settings of the cohort.

11.01.02 Information Bias

In this subsection, the risk of misclassification of exposures and outcomes in the studies included in this thesis will be discussed.

Study I: In this study, the main exposure of interest was type of loss, defined by information on gestational age at birth, mode of delivery, and whether the child was live- or stillborn. Data was self-reported at entry to the cohort, which in this study was at either one or seven months after the loss. Recall bias was not considered a risk, but misclassification due to uncertainty regarding whether the child was live- or stillborn may have been introduced. From clinical experience we know that there may be disparities between the health-care professionals' and the parents' assessment of signs of life especially at lower gestational ages. However, we considered it unlikely that any misclassification of type of loss should have been dependent on the outcome, PGD symptoms, and therefore concluded that any misclassification would have been undifferentiated causing bias toward the null.

In Study I and Study II, symptoms of PGD were used as the outcome measure. We evaluated this outcome on a continuous scale, thereby allowing for all nuances of this estimate. We used the PGD framework as set forth by Prigerson et al. (55) in 2009. We did not estimate probable PGD caseness, as this requires a formal psychiatric evaluation. Furthermore, the diagnostic criteria for PGD have undergone changes in recent years, and an estimation of probable PGD using the PG-13 would therefore not be translatable to actual PGD.

In the overall study, trajectories of PGD symptoms were the main outcome measure. We used LGMM to identify three distinct grief trajectories. As the best-fitting model was chosen based on interpretability, model parsimony, and theoretical coherence, some individuals may have been misclassified. One of the model-fit indices used was entropy. Entropy is an absolute, rather than relative, measure of model fit and an entropy of 0.7 is internationally considered adequate classification accuracy (74). The entropy was close to 0.8 for the three-class model used, thus indicating excellent classification accuracy.

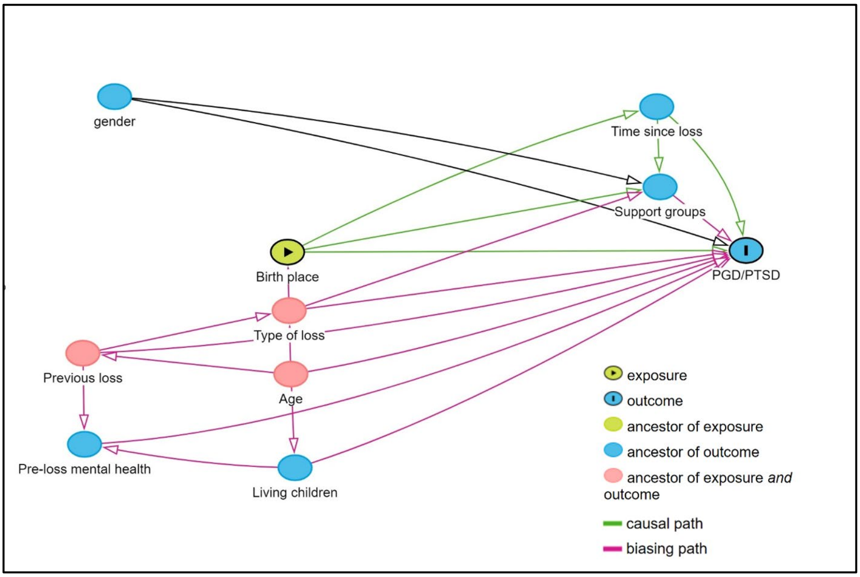
Study II: In this study, we compared exposure to specialized care to that of standard care, determined from information on place of birth, which, in turn, was obtained from the one-month questionnaire. All births at Aarhus University Hospital were categorized as specialized care and all others as standard care. Although misclassification of place of birth was considered unlikely, we underlined that misclassification of exposure may have been present as giving birth at Aarhus University Hospital did not always correspond to having received specialized care. At night, from 8 pm to 7 am, the Unit for Loss at Aarhus University Hospital is staffed by non-specialized midwives, and on rare occasions, transfer to standard care may have been necessary due to capacity issues. However, any such misclassification would have resulted in an underestimation of the association between specialized care and PGD and PTSD symptoms causing bias towards the null.

We investigated symptoms of PGD and PTSD along with support from midwives as outcome measures. All outcome measures were based on self-reported data one month after the loss. As was the case for PGD symptoms, PTSD symptoms were investigated on a continuous scale, and we considered misclassification bias to be unlikely. Support from midwives were evaluated on a 4-point Likert scale. The parents were asked “to which degree have the following been of support to you?" and in addition "If you have had experiences with, for example, several different midwives, then answer with regard to the experience that currently weighs most on your mind." The parents answered regarding the midwife and could choose either "not at all", "to some degree", "to a high degree", "to a very high degree", or "not relevant." The question did not refer to any time point, and the responses may therefore reflect experiences before, during, and after the birth. This, however, was considered undifferentiated and unlikely to introduce any bias.

11.01.03 Confounding

Study I: In this study, we investigated type of loss, gender, having living children, and previous losses as possible indicators of grief trajectories. Other important factors to investigate include pre-loss mental health and use of medication such as antidepressants, neither of which were information available to us. During peer-review of the paper associated with Study I, additional factors to include in the models were proposed. These included use of psychotherapy, support groups, additional pregnancy losses, or obtained pregnancy during follow-up, most of which were available to us. While these factors were considered highly relevant for grief experiences, including them in our models would entail conditioning on the future and introduce issues of possible reverse causation, i.e., the choice of trying for another pregnancy could be related to grief symptoms or the other way around.

Study II: We investigated the association between specialized care compared to standard care and symptoms of PGD and PTSD. Using a DAG to visualize possible confounding paths, we identified the minimum set of covariates needed to control for confounding of the effect estimates.



Firstly, given that pre-loss mental health, living children, and gender were neither directly nor indirectly associated with the care at the birthplace, these covariates were not included in the model. Secondly, use of support groups and time since the loss were identified as mediators of the studied association and were thus not accounted for in the analysis. Finally, type of loss, age, and previous losses in pregnancy were identified as possible confounders. Interaction analysis was subsequently conducted, and on the basis of this analysis, we concluded that type of loss contributed with effect modification. Consequently, all analyses were stratified by type of loss.

11.01.04 Generalizability

The Life After the Loss cohort comprises data on bereaved parents from Denmark. In Denmark, visits to the general practitioner, hospital services, and specialist services are tax-funded and free of charge for all citizens. The general practitioner can prescribe medication and may refer patients to a psychologist, but neither pharmacotherapy nor psychological treatment are offered routinely as part of bereavement care in Denmark. In addition, Denmark is a highly secularized country (75) although religious/spiritual beliefs and practices may increase during bereavement (76). The context of the Life After the Loss cohort is by and large comparable to settings in other Scandinavian and Western European countries. Whether studies from this cohort can be generalized to other cultural contexts e.g., to low- and middle-income countries with limited access to health care, or countries characterized by a more collectivistic mindset, has yet to be explored. Studies on African women's experiences of stillbirth showed that the women experienced isolation, stigmatization, and blame (77, 78). This cultural context meant that the women were prevented from ritualizations, such as seeing and holding their stillborn baby, making mementoes, and attending the burial. Such conflict between the needs of these women and cultural expectations exacerbated their grief (78). In a review, women from low and middle-income countries, who had experienced a stillbirth, experienced stigmatization and rejection and were more often blamed for the death of their babies than women from high-income countries (27). As self-blame, stigma, and lack of social support have been linked to elevated grief levels (27), the significance of cultural norms in grief experiences is evident. Extrapolating the results from studies using data from the Life After the Loss cohort should therefore take these aspects into consideration. Furthermore, studies on grief in diverse populations are needed to foster a more nuanced understanding of grief after pregnancy and neonatal loss.

11.02 Perspectives on Grief

As the Life After the Loss cohort was established in 2016, PGD symptoms were measured using the criteria set forth by Prigerson et al. in 2009 using the PG-13 (55). While most symptoms from ICD-11 are included in the original PG-13 scale, some, such as preoccupation with the deceased, is not. In the present study we therefore used the PG-13 for a single, continuous measure of intensity of overall PGD symptoms. Consequently, our results cannot be directly translated to ICD-11 PGD. Our study describes variations in PGD symptoms over time and PGD caseness was not measured.

11.02.05 Grief as a Diagnosis

PGD is a relatively new diagnosis, having only recently been included in the ICD-11 and the DSM-5. However, implementing PGD as a mental disorder has been a topic of considerable debate within the field of mental health. Like any diagnostic category, there are potential benefits and disadvantages associated with labeling prolonged grief in this manner. A diagnosis offers legitimization of severe grief and may help those struggling feel acknowledged by the healthcare system. However, as with any mental disorder, diagnosis may lead to stigmatization. The prevalence of PGD is around 10% (12), meaning that most grief responses are normalized, a fact which may provide reassurance to the bereaved. Conversely, as the grief diagnosis may be seen as the ultimate expression of grief, not getting the diagnosis may be experienced as failure. Furthermore, a formal diagnosis may guide mental health professionals in providing targeted interventions and facilitating treatment but not without the inherent risk of misdiagnosis and consequently pathologizing and medicalizing otherwise normal grief reactions.

Diagnosing mental disorders, including PGD, can be subjective and dependent on both the individual's and the clinician’s cultural, social, and personal context, and the PGD diagnosis will arguably influence the discourse on grief and mediate what is perceived as normal or normative grief. The cultural context has already been discussed in relation to the generalizability of the findings from the present PhD. Next, the cultural and socially internalized expectations associated with bereavement will be discussed.

11.02.06 Normative Grief

On the one hand, grief can be seen objectively as a measurable phenomenon, which has been the framework for the research presented in this PhD. On the other hand, grief can be viewed as an expression of emotions that are intrinsically linked to what we conceive as normative within a given social or cultural context (79). Within this framework, prevailing social and cultural norms and expectations are believed to mediate the individual experience of grief.

Throughout history, the approach to pregnancy and neonatal loss has undergone notable shifts. Earlier, caregivers typically removed the infant immediately after birth, and parents were often encouraged to "move on", as it was commonly believed that this approach would benefit the parents (80). Consequently, the loss remained largely invisible to the surrounding community, leading to a dissonance between the grief experienced by the parents and wider societal expectations. For some parents, this ambiguity may have led to what is termed disenfranchised grief (27). While cultural attitudes have evolved, with pregnancy and neonatal losses now recognized as genuine losses within broader society, the ambiguous status of the infant, simultaneously newborn and dead, continues to contribute to cultural uncertainty regarding the infant's status. This is expressed through coexisting but culturally opposite discourses: one claiming that the loss of a child is the worst thing a human can experience and another that implies that the parents did not get to know their child and therefore should not grieve as profoundly as parents who lose older children (79). The latter is also reflected in the presumption that parents who lose a child late in pregnancy grieve more intensely than parents who experience their loss at an earlier stage. The nature of the loss, i.e., whether the loss was spontaneous or by termination, may also be subject to cultural norms, as the grief of parents who undergo TOPFA may be mediated by self-blame, guilt, and stigmatization (81). The mediation of grief by cultural norms related to the status of the newborn, the duration of pregnancy, and the nature of the loss, be it spontaneous or by termination, provides a meaningful perspective on the variations in grief experiences related to type of loss that was observed in Study I.

11.02.07 Gendered Grief

Grief experiences may further be influenced by cultural norms and expectations surrounding gender roles. Research indicates that men prioritize supporting and comforting their partners over attending to their own grief and emotional needs (82, 83). In a study by McCreight from 2004 (82), fathers expressed feeling marginalized by the broader community following the loss of a child, as their grief was often overlooked or overshadowed by concerns for their partners' well-being. This was exemplified by an informant in the study who said, "when the phone rang it was always the same question, "how is Maria [partner], how is she coping?" At one stage I wanted to scream, what about me? No-one ever asked how I was" (82). Such narratives shed light on the prevailing gendered discourses surrounding grief, which tend to center predominantly on women's experiences. This is also evident by the gap in research on men's grief after pregnancy and neonatal loss, a gap that Study I was aimed at addressing. In conformance to previous research on gender differences in grief, the findings from Study I also suggested gendered variations in grief following pregnancy and neonatal loss. These variations may, in part, be explained by how gender norms intersect with grief experiences.

By adopting a framework of grief as an expression of emotions intertwined with societal and cultural norms, we have gained valuable insights into interpreting and understanding the diverse range of grief experiences observed in the studies of the present thesis.

12 Conclusion

The studies presented here leveraged the unique data available in the Life After the Loss cohort to investigate grief after pregnancy and neonatal loss.

We found that a majority of bereaved parents seemed to adapt adequately to the loss within the first year, while 10% followed a trajectory of stable elevated PGD symptoms. This trajectory had an overrepresentation of parents who had experienced stillbirth and neonatal death, parents who did not have any living children, and women. Overall, this knowledge contributes to a better understanding of the diverse experiences of bereaved parents. It may also inform strategies to support individuals coping with the loss of a child without removing the focus from the fact that an individualistic approach is best adopted, bearing in mind that no set of characteristics can determine the grief trajectory.

In our second study, we found that specialized care compared to standard care indicated lower levels of PGD and PTSD symptoms and that parents received specialized care were more likely to experience very high degrees of support from midwives. Although the effect sizes for PGD and PTSD symptoms were small and the clinically relevant impact therefore debatable, the results pointed to potential benefits of specialized care. This should be explored further in future studies.

In conclusion, our findings highlight the importance of striking a balance that acknowledges the complexity of grief while providing appropriate support and interventions as crucial aspects of bereavement care for parents after pregnancy and neonatal loss.

12.01 Perspectives for Research

The studies presented in this thesis have made important contributions to the knowledge of grief in bereaved parents having experienced a loss in pregnancy or during the neonatal period. However, as is always the case when conducting research: answering one question results in the emergence of a plethora of new ones.

We identified three trajectories and investigated risk-factors for the trajectory we named chronic grief. We have yet to answer questions pertaining to the characteristics of those parents that follow the *recovery* as well as the *resilient* trajectory. How do factors such as social support, use of therapy, and use of support groups exert their influence? Is grief intensity modified by difficulty obtaining a pregnancy? Is long-term grief mitigated by experiencing a healthy pregnancy after the loss?

We observed variations in grief by type of loss and discussed whether this was based on differences inherent to the categorization. Were the variations modified by gestational age, whether the loss was spontaneous or by TOPFA, whether the child was liveborn or stillborn, lifespan of the child in case of livebirth, or, perhaps, all of the above? We are currently investigating the association between gestational age and grief symptoms and are eagerly awaiting the results.

In line with results from research on other populations, we observed variations in grief by gender. However, a very important distinction in our study was that one parent carried the child, and we were thus not able to determine whether the variations were in fact due to gender or if they were due to differences in attachment or bodily experiences.

These and more question have surfaced during the past three years and demonstrate how attempting to fulfill any research goal inevitably produces more goals to be fulfilled. Hopefully, future research will close some of these knowledge gaps; all the while generating new questions to be answered.

13 References

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14 Appendix