

# BMJ Open Life after the loss: protocol for a Danish longitudinal follow-up study unfolding life and grief after the death of a child during pregnancy from gestational week 14, during birth or in the first 4 weeks of life

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## ABSTRACT

**Introduction** After the death of a child during pregnancy, birth or in the neonatal period, parents often experience feelings of guilt, disenfranchisement, feelings of betrayal by one's own body and envy of others. Such bereavement results in high rates of distress: psychologically, emotionally, physiologically and existentially. These data are collected using a national, longitudinal cohort to assess grief in mothers and their partners after the death of a child during pregnancy, birth or in the neonatal period. Our aim is to achieve a general description of grief, emotional health, and existential values after pregnancy or perinatal death in a Danish population.

**Methods and analysis** The cohort comprises mothers and their partners in Denmark who lost a child during pregnancy from gestational week 14, during birth or in the neonatal period (4 weeks post partum). We began data collection in 2015 and plan to continue until 2024. The aim is to include 5000 participants by 2024, generating the largest cohort in the field to date. Parents are invited to participate at the time of hospital discharge or via the Patient Associations homepage. Data are collected using web-based questionnaires distributed at 1–2, 7 and 13 months after the loss. Sociodemographic and obstetric variables are collected. Validated psychometric measures covering attachment, continuing bonds, post-traumatic stress, prolonged grief, perinatal grief and existential values were chosen to reach our aim.

**Ethics and dissemination** The study was approved by The Danish National Data Protection Agency (no. 18/15684, 7 October 2014). The results will be disseminated in peer-reviewed and professional journals as well as in layman magazines, lectures and radio broadcasts.

## INTRODUCTION

When we lose a person we love, we grieve. Grief is a simultaneously universal phenomenon and yet an entirely individual experience. Grief is also a cultural phenomenon, influenced by alternating normativity and

## Strengths and limitations of this study

- A comprehensive population-based longitudinal study targeting at 5000 participants.
- Uses multiple validated, self-administered questionnaires enabling studies within attachment, continuing bonds, post-traumatic stress, prolonged grief, perinatal grief, existential values and the quality of health services.
- Multiprofessional approach including psychologist, midwives, perinatal epidemiologists and anthropologists ensuring a resourceful approach.
- A robust response rate around 50%.
- Representativeness and non-participation will be assessed according to age, parity, gestational age at birth and type of loss.

beliefs over time.<sup>1</sup> In contemporary Western countries, grief and suffering are increasingly embedded in medical and psychiatric paradigms.<sup>2 3</sup> For example, WHO is preparing criteria for a new diagnosis termed prolonged grief disorder (PGD), anticipated to be introduced in the diagnostic manuals for mental disorders in 2018.<sup>4</sup> Discussions about how to define pathological grief are actualised both in professional settings and the broader population.<sup>5–8</sup> There is general agreement that the majority of bereaved individuals eventually, and without professional interventions, will arrive at a new emotional equilibrium after loss. According to Litz, only a minority will experience PGD, suffering significant impairment in important areas of daily life to a disabling degree more than 6 months after loss.<sup>9</sup> A recent meta-analysis found a prevalence of PGD in approximately 10% in bereaved adults; however, only a small

fraction of the bereaved in these 14 studies included bereaved parents.<sup>10</sup>

Thus, it is not clear how well these findings apply to the grieving process among parents after the death of a baby. Their grieving process might differ from grief processes in general, and a larger proportion may experience the symptoms of PGD. Put differently, a longer period of intense grief may be the normal response for parents grieving after the death of a baby. This hypothesis forms the basis of this longitudinal, follow-up study where we aim to assess grief among mothers and partners after the loss of a child during pregnancy from gestational week 14, during birth or in the neonatal period (4 weeks post partum). We include miscarriages, termination of pregnancy due to fetal anomaly (TOPFA), and the death of babies due to stillbirths and neonatal deaths.

### Nature of perinatal grief

The death of a baby can be a life-changing and devastating experience.<sup>11</sup> A growing body of literature has assessed the nature of grief among parents who lose a child during pregnancy, birth or in the neonatal period. One meta-analysis analysing 144 studies about parental grief demonstrates that the majority of studies originate in North America, followed by Great Britain, Sweden and Australia.<sup>12</sup> Findings conclude that loss from miscarriage, stillbirth, TOPFA or neonatal death often involves feelings of guilt, disenfranchisement, feelings of betrayal by one's body and envy of others.<sup>12 13</sup> Parents lose the prospect of an entire life with the child and all the moments they dreamt of sharing.<sup>14</sup> Furthermore, bereaved parents of young babies who die have few mementoes of the child, none or few pictures and a very short narrative.<sup>15</sup> The loss has been called 'invisible', and especially if the child died before or during birth, family and friends might not regard the child as real. They may also be reluctant to talk about the dead child, leading to emotional isolation complicating the grief process.<sup>12 16 17</sup> Some parents, mostly mothers, describe a loss of self-esteem.<sup>14 16 18 19</sup> For the mother, the bodily unity with the dead child might be still another stressful element.<sup>20</sup> For parents choosing TOPFA, feelings of guilt and doubt can further thwart the grief process.<sup>21 22</sup>

### Outcomes of pregnancy and perinatal bereavement

The outcomes of pregnancy and perinatal bereavement are also assessed in international studies, finding high rates of psychological and emotional distress and diagnoses including major depressive disorder, general anxiety disorder, post-traumatic stress disorder (PTSD), sense of failure, long-term guilt and intense grief for more than 2 years.<sup>12 14 20 23</sup>

Generally, measured by similar instruments, mothers appear to be more afflicted than fathers.<sup>14 24 25</sup> A review of 11 studies assessed the association between type of loss and mental health and found lower or comparable levels of depression, anxiety and PTSD among mothers losing a child from TOPFA and mothers losing a child from

stillbirth.<sup>26</sup> The risk for PTSD was assessed in a systematic review of 48 studies. They found an increasing risk of PTSD related to higher gestational age at time of loss and certain sociodemographic and psychosocial characteristics predicting PTSD.<sup>27</sup> Unsurprisingly, the PTSD risk appears to be seven times higher in mothers after a perinatal death compared with mothers with a live birth.<sup>28</sup> A review of 18 studies on self-blame, guilt and shame among bereaved parents (including stillbirths and the loss of older children) showed a high prevalence of all three states and an association with grief intensity.<sup>29</sup> Higher mortality rates from natural causes among mothers who experienced a perinatal death were found in two large population-based studies established on register data.<sup>30 31</sup>

Explorations of subsequent pregnancy following the loss suggest that some mothers are at an increased risk of depression and anxiety.<sup>32 33</sup> Patient-centred compassionate care is valued by the parents,<sup>20</sup> but we identified no studies assessing the long-term effect of the type of care provided at the hospital.

Despite the aforementioned outcomes, some bereaved parents describe the loss as a pivotal event in a broader and more life-changing sense. Grief can make an existential imprint on the bereaved parents potentially leading to both post-traumatic growth as well as post-traumatic stress, which is often mentioned in the literature.<sup>11 34-36</sup>

### Theoretical framework

In this section, we explicate the theoretical framework, which piloted the preparation of the questionnaires and the forthcoming data analyses.

In general, unexpected and traumatic loss increases the risk of impaired physical and emotional health in the bereaved, and the loss of a child in the perinatal period will most often be unexpected and traumatic.<sup>24</sup>

Attachment style is shown to be related to adaption to the loss with more intense and enduring symptoms of grief and depression, complicated grief reactions and decreased resilience in parents with an insecure attachment style (on both avoidance and anxiety attachment).<sup>37 38</sup> Attachment theory, first introduced by John Bowlby in the 1970s, provides a unique way to characterise individual differences in reactions to loss because it illuminates the nature of a person's relationships and adjustment in situations of separation.<sup>37</sup> Different styles of attachment, developed through the early parent-child relationship, will form the basis for responses to emotionally distressing situations such as bereavement.<sup>39</sup>

The dual process model (DPM) has become a widespread model in understanding grief in contemporary Western countries.<sup>40</sup> The DPM emphasises two concurrent types of stressors and coping processes: loss-oriented and restoration-oriented. It underscores that bereaved individuals often oscillate between these two processes throughout the course of bereavement, and a standstill in one of the two processes might be associated with prolonged grief.<sup>40</sup>

In Freud's classic grief work theory, detachment from the person who died is emphasised as fundamental for adaptation to the loss, and this idea has influenced the attitude of society and bereaved individuals for nearly 100 years. This philosophy is now challenged by the continuing bonds theory.<sup>41</sup> Continuing bonds has been defined as *'the presence of an on-going inner relationship with the deceased person by the bereaved individual'* representing diverse behaviours.<sup>42</sup> The literature reveals contradictory findings of the role of continuing bonds in bereavement, with certain types of continuing bonds associated with both adaptive and maladaptive adjustment in various studies. Moreover, outcomes are influenced by the social and cultural acceptance of grieving individuals and their continued relationship with the deceased.<sup>43</sup>

When a child dies at birth, the natural order of life is disturbed and assumptive worldviews shatter, challenging three primary core beliefs relating to benevolence, meaningfulness of the world and worthiness of the self, and requiring a reorganisation of worldviews.<sup>11 44</sup> This disruption of core belief might lead to changes in philosophy of life or spiritual beliefs.<sup>11</sup> These changes may be perceived as helpful or unhelpful, as the literature shows incongruent findings in how religiosity and spirituality relate to bereavement outcomes.<sup>38</sup>

### Danish setting

There are huge dissimilarities between the healthcare systems in Denmark and North America from where most of the studies originate. Danish healthcare is publicly available and free. Furthermore, there are different approaches in the way healthcare professionals support bereaved parents in creating a relationship with their dead child and acknowledging their grief.<sup>12 45</sup> Additionally, patient-centred psychosocial care is a basic standard of care in Danish hospitals, while the prescription of psychiatric medication appears to be much more common in the USA.<sup>3 45</sup> Specifically, when we explore existential values and spiritual beliefs, findings from more religious countries, such as the USA, have poor external validity when compared with a secularised country such as Denmark.<sup>46–48</sup> Hence, studies in a Danish context can expand our knowledge on grief after perinatal death.

### Aim

In this longitudinal national follow-up study, we aim to assess grief symptoms among mothers and partners after the loss of a child during pregnancy, birth or in the neonatal period. We aim to achieve a general description of grief, emotional health and existential values after pregnancy or neonatal loss in a Danish population.

To achieve our objectives, we based the study on the following overall research questions:

1. How does the process of grief change for bereaved parents in the first 13 months after the loss?
2. What, if any, gender differences exist in the grief process?

3. How is attachment style associated with continuing bonds and grief?
4. Does gestational age at the time of death influence grief?
5. Does the loss change existential or spiritual values or practices?

### Methods and analysis

This nationwide population-based cohort study comprises mothers and partners who lost a child during pregnancy after gestational week 14, during or after birth or in the neonatal period. We include miscarriage, TOPFA, stillbirth and neonatal death. In Denmark, a regional counsel can grant permission to perform TOPFA until gestational age (GA) week 22; stillbirth is defined as intrauterine fetal death from GA week 22. We use web-based questionnaires distributed at three specific time points in the first 13 months after the loss. Study data were collected and managed using REDCap electronic data capture tools hosted at University of Southern Denmark.<sup>49</sup> Mothers and their partners are asked to reply to the questionnaires individually.

Data collection started in the Region of Southern Denmark in January 2016 and in the Region of Central Jutland in January 2017. In the summer of 2018, we expanded the study nationally and included the remaining three regions in Denmark. Data collection was permitted by The Danish Data Protection Agency until January 2025.

In the Regions of Southern Denmark and Central Jutland, parents receive short written and verbal information from healthcare professionals about the study before leaving hospital. Subsequently, they receive the first email from the project manager 4 to 8 weeks after the loss with comprehensive information about the study and a link to the questionnaire. In the rest of Denmark, parents are invited to participate through announcements on the homepage for the national patient organisation 'Landsforeningen Spædbarnsdød'. This agency offers free counselling to perinatally bereaved families. Via a link at the homepage, parents sign up with an email address and receive comprehensive information and a questionnaire. Access to the study questionnaire is given only when the parents have consented to participation.

The questionnaire is sent to parents at three time points: 4 to 8 weeks, 7 and 13 months after the loss. If not returned, each questionnaire is followed by reminders, the first one after 3 weeks and the second one after 6 weeks. Due to an initial low response rate, we further introduced a verbal reminder in January 2018 via a telephone call made by a research assistant with experience in grief counselling. In the Region of Southern Denmark, basic information (age, date of birth, date of death, gestational age at birth, parity and type of loss) on all potential participants are registered, allowing us to conduct a drop-out analysis.

**Table 1** Overview of domains and psychometric scales included in the three questionnaires, showing the number of questions within the specific scales at specific times

Scales	Questionnaire 1	Questionnaire 2	Questionnaire 3
Time since the loss	24–60 days	7 months	13 months
Sociodemographic and obstetric variables	22		
The Inventory of Daily Widowed Life (IDWL) Caserta and Lund <sup>53</sup> 2007	15	15	15
The Two Track Bereavement Questionnaire on Life Following Loss (TTBQ) Rubin <i>et al</i> <sup>55</sup> 2009	60	60	60
The Experience in Close Relationships Scale—revised, short form (ECR-R) Fraley <i>et al</i> <sup>50</sup> 2011	12		
Selected questions from The European Value Survey Survey <sup>57</sup> 2006	23		23
Prolonged Grief Disorder (PG-13) <sup>56</sup>	13	13	13
Post Traumatic Stress Disorder Checklist (PCL-PTSD) Blevins <i>et al</i> <sup>54</sup> 2015	17	17	17
Perinatal Grief Scale (PGS), Toedter <i>et al</i> <sup>13</sup> 1988	33	33	33
Total no of questions	195	138	161

### Questionnaires

The survey was constructed with a combination of basic information in relation to sociodemographics and obstetric variables, state-of-the-art psychometric testing by validated questionnaires and ad hoc questions specifically prepared for this study. We included seven psychometric scales addressing the different aspects of our research questions (table 1).

### Sociodemographic variables

We included the following sociodemographic variables: age, sex of partner (to identify female partners), marital status (married, cohabiting, single), educational level (basic school (9–10 years of education), intermediate length education (11–16 years of education) and university education (17 or more years of education)), present occupation and occupation before the loss (on maternity leave, on sick leave, unemployed, at work or studying).

### Obstetric and organisational variables

The following obstetrical variables were included: previous perinatal loss, parity, assisted reproduction, single or multiple pregnancies, type of loss (missed abortion, miscarriage, TOPFA, stillbirth, death after birth), mode of birth (vaginal vs caesarean section), gestational age at the time of loss, admission to the neonatal intensive care unit, age of child if death occurred after birth, and seeing and holding the dead child. Organisational variables were hospital and type of department to which the couple was admitted, and experienced quality of psychosocial support (midwives, doctors, nurses, social worker, undertaker, religious person (chaplain, imam or other) and patient organisation).

### Psychometric scales

To measure attachment style, we included a version of ‘The Experience in Close Relationships Scale—revised,

short form (ECR-R)’ modified to bereaved samples.<sup>50</sup> Participants were asked to express how much they agreed or disagreed with 12 statements concerning how they feel in emotionally intimate relationships on a 7-point scale ranging from highly disagree to strongly agree. Scores for attachment-related anxiety and attachment-related avoidance were obtained by averaging a person’s scores (0 to 6) on each of the 12 items and the composite scores for anxiety and avoidance were highly reliable (alpha score >0.80) despite based on a small number of items.<sup>50</sup>

We used the Perinatal Grief Scale (PGS) developed in 1988 to construct a comprehensive measure of perinatal grief to facilitate comparison among findings in the field.<sup>13 51</sup> The scale was constructed to address the potential disparities between non-specific grief and perinatal grief.<sup>13</sup> The PGS contains 33 statements covering dimensions as for example, guilt, loneliness and jealousy with an option of answering on a 5-point scale ranging from highly disagree to strongly agree.<sup>52</sup> The PGS has good internal consistency (alpha 0.95).<sup>52</sup> A clinical cut-off of 91 has been established for the PGS, where greater scores indicate a high level of perinatal grief.<sup>52</sup>

To assess the process of bereavement within the DPM paradigm, the Inventory of Daily Widowed Life (IDWL) was used.<sup>53</sup> The IDWL was developed studying a group of widows in 2007. However, items in the scale could be adaptable to other losses and relationships with some modifications.<sup>53</sup> The inventory comprises 15 items on doings, thoughts or feelings and the participants answer how often within the last week they have been preoccupied by each task by choosing one of four categories; seldom or never, sometimes, quite often and nearly all the time. IDWL was developed to measure the processes of loss orientation (LO) and restoration orientation (RO) and the oscillation between. The LO and RO

subscales produced alpha coefficients of 0.90 and 0.79, respectively.<sup>53</sup>

We also included the Post Traumatic Stress Disorder Checklist (PCL-PTSD).<sup>54</sup> The PCL was developed in 1990 and comprises 17 items corresponding to the PTSD symptom criteria in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.).<sup>54</sup> Respondents indicate how much they have been bothered by each PTSD symptom over the past month, using a 5-point scale ranging from not at all to extremely (scores 1 to 5). PCL scores exhibited strong internal consistency ( $\alpha=0.94$ ) and test-retest reliability ( $r=0.82$ ).<sup>54</sup>

To address the question of continuing bonds, we included 'The Two Track Bereavement Questionnaire on Life Following Loss'.<sup>55</sup> This model aims to devote balanced attention to two domains of the bereavement experience: the nature of biopsychosocial functioning and the nature of the ongoing relationship to the deceased. Construct and concurrent validity were examined and were found satisfactory.<sup>55</sup>

In order to assess the likelihood of symptoms related to the diagnosis of PGD within this cohort, we incorporated Prolonged Grief Disorder-13.<sup>56</sup> The scale includes 13 items related to feelings, thoughts and behaviours. High scores within the specific items associated with severe functional impairment fulfil the criterion for PGD. Item response theory analyses derived the most informative, unbiased PGD symptoms, combination analyses identified the most sensitive and specific PGD algorithm and the scale was then tested finding high psychometric validity.

We also included questions from 'The European Value Survey',<sup>57</sup> supplemented by questions on worldviews, existential values, and spiritual beliefs developed for a study on existential meaning and motherhood.<sup>47</sup> The questions addressed alterations in meaning and purpose in life, religious faith, belief in afterlife, church attendance, prayer, and meditation and whether there was a need (met or unmet) for discussing these existential matters with others.

### Preparation and pilot test

The first author and a research assistant (L Bilenberg Pedersen) translated the psychometric scales into English: PGS, Two Track Bereavement Questionnaire on Life Following Loss and PCL from English to Danish and the last author back-translated to English after which consensus was reached based on the original and back-translated versions of the scales. The survey was tested for comprehensibility by seven healthcare professionals with experience in the field of bereavement, and 18 parents, mostly mothers, with a previous loss of a young child. The final survey was adjusted according to their evaluation and comments.

### Data analyses plan

By 1 January 2018, we had received 300 completed first questionnaires. We estimate that 800 parents in Denmark every year will experience a loss from GA week 14 up to

4 weeks after birth. With the data collection now on-going in all of Denmark, we expect to include 400 mothers and 240 partners every year, with an estimated response rate of 50% among mothers and 30% among partners. We anticipate approximately 5000 participants by January 2024, comprising the largest cohort in this field to date.

In the region of Southern Denmark, we have the following information on non-responders: mother/partner, age, date contacted, parity, gestational age at birth and age at death, whether the loss was TOPFA, miscarriage, stillbirth or death post partum, and whether the participant wanted to take part in a bereavement support group. We will describe the non-responders/responders according to these variables.

We expect to enrol the first PhD student in September 2018 in a study focusing on attachment style and continuing bonds.

### Statistical analysis plan

The characteristics of the cohort will be described by means and IQRs for continuous data and by frequencies with 95% CI for categorised and dichotomised data. Hypotheses will be modelled and tested using logistic regression models for dichotomous outcomes and ordinal logistic regression models where the dependent variable is based on ordinal data according to, for example, type of attachment, gender of the bereaved or type of loss. We will use mixed-effect models to examine time trends when examining changes over time in answering the same questions up to three times. All analyses will be adjusted for relevant sociodemographic and medical covariates depending on the underlying hypothesis. Data will be analysed using STATA V.15.0 (StataCorp, College Station, Texas, USA).

### Patient and public involvement

Eighteen parents who had previously lost a baby tested the questionnaire and their priorities, experience and preferences were taken into account in the final version of the survey. The patient organisation 'Landsforeningen Spædbarnsdød' played a very active part in the design of the study. The study has a homepage where published papers will be presented to ensure that participants have access to the results ([https://www.sdu.dk/da/om\\_sdu/institutter\\_centre/klinisk\\_institut/forskning/forskningsenheder/gynaekologiobstetrik/forskningsprojekter/livteftertabet](https://www.sdu.dk/da/om_sdu/institutter_centre/klinisk_institut/forskning/forskningsenheder/gynaekologiobstetrik/forskningsprojekter/livteftertabet)).

### Ethics and dissemination

The project will be enacted according to the recommendations for good scientific practice.<sup>58</sup> Bereaved parents are a particularly vulnerable population and inviting them to partake in research requires specific ethical considerations. However, studies show that bereaved parents find partaking in research projects to be a positive experience,<sup>59</sup> motivated by an aspiration to help other parents.<sup>59 60</sup> Participation was voluntary, anonymous and confidential. No incentives or compensation

were offered. Participants gave their consent by ticking a box stating confirmation to participate in the study and afterwards access to the questionnaire itself was given.

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