

Life after loss: long-term impact of parental death during childhood

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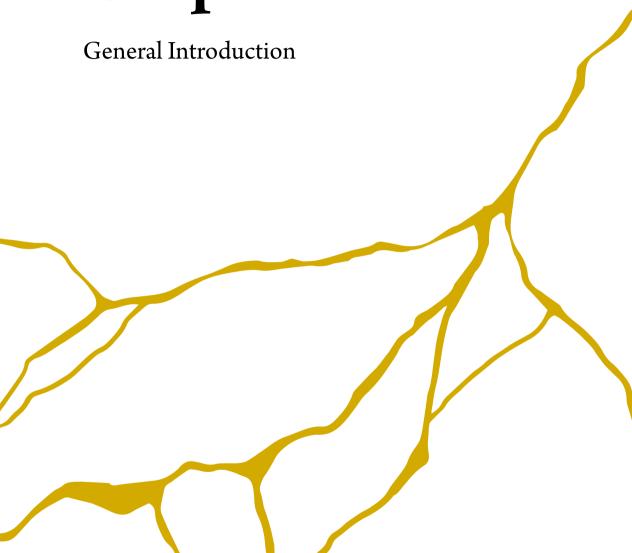
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Chapter 1



CHAPTER 1

General Introduction

In the Netherlands, approximately 2% of all children experience the death of their parent before the age of 18 years old (Centraal Bureau voor de Statistiek, 2022). Although the death of a parent during childhood can be seen as a single event, this permanent loss has large implications throughout the child's life (Birkeland et al., 2022; Terr, 1991). Relatively few studies examined the long-term impact of experiencing the loss of a parent during childhood. Given the potential lasting impact of such a loss, it is important to gain more insight into the long-term consequences and into risk and protective factors. This could yield more concrete recommendations on how to adequately provide tailored support for children who experienced the death of their parent.

Understanding the Impact of the Loss of a Parent During Childhood

The death of a parent during childhood affects the child's life in various ways. First, the parent's death represents the permanent, uncontrollable, and to a great extent unpredictable disruption of an important attachment bond (Bowlby, 1969, 1980; Luecken & Roubinov, 2012). Children have to deal with their grief over this loss. This grieving (or bereavement) process can be considered a primary reaction in response to the loss, which encompasses a variety of complex emotions/feelings, physical reactions, thoughts, and behaviors (Osterweis et al., 1984; De Keijser et al., 2019; Spuij, 2017). These emotions/feelings can rapidly change and can be negative as well as positive (e.g., relief; Spuij, 2017). Additionally, the uncontrollable nature of the death may give rise to feelings of unsafety, insecurity, or helplessness experienced by the child (e.g., Biank & Werner-Lin, 2011; Cavanagh et al., 2008; Fraley & Bonanno, 2004; Schoenfelder et al., 2011; Worden & Silverman, 1996). The loss may also lead to alterations in expectations, perceptions, or schemas regarding themselves (e.g., 'I am responsible for the loss'), interpersonal relationships (e.g., 'people I care about will leave me'), the world (e.g., 'the world is an unsafe place'), and the future (e.g., Pynoos et al., 1995; Spuij, 2017; Spuij, & Boelen, 2023). The loss itself and the subsequent grieving process are likely to interfere with the child's 'normal' socioemotional developmental tasks and daily functioning (Biank & Werner-Lin, 2011; Farella Guzzo & Gobbi, 2023; Pynoos et al., 1995; Mooren et al., 2022; Spuij, 2017).

Besides the grieving process and the disrupted attachment bond with the deceased parent, the attachment bond between the remaining parent and the child is also likely to be affected by the loss. The attachment bond is the emotional bond between a child and their caregiver that is formed in early childhood when the child is highly dependent on others for care, support, protection, and a secure base from which to explore the world

(Bowlby, 1969, 1980). These attachment bonds provide an important foundation for the child's social-emotional development (Bowlby, 1969, 1980; Luecken & Roubinov, 2012). After the loss, the remaining parent is often to a lesser extent emotionally available for the children due to their own grieving process, and may therefore not be able to fully attend to and support the child's basic developmental and emotional needs (Luecken & Roubinov. 2012; Sandler, 2001; Spuij, 2017). The death of the deceased parent thus disrupts the attachment bond with this parent as well as the bond with the remaining parent, which may pose a risk of future difficulties in the child's development. Also after the early childhood years during which the parent-child attachment bond is formed, children are to a great extent dependent on their caregiver(s), for example to provide structure and stability and to (help) regulate their emotions. The death of a parent disrupts this structure and stability, which affects both the child and the remaining parent. They have to adjust to a changed world without one of their parents or spouse (Stroebe & Schut, 1999, 2010, 2015).

Besides a potential change in the emotional availability of the remaining parent, the death causes a lot of other secondary stressors, losses, and changes. Examples of these secondary changes are changes in routines and rituals, a potential move or change of school, potential socioeconomic changes of the family, and changes in family dynamics. Regarding changes within the family, interactions between family members and roles within the family may change as a result of parental death. In line with the family systems theory (Bowen, 1966; Cox & Paley, 1997; Walsh & McGoldrick, 2004, 2013), the individual grief and adjustment processes of all family members are likely to affect the other family members and familial relationships. This dynamic process in which all individual family members are adjusting to the new reality after the loss might either interfere with or aid the grieving process and adaptation of the individual family members as well as adjustment of the family as a whole (Stroebe & Schut, 2015). These secondary family-related stressors and changes add to the difficulty of dealing with the loss and adapting to a changed world after the loss of a parent. Thus, the combination of the impact of the death on the attachment bonds with both parents, the disrupted structure and stability, and secondary changes and losses within the family context might pose a risk for physical and mental health and social-emotional functioning in both the short and longer term.

Towards an Understanding of the Long-Term Impact of the Loss of a Parent

The loss of a parent during childhood clearly has a profound impact on children's daily life, which may affect 'normal' developmental tasks and socioemotional functioning during

the first period after the loss. It is also likely that the loss of a parent has an enduring impact on the subsequent developmental process of the child, and this impact might also extend into adulthood. For example, different developmental phases and important negative or positive life events or periods may trigger and intensify grief, which is also known as re-grieving (e.g., Biank & Werner-Lin, 2011; Chater, 2022; Koblenz, 2016; Meyer-Lee et al., 2020; Spuij, 2017). Furthermore, the impact of alterations in expectations, perceptions, or schemas regarding themselves, interpersonal relationships, the world, and the future on wellbeing and social functioning may also extend into adulthood (e.g., Pynoos et al., 1995). Therefore, it is important to study the long-term impact of the loss to gain more insight into how to adequately support children who lost their parent in an effort to help avoid or reduce difficulties later in life.

To understand the complexity of grief, grief models have been developed and adapted through the years, such as the grief task model (Worden, 1982, 2009) and the dual process model of coping with bereavement (DPM; Stroebe & Schut, 1999, 2010). Both of these models describe how individuals could grieve over and cope with the loss of a loved one. Worden's grief model describes four tasks, namely "to accept the reality of the loss", "to process the pain of grief", "to adjust to a world without the deceased", and "to find an enduring connection with the deceased in the midst of embarking on a new life" (Worden, 1982, 2009, p. 39-53). The DPM distinguishes loss-oriented tasks (e.g., related to dealing with the loss and grief) and restoration-oriented tasks (e.g., related to adapting to a changed world after the loss) in the grieving process and illustrates the importance of a balance ('oscillation') between these two types of tasks (Stroebe & Schut, 1999, 2010, 2015). Adaptations for the application of these theories to children and families have been suggested. For example, the grief task model of Worden (1982, 2009) has been adapted to take into account the cognitive and developmental stages of children (Baker et al., 1992; Baker & Sedney 1996; Cook & Oltjenbruns, 1998). Another example is the revised dual process model of coping with bereavement (DPM-R) that incorporated the family context (Stroebe & Schut, 2015). The DPM-R describes how both loss-oriented and restoration-oriented tasks of each individual family member are interrelated with these tasks and coping on a family level (Stroebe & Schut, 2015).

Regarding the long-term impact of grief, these models depict grief as an ongoing dynamic process rather than a finite phase or period, and illustrate how grief can fluctuate over time. However, societal norms and expectations seem to be centered around the temporality of grief; there seems to be a perceived 'expiration date' for grief (Van Sadelhoff, 2022) and grieving individuals seem to experience less support over time (e.g., Biank & Werner-Lin, 2011; Koblenz, 2016; Wray et al., 2022). Moreover,

empirical research shows inconsistent findings regarding the long-term outcomes of parental death, which underlines the need for more knowledge regarding the long-term impact of experiencing the loss of a parent.

Investigating the long-term impact of experiencing the death of a parent during childhood is important from a prevention as well as intervention perspective. It is crucial to provide adequate guidance and support to children and adolescents (hereafter referred to as children) who lost a parent and their families to help them cope with their loss and all associated difficulties and changes. More knowledge on the long-term impact of parental loss and protective and risk factors may help inform important others in the close environment of a child. For example, this knowledge may help others to adequately support and address the needs of these children. This applies to people in the close environment of the child, such as the remaining parent, extended family, friends, and neighbors, but also to professionals such as teachers, general practitioners, and other health care professionals. As the impact of the early loss may also extend into adulthood, it is essential to increase understanding and awareness of how experiencing the death of a parent may affect adults who experienced the loss of their parent during childhood. This knowledge helps to support these adults later in life, for example surrounding different transitional stages later in life, such as when developing and maintaining relationships and becoming a parent themselves.

Empirical Studies Examining the Short- and Long-Term Outcomes of the Loss of a Parent During Childhood

The loss of a parent during childhood (i.e., childhood parental death, or CPD) is considered as one of the adverse childhood experiences (ACEs). Whereas the association between various different ACEs such as child maltreatment and short- and long-term outcomes has been investigated frequently (e.g., Bellis et al., 2019; Campbell et al., 2016; Felitti et al., 1998; Hughes et al., 2017), CPD as a specific, impactful ACE has only recently received more attention. Furthermore, CPD is sometimes included in a broader construct of parental loss which also includes parental separation, or is studied in the context of the death of a loved one in general.

The majority of studies on CPD focused on the short-term impact of the loss of a parent within the first few years after the loss or during childhood. These studies reported an increased risk of various psychological problems in children who experienced CPD, compared to those who did not experience CPD, such as depressive symptoms, anxiety symptoms, suicidality, posttraumatic stress symptoms, and externalizing problems (Cerel et al., 2006; Dowdney, 2000; Farella Guzzo & Gobbi, 2023; Lytje & Dyregrov, 2019;

Pham et al., 2018; Silverman & Worden, 1992; Stikkelbroek et al., 2016; Thompson et al., 1998). Furthermore, a recent systematic review also showed a negative impact of parental loss on educational outcomes (Elsner et al., 2022). Other adverse outcomes that have been related to experiencing parental death include physical symptoms, obesity, sleep problems, self-harm, and violent delinquency in adolescence or early adulthood (Berg et al., 2019; Carr et al., 2019; Silverman & Worden, 1992; Weinberg et al., 2013).

Similar to the studies investigating short-term outcomes, studies that did focus on the long-term outcomes primarily investigated the association between having experienced CPD and psychological and health-related problems. Several of these studies, including some meta-analyses and a narrative review, found an association between experiencing CPD and several mental and physical health indices, such as depressive, anxiety, or psychotic symptoms and disorders, alcohol dependence, and mortality (e.g., Appel et al., 2016; Böckerman et al., 2023; Hiyoshi et al., 2021; Kamis et al., 2022; Lytje & Dyregrov, 2019; Mack, 2001; McKay et al., 2021; Peng et al., 2022; Simbi et al., 2020; Varese et al., 2012). However, other studies did not find this association with various mental or physical health outcomes or reported mixed findings regarding depressive and anxiety symptoms or disorders, suicidal ideation, suicidal attempts, and associated limitations or the use of professional help (e.g., Chang et al., 2015; Otowa et al., 2014; Saarela & Rostila, 2019; Sareen et al., 2005; Singer et al., 2024; Tebeka et al., 2016; Thompson et al., 2019). Potential explanations of these inconsistent findings are the large variability in study design and samples (e.g., clinical samples, convenience samples, register-based population studies) as well as in operationalization of outcome measures (e.g., symptoms or diagnoses). Additionally, cross-sectional studies that investigate the long-term outcomes vary in time after the loss when they assess outcomes, which may explain inconsistent findings as there may be a large variability in the onset and duration of mental health symptoms as a result of the loss (Dowdney, 2000; Hoppe et al., 2024).

To conclude, previous research on the short- and long-term consequences after the experience of parental death during childhood yielded inconsistent findings. Only a small percentage experience enduring grief-related symptoms, which are described as 'prolonged grief disorder' in the latest text revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR; American Psychiatric Association, 2022; Boelen et al., 2017; Melhem et al., 2011). Although some studies reported an overall increased risk of adverse outcomes, other studies did not find these associations and seem to point towards adaptive or resilient functioning of a majority of children who experienced the loss of a parent. Moreover, various studies, including a review study and meta-analysis, that do find an association also show and emphasize that the majority of

those who experienced the death of a parent during childhood do not report increased problems regarding their mental health or other outcomes (e.g., Bonanno, 2004; Dowdney, 2000; Gray et al., 2011; Luecken & Roubinov, 2012; Lytje & Dyregrov, 2019; McKay et al., 2021; Stikkelbroek et al., 2012; Worden, 1996). This is also referred to as resilience or resilient functioning of those who experienced the loss of a parent during childhood.

Although there are various definitions and operationalizations of resilience, resilience can generally be defined as a "dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar et al., 2000, p. 543), in which "positive adaptation, or resilience, is typically defined as displaying average functioning (rather than doing exceptionally well), the lack of trauma symptoms or pathology, and/or accomplishing stage-salient tasks" (Walsh et al., 2010, p. 28). Resilience can be considered a complex, multidimensional, and dynamic concept (e.g., Bonanno, 2004; Ioannidis et al., 2020; Luthar et al., 2000; Rutter, 2012). In line with this conceptualization, studies on resilience should adopt a lifespan approach, consider different domains of functioning, and take into account the interaction with the child's family and broader social context given its importance for positive adaptation (Masten, 2019; Southwick et al., 2016; Walsh, 2003). Regarding the multidimensionality of this construct, it is important to note that previous research mainly investigated mental and physical health outcomes on both short and longer term, whereas less attention is paid towards other areas of functioning that could potentially be affected after the loss of a parent, such as social and relational functioning. The current dissertation adds to previous literature by investigating the long-term impact of CPD on different, relatively understudied areas of functioning. For example, we examined outcomes such as the formation, stability, and quality of adult romantic relationships as well as the perception of own subsequent parenting and parenting anxieties.

Importance of Investigating Various Loss-Related Factors

The inconsistent findings regarding the long-term outcomes and the overall view of resilient functioning also raise the question whether we should only focus on whether the death of a parent in itself is related to less optimal levels of functioning (e.g., Cerel et al., 2006; McKay et al., 2021; Dowdney, 2000; Luecken & Roubinov, 2012). Investigating the loss of a parent without considering other potential influential factors related to the family, secondary changes, and the child's social environment might not reflect the broad diversity of experiences surrounding the impactful loss of a parent. It is important to further disentangle how factors related to the loss are associated with individual

differences in outcomes later in life. More insight into potential risk and protective factors can help understand these differential outcomes and to identify children who may be at risk to develop adverse outcomes. Additionally, this might help to identify potential targets for (additional) support, prevention strategies (e.g., general psychoeducation), or interventions by important persons in the close environment of children after they experience the loss of a parent, such as the remaining parent or extended family, but also professionals within the school context or in health care.

To date, literature mainly focused on 'objective' loss-related factors, such as the cause of parental death, the gender of the deceased parent, and the age of the child when the parent passed away. Although these factors have been investigated frequently, no clear patterns have emerged regarding gender of the deceased parent or the age of the child (e.g., Berg et al., 2016; Dowdney, 2000; Li et al., 2014; Rostila et al., 2016). Regarding the cause of parental death, studies show that external or unnatural causes (e.g., suicide, accidents, homicide) are generally associated with less optimal outcomes (e.g., Berg et al., 2016; Bergink et al., 2016). Additionally, previous research mainly focused on the role of the remaining parent after the loss (Hope & Hodge, 2006; Jiao et al., 2021; Kwok et al., 2005). A recent scoping review on quantitative and qualitative studies found that positive and child-centered parenting, open communication by the remaining parent, and the remaining parent's own coping are considered protective factors in the association between experiencing the loss of a parent and less optimal mental health outcomes of the child (Jiao et al., 2021). The studies described in the current dissertation examined these 'objective' and relatively well-studied loss-related factors to identify individuals who are potentially at risk, but also included other factors that may be influential in children's experiences surrounding the loss of their parent to broaden our knowledge on possible protective factors. An example of such a factor is the support they did or did not receive from their social network. Children often grow up not only in their own family with their remaining parent and siblings but also in a broader social context within a school, peer group, neighborhood, and community (Bronfenbrenner, 1977, 1979). This broader social context can also play an important positive or negative role in the development of children and their adaptation after the loss of a parent (Bronfenbrenner, 1977, 1979; Masten, 2019; Southwick et al., 2016; Walsh, 2003).

In addition to investigating the role of these loss-related factors within quantitative studies, conducting qualitative studies is important to gain more insight into potential other influential factors related to children's social context. Individual interviews with adults are valuable to shed more light on the complexity of experiences surrounding the loss. Subjective aspects and nuances regarding experiences of contextual factors

related to family dynamics and social support networks, are more difficult to capture in questionnaires within quantitative studies, for example regarding what aspects of social support are experienced as positive or negative and how both these experiences can go alongside each other. These subjective experiences regarding support and the complexity of the grieving process are valuable to inform prevention strategies and to further improve the support for children who experienced the loss of their parent. Lastly, qualitative studies on the impact of CPD add to the literature by providing more insight into potential influential factors that can help inform future studies. In the current dissertation, we will shed light on adults' subjective experiences to explore potential factors that either helped them to cope with their loss through the years or may have interfered with this process.

Description of the Research Projects

To investigate the long-term consequences of experiencing the death of a parent during childhood in the current dissertation, we have focused on two research projects. First, we investigated the long-term health outcomes after having experienced parental death during childhood, based on data from the Netherlands Study of Depression and Anxiety (NESDA) in **Chapter 2**. NESDA is an ongoing multisite longitudinal study to investigate the course and consequences of depressive and anxiety disorders (Penninx et al., 2008). At the first, baseline measurement (between 2004 and 2007), the NESDA sample included 2981 adult participants between the age of 18 and 65 years old (for more information on the design of the study, sample, and sampling procedure, see Penninx et al., 2008). In this dissertation, we used baseline data from this large research project. As the sample was recruited in various settings (i.e., general population, and via general practitioners and mental health organizations) with an overall research aim that was not related to studying outcomes after CPD, this sample provides a unique opportunity to study this topic without sampling bias regarding grief after the loss of a parent.

To investigate long-term consequences of experiencing the death of a parent during childhood regarding relational and parenting outcomes as well as adults' experiences surrounding the loss of their parent, we set up the research project 'Resilience after Loss' (Dutch translation: 'Veerkracht na Verlies'). This research project has a retrospective, cross-sectional design and is described in **Chapters 3 to 6**. Dutch-speaking adults between 25 and 45 years old were invited to participate. Three groups of adults participated: adults who experienced the death of one of their biological parents during childhood (between the age of 4 and 17 years old), adults who experienced the death of one of their biological parents after childhood (after the age of 17 years old), and adults who did not experience

the death of their biological parents. We recruited both adults who experienced the death of a parent during childhood and during adulthood to be able to examine whether outcomes were specific for those individuals who lost a parent during childhood. To recruit these three groups of adults, two different flyers were used as advertisements: one to recruit participants who experienced parental death (either during or after childhood) and one to also recruit participants whose parents were still alive. The introductory text of the latter advertisement was focused on both the experience of parental death and more general on parent-child relationships. Additionally, all participants were asked to invite their siblings to participate to be able to study long-term outcomes within families and similarities and differences in siblings' experiences. The research project consisted of several subprojects, which were conducted between October 2020 and September 2023. The project included both quantitative data (Chapters 3 and 4) as well as qualitative data (Chapters 5 and 6).

Outline and Objectives of This Dissertation

First, this dissertation investigated the long-term consequences of experiencing the death of a parent during childhood and aimed to provide insights into potential risk or protective factors in this association (Chapters 2, 3, and 4). In Chapter 2, we investigated the long-term health outcomes based on data of the Netherlands Study of Depression and Anxiety (NESDA). In this large sample (n = 2640), we examined the association between experiencing CPD and various indicators of mental health, physical health, and health behavior. Furthermore, we examined the role of the child's age when the parent passed away and the gender of the deceased parent in relation to these health outcomes. Chapter 3 and Chapter 4 both focus on long-term outcomes on areas of functioning later in life that are underrepresented in the literature, namely relational functioning and parenting. In Chapter 3, we examined the association between experiencing CPD and various romantic relationship outcomes in adulthood. Additionally, for individuals who experienced CPD, we investigated whether the child's age when the parent passed away, the gender of the deceased parent, and the perception of parental bonding during their childhood were associated with romantic relationship outcomes. Chapter 4 focused on the association with the perception of parenting and parenting anxieties after having experienced the death of a parent during childhood, while also shedding light on the role of the gender of the deceased parent for females who experienced CPD.

A second objective of this dissertation was to investigate adults' experiences with the loss of their parent early in life, to gain more insight into factors that might be important for adaptive functioning as perceived by those who experienced such a loss (**Chapters 5**

and 6). Chapter 5 focused on the experiences of participants regarding which aspects they found supportive or unsupportive in learning to cope with the loss of their parent throughout their lives. This qualitative study included 60 adults who participated in a semi-structured interview. Furthermore, this study provided insight into the role of the child's age when the parent passed away and the gender of the deceased parent. Chapter 6 is a qualitative study in which we exploratively investigated the experiences surrounding the loss of a parent of multiple siblings within a family. By inviting adult sibling pairs to participate in a joint interview, we aimed to provide insights into how the loss of a parent during childhood may potentially affect their sibling relationship.

To conclude, **Chapter 7** provides a summary of the findings and an overall conclusion of the chapters within this dissertation. The findings are discussed in a broader context and methodological considerations, directions for future research, and clinical implications of the dissertation are discussed.

GENERAL INTRODUCTION