

Bereaved mothers and fathers

Grief and psychological health 1 to 5 years after losing child to cancer



Lilian Pohlkamp

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Ersta Sköndal Bräcke University College

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Abstract

Bereaved mothers and fathers. Grief and psychological health
1 to 5 years after losing a child to cancer

Lilian Poblkamp

Bereaved parents often experience severe suffering and are at elevated risk for developing grief complications such as prolonged grief and other negative psychological health outcomes. **The general aim** of this thesis was to investigate symptoms of prolonged grief, depression, posttraumatic stress, anxiety, rumination, and sleep disturbance in parents who had lost a child to cancer 1 to 5 years earlier. Attention was also given to the potential impact on the parents' grief of their experiences during the child's illness, and finally to the parents' views on their coping with grief. **Methods:** A cross-sectional design for data collection was used for all four studies in this thesis. Both quantitative and qualitative methods were used for data analysis, to provide various and complementing perspectives on bereaved parents' grief and their psychological health. **Results:** Bereaved parents' symptom levels of prolonged grief and psychological symptoms were found to be elevated and neither time- nor gender-dependent across the first five years after the loss. We also found that some of the parents' experiences during their child's illness were associated with their grief and psychological symptoms. These factors differed for mothers and fathers. Mothers valued trustful relations with health care professionals, while fathers reported better psychological health when they had received support in practical matters. Findings also showed that parents found certain factors facilitated or complicated their coping with grief. Unsurprisingly, social support promoted positive coping with grief, while a less familiar factor – going back to work – could make coping with grief harder. **Clinical implications:** The findings provide knowledge which can improve the care for children, through development of support to their parents in pediatric oncology contexts and in bereavement.

Keywords: *Bereavement, grief, pediatric oncology, parents, psychological health*

Thank you for your stories

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I. Pohlkamp, L., Kreicbergs, U., Prigerson, H. G., & Sveen, J. (2018). Psychometric properties of the Prolonged Grief Disorder-13 (PG-13) in bereaved Swedish parents. *Psychiatry Research*.
- II. Pohlkamp, L., Kreicbergs, U., & Sveen, J. (2019). Bereaved mothers' and fathers' prolonged grief and psychological health 1-5 years after loss—a nationwide study. *Psycho-Oncology*.
- III. Pohlkamp, L., Kreicbergs, U., & Sveen, J. (2019). Factors during a child's illness are associated with levels of prolonged grief symptoms in bereaved mothers and fathers. *Journal of Clinical Oncology*.
- IV. Pohlkamp, L., Kreicbergs, U., Sveen, J., & Lövgren, M. (2020). Parents' views on what facilitated or complicated their grief after losing a child to cancer. Submitted.

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Abbreviations

DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
GAD-7	The Generalized Anxiety Disorder scale
EAPC	European Association for Palliative Care
ICD	International Statistical Classification of Diseases and Related Health Problems
MADRS	Montgomery-Åsberg Depression Rating Scale
PCL-5	Posttraumatic Stress Disorder Checklist (version 5)
PG-13	Prolonged Grief Disorder Instrument
PGD	Prolonged Grief Disorder
PTSD	Posttraumatic Stress Disorder
UGRS	The Utrecht Grief Rumination Scale
WHO	World Health Organization

Preface

Resilience in mental health and how people regain balance after adverse life events have been interests of mine throughout my professional life, starting as a nurse specialized in mental health care. I found the field very rewarding: there was much to learn about life and people living life. Progressing to higher education of health care professionals, I focused on communication and professional relationships within assessment and treatment in mental health.

Practicing as a registered psychotherapist during the past decade, the many encounters I have had with people who found it hard to recover and reconstruct meaning in their lives after a painful loss or other challenging life events, have further deepened my interest in the area. During the 5 years before the start of this research project, I was a group therapist in support groups for bereaved parents, sponsored by the Swedish Childhood Cancer Fund. We had time to talk in depth, as each group met 15 times over the course of 18 months. The stories of these parents regarding their distressing experiences made me aware of the necessity for improved assessment of parents' need for support during the illness and after the death of a child. Simultaneously, I guided healthcare professionals working in palliative care, gaining further insights into their challenges in supporting dying patients and their families.

As I had begun to understand the full complexity of the process of grief, and the varying ways of adjusting to loss, I joined the Palliative Care PhD program at Ersta Sköndal Bräcke University College, within a newly framed research area: The individual in welfare society. It was time to plunge into research in the landscape of grief, the consequences of death – sometimes considered to be our last societal taboo. The deepened knowledge on loss and life I have gained during my graduate studies will be presented in this thesis.

1. Introduction

The death of a child violates the perceived order of living in the family life cycle; combined with strong attachment bonds, this puts parents at increased risk for severe suffering and developing grief complications, such as prolonged grief and other negative psychological health outcomes (Barrera et al., 2007; Morris, Fletcher, & Goldstein, 2018). The term ‘prolonged grief’ refers to an intense and persistent type of grief, impairing a person’s psycho-social functioning in daily life.

Every year, just over 300 children in Sweden are diagnosed with childhood cancer (Childhood Cancer Fund Annual Report, 2019). The most common cancer forms are leukemias and brain tumors. Improved treatment has raised survival rates for childhood cancer over the past decades, but around 60 children still die of their disease each year, leaving their families in great despair. To develop the best possible support and reduce suffering in cancer-bereaved parents, it is important to obtain more knowledge and deeper understanding of parental grief and possible psychological symptoms, and to identify factors associated with prolonged grief.

2. Background

2.1. Death and grief in society

One key aspect of a welfare society is how it supports people in connection with adverse life events. For clarity, it should be stated that the welfare society and the welfare state are, to some extent, different concepts. In the welfare society, there is a large shared community responsibility for support in illness and bereavement in addition to state-organized health care. In the welfare state, people often expect the state to carry full responsibility for health care, including mental health care. This is the case in Sweden, where tax levels enable welfare to cover broad groups of the population (Jegermalm & Jeppsson Grassman, 2012). However, the Swedish health care system does not yet have a clear structure for bereavement support. Some pediatric care units offer bereavement follow-up to parents and siblings, and grief counseling is offered at certain primary care clinics. However, primary care health care staff often need to guide bereaved persons who ask for support to private counselling or informal structures, where support is usually offered by volunteer patient organizations and churches. Sometimes, support is provided based on self-help models in groups with bereaved peers, while sometimes professionals are employed (The Swedish Family Care Competence Centre, 2019). To what extent and how bereavement care is provided in other European countries is not well-known according to the European Association for Palliative Care, and planning of bereavement care provision needs to be formalized (Guldin et al., 2015).

The loss of a loved one can cause widely varying grief reactions, and everyone's grieving process is influenced by individual characteristics. However, the complexity of an individual's grief is also affected by cultural and societal traditions associated with death and loss and the accepted or expected expressions of mourning (Harris, 2009; Zisook & Shear, 2009). Sometimes, the terms grief and mourning cause confusion with regard to definitions, but grief is often seen as the personal range of reactions that an individual feels or shows after the loss of a loved one, whereas mourning refers to the more public course of managing bereavement (Stroebe, Hansson, Schut, & Stroebe, 2008).

People have in all times pondered their mortality and the questions related thereto. Through literature, art, and philosophy, humans have attempted to explore and uncover possible truths and meanings of death. Clearly, death is a universal part of human existence, but our approaches to it fluctuate over time (Harris, 2009; Walter, 2012). At a societal level, death is sometimes suggested to be subconsciously felt to threaten the security that comes from being a group, which has historically been necessary for survival. As a way of coping with this subconscious fear of death, social structures are set up to regulate accepted emotions in mourning – for example, the “year of mourning” was common in Sweden in earlier days – and how memorial services are to be conducted. An alternative perspective is offered by Bauman (1992), who describes youth, health, and hopes of immortality as ideals in the postmodern society. He implies that we try to ‘solve’ our death anxiety by acting as if we will live forever, and that this attitude also directs our actions in the care of severely ill persons, when we suffer the loss of loved ones, and how we mourn (Bauman, 1992).

Death shatters our illusion of or wish for order and control in life. Cultural rituals around death and grief help us manage the chaos that death can cause, and create some sense of order. Cultural ideas influence how members of a society talk and think about loss and grief and also how they expect themselves and others to react to the loss of a loved one. The assumptions about death and grief responses that exist within every culture and society provide the people in that social context with possible models for making sense of death and loss (Harris, 2009). Conversations about dying and impending death may sometimes be hindered by cultural taboos, often expressed as well-meaning attitudes of never giving up hope. Unfortunately, when the need for mourning before and after a loss is not met, a person’s perceived suffering and loneliness may increase (Kellehear, 2009). Taking cultural ideas into consideration is important when creating structures for relevant bereavement support in a society, because the thought models used by the bereaved society members affect their ability to adjust to bereavement and care for each other.

2.2. The palliative care context

The term ‘palliative care’ is used to describe both the philosophy of care for patients with a life-threatening illness and the specialized clinical services delivered

by specialized health care professionals to meet the needs of seriously ill and dying patients and their relatives. Palliative care aims to provide comprehensive treatment for the discomfort, stress, physical, and psychological symptoms related to a patient's illness. In order to meet the complex needs for physical, social, psychological, and spiritual support, palliative care should preferably be delivered by a multi-professional team (Ahmedzai et al., 2004; Clark, 2007). The term 'supportive care' is sometimes used either as a synonym to palliative care or to describe palliative care at an early stage.

In addition, the phrase 'a palliative care approach' has emerged to describe the total system of care for people at the end of life regardless of place. Palliative care encompasses an attitude intended to integrate a holistic approach in care and to promote quality of life for the patient until death, as well as the services delivered in this spirit (Sawatzky et al., 2016; World Health Organization (WHO), 1990). Some confusion over the changing concept of palliative care, regarding features, core elements, and terminology, is common (Meghani, 2004). A recently proposed conceptual model of the palliative care approach entails the following three main domains: whole-person care, quality of life focus, and mortality acknowledgement. Each domain represents elements that were included in the majority of 19 reviewed definitions of palliative care. Another concept frequently mentioned in this review was the inclusion of family members in the unit of care. However, this did not clearly fall within any of the three domains (Touzel & Shadd, 2018). It could be argued that the family concept would be relevant for the domain of whole-person care, but this was not the result of the aforementioned content analysis. However, that would be in line with Clarke et al., who stated that communication with the patient and all family members about care decisions and goals is fundamental to palliative care (Clark, 2007).

Another important feature of palliative care is the intention to adjust the care to the severely ill person's individual needs (person-centered care). It is sometimes described as being delivered at different intensity levels: a palliative care approach, general palliative care, and specialized palliative care. However, the palliative care approach remains applicable when proceeding to the next intensity level (Ahmedzai et al., 2004; Radbruch, Payne, & Directors., 2009). Most parents with a child with cancer have experienced these levels of intensity of care in relation to their severely ill child. They have met with either a palliative approach or general

palliative care in pediatric settings where young patients with a life-threatening disease are cared for, such as pediatric oncology or intensive care wards. Often, they have also encountered specialized palliative care, which is required for children suffering of incurable and life-limiting cancer diseases with complex and difficult needs. This is offered either in specialized palliative care settings or at home (Jalmsell et al., 2013).

2.2.1. Pediatric palliative care

In Sweden, care of children with cancer is offered primarily at six pediatric oncology units. Integration of pediatric palliative care with ongoing cancer treatment is common in hospital care, but is also provided in the child's home in some regions (Jalmsell et al., 2013). The only hospice for children in Sweden is located in the Stockholm area. A main concept in pediatric palliative care is family support. This includes support to the parents who are caring for a seriously ill child, but also to other close relatives, such as siblings (Lovgren, Jalmsell, Eilegard Wallin, Steineck, & Kreicbergs, 2016) or grandparents. Specialized palliative care is not yet easily accessible to all families in Sweden who need such care, partly due to large distances in the rural areas of the country. However, the intention in pediatric palliative care is to apply an early integration of the palliative care approach in the care of the ill child, similarly called supportive care, focusing on symptom control and quality of life. This working line has been evidenced to provide meaningful opportunities to improve quality of life for both the child and the whole family, and to offer bereavement support (Stephen, 2014; Weaver et al., 2015; Weidner et al., 2011; Wolfe et al., 2000).

When a child dies due to cancer, this is often preceded by a long period of illness and demanding treatments, causing suffering to the whole family (Kreicbergs et al., 2005). Times of hope, when treatment has positive results, are interspersed with periods of despair when relapses occur or tumors resist treatment and progress. Many parents experience significant psycho-social distress when their child is cared for in a pediatric cancer setting and this may make them vulnerable to prolonged grief (van der Geest et al., 2014). Evidence shows that protective factors from this distressing period were a good relationship and communication with the physician, when parents felt trust for health care professionals regarding symptom management of the child's anxiety and pain, and when they felt they

could share responsibility for the child. Awareness of the child's prognosis (Valdimarsdóttir et al., 2007) and receiving psycho-social support from health care professionals during the last month of the child's life were also perceived by the parents as being supportive in their distress (Kreicbergs, Lannen, Onelov, & Wolfe, 2007).

The need for good communication in complex care situations for seriously ill children is obvious. However, recent findings from pediatric care settings revealed that although health care providers spent a lot of time relaying medical information, parents stated that they could not fully understand what they were told (Lannen et al., 2010; Michelson et al., 2011). This might have been due to the distressing circumstances of having a child with a life-threatening illness or unclear information, or both these factors. Improving prognostic communication and guiding parents through the trajectory of cancer treatments would make parents feel more involved in care decisions, give them opportunities to prepare for the worst, and might decrease parental regret in relation to treatment decisions (Mack et al., 2019). Health care professionals may keep a distance out of fear of intruding on private emotions, leading to parents with dying children occasionally feeling abandoned in their time of sorrow (Weidner et al., 2011). This calls for a progression in pediatric palliative care, whereby all members in a family with dying children become the main focus for care. Families should gently be made aware of the child's prognosis and what still can be offered when shifting the focus from curative treatment to increasing quality of life (Breen, Aoun, O'Connor, & Rumbold, 2014). Evidence shows that when parents were involved in treatment decisions during end-of-life, they felt that their child suffered less (Edwards et al., 2008; Mack, Cronin, & Kang, 2016). Clinicians need to adopt a curious and humble approach when trying to understand children's and their families' changing definitions of goals of care, listening to each family's unique narrative on their experiences of being ill and receiving care for a life-limiting disease (M. Jordan et al., 2018).

Health care professionals carefully, but actively, addressing topics of grief and distress with the dying child and their family members may alleviate suffering in the emotional and social experience of mourning. In this, they should try to stay positive, but also be realistic and transparent (Nuss, 2014). Of course, all communication needs to be moderated to the child's development, and to the

parents' needs, either as a couple or individually. It is a challenge for health care professionals to identify the level of support needed by the child and family members (i.e., information and compassion, nonspecialized support, or specialist intervention). Compassionate and respectful end-of-life conversations may have positive implications for how children live the end of their lives, how they die, and how their families manage to cope with bereavement. Therefore, they are well worth the effort (Rosenberg, Wolfe, Wiener, Lyon, & Feudtner, 2016). Evidence indicates that parents' experiences during a child's illness trajectory may affect bereavement outcomes; however, it is still unclear what impact they have on parents' grief and also whether they differ between mothers and fathers (Clarke, McCarthy, Downie, Ashley, & Anderson, 2009).

2.3. Bereavement

2.3.1. Grief

Grief in a wider meaning is everything experienced by a person in response to a loss. Grief is the emotional suffering experienced when someone we were attached to has died. Death is a natural part of human life, and grief is our natural reaction to loss. Grief is the painful cost of having relationships with our loved ones. Grief can change shape or be experienced in different ways during a person's life course.

Despite the universality of grief as a natural response to the loss of a beloved one, discussions have been ongoing as to whether grief should be defined as an adaptational response, a possible trauma, a crisis, or a mental illness (Archer & Freeman, 1999). The efforts to understand and label grief reactions have a long history; Freud (1917) tried to clarify the distinction between mourning as a natural reaction and major depression as a mental disorder already a century ago. Grief as a reason for ill health in its own right was put forward in the 1940s, after a night club fire with many victims: the Cocoanut Grove disaster in Boston. Survivors, relatives, and friends reported symptoms such as respiratory problems, extreme exhaustion, emotional numbness or agitation, and problems with appetite and digestion related to bereavement. A distinction between normal and pathological grief was indicated, with consequences on duration, intensity, and need for professional support. The term 'anticipatory grief' was suggested to describe the

separation anxiety experienced in the face of a threat of death when close relatives were sent to war (Lindemann, 1994). Theories on grief and bereavement have evolved during the last century, from 'grief work' models to stage models of the grieving process, where efforts to work through emotions eventually may lead to acceptance. Bowlby's and Parke's pioneering works on separation stage theory and attachment theory led to greater understanding of bereavement adjustment (Bowlby, 1980; Parkes, 1993) and increased understanding of why grief reactions differ between individuals. How grief is experienced and expressed can be related to individual attachment styles, and what the attachment bond to the lost loved one looks like. A person's more or less secure attachment style can give an understanding of how the person develops new relationships, but also how the person copes with loss (N. Field, Gao, & Paderna, 2005).

An alternative explanation for the social and individual experience of grief and finding ways of adjusting to the loss comes from social constructivism theory, which assumes that human beings seek meaning in mourning and do so by struggling to reconstruct a coherent narrative in their bereavement, thus preserving a sense of direction in life (Neimeyer, Prigerson, & Davies, 2016). The ongoing process of grappling with telling and retelling the stories of our lives may take time and not always go in one straight direction. In Walter's model, bereavement is seen as part of how people reconstruct their biography, finding ways to live with the dead (1996). This indicates that the recovery concept, as seen from a medical perspective, i.e., the return to an earlier, normal state of health, is probably not relevant to grief. It may be better to look at recovery as is commonly done within the mental health field, where the concept of recovery implies that people may not return to their pre-illness state, but to a new acceptable state, regained quality of life, given the new circumstances (Parkes, 2009). As an analogy to this, the goal of coping with grief may not be to return to previous levels of functioning, but rather to navigate and find ways forward to a meaningful life without the deceased. It is likely that bereaved persons experience long-lasting changes because of their loss. These changes may be negative, such as a reduced ability to regulate anxiety (Rubin & Malkinson, 2001), as well as positive, such as enhanced feelings of competence and self-esteem (Wortman, Silver, & Kessler, 1993), or changes in identity, relationships, values and worldview, sometimes called post-traumatic growth (Neimeyer et al., 2016).

2.3.2. Coping with bereavement

Coping is often understood based on the classic definition of Lazarus and Folkman: as an individual's constantly changing cognitive and behavioral efforts to manage demands that are appraised as taxing or exceeding the resources of the person. This is illustrated in their transactional model for stress, appraisal, and coping (Lazarus, 1984). The loss of a child can be one such demanding situation, where persons feel they do not have earlier experiences to use as resources or they lack trust in their ability to manage their grief. Coping with bereavement and the eventual adjustment to loss are associated with personal and relational factors in the individual loss experience (van der Houwen, Stroebe, Schut, Stroebe, & van den Bout, 2010). Proactive coping, i.e., focusing on coping with transitions and preparedness for the impending death of a loved one, is sometimes proposed as a resilience factor for coping with loss. Social support, feelings of security, and habits of communication within the family are also suggested to promote positive coping with grief (Stroebe & Schut, 2015). In the 1990s, the exploration of concepts in coping and attachment theories related to bereavement, resulted in the formulation of the Dual Process Model of coping with bereavement (Stroebe & Schut, 1999), which is now an important conceptual framework for understanding coping with grief, both in research and for professionals meeting bereaved persons.

The everyday course of coping in bereaved individuals is illustrated in the Dual Process Model (DPM), which assumes that bereaved individuals oscillate between two types of coping processes. One coping track includes appraisal and dealing with loss orientation (sadness, yearning, helplessness, crying). The other track focuses on restoration orientation, e.g., engaging necessary instrumental tasks and experimenting with new life roles. Loss orientation is a more emotionally directed coping track, trying to make sense of the loss and the lost relationship. The restoration orientation track is more of a task-oriented coping. Alternating between the two coping processes is considered necessary in grief work in everyday life. DPM describes emotional regulation through a person's oscillation between the coping processes. This means dealing with stressors by alternating between the loss-oriented and restorative coping processes and is fundamental for adaptation to bereavement (Stroebe & Schut, 1999). Some gender differences are known regarding the process of grieving: women tend to show a preference

for loss-oriented coping, while a majority of men tend to choose a restoration-oriented style, especially in acute situations (Stroebe, 1998).

The death of a family member can lead to individual grief responses, and trigger painful differences in how each family member grieves and attempts to make sense of the death of a loved one. The loss of a child is painful for each individual family member (as a child or a sibling), but it is also a loss in the family system. Reactions to the loss influence family relations and ongoing family conversations. Thus, developing a coherent life narrative is crucial for families trying to make sense of their loss. This helps family members reconstruct family-meaning, supports the restoration of secure attachment bonds, and helps them eventually adjust to their loss (Nadeau, 1998). The concept of maintaining bonds with the deceased (Klass, 1997) is described in modern multi-domain models of grief work and highlights the importance of keeping memories of the deceased child alive in the family and other contexts.

2.3.3. Problems in adjusting to loss

Usually, most people can gradually adjust to the loss of a loved one, using their own resources and the support of their social network to recover. However, a loss and subsequent grief reactions lead to serious health concerns for approximately 10% of a general population (Parkes, 2009). Understanding and explaining mental health and mental illness is complex. Why do some people develop a mental health disorder, while others in similar circumstances are more resilient? People are raised in more or less resourceful families (nurture) and are born more or less robust (nature), and some are more vulnerable with an increased risk for some kind of mental illness (Walsh, 2002), but overwhelming adverse life events may cause mental illness also in less vulnerable persons.

A clinically significant deviant manifestation of grief regarding time course, intensity, and level of impairment is commonly understood as some kind of complicated or disturbed grief. There are no clear boundaries for when a person's grief responses should be considered more complicated than the expected, normal, usually painful process of adapting to the loss of a significant person (Bonanno, 2004; Bonnano & Kaltman, 2001; Walter, 2006). However, grief being a normal part of life, many clinicians meet bereaved people with severe problems

in adjusting to loss and these complications have been characterized in the literature as prolonged, absent, delayed, “frozen,” complicated, or chronic grief. By now, it is accepted to state that there are complications in bereavement, aside from grief, that merit clinical attention (Parkes, 2009; Shear, 2012). This is considered a very important topic of concern for health care professionals and bereavement research: what makes grief go awry? Contemporary research literature on bereavement has expanded enormously in the last decades and difficulties in operationalizing definitions and concepts are frequently discussed (Bonanno & Malgaroli, 2019).

Loss and bereavement are natural and unavoidable elements of life. Their consequences can be resolved, but they can also complicate people’s life and mental health. When we say that a grief reaction is a medical disorder rather than a normal form of human suffering, some aspects have to be considered (Wakefield, 2007). Within mental health history, the term ‘disorder’ has been a value-laden concept and a discussion on whether grief reactions are to be considered a disorder has been going on for the last decades. The stress-vulnerability model is sometimes used to explain differences in individual stress responses. Healthy grief should not be seen as a disorder, as it is a normal response to a loss and there is no dysfunction. This is the leading idea in this view (Bonanno, 2004).

On the other hand, the acknowledgment of impairing grief reactions and understanding that grief complications can be pathological, has been increasing for many years and gradually become more accepted. Unfortunately, the concept of dysfunction in medical tradition has often been associated with biological dysfunction, which is not always prominent in disturbed grief, even though physical features of grief were described already in 1944 (Lindemann). Another challenge is to understand what is prototypical for complicated grief, as a mental condition needs to be frequent and prototypically described to be called a disorder. The concept of mental disorder has scientific, factual, and value components and challenges simple description. To date, neither clinicians or grief scholars are in full agreement about what constitutes complicated grief (Stroebe, Schut, & Van den Bout, 2013); furthermore, what is written about grief is mainly applicable to Western cultures (Harris, 2009; Rosenblatt, 1988). In this thesis,

prolonged grief is considered as a distinct concept within the wider range of complicated grief responses.

Grief rumination is another behavior that is common in grief responses, here referring to repetitive and recurrent thinking about the causes and consequences of a loss and loss-related negative emotions. Reflection and adaptive rumination are common in connection with adverse life events and do not always become a problem. However, if a bereaved person develops a ruminative approach to coping with grief, and a more brooding way of thinking, for example focusing around feelings of guilt towards the deceased, this can become problematic and may lead to prolonged grief. Rumination occurs also in depression (M. Eisma et al., 2015; M. Eisma & Stroebe, 2017; Marroquin, Fontes, Scilletta, & Miranda, 2010).

2.3.3.1. Prolonged grief

As stated earlier, grief is a normal reaction to loss, and includes psychological, physical, spiritual, social, and cultural dimensions (Stroebe et al., 2008; Stroebe, Schut, & Boerner, 2017). While most bereaved individuals find that time heals their suffering and discover ways to adjust to the loss of a loved one, the grieving process is debilitating, intense, and persistent for some. They appear to get “stuck” in their grief (A. Jordan & Litz, 2014; Maercker et al., 2013a; Prigerson et al., 2009) and the terms ‘prolonged’ or ‘complicated grief’ are used. Evidence shows that prolonged grief symptoms tend to be more prevalent among women than men (Kersting, Braehler, Glaesmer, & Wagner, 2011; van der Geest et al., 2014).

Grief reactions in prolonged grief are essentially similar to those in normal grief. When separation distress is so persistent and pervasive that it impairs the bereaved person’s functioning in daily life more than six months after the loss, the concept of prolonged grief may be applicable. Complicated grief includes a broader range of pathological complications than normal grief (Shear & Shair, 2005). To date, five different sets of criteria are used for variants of pathological grief, and the number of symptoms varies between 7 and 16 for each variant (Lenferink, Boelen, Smid, & Paap, 2019). The term ‘prolonged grief’ was introduced by Prigerson et al. (2009), while Shear et al. proposed criteria for a diagnosis called ‘complicated grief.’ The proposed criteria were devised for the

diagnosis to be included in diagnostic manuals, such as ICD-11 and DSM-5. Maercker et al. presented a set of alternative, nonetheless similar, diagnosis criteria (2013b). The criteria were presented to characterize “caseness,” when the persistent yearning, preoccupation with the deceased, and intense emotional pain cause significant functional impairment more than 6 months after the loss. Other symptoms are: feeling that a part of yourself died, trouble accepting the death, avoidance of reminders, finding it hard to trust others, feelings of anger, bitterness, numbness, lack of meaning in life, feeling stunned by the loss, and having trouble to move on in life (Boelen & Smid, 2017). Prolonged grief disorder (PGD) has recently been included as a diagnosis in the 11th revision of the International Classification of Diseases (2019). The DSM-5 (2013) had already introduced criteria for persistent complex bereavement disorder (PCBD), which can be diagnosed 12 months after a loss, and is classified as a condition that should be the focus of further research. While there are differences between PGD and PCBD – the scope of PGD is little wider – they are essentially the same entity. Differences between all the diagnostic entities may be partly semantic, but all hinge on the question if all grief is normal. A short answer to this complex question is that all symptoms of grief are normal, but some impairing combinations of symptoms duration and severity are not, and the persons suffering from these may need professional support (Maciejewski, Maercker, Boelen, & Prigerson, 2016).

2.3.4. Psychological symptoms in bereavement

Common psychological symptoms associated with bereavement include symptoms of depression, insomnia, and posttraumatic stress (Stroebe, Schut, & Stroebe, 2007). Evidence shows that prolonged grief, depression, and posttraumatic stress are distinguishable concepts, even though they are strongly related, with partially similar symptoms (Aoyama et al., 2018). A loss that is unexpected, violent, or too early in life can cause a range of psychological symptoms. Sometimes, it is hard to understand the difference between grief and depression, since many symptoms – such as sadness, tearfulness, insomnia, and decreased appetite – are similar. However, two well-known and distinctive symptoms of depression are feelings of worthlessness or low self-esteem. In a longitudinal study on bereaved couples, it was shown that grief was predicted by bereavement-specific factors, while depression was predicted by individual factors

(Wijngaards-de Meij et al., 2005). This means that grief is always preceded by a loss, whereas depression can occur at any time in depression-sensitive persons. Sometimes it occurs after a loss, but not always. Notably, the explicit and persistent suicidal ideation typical of major depression is uncommon in grief, although bereaved persons may sometimes fantasize about being reunited with a lost loved one through death (Friedman, 2012). Loss of meaning can be experienced in both depression and bereavement, but in bereavement one can often see a connection to the loss, which makes the bereaved feel that the world is an empty place, in depression such a connection is rare (Neimeyer et al., 2016).

A common health problem associated with bereavement is disturbed sleep (Boelen & Lancee, 2013; Buckley et al., 2012) or its debilitating form: insomnia. Sleep disturbances have also been associated with elevated symptom levels of prolonged grief (Prigerson, Frank, et al., 1995), depression (Alvaro, Roberts, & Harris, 2013), and posttraumatic stress (Germain, Hall, Krakow, Shear, & Buysse, 2005).

2.3.5. Bereaved parents are at risk for prolonged grief and psychological symptoms

Parents who lose a child often experience this as a traumatic life event (Dias, Brandon, Haase, & Tanabe, 2018). Moreover, parents who cared for a seriously ill child over an extended period may often have overlooked their own needs, and are already tired and worn out when faced with bereavement. Having lived in uncertainty for a longer time, as many do, and fearing a relapse of the child's illness, may further increase vulnerability due to high stress levels (De Graves & Aranda, 2008).

Bereaved parents are known to be at elevated risk for developing prolonged grief disorder and other negative psychological health outcomes, lasting over an extended period (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Middleton, Raphael, Burnett, & Martinek, 1998). Prolonged or otherwise complicated grief affects about 10% in adult non-violent bereavement (Lundorff, Holmgren, Zachariae, Farver-Vestergaard, & O'Connor, 2017), but prevalence tends to be higher in samples of people experiencing a violent loss or the loss of a child (Kersting et al., 2011) or spouse (Kersting et al., 2011; Lichtenthal, Corner,

et al., 2015). Regarding bereaved parents, several studies show a higher risk for mothers than fathers as regards symptoms of prolonged grief and psychological ill health after the loss of a child. For example, bereaved mothers are reported to show more intense grief reactions (Büchi et al., 2007; Keesee, Currier, & Neimeyer, 2008), more symptoms of depression (Vance et al., 1995), and more posttraumatic stress symptoms (Christiansen, Elklit, & Olf, 2013) than fathers. A recent review encompassing bereaved parents suggested that the death of an infant was such a traumatic event, with higher risk for mothers than fathers, that healthcare professionals should consider the possibility of posttraumatic stress symptoms when meeting bereaved parents (Christiansen, 2017). A longitudinal study also showed elevated levels of posttraumatic stress symptoms in cancer-bereaved parents, five years after the child's death, with higher symptom levels in mothers (Ljungman, Hoven, Ljungman, Cernvall, & von Essen, 2015).

2.4. Project rationale

Parents who have experienced the death of a child are at risk for developing prolonged grief and elevated psychological symptoms. Exploring parents' grief and their experiences during their child's illness will give a deeper understanding and promote development of appropriate bereavement support to bereaved parents. More knowledge and deeper understanding are needed regarding factors that may be associated with parents' grief and psychological symptoms, and whether these factors differ between mothers and fathers. This knowledge may be important for staff in pediatric care settings and others to improve specialized palliative care for families with children and may hopefully help the families alleviate suffering and gain better health in both the short and long term.

3. Aims

The general aim of this thesis was to investigate symptoms of prolonged grief, depression, posttraumatic stress, anxiety, rumination, and sleep disturbance in parents who had lost a child to cancer 1 to 5 years earlier. Attention was also given to the potential impact on the parents' grief of their experiences during the child's illness, and to the parents' views on their coping with grief.

The specific aims of the studies in this thesis were:

3.1. Study I

To examine the psychometric properties of the Swedish version of the Prolonged Grief Disorder scale (PG-13) in bereaved parents 1 to 5 years post loss.

3.2. Study II

To assess differences in prolonged grief, depression, posttraumatic stress, and sleep disturbances in bereaved parents across years since their loss (1 to 5 years) and by gender. A secondary aim was to assess potential interactive effects of time since loss and gender on bereavement outcomes.

3.3. Study III

To examine possible contributing factors associated with prolonged grief in cancer-bereaved mothers and fathers 1–5 years post loss.

3.4. Study IV

To explore bereaved parents' views on what facilitated or complicated their grief 1–5 years after losing a child to cancer.

4. Methods

4.1. Overview of the studies

Exploring grief and psychological health of cancer-bereaved parents has been central in this thesis. A cross-sectional design for data collection was used for all four studies in this thesis. Both quantitative and qualitative methods were used for data analysis, to provide various and complementing perspectives on bereaved parents' grief and their psychological health. An overview of samples, measures, and analyses for Studies I–IV is shown in Table 1.

Table 1. The samples and methods for Studies I–IV.

	Study I	Study II	Study III	Study IV
Sample	225 parents	225 parents	225 parents	161 parents
Measures	Symptoms of prolonged grief, anxiety, depression, posttraumatic stress, and rumination	Symptoms of prolonged grief, depression, posttraumatic stress, and insomnia	Symptoms of prolonged grief, study-specific questions on the illness and death of the child and parents' relations and communications with pediatric care staff	Two open-ended questions on parental coping with grief
Analyses	Wilcoxon's rank-sum test, chi-squared analyses, Spearman's correlation analyses, factor analysis with oblique rotation, mean inter-item correlation, Cronbach's α	Wilcoxon's rank-sum test, chi-squared analyses, Spearman's correlation analyses, ANOVA	Wilcoxon's rank-sum test, chi-squared analyses, Spearman's correlation analyses, descriptive analysis, univariable and multivariable regressions	Qualitative content analysis

4.2. Population

The data for the studies in this doctoral project were collected in 2016 by means of a population-based nationwide postal survey among parents who had lost a child to cancer. When the study had been approved by the Regional Ethical Review Board in Stockholm, Sweden (No: 2015/2183-31/5), potential participants were identified using the Swedish Childhood Cancer Registry, the Cause of Death Registry, and the Swedish Population Register at the Swedish Tax Agency. The Swedish Childhood Cancer Registry is a national database with information on all children who have received a cancer diagnosis. The children who had died because of their cancer were identified by linkage with the Cause of Death Registry. Their personal identification numbers were used to identify their parents through the Swedish Population Register at the Swedish Tax Agency. The inclusion criteria were: all parents who lost children or young adults (age 0–24 years) to childhood cancer (diagnosis age 0–16 years) during the period August 2010–July 2015 in Sweden. At the time of the study, the parent should live in Sweden and understand enough Swedish to be able to respond to the questionnaire based on their own opinions. This was impossible to check before sending out information letters.

4.3. Data collection

4.3.1. Procedure

Eligible parents ($N = 512$) received an information letter describing the study purpose and procedure and inviting them to participate, see Figure 1. Parents could contact the PhD candidate or the professor responsible for the project with questions, by mail or telephone. In the information letter, the potential participants were also informed of the possibility to opt out of the study or further contact, without needing to give a reason. After two weeks, each parent of each child was contacted separately, by telephone, and asked if they would consent to participate. Some parents mailed or called (LP) soon after they received the letter, stating that they wanted to participate, so they were not contacted by telephone. Parents with unlisted telephone numbers received a request by post to contact us. In total, 373 consented to participate, 76 parents could not be reached, and 63 declined to participate. Those who consented to participate were sent a

questionnaire with a prepaid return envelope. No questionnaires were sent without consent. After a few weeks, reminder calls were made to those who had not returned the questionnaire. Out of 373 individuals who consented to participate, 232 returned the questionnaire and 225 filled out all the questions, included the psychometric validated measures, while 7 parents only responded to the study-specific questions.

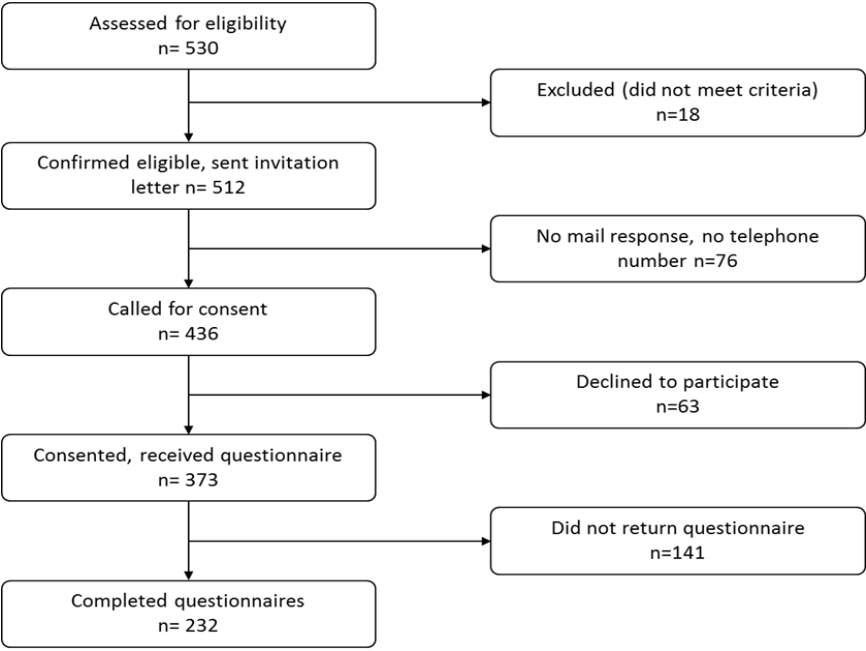


Figure 1. Participant invitation and responses received in the doctoral project.

No statistically significant differences were found between responders ($n = 232$) and non-responders ($n = 280$) regarding the parents' age at the time of the study, age at the time of the child's death, years passed since loss, child's gender, or child's age at time of diagnosis or death. The only significant difference was that the percentage of women was higher among responders than among non-responders ($X^2 = 8.83, p < 0.05$). Data on all parents and children (including non-

responders) were derived from the Swedish Childhood Cancer Registry combined with the Swedish Population Register.

4.4. Measures

4.4.1. Questionnaire

The questionnaire was largely based on items from an earlier survey, which was developed using a stepwise approach described by Charlton (2000). It consisted of 90 questions covering socio-demographics, parents' experiences from their child's illness and death, parents' communication with health care professionals, perceived social support and family communication with closed-ended multiple choice answers (Kreicbergs, Valdimarsdottir, Onelov, et al., 2004). Several open-ended questions were also included in the questionnaire. See Table 2. for the study-specific questions selected for this thesis, translated into English.

4.4.2. Questionnaire validation

The questionnaire was validated through face-to-face interviews (LP) with eight cancer-bereaved parents. The aim was to determine whether the survey seemed to measure what it was supposed to measure and appeared clear and relevant to the participants, as a step in developing a questionnaire (Charlton, 2000). The eight parents were asked if they found the questions clear and phrased in a respectful manner and if they thought any relevant topics were missing for them to adequately describe their experiences. They received the questionnaire some days before their interview, so that they had time to read it and reflect on possible suggestions. During the interview sessions, which took around 45 minutes, we read through the entire questionnaire together, including the questions in the instruments assessing psychological health. The parents reflected on the individual items and the questionnaire as a whole.

The parents who were invited for the face validation interviews were a so-called convenience sample, consisting of parents I had gotten to know in a recent bereavement support group, whom I had told about the planned study. They volunteered to read and reflect on the questions in the preliminary questionnaire and participate in an interview. The support group meetings were finished by then, so that processes were not mixed. Six of the parents participated individually

and two as a couple. Some of the parents had discussed the questions with their respective partners before the interview.

Minor adjustments were made to the wordings of some questions, based on the parents' suggestions. All eight parents participating in the interviews felt that it was appropriate, and even important, to invite bereaved parents to participate in research, which is in line with earlier evidence showing that bereaved parents can find benefit in research participation (Omerov, Steineck, Dyregrov, Runeson, & Nyberg, 2014).

4.4.3. Measurement

In addition to the study-specific questions, the following commonly used instruments for psychological health assessment were included in the questionnaire.

4.4.3.1. The Prolonged Grief Disorder-13 Instrument

The Prolonged Grief Disorder-13 instrument (PG-13) was used to assess prolonged grief symptoms (Studies I–III), in accordance with Prigerson's criteria (Prigerson et al., 2009). It consists of 13 items: 2 items on duration and impairment that are to be answered “yes” or “no,” and 11 items assessing cognitive, behavioral, and emotional symptoms experienced during the past month. Four of those symptom items are rated on a 5-point frequency scale ranging from “not at all” to “several times a day” (scoring 1–5), and six items on an intensity scale ranging from “not at all” to “overwhelmingly” (scoring 1–5). PG-13 is scored as a continuous measure by summing the eleven symptom items and excluding the two duration and functional impairment items (Prigerson et al., 2009). The total score ranges from 11 to 55, with a higher score indicating more symptoms of prolonged grief; the cut-off is ≥ 35 (Pohlkamp, Kreicbergs, Prigerson, & Sveen, 2018). Cronbach's α was 0.89.

4.4.3.2. The Generalized Anxiety Disorder Scale

The Generalized Anxiety Disorder scale (GAD-7) (Kroenke, Spitzer, Williams, Monahan, & Lowe, 2007) was used to assess symptoms of generalized anxiety disorder (Study I). It consists of 7 items, rated on a 4-point scale with response categories from “not at all” to “nearly every day” (scoring 0–3). The total score

can range from 0 to 21 points, with a higher score indicating a greater risk for anxiety. Cronbach's α was 0.92.

4.4.3.3. Montgomery-Åsberg Depression Rating Scale

The Montgomery-Åsberg Depression Rating Scale (MADRS) (Montgomery & Åsberg, 1979) was used to assess symptoms of depression (Studies I–II). It consists of 9 items: sadness, inner tension, reduced sleep, reduced appetite, concentration difficulties, fatigue, inability to feel, pessimistic thoughts, and suicidal thoughts. The items are rated on a 7-point scale (scoring 0–6) and the total score ranges from 0 to 54; a higher score indicates a greater risk for depression. The range for mild depression is 13 to 19, for moderate depression it is 20 to 34, and the cut-off for severe depression is > 34 . Cronbach's α was 0.90.

4.4.3.4. Posttraumatic Stress Disorder Checklist for DSM-5

The Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5) (Weathers, 2013) was used to assess symptoms of PTSD (Study I–II). It consists of 20 items divided into four subscales: Intrusion, Avoidance, Negative alterations in cognitions and mood, and Alterations in arousal and reactivity. The items are rated on a 5-point scale (scoring 0–4) and the total score ranges from 0 to 80; a higher score indicates more symptoms of PTSD. The cut-off is ≥ 33 . Cronbach's α was 0.94.

4.4.3.5. The Utrecht Grief Rumination Scale

The Utrecht Grief Rumination Scale (UGRS) (M. Eisma et al., 2014) was used to measure grief-specific rumination, defined as recurrent, repetitive, and self-focused thoughts about the causes and consequences of the loss and related to negative feelings (Study I). The scale consists of 15 items including five subscales. The items were rated on a 5-point scale with response categories from “never” to “always.” The UGRS was translated from Dutch and English into Swedish by two of the authors (LP and JS) and then back-translated by a professional translator and validated for the Swedish sample (Sveen, Pohlkamp, Kreicbergs, & Eisma, 2019). Cronbach's α was 0.92.

4.4.3.6. The Insomnia Severity Index

The Insomnia Severity Index (ISI) (Morin, 1993) was used to assess symptoms of insomnia (Study II), and consisted of 7 items: severity of problems falling asleep, staying asleep, and early morning awakening problems, sleep dissatisfaction, interference of sleep difficulties with daytime functioning, noticeability of sleep problems to others, and distress caused by the sleep difficulties. The items are rated on a 5-point scale from “no problem” to “severe problem” (scoring 0–4) and the total score ranges from 0 to 28; a higher score indicates more symptoms of insomnia. The cut-off is ≥ 10 . Cronbach’s α was 0.94.

4.5. Analysis of data

4.5.1. Quantitative analyses (Studies I–III)

In Study I, the characteristics of responders and non-responders to the questionnaire were compared using Wilcoxon’s rank-sum test and chi-squared analysis. We continued analyses of the responders ($n = 232$), with the sample for the first study consisting of 225 parents, since 7 participants did not fill out the PG-13 instrument. In total, the nationwide sample included 76 parent dyads. Spearman’s correlation analyses and scatter plots were used to evaluate dependency of data because parent dyads of the same child were included (i.e., 152/323 parents in the study). The analysis indicated a weak but significant correlation for MADRS, assessing depression (Spearman’s $\rho = 0.26$, $p = 0.03$), and a moderate correlation for scores on PG-13, assessing symptoms of prolonged grief (Spearman’s $\rho = 0.44$, $p < 0.001$) between mothers and fathers of the same child. No significant correlations were seen for PCL-5 (assessing posttraumatic stress) or ISI (assessing insomnia). The significance level for all analyses was $p < 0.05$. Cronbach’s α was used to measure internal consistency for the items in all measures included in the questionnaire.

A principal component analysis with oblique rotation (in the study referred to as a factor analysis) was performed to examine the factor structure of PG-13 in the Swedish sample. After having validated the PG-13 in this sample, symptom levels of prolonged grief, depression, posttraumatic stress, and insomnia were examined in Study II among the bereaved parents, including 133 mothers and 92 fathers. The sample was subdivided into five subsamples, one for each year since loss. A

two-way analysis of variance (ANOVA) was used to assess differences in psychological symptom levels associated with years since loss and parent’s gender, as well as interaction effects between time since loss and gender.

In Study III, first univariable and then multiple regression analyses were used to assess the associations between symptoms of prolonged grief and possible contributing parent variables. These parent variables were the parents’ responses to questions concerning experiences during their child’s illness and death (see questions listed below in Table 2). They were categorized as loss-oriented factors, i.e., related to circumstances of the death of the child, relational factors regarding parent with health care professionals, relational factors regarding parents with family and friends, and other factors. Some response alternatives were dichotomized for analysis purposes.

Table 2. The study-specific questions included in the questionnaire, translated into English.

Loss-oriented factors
Did you intellectually understand that your child would die earlier than one day before the actual event? (yes vs. no)
Did you emotionally understand that your child would die earlier than one day before the actual event? (yes vs. no)
Could you understand and accept the information that your child’s illness could not be cured? (yes/to a great extent/to some extent/no, coded 1–4)
Was there any health care staff present at the moment of death? (yes vs. no)
Was there an atmosphere of peace and quiet at the moment of death? (yes/to a great extent/to some extent/no, coded 1–4)
Could you say farewell after your child’s death in the way that you wanted? (yes/to a great extent/to some extent/no, coded 1–4)
Did your child, at any time during the last month before death, have pain which lasted 4 hours or longer and could not be relieved? (yes vs. no)
Did your child have any anxiety at any time during the illness? (no/yes, once/yes, occasionally/yes, several times, coded 1–4)
Could you talk to your child about important things during the last month of his/her life? (yes vs. no)

Relational factors; health care professionals

When you were told that your child's cancer was incurable, was this said in a respectful way? (yes/to a great extent/to some extent/no, coded 1–4)

Did you receive sufficient information on your child's illness trajectory? (yes vs. no)

Did you receive sufficient information on how to handle acute problems related to your child's illness? (yes vs. no)

Did you receive sufficient information from health care professionals on how to take care of your child? (yes vs. no)

Do you feel that you had an adequate level of responsibility for your child's care during his/her last month of life? (yes vs. no)

Did you receive sufficient information on who could answer questions regarding the care of your child? (yes vs. no)

Did you receive practical support from health care professionals during the illness trajectory? (no/yes, a little/yes, sufficiently, coded 0–2)

Do you trust that every possible effort was made by health care professionals to cure your child? (yes/to a great extent/to some extent/no, coded 1–4)

Were you able to influence decisions regarding your child's care? (yes/to a great extent/to some extent/no, coded 1–4)

Did you receive sufficient information regarding who you could turn to for personal psycho-social support? (yes vs. no)

Relational factors, family and friends

Did you receive any practical support from your family during your child's illness? (no/yes, a little/yes, sufficiently, coded 0–2)

Did you receive any practical support from friends during your child's illness? (no/yes, a little/yes, sufficiently, coded 0–2)

Did you speak with your partner about your child's anticipated death? (yes vs. no)

During your child's illness, could you talk within your family about how you were feeling? (yes/to a great extent/to some extent/no, coded 1–4)

Other factors

Do you have any children today other than the child you lost? (yes vs. no)

Are you religious? (yes vs. no)

If yes, has your faith been affected by your child's illness and death? (yes vs. no)

The following adjustment variables were also added to the linear regression models: the parents' age at the time of the child's death, education level and employment at the time of diagnosis, time from diagnosis to loss, the child's gender, and the child's age at diagnosis.

IBM SPSS Statistics version 22 was used for all statistical analyses. Results of the analyses were discussed in the research group and with a statistician to increase understanding and ensure evidence.

4.5.2. Qualitative content analysis (Study IV)

Qualitative content analysis was chosen for Study IV to broaden the understanding of the collected data. Content analysis is widely used as a research method in health studies. It entails a range of techniques used to analyze text data. The aim is to interpret meaning from the content of text data. Content analysis focuses on words and language as communication concerning the content or contextual meaning of the text. The text that was analyzed in this study encompassed the written responses from the parents to open-ended questions in the questionnaire. In brief, the analysis procedure of conventional content analysis means that meaning units derived from the text, that respond to the research question, are first coded and then sorted into categories (Hsieh & Shannon, 2005).

The analysis was based on two open-ended questions from the questionnaire: "Is there anything that has helped you cope with your grief after your child's death?" and "Is there anything that made it harder for you to cope with your grief?". All the parents' responses to both open-ended questions were documented in a text file (LP), and they were repeatedly read, to obtain a sense of the whole, by four researchers independently. Overall first impressions were discussed within the author group. The responses were then condensed into meaning units (LP), which were then coded based on similarities in their content. These codes led to formation of categories which were discussed at group meetings. During this process, the categories were narrowed and refined, with the goal of creating categories that reflected important yet distinct aspects of the parents' responses. Finally, all categories were revised in the group until agreement was achieved and the categories presented in the study were established.

4.6. Ethical considerations

The studies were conducted in accordance with the Helsinki Declaration of 1975, developed by the World Medical Association (WMA), as revised in 2013, and all procedures contributing to this work complied with the ethical standards of the relevant national and institutional committees. The Regional Ethical Review Board in Stockholm, Sweden, gave ethical approval for this study (No 2015/2183-31/5).

There are four key principles developed from moral principles that have played a central role in the history of ethics which are still widely acknowledged as general guidelines in medical research: respect for autonomy (respecting autonomous decisions), non-maleficence (avoiding causing harm), beneficence (balancing benefits against risks), and justice (fairly distributing benefits, risks and costs) (Beauchamp & Childress, 2009).

The ethical issues necessary to consider in this doctoral project were: autonomy in the participation decision, feeling secure in that the results of the research would be used for a good cause (beneficence), avoiding the risk of inflicting emotional harm to bereaved parents (non-maleficence) when inviting them to the study and filling out the questionnaire, and, lastly, making an effort to be just when collecting data and publishing results of the studies (justice).

To support autonomy in participant decision-making, informed consent was achieved by sending an information letter to bereaved parents describing the study purpose and procedure when inviting them to participate. They could contact members of the research group with any questions, or to opt out of the study and further contact, without giving a reason. We included information on both e-mail addresses and telephone numbers, and used an answering machine. We informed them that participation was voluntary and that confidentiality was guaranteed. After 1–2 weeks, each parent of each child was contacted by telephone separately (unless they had opted out), to ask if they would consent to participate and if they had any questions. We were careful to respect the autonomy of each person and not to influence the decision-making process.

Concerns on possible harm were alleviated by evidence showing that many bereaved parents find research participation a positive experience. It is linked to

a valuable possibility to share the experiences of a very distressing time, which may provide relief and also raise hope of helping others in the future. Although reminiscence can be painful, the benefits seem to outweigh the risks (K. Dyregrov, 2004; Kreicbergs, Valdimarsdottir, Steineck, & Henter, 2004; Omerov et al., 2014). The possible harm that a project may inflict should also be balanced against the scientific knowledge it produces. We informed possible participants that the results of the research were going to be published in international research literature or presented at conferences. We mentioned that deeper understanding of aspects of bereaved parents' grief process resulting of the research might provide health care professionals with enhanced knowledge to improve support to parents and severely ill children in pediatric palliative care settings, and to bereaved parents. Moreover, results might be used for the purpose of education of health care professionals. During the consent request call or when they returned the questionnaires, many parents in the study mentioned altruism as an important reason to participate. Something good that might come of their suffering felt rewarding. Finally, the effort to be just was adopted in this data collection by having very open inclusion criteria for participation, not excluding any cancer-bereaved parents in the time frame of the study. The collected data were stored on a secure university server and all data were anonymized, without names and identity numbers. Thus, no identification of individuals was possible during data analysis procedures.

5. Results

5.1. Sample characteristics

The demographic characteristics of the parents are summarized in Table 3. At the time of the data collection for the research project, the mean age of the parents (Studies I–III) was 46.0 years. The sample contained 133 (59%) mothers and 92 (41%) fathers, with 196 (87%) parents either employed or studying and 126 parents (56%) living in an urban area. When examining statistical differences between mothers and fathers with regard to their characteristics, no statistically significant differences were found, except in age and employment; fathers were older than the mothers, $t(230) = 2.05$, $p < 0.05$, and fathers were more often in employment than mothers, $\chi^2 = (1, N = 224) 9.49$, $p < 0.01$, as more mothers were on parental leave.

Table 3. *Characteristics of the bereaved parents (n = 225).*

	Mean (SD)	Range
Parent age at study (years)	46.0 (8.15)	24–66
Parent age at child death (years)	42.2 (8.01)	20–62
Years since loss	3.1 (1.47)	1–5
Characteristics of the parents at the time of the study	n (%)	
Parent gender		
Female	133 (59)	
Male	92 (41)	
Other children than the deceased child	201 (90)	
Not stated	1 (0.4)	
Religious	90 (40)	
Not religious	131 (58)	
Marital status		
Married/cohabiting	206 (91)	
Single	17 (8)	
Not stated	2 (1)	
Level of education completed		
Primary/secondary school	117 (52)	
University	107 (48)	
Not stated	1 (0.4)	
Residential region		
Rural	96 (43)	
Town	71 (32)	
City	55 (24)	
Not stated	2 (1)	
Occupation		
Employed/studying	196 (87)	
On sick leave/parental leave/unemployed	28 (12)	
Not stated	1 (0.4)	

Characteristics of the deceased children are summarized in Table 4. The mean age of the deceased children ($n = 151$) was 7.3 years at diagnosis and 9.9 years at death, with mean length of the children's illness being 2.7 years. Out of 232 parents, 160 stated that they perceived that their child had received palliative care.

Table 4. Characteristics of the deceased children ($n = 151$).

	Mean (SD)	Range
Child age at diagnosis (years)	7.25 (5.3)	0–16
Child age at death (years)	9.93 (6.5)	0–24
Child illness length in years	2.7 (3.51)	0–21
	n (%)	
Child gender		
Girl	66 (44)	
Boy	85 (56)	
Diagnosis		
Brain tumor	56 (37)	
Leukemia/lymphoma	42 (28)	
Sarcoma	22 (14)	
Other	32 (21)	

5.2. Results of Study I

As a first step in this doctoral project, the internationally used instrument PG-13, used to assess symptoms of prolonged grief, was validated in a Swedish sample of bereaved parents, in preparation for the use of the instrument in the planned studies. The results of the principal component analysis, hereafter referred to as factor analysis, indicated that the PG-13 items were best characterized as one factor. A one-factor analysis rendered a significant Bartlett's test of sphericity ($P < 0.001$); the sampling adequacy was 0.88 (Kaiser-Meyer-Olkin), which is considered excellent (A. Field, 2013). The one-factor analysis explained 48.4% of the total variance.

All items had loadings above 0.40; nine of the items had high loadings (range 0.64–0.81) and two items – item 4 (avoid reminders) and item 8 (distrust others) – had somewhat lower loadings, 0.45 and 0.59, respectively.

The internal consistency of PG-13 was good, as measured with mean inter-item correlation (MIIC) and Cronbach's α coefficients. The MIIC was 0.42 (range 0.22–0.74), which is very good, and Cronbach's α was high ($\alpha = 0.89$). The internal consistency of the scale did not improve when examining Cronbach's α values "if item is deleted."

At a group level, the participating parents scored highest on the item assessing "yearning" and second highest on "having trouble accepting the loss," which may show these to be the strongest symptoms of prolonged grief in PG-13. The lowest score was on "avoiding reminders of the deceased" and the second lowest score was on "distrusting others." The mean item score was 2.7 (SD = 0.86).

The concurrent validity of PG-13 was assessed in relation to other variables (i.e., symptoms measured by GAD-7, MADRS, PCL-5, UGRS, and ISI), and statistically significant correlations were found with all the psychological symptoms. The strongest correlation was found with symptoms of posttraumatic stress.

Significant correlations were found between parents' prolonged grief and the child's age – both at diagnosis and at time of death – with more symptoms when children were older, and also with the parent's gender; mothers reported higher scores. There were no significant correlations between a parent's prolonged grief and time since loss or the parent's age.

To summarize, the results indicate satisfactory psychometric properties of the instrument, supporting the use of the PG-13 as a valid measure of prolonged grief in our sample.

5.3. Results of Study II

The second study examined prolonged grief and psychological symptoms in the bereaved parents in our sample. At a group level, parents reported elevated levels of prolonged grief, depression, posttraumatic stress, and insomnia across the first five years post loss, regardless of how many years had passed since the loss. Mothers reported higher symptom levels of prolonged grief, depression, and posttraumatic stress than fathers, but no statistically significant differences between mothers and fathers were found regarding insomnia.

Parents' average score for symptoms of prolonged grief was 29.7 (range 11 to 55). Parents' average score on depression was 12.9, indicating mild depression. The average score for posttraumatic stress symptoms was 21.3, indicating moderate symptom levels, and parents reported an average insomnia score of 10.1, which was over the cut-off for diagnosis. Table 5 presents all mean scores for symptoms of prolonged grief, depression, posttraumatic stress, and insomnia for the total sample and for mothers and fathers separately.

Table 5. Self-reported mean symptom levels in bereaved parents.

	All parents Mean (SD)	Mothers Mean (SD)	Fathers Mean (SD)
Prolonged grief (range 11 to 55)	29.70 (9.54)	31.01 (10.11)	27.80 (8.34)
Depression (range 0 to 54)	12.91 (9.30)	13.89 (9.64)	11.36 (8.59)
Posttraumatic stress (range 0 to 80)	21.34 (15.94)	23.40 (16.59)	18.24 (14.58)
Insomnia (range 0 to 28)	10.12 (7.46)	10.70 (7.63)	9.11 (7.06)

Overall, symptom levels were elevated for all subsamples of parents grouped according to years since loss (see Table 6).

Table 6. Self-reported symptom levels in bereaved parents; subsamples by years since loss.

Years since loss	Prolonged grief Mean (SD; n) N = 225	Depression Mean (SD; n) N = 225	Posttraumatic stress Mean (SD; n) N = 222	Insomnia Mean (SD; n) N = 222
1 year	30.47 (9.59; 45)	12.22 (9.00; 45)	19.33 (14.21; 44)	9.56 (7.23; 43)
2 years	31.26 (10.28; 43)	13.86 (10.49; 42)	23.36 (18.20; 43)	9.59 (7.80; 42)
3 years	29.56 (9.52; 45)	12.84 (10.17; 45)	20.26 (15.27; 43)	8.98 (6.35; 45)
4 years	29.14 (9.64; 37)	13.79 (8.97; 38)	22.48 (16.08; 37)	11.92 (8.85; 39)
5 years	28.35 (8.95; 55)	12.20 (8.23; 55)	21.44 (16.11; 55)	10.65 (7.10; 53)

The two-way ANOVA analysis showed no significant interaction effect between years since loss and gender (or vice versa) on the symptom levels of prolonged grief, depression, posttraumatic stress, and insomnia (see Table 7). Mothers had significantly higher symptom levels of PGD, depression, and posttraumatic stress than fathers, while no difference was found between mothers and fathers regarding symptoms of insomnia.

We found no significant interaction effect between years since loss or gender and the bereavement outcomes. However, the graphs presented in the published study (Pohlkamp, Kreichbergs, & Sveen, 2019) show a pattern of mothers reporting more intense reactions than fathers in years one to three, while the intensity of mothers’ and fathers’ grief and psychological reactions were rather similar in years four and five. Interestingly, for insomnia, the pattern was somewhat different, with fathers showing increased symptoms four years after loss, with levels higher than those of the mothers.

Table 7. Results of ANOVA analysis.

	df	Prolonged grief		Depression		Posttraumatic stress		Insomnia	
		F	p	F	p	F	p	F	p
Years since loss	4	0.74	0.57	0.27	0.90	0.49	0.75	1.12	0.35
Gender	1	6.22	0.01	4.06	0.05	5.24	0.02	1.92	0.17
Interaction effect	4	0.98	0.42	1.17	0.32	1.60	0.17	1.16	0.33

5.4. Results of Study III

The third study reported on factors during a child’s illness trajectory (see Table 2) that might contribute to levels of prolonged grief symptoms in mothers and fathers one to five years after the loss of their child to cancer.

A univariable analysis showed that higher levels of prolonged grief in mothers were associated with feeling that their child suffered from anxiety during the illness trajectory or was in pain during the last month of life. When they felt that they had not received sufficient information on how to take care of their child or

handle acute problems related to the illness, this was also associated with more prolonged grief. In fathers, higher levels of prolonged grief symptoms were found when they had perceived an inadequate (too high or low) level of responsibility for their child's care during the last month of their child's life. Higher levels were also seen when fathers felt they lacked enough information about their child's illness trajectory or about where they could turn for their own psycho-social support.

In the multivariable regression, variables found to be associated with lower levels of prolonged grief symptoms for mothers were if they had been able to talk about feelings within the family and if they felt that they could trust that health care professionals made every possible effort to cure the child. In the final model of the multiple regression analysis, after inclusion of demographic adjustment variables, 20.5% of the variance (adjusted R^2) was explained by the variables: "being able to talk within the family" ($\beta = 2.83$; 95% CI 1.09–4.57; $P = 0.0017$) and "trust in health care" ($\beta = 2.56$; 95% CI 0.78–4.35; $P = 0.0055$).

The statistically significantly associated variables for fathers' lower levels of prolonged grief were: having said farewell to the deceased child in the way they wanted and feeling that they had received practical support from health care professionals during the child's illness trajectory. In the final model of the multiple regression analysis, after inclusion of demographic adjustment variables, 33.2% of the variance (adjusted R^2) was explained by the variables "having said farewell to your deceased child in the way you wanted" ($\beta = 3.40$; 95% CI 1.70–5.10; $P = 0.00016$) and "received support from health care professionals in practical matters" ($\beta = -3.43$; 95% CI -5.90–0.95; $P = 0.0073$).

5.5. Results of Study IV

The results of the fourth study showed parents' views on what facilitated or complicated their grief. Six categories emerged from the parents' responses to the open-ended questions. They were categorized as follows: (1) the social network of family and friends, (2) memories of the child, (3) sharing experiences with other bereaved parents, (4) professional counselling support, (5) activity and work, and (6) personal growth and spirituality.

Parents reported that having a supportive social network of family and friends that was open for sharing and expression of thoughts and emotions, and having remaining children, promoted positive coping with grief. This helped them back to life. Meeting professional counselors was necessary for some to be able to ‘move forward’ and being able to share experiences with other bereaved parents was beneficial to many. They felt it promoted their coping if they felt deeply understood in their sorrow. Taking action to keep memories of the child alive in various contexts – family, friends, the child’s school, and together with staff at pediatric care settings where the ill child had been cared for – was also reported as facilitating their coping.

Parents expressed that the following experiences complicated their coping: when they could not share emotions with their partner or when they perceived that friends, relatives, or colleagues lacked empathy or patience. Some suffered additional losses in their social networks, which made them feel overwhelmed. The parents’ work places could complicate their coping when they felt demands from employers to manage tasks that were too challenging at an early stage.

6. Discussion

The main focus of this doctoral project was to explore parental grief after the loss of a child due to cancer by means of a nationwide survey, including questions on the parents' experiences during the child's illness. The findings of the project revealed that the parents' symptom levels of prolonged grief and psychological symptoms were elevated and neither time- nor gender-dependent across the first five years after the loss. We also found that some of the parents' experiences during the child's illness were associated with their grief and psychological symptoms. These factors differed for mothers and fathers. Findings also showed that parents found certain factors facilitated or complicated their coping with grief. Unsurprisingly, social support promoted positive coping with grief, while a less familiar factor – going back to work – could make coping with grief harder.

6.1. Prolonged grief is a measurable construct

As an element of this research project, the internationally used instrument PG-13, developed to assess prolonged grief, was validated in a Swedish sample of bereaved parents. It demonstrated good psychometric properties. The PG-13 showed good internal consistency, indicating that the items of the instrument measured the same attribute, thus supporting reliability. The factor analysis confirmed evidence from other samples (1995; 1999), showing a unidimensional factor structure of prolonged grief, hence demonstrating construct validity. The associations between prolonged grief symptoms and symptom levels of depression, anxiety, posttraumatic stress, rumination, and insomnia provided evidence in support of the instrument's concurrent validity.

The significant correlations between scores for prolonged grief, anxiety, depression, and posttraumatic stress indicated that the conditions measured by these instruments often overlap. However, evidence confirms that prolonged grief is distinct from other possible bereavement-related disorders, such as posttraumatic stress and depression (Boelen, van de Schoot, van den Hout, de Keijser, & van den Bout, 2010; Prigerson, Maciejewski, et al., 1995). The low loadings on the avoidance and distrust items may help to distinguish grief from posttraumatic stress, showing that they are related, but still different concepts.

The two items found to show lowest factor loadings, items 4 (avoidance of reminders) and 8 (distrust others), were consistent with previous studies (Boelen et al., 2010; Boelen, Van Den Bout, De Keijser, & Hoijtink, 2003; Prigerson et al., 1999). Comparing with another grief-measuring instrument, the Inventory of Complicated Grief (ICG), Boelen et al. (Boelen & Smid, 2017) found a low factor loading for the avoidance item. These findings may indicate that avoidance and distrust are weak markers of prolonged grief as a pathological phenomenon, i.e., that persons may experience avoidance and distrust, but for other reasons and in other ways. People with posttraumatic stress feel a fear response that leads to avoidance of triggers or persons. Prolonged grief symptoms are based on attachment and separation anxiety and the emotion of fear in prolonged grief is related to the painful separation that one has experienced. Parents want to think about their child, but also want to avoid being reminded of the loss of the child.

From a theoretical perspective, one might consider the fact that parents sometimes try to avoid being reminded about the loss of the child to be a restorative element in their coping, in line with what is suggested in the DPM (Stroebe & Schut, 1999). Involvement in restorative coping may be a (subconscious) strategy to avoid being confronted with reminders of the loss – “taking a break” from the energy-demanding involvement in the emotions and cognitions of loss-oriented coping.

6.2. Prolonged grief, psychological health, and gender differences

In the devastating experience of losing a child to cancer, most parents rely heavily on each other for sustained support. Nonetheless, they may experience difficulties in comforting and supporting each other. They sometimes feel that their partner has experienced the same loss, but is going through a different grieving process (Lannen, Wolfe, Prigerson, Onelov, & Kreichbergs, 2008) (Wing, Burge-Callaway, Rose Clance, & Armistead, 2001). They may, in coping with their grief, focus on differing experiences during the child’s period of illness and treatment. We found associations between high levels of prolonged grief symptoms and experiences when the child was ill, which is interesting information for health care professionals. Even more interesting was that these significant experiences differed for mothers and fathers. This may imply gender differences in coping

with distress both during the time a child is ill in cancer and after the death of the child. Differing individual themes promote positive coping with grief. Increased awareness of the differences in traumatizing experiences during a child's illness may facilitate communication between bereaved parents.

Prolonged grief was shown to be more prevalent among mothers than fathers in this sample, confirming earlier evidence (Kersting et al., 2011; Li, Precht, Mortensen, & Olsen, 2003; van der Geest et al., 2014; Wijngaards-de Meij et al., 2005). However, although the current study was not longitudinal, an interesting pattern was observed (in the subsamples divided based on years since loss), where mothers showed higher symptom levels and fathers showed lower symptom levels at one year post loss. However, at five years post loss, fathers' symptoms were the same or higher than mothers' symptoms in later years. Mothers' symptoms were reduced and fathers' symptoms had increased. The prevalence rate of prolonged grief in all bereaved parents in this sample was 16%, which is higher than the 12% that Lichtenthal et al. (2015) found in a similar sample of 120 cancer-bereaved parents. We do not know the reason for the difference.

Ljungman et al. (2015) found that cancer-bereaved mothers reported higher symptom levels of posttraumatic stress than fathers soon after the loss of the child. These symptoms declined from 9 months to 5 years post loss. While the posttraumatic stress symptoms of fathers were initially lower than those of mothers, they declined more slowly. At 5 years post loss, mothers and fathers had similar symptom levels. Observing such gender differences in the course of the symptoms raises questions about the often-reported higher symptom levels of women: is it possible that they are due to a lack of longitudinal studies in which a decline over time could be observed? Might an increase of fathers' symptoms be observed after a few years?

Both mothers and fathers reported values near or over the cut-off for insomnia symptoms. These findings indicate that parents may also suffer from multiple psychological symptoms that are associated with insomnia (Alvaro et al., 2013; Monk, Germain, & Reynolds, 2008). This reveals the risk for a vicious circle of grief reactions, sleep disturbances, and psychological symptoms. It has been hypothesized that starting treatment of one of the problems – in this case, sleep disturbances – may gradually also have a positive impact on other symptoms

(Blom et al., 2015). An internet-based sleep intervention is being conducted within this research project, but the study is not included in this thesis (Sveen, 2020, in manuscript).

Apart from methodological accounts, possible theoretical explanations for differences between mothers' and fathers' grief reactions may also be found in the Dual Process Model of coping with bereavement (Stroebe & Schut, 1999). While women tend to cope with loss-oriented stressors, focusing on their grief and expressing emotions, men often prefer more externally oriented coping, engaging in practical tasks. This may reflect cultural and societal habits regarding behavior and emotional reactions in both genders (A. Dyregrov & Matthiesen, 1987). Women are considered to be at higher risk for prolonged grief. However, this may not mean that they grieve more than men, only differently and sooner after the event of the loss. For their part, men do not grieve less, only differently and somewhat later after the loss. Gender patterns are important to reflect on: all people have effective ways of adapting to loss, but they are also socialized in ways of mourning and expressing emotions, or regarding when to seek support (Doka & Martin, 2014).

6.3. Towards improved care for families with severely ill children with cancer

6.3.1. Parents' experiences during their child's illness

The experiences of parents during their child's illness were shown to be associated with symptom levels of prolonged grief years after their loss. In mothers, factors found to predict lower levels of prolonged grief symptoms were the feeling that they could talk within their family about thoughts and emotions, and trusting that health care professionals had made every possible effort to cure their child. In fathers, factors found to predict higher levels of prolonged grief symptoms were not having been able to say farewell to their deceased child in the way they wanted and not feeling that they received practical support during the child's illness trajectory.

The association between lower levels of prolonged grief symptoms in mothers and being able to talk within the family indicates that facilitating communication

about feelings among members of the family during times of emotional upheaval might reduce long-term distress in bereaved mothers. This confirms earlier results in parents who lost their child 4–9 years earlier (Kreicbergs et al., 2007). The finding shows that parents may need information on possible differences in their emotional reactions to what is happening to their child; understanding this may help maintain family cohesion and family communication. Furthermore, evidence shows that parental concordance in decision-making and sharing how they feel during their child's illness improves both their own and their child's well-being (Hill, Nathanson, Fenderson, Carroll, & Feudtner, 2017).

The findings in this thesis showed that perceived pain and anxiety in children correlated with higher levels of prolonged grief in their mothers, while trust that health care professionals had made every possible effort to cure the child was associated with lower levels of prolonged grief symptoms. The importance of trust in a therapeutic alliance, as found in this study, supports an earlier study of parents with children with cancer, who felt that trust in health care professionals made them feel more secure, despite uncertainty and upsetting information (Sisk, Mack, Ashworth, & DuBois, 2018).

For fathers, not having been able to say farewell to their deceased child in the way they wanted contributed to higher levels of prolonged grief symptoms. This calls for health care professionals to support fathers in prognostic awareness throughout the difficult journey towards their child's death and to ask questions about their needs and wishes during the end-of-life period. The concept of having 'continuing bonds' with the deceased, as described in modern theoretical models of grief work (Klass, 1997), may provide a basis for new strategies for clinicians to support parents. The idea is that parents, to cope with their loss, need to feel the continued presence of their child. Having mementos from the child after death, such as footprints, can be of help. Offering suggestions about farewell rituals, such as taking photographs of the child, can also be beneficial (Riches & Dawson, 1998). Health care professionals need to be aware of the importance and positive impact of good, trustful relations, and offer the parents what is called a 'safe haven' in attachment theory, to support them during the most difficult time of the parents' life, when the parent-child relationship is under threat (Bowlby, 1973; Kearney & Byrne, 2015).

Fathers' reports that they lacked practical support from health care professionals may reflect the fathers' needs for information on how to handle their child's clinical condition, since the treatment and symptoms of severely ill children can be highly distressing for family members (Blazin, Cecchini, Habashy, Kaye, & Baker, 2018). Targeted supportive interventions may need to be offered to each parent separately, because of different needs and communication styles. The findings in this thesis also confirm earlier evidence that health care professionals can influence parental coping with bereavement by providing sufficient so-called prognostic guidance. This involves providing information continuously, starting before the death of the child, verifying that the parents have understood the information (Rando, 1983), and communication and preparations for the death of the child (Mack et al., 2005; Rini & Lorig, 2007).

6.3.2. Parents' experiences after their child's death

Struggling with meaning was common among many parents who had lost a child. Parents stated that having a supportive social network of family and friends was of a great help in surviving what felt unbearable. This involved others being open for sharing and expression of thoughts and emotions. When parents perceived that friends or relatives lacked empathy or patience, this made them feel isolated in their grief. Having remaining children was seen as helpful in coping with grief, since this forced them to function as parents. Meeting professional counselors and sharing experiences with other bereaved parents was also reported as facilitating coping with parental grief. Taking action to keep memories of the child alive in various contexts, including with staff at the pediatric care settings where the child was cared for, was reported by parents to be important in coping with grief.

Parents stated that the following experiences made coping with grief difficult: when they suffered additional losses in their family or social network, when they could not share emotions with their partner, and when they felt demands from employers that were too challenging at an early stage.

The facilitating and complicating factors for coping with grief found in the fourth study partly support the results in a recent review article (Snaman et al., 2019) involving parents of children who had died from cancer. Protective factors were

social support and personal growth, and these were also mentioned by the parents in our study as crucial for positive coping with grief. Other findings in the current study, e.g., that parents found it hard to go back to work and meet demands from employers, were not mentioned by the parents in the review article. However, the review did find that financial strain was a risk factor. This can be a result of not having been able to work full-time when the child was ill. In a study on bereaved parents in Australia and the US (Dussel et al., 2011), economic stress was common in families that had suffered work disruptions during a child's illness. The parents in this study did not report being under any financial strain, probably because of social welfare systems in Sweden covering the costs for health care and treatment of children with cancer. Nevertheless, parents found it hard to meet colleagues and talk about other things, if managers and colleagues had not mentioned the deceased child. The bereaved parents felt the need for some sort of acknowledgement of their new 'status,' but felt that many were afraid to ask or say something. The Childhood Cancer Fund in Sweden offers support groups for bereaved parents and many appreciate these meetings and continue to meet without a therapist after the organized sessions end.

6.4. Methodological considerations

In quantitative research, the concepts of validity, reliability, and generalizability are used to evaluate the use of the research methods, while the preferred concepts in qualitative research are credibility, dependability, and transferability (Creswell & Creswell, 2017; Polit & Beck, 2010). The studies in the thesis used both quantitative and qualitative analysis methods to provide a depth of understanding and to elicit the perspectives of the participating parents.

Evidence of face validity was collected through interviews with cancer-bereaved parents, to ensure that the targeted cohort understood the questions. In the fourth study, which contained content analysis, efforts were made to reach credibility through repeated readings of the open-ended text responses, as well as discussion of the emerged categories among several researchers, to ensure that no information was missed and that the interpretations and coding were trustworthy.

The psychometric properties of the PG-13 instrument were examined in this sample. All properties, i.e., its concurrent and construct validity as well as its reliability, were found to be good. Symptoms of depression, anxiety,

posttraumatic, stress, and insomnia were examined by means of internationally widely used instruments tested in many populations, which can be considered to be a strength. Another strength was that the relatively new instrument, UGRS, used to measure grief rumination, was also evaluated in this sample and shown to have good psychometric properties (Sveen et al., 2019).

No data were available on the psychological health of non-responders, which limits the generalizability of our findings. Bereaved parents with poor psychological health may not have responded due to fear of triggering difficult memories. On the other hand, non-response may also be due to a lack of interest among parents who are recovering and do not feel motivated to participate in an extensive survey given their current life situation. Some of the non-responders may have been bereaved parents who did not understand enough Swedish to understand the questionnaire. Of the parents who agreed to participate, 62% returned the questionnaires and the number of missing responses within the questionnaire was small. This may be considered to be a fairly high response rate, as the tendency for nationwide studies is falling.

The findings are based on self-reported data, and no clinical assessment interviews were conducted, which should be considered when evaluating the results of this project. Clinical interviews may give a deeper knowledge of some aspects of the parents' lives after the loss of a child and would add the assessment of a professional. However, it is convenient and cost-effective to use self-report questionnaires, enabling data collection in large nationwide samples which include most of the people in a population, within a limited time frame. The participants may also find this convenient, as they can fill out the questionnaire at home, at their own pace. There was a fairly equal gender distribution among responders, which is unusual in this type of research, and there were participants from all parts of Sweden. The validity interview showed that the parents found the topics of the questions relevant to the reality of cancer-bereaved parents, which may have increased motivation to participate.

Since the parents were surveyed one to five years after their child's death, there is a possibility of recall bias: the recalled memories may have changed over time. Parents with current high levels of prolonged grief and/or psychological symptoms may remember their experiences during the child's illness and death in

a more critical light than those with lower levels of grief symptoms, which may have affected results. On the other hand, one could argue that whatever they remember is part of their story.

Since the findings of this study are based on a Swedish nationwide population, one could assume our results to be valid for parents in Sweden who have lost a child to cancer, as study results are always specific for the place, time, and participants. It is not certain that the results can be generalized to other cultural contexts or to other causes of children's death, as other aspects may be more prominent in those situations than they were in this population. However, one could assume that some of the findings are generalizable to other populations of parents to children with other life-threatening illnesses. Hopefully, the findings enable a richer understanding of the experiences of bereaved parents. Further research should try to assess grief and psychological symptoms among parents who have lost children due to varying causes, in samples from other countries, and compare results to gain even deeper understanding.

7. Conclusions

This thesis has increased the understanding of grief, prolonged grief, and psychological ill health in cancer-bereaved mothers and fathers. Evidence was found for the use of the PG-13 instrument to measure prolonged grief, and the loss of a child was shown to have long-lasting effects on the psychological health of the parents. Cancer-bereaved mothers and fathers are vulnerable to symptoms of prolonged grief, depression, anxiety, posttraumatic stress, and sleep disturbances up to five years after the death of their child. Elevated symptom levels of prolonged grief were found to be associated with certain parental experiences during the child's illness; in mothers with not being able to talk about feelings within the family and when they could not trust that health care professionals made every possible effort to alleviate the suffering of the child. In fathers, more prolonged grief was associated to feeling they had not received sufficient information or were not able to take farewell in the way they wanted.

The deepened knowledge of the differing patterns of mothers and fathers regarding significant experiences during the child's illness associated to psychological suffering may contribute to a more targeted communication approach in pediatric care contexts. The aspects of what parents found promoted or complicated their coping with grief may be of use to health care professionals and others when developing bereavement support. Grief after the loss of a child deserves attention in its own right, both in future research and in the development of bereavement care.

8. Implications

The findings indicate that some cancer-bereaved parents may suffer from prolonged grief and psychological symptoms up to at least five years after the death of their child. Clinicians should be aware of this when meeting bereaved parents – as this may be a much longer timespan than expected – and find respectful ways to ask about possible prior losses. The psychological problems reported by the parents in the project accentuate the need to establish policy guidelines for assessment of the need for bereavement support to cancer-bereaved parents, which may remain for many years after a child's death. To reach out to the parents for yearly follow-ups would enable identification of those at risk for psychological symptoms, who could then be directed to targeted support if needed (Lichtenthal, Sweeney, et al., 2015).

Lichtenthal et al. (2015) showed that many cancer-bereaved parents do not receive bereavement support, partly because the loss is too painful for them to talk about, but also due to difficulties in finding such services. This may be a task for a professional care pilot to guide those in need of support. The grief process is fluid and repeated assessment of the need for support may be necessary to meet bereaved parents' changing needs over time. Currently, childhood cancer centers often lack routines for assessment of the parents' needs of bereavement care, prior to and after loss, and even if such services are available, there are large variations in how they are delivered (Wiener, Rosenberg, Lichtenthal, Tager, & Weaver, 2018).

Grief experienced by parents is generally very severe (Dias et al., 2018), possibly reflecting the strong attachment relationship between parents and children. Therapeutic alliances between parents and health care professionals established during the child's illness may be a comfort to the parents following the loss of their child (Morris et al., 2017). Parents with severely ill children often develop strong relationships with health care staff whom they have come to rely on during the distressing time when their child was ill. The needs of the parents for continued bonds with health care staff and the hospital community, which offer them a chance to reconnect, may be considered when developing interventions aimed at improving parents' bereavement outcomes. For example, friends, relatives, and all parents who have ever had a child cared for at a given pediatric

oncology center could be invited to an 'open house' once a year, to reminisce and talk about their children. This is a gesture that many bereaved parents would be likely to appreciate highly. Grief is an individual process regarding time and needs. Inviting bereaved parents even years later may be of value for them; during the first year, it may be too difficult to come back to the hospital and be confronted with painful memories. Apart from reconnecting to health care professionals, parents have reported the benefit of meeting other families with recognizable experiences. To share and compare emotions, behavior and thoughts, to find out what is 'normal' in their shattered world of grief and to be able to support others may be empowering.

As shown in this thesis, people have differing preferences regarding what kind of support they want when their child is ill in cancer. Health care professionals must find ways to assess parents' differing needs in order to offer relevant support. The findings provide knowledge that can be used in the improvement of care for children with cancer and in the support to their parents and families in pediatric oncology contexts and in bereavement. Interventions may focus on psycho-education regarding grief reactions for bereaved parents, their networks, and at a societal level. Knowledge should be shared about the grieving process and the varying need for support that may take time to develop in the bereaved. At a societal level, health insurance organizations and workplaces may need to develop facilitating policies for bereaved parents who return to work.

Sammanfattning

Sorg är en normal reaktion på en förlust. De flesta människor kan hantera sin saknad och smärta på egen hand eller med hjälp av nära och kära. Sorg efter förlusten av ett barn anses vara mycket intensiv och långvarig, och föräldrar som har mist ett barn har därmed en ökad risk att uppleva så kallad 'förlängd sorg' och utveckla psykisk ohälsa. Syskon och andra i och nära familjen är självklart också berörda. I Sverige är det varje år drygt 300 barn som får en cancerdiagnos och trots förbättrade behandlingsmetoder under de senaste decennierna dör runt 55 till 60 barn varje år i sin sjukdom.

Föräldrars sorg och psykiska ohälsa under de första fem åren efter förlusten av sitt barn i cancer har inte studerats i Sverige tidigare. Syftet med avhandlingsprojektet som helhet var att undersöka sorg och psykisk ohälsa hos föräldrar ett till fem år efter förlusten av sitt barn i cancer, samt om det fanns faktorer under barnets sjukdomstid som eventuellt påverkat sorgen och den psykiska hälsan hos föräldrarna. Frågan om hur föräldrarna såg på vad som hade hjälpt respektive försvårat deras sorgprocess var också en del i undersökningen. Den undersökta populationen var föräldrar/vårdnadshavare som hade mist barn som var upp till 24 år gamla i cancer, under åren 2010–2015, i Sverige.

Den första delstudien i avhandlingsprojektet testade mätinstrumentet Prolonged Grief-13 för bedömning av förlängd sorg i en nationell population av föräldrar som hade mist barn i cancer i Sverige. Studien visade att instrumentet var tillförlitligt i de här gruppen. Den andra delstudien visade att tiden sedan en förlust (ett till fem år) inte påverkade sorgen eller den psykiska ohälsan hos föräldrarna. I gruppen föräldrar som hade mist sitt barn för ett år sedan rapporterade visserligen mammor fler symptom av förlängd sorg och psykisk ohälsa än pappor, men från två till fem år efter förlusten av barnet fanns inga sådana skillnader. Det är känt bland kliniker att föräldrar som mist ett barn i cancer har långvarig sorg och psykisk ohälsa, som inte minskar under de första fem åren, men detta har inte tidigare visats lika tydligt i forskning som omfattat ett nationellt urval.

Den tredje delstudien visade att mammor och pappor har olika erfarenheter under barnets sjukdomstid som påverkar deras mående efter barnets död. För mammor

var det viktigt att kunna prata inom familjen om allt som hände dem och att kunna lita på att personalen gjorde allt de kunde för deras sjuka barn samt kunde lindra barnets smärta och andra symptom. För pappor kändes det viktigt att under barnets sjukdomstid få hjälp med praktiska saker och att få ta avsked av barnet på det sätt man själv önskade. Föräldrar har alltså individuella behov av stöd under tiden deras barn får vård, delvis olika beroende på kön, vilket kan vara viktigt för vårdpersonal att vara medveten om, för att kunna ge god vård till hela familjen.

Den fjärde delstudien visade vad föräldrarna tyckte hade underlättat respektive försvårat deras sorg. Att ha en partner som man kan prata med och ett socialt nätverk som förstår och där man kan dela känslor och prata om sitt barn hade gjort sorgen lättare för många föräldrar, liksom att ha syskon till barnet som dog och därmed få ett fortsatt familjeliv. Annat som var till hjälp i att komma vidare var att få träffa och dela sina erfarenheter med andra föräldrar som hade mist barn i cancer, samt att få professionellt stöd. Det som å andra sidan hade försvårat bearbetning av sorgen var när föräldrarna var med om andra förluster av en nära anhörig eller upplevde att vänner inte ville eller kunde prata om barnet och sjukdomstiden. Att behöva gå tillbaka till arbetet för tidigt eller där behöva presterar mer än vad man orkade gjorde också sorgen svårare att ta sig igenom, enligt föräldrarna.

Resultaten av avhandlingsarbetet som helhet bidrar med viktig kunskap inom forskningsområdet onkologisk och palliativ vård av barn, och det kliniska värdet av studien är därför stort både nationellt och internationellt. Det har visat sig att riktlinjer om stöd vid sorg i samhälle och vården behöver utvecklas. Den nya kunskapen kan förhoppningsvis bidra till utveckling av vården av barn med cancer och stödet till deras familjer, både under och efter barnets sjukdomstid.

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Theses from Ersta Sköndal Bräcke University College

No. 1. Anna Holmqvist (2020) Integritet på undantag? En studie av barns röst i patientlagen och patientorganisationer.

No. 2. Megan Weber Falk (2020) Development and Evaluation of the Grief and Communication Family Support Intervention for Parentally Bereaved Families in Sweden.

No. 3. Lilian Pohlkamp (2020) Bereaved mothers and fathers. Grief and psychological health 1 to 5 years after losing a child to cancer.

Bereaved mothers and fathers

Grief and psychological health 1 to 5 years after losing child to cancer

The loss of a child is a devastating event for parents. This thesis increases the understanding of grief and psychological ill health in cancer-bereaved parents. It also examined mothers' and fathers' experiences during their child's illness and what parents found affected their coping with grief. The findings provide knowledge to better support parents in pediatric oncology contexts and in bereavement, which can also improve care for their children.



Lilian Pohlkamp is a registered nurse and registered psychotherapist, with long clinical experience in mental health and palliative care settings. In addition to teaching and supervising health care professionals, she provides psychotherapy, especially in the areas of coping with grief and loss.

Ersta Sköndal Bräcke College has a PhD programme within the field The Individual in the welfare society, with currently two third-cycle subject areas, Palliative care and Social welfare and the civil society. The area frames a field of knowledge in which both the individual in palliative care and social welfare as well as societal interests and conditions are accommodated.