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## Living with Grief

A Qualitative Study of Cancer-bereaved Parents' Experiences of Helpful and Hindering Factors in the Grieving Process After the Loss of a Child

Graduate thesis in Clinical Psychology

Supervisor: Trude Reinfjell

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## Acknowledgements

This thesis marks the end of my studies in clinical psychology. The process of examining an area of interest in such depth has been both challenging and rewarding. I started out with an interest in next of kin of people with disease, and the interest in grief grew from there. My interest in relatives of people living with disease started long before I started my studies, since I first started working as a care-assistant in care homes and hospitals. It continues to amaze me how well people can adapt when faced with devastating life-experiences, and how little things that seem insignificant can have such an effect on people. When I worked on the study aim for this thesis, I had this interest in mind, and tried to find an area where I could contribute to help people facing challenging life-events such as disease of people close to them.

I am very grateful for the opportunity to use qualitative data from Mary-Elizabeth Bradley Eilertsens' project with cancer-bereaved parents. I have learned much from the process of both getting an overview of the literature in the field of bereavement, doing a qualitative analysis and trying to convey my thoughts into written text. Although it has been challenging at times, the process has given me much joy and greater academic interest.

I want to thank my supervisors, Trude Reinfjell and Mary-Elizabeth Bradley Eilertsen, who have been of great support, both professionally and emotionally. I also want to thank Omid Rashid, although not formally a supervisor, he has been a great help in the literature review and working through the text. Lastly, I want to thank my friends and family, who have helped me through frustrating times working with this thesis.

### **Abstract**

Cancer-bereaved parents are at higher risk of several morbidities after the death of their child, but studies have found that many parents are able to integrate their grief process. This study aimed to explore cancer-bereaved parents' perceptions of what helped and hindered their grieving process. Using a thematic analysis approach, 148 answers to two open-ended questions in a nationwide study of cancer-bereaved parents were analysed, 2-8 years after their child's death. Three main themes were found: (1) Memories of the disease period and death, (2) Going forward in life and (3) Relationships – a resource and a barrier. The first theme captured both the salutary process of accepting what happened during the disease period and death, as well as the devastation and difficulties of moving on with the remembrance of painful memories. In the second theme, the fact of moving on with one's life was expressed helpful, both living as normal as possible, as well as the acknowledgement that the grief will always be a part of one's life. In the last theme parents expressed how relationships could be a source of social support, thereby helping the grieving process, whereas difficult relationships and lacking support from others hindered the grieving process. The findings may guide health professionals in facilitating important factors in helping cancer-bereaved parents adjust after the death of their child.

*Keywords:* cancer-bereaved parents, bereavement, grief, paediatric oncology

### Sammendrag

Etterlatte foreldre som har mistet barn til kreft har høyere risiko for flere fysiske og psykiske plager etter deres barns dødsfall. Studier har likevel funnet at mange foreldre klarer å integrere sorgen deres på en god måte. Denne studien hadde som mål å utforske etterlatte foreldre som har mistet barn i kreft sine opplevelser og oppfatninger av hva som hjalp dem i sorgen og hva som gjorde sorgprosessen vanskeligere. Studien brukte tematisk analyse for å analysere 148 skriftlige svar på to åpne spørsmål i en nasjonal studie av kreft-etterlatte foreldre 2-8 år etter barnets død. Tre hovedtema ble funnet: (1) Minner fra sykdomsperioden og døden, (2) Gå videre i livet og (3) Relasjoner – a ressurs og barriere. Det første temaet innebar både hvordan det å akseptere det som hadde skjedd i sykdomsperioden og rundt barnets dødsfall var hjelpsomt for foreldres sorgprosess, samtidig som vonde minner gjorde den vanskeligere. I det andre temaet var det å gå videre i livet, samtidig som man har minnene om barnet og sorgen med seg videre og aksept for dette, en viktig hjelpsom faktor for foreldre. I det siste temaet uttrykte foreldre hvordan gode relasjoner kan være til støtte og hjelpe sorgprosessen, samtidig som vanskelige relasjoner og/eller mangel på støtte gjorde sorgen vanskeligere. Funnene fra denne studien kan bidra til å veilede helsepersonell til å fasilitere viktige beskyttende faktorer for å hjelpe kreft-etterlatte foreldres tilpasning etter deres barns død.

*Nøkkelord:* foreldre i sorg, etterlatte foreldre, sorg, kreft hos barn, pediatrik onkologi

## **Living with grief: a qualitative study of cancer-bereaved parents' experiences of helpful and hindering factors in the grieving process after the loss of a child**

To lose a child is a devastating experience for parents. Bereaved parents are at increased risk of developing several mental and physical problems, such as depressive symptoms, anxiety, low quality of life, and post-traumatic stress disorder (PTSD; Ljungman et al., 2015; October et al., 2018; Rogers et al., 2008; Rosenberg et al., 2012). It has also been suggested that losing a child can affect the marital relationship between parents; it could either make the relationship stronger or more difficult (Albuquerque et al., 2016).

Bereavement has been defined as "the objective situation of having lost someone significant through death (Stroebe et al., 2008, p. 4). Bereavement following the death of a child is often characterised by more intense grieving and devastation than bereavement following the death of other family members (Fernández-Alcántara & Zech, 2017; Middleton et al., 1998), leading to feelings of intense yearning for their deceased child (Baddeley et al., 2015; Zetumer et al., 2015). In light of the significant attachment between parent and child and the role of the parent as a nurturer and protector (Bowlby, 1980), it seems reasonable that yearning in bereaved parents causes significant distress, underpinning the importance of providing adequate support for this group.

In Norway, cancer is the leading cause of death by disease among children over one-year-old (Cancer Registry of Norway, 2019, p.19). However, the literature on the psychological impacts of cancer-bereaved parents is less studied. Of the few studies examining this group, some found that most cancer-bereaved parents were able to integrate and work through their grief (Alam et al., 2012; Barrera et al., 2009; Kreicbergs et al., 2007; Vegsund et al., 2019). In contrast, others found that parents did not successfully work through their grief (Lannen et al., 2008), developed complicated grief reactions (Morris et al., 2019), and were more prone to physical and psychological morbidities (Ljungman et al., 2015; Rosenberg et al., 2012; Van Der Geest et al., 2015). Studies also suggest that cancer-bereaved parents want to and need to use mental health services (Hovén et al., 2020; Lichtenthal et al., 2015). Thus, while some cancer-bereaved parents seem to handle the grieving process reasonably well, others struggle with severe mental and psychical morbidities.

Interestingly, more recent research has focused on the more health-promoting aspects of bereavement. Post-traumatic growth refers to the positive changes in an individual after a challenging life event (Tedeschi & Calhoun, 2004). It has been suggested that loss might facilitate a process of rebuilding and understanding, realisation of one's strengths, stronger appreciation of close relationships, and new spiritual insights (Calhoun et al., 2010). These



processes may help explain why some bereaved parents seem to adjust more favourably than others.

### **Theories of grief**

Before moving on to exploring previous research on different helpful and hindering factors for the grieving process in cancer-bereaved parents, some of the central theories explaining bereavement will be reviewed. In addition to empirical evidence regarding factors related to positive and negative psychological outcomes, the development of interventions should be based on theory (Bowlby, 1982). The earliest psychological theories of grief came from the psychoanalytic theory of Freud, which stated that the function of grief was to help the individual detach from the deceased, and in order to achieve this, the bereaved individual needs to actively engage in the grieving process, later known as grief work (Archer, 2008; Stroebe & Schut, 1999; Supiano, 2019). The idea of grief work, which postulates that working through grief is necessary for a normal grieving process, is still influential in the bereavement literature.

Another influential psychological theory of bereavement is Bowlby's attachment theory (Bowlby, 1980). Bowlby provided ideas of the different stages in normal grief, and responses indicating pathological grieving, such as chronic grieving or absence of grieving (Bowlby, 1980). The attachment theory of loss states that the individual engages in searching behaviour following the loss of an attachment person. Bowlby regarded this as a normal response in the first period following loss, and that healthy adjustment following this period is a reorganisation of the bond to the attachment person. Building on the attachment theory, the perspective of the continuing bond states that continuing the emotional bond with the deceased is important for healthy adjustment following the loss of a significant other (Field, 2008; Foster & Gilmer, 2008). This perspective seems to be in contrast with Freud's aim to detach from the deceased. However, Rando (1973; as cited in Field, 2008) argued that there is no definite division between relinquishing or continuing the bond, but rather that some components should be continued and some relinquished.

There have been many different theoretical perspectives on meaning-making in relation to stressful life events, and Park (2010) proposed the meaning making model which synthesises the common features of these theories. According to the model, the individual applies a situational meaning to a stressful event (e.g., attributions, degree of controllability), which may contrast one's global meaning (i.e., belief system, identity), and hence cause distress. Successful coping involves reducing this discrepancy, thereby achieving "meaning-

made” (e.g., sense of having made sense, acceptance, changed identity). The Meaning Reconstruction Theory is another meaning-making perspective, and relates specifically to the process of bereavement (Neimeyer, 2019; Neimeyer et al., 2002). Building on the psychological constructivism perspective, the theory suggests that following loss, the bereaved individual searches for meaning in the new world without the deceased. Searching for meaning includes making sense of the loss and finding benefits of the life event to integrate the loss experience.

Stroebe and Schut (1999) proposed a dual-process model of coping with losses, which has gained a lot of interest in the study of bereavement. The model is a synthesis between theories of coping with stress and theories of coping with bereavement. The dual-process model proposes that when coping with loss there are two categories of stressors that need to be dealt with. Bereaved individuals shift between a loss-oriented coping and restoration-oriented coping, as well as everyday living without the aspect of coping with grief. Loss oriented coping involves focusing on the death of the loved one itself and how to cope with that, whereas restoration-oriented coping involves focusing on the secondary stressors of bereavement (e.g., loneliness or development of a new identity), and coping with them. The theory proposes that shifting between these coping strategies are essential for healthy bereavement.

Although there are several theoretical frameworks which may help explain the grieving process of parents, there is no consensus on a general theory of grief which dominates the field (Archer, 2008; Supiano, 2019). Further, some interventions for bereaved parents have also been developed without any theoretical standpoint (Dias et al., 2019). This can make comparison across studies difficult, because different findings are understood in different ways. Nevertheless, the variety of theories also gives different opportunities in understanding and explaining bereavement.

### **Risk and Protective Factors**

As initially mentioned, there are great individual variations in how well parents adjust following the death of a child, and several protective and risk factors have been identified to explain these differences. These factors can be divided into three groups: intra-individual (i.e., factors within the individual), inter-individual (i.e., factors between different individuals) and situational factors.

### ***Intra-individual Factors***

There has been an increased interest in resilience as a protective factor when facing a challenging life event (Rosenberg et al., 2013). While there is a lack of consensus in the literature concerning its definition (Fletcher & Sarkar, 2013; Herrman et al., 2011), resilience can be defined as “a dynamic process wherein individuals display positive adaptation despite experiences of significant adversity or trauma” (Luthar & Cicchetti, 2000, p.858). One literature review conceptualised resilience in three different ways; in terms of inner traits, as the process of adaptation, or as psychosocial outcomes (Rosenberg et al., 2013). Thus, the concept of resilience is not only understood as an intra-individual factor, but also other factors relating to successful adaption (Rosenberg et al., 2013; Luthar & Cicchetti, 2000).

Higher levels of resilience have been implicated in predicting cancer-bereaved parents coming to terms with their loss (Vegsund et al., 2019). Vegsund et al. found that the total score of resilience correlated positively with parents working through their grief. Interestingly, the intra-individual sub-factors “perception of self” and “social resources” predicted the participants having worked through the grief, thus being protective factors. In contrast, the inter-individual factor “family cohesion” was a significant predictor in the opposite direction, hence appearing as a risk factor. Resilience has also been found to increase the likelihood of post-traumatic growth in bereaved parents (Albuquerque et al., 2018b), although this has not been studied in a specific cancer-bereaved population. Thus, research indicates that resilience may be an important intra-individual factor among cancer-bereaved parents with respect to working through their grief, both in the positive and negative direction.

Albuquerque et al. (2017) examined how the coping styles in couples of bereaved parents were related to outcome in terms of “meaning-made”. Albuquerque et al. found that the combination of both loss-oriented and restoration-oriented coping predicted meaning-made. However, either high levels of loss-oriented coping or high levels of restoration-oriented coping were related to lower meaning-made. The study also found that women reported more loss-orientation than restoration-orientation compared to men, in line with some preliminary qualitative studies indicating the same gender pattern (Alam et al., 2012; Stevenson et al., 2017). Another study found that both processing and avoidance of grief were related to poor long-term adjustment of American bereaved parents, but not Chinese parents (Bonanno et al., 2005), which indicate that different cultures may benefit from different coping styles. Higher levels of avoidance in combination with depression and lower cognitive restructuring predicted higher levels of grief in another study (Harper et al., 2014). Taken

together, these studies suggest that coping style is an important intra-individual factor influencing adjustment following the loss of a child, implicating that a flexible use of different coping styles might be beneficial.

Other intra-individual factors have also been found to affect parents' well-being after the death of a child, such as being a mother (Ljungman et al., 2015), depressive symptoms pre-loss, higher alcohol use and higher maternal age (Goldstein et al., 2019), and faith and hope for a cure (Snaman et al., 2016b). In other words, there are a high number of intra-individual factors that potentially could affect parents' well-being, but it is beyond the scope of this thesis to review all of them.

### ***Inter-individual Factors***

Qualitative interviews of cancer-bereaved parents have suggested that efficient social support can be helpful in the grieving process (Alam et al., 2012; Barrera et al., 2009; Snaman et al., 2016a, 2016b). Major coping factors were perceptions of having a support from family and peers (Barrera et al., 2009; Alam et al. 2012), self-help groups and health care personnel, in addition to continued contact between the hospital staff where their child was treated (Snaman et al., 2016a; 2016b). On the other hand, lack of communication and isolation from friends and family made the grieving more difficult (Barrera et al., 2009). A large quantitative study found that cancer-bereaved parents who reported having social support during or after the death of their child were more likely to have worked through their grief 4-9 years after the loss (Kreicbergs et al., 2007). The ability to share one's thoughts and feelings both during illness and after the child's death was found to be the most important source of social support. Fathers gained the most support from the child's mother, while mothers gained the most support from friends and family. Professional support in terms of counselling from psychologists and support from hospital staff was also associated with higher levels of working through the grief. This is in line with other evidence suggesting better outcome and adjustment following support from health care professionals (Hovén et al., 2020; Van Der Geest et al., 2014). In Waugh et al.'s (2018) systematic review of post-traumatic growth in bereaved parents, being with other bereaved families and their own family seemed to facilitate post-traumatic growth. Thus, both qualitative and quantitative evidence suggests that social support is a major factor in contributing to healthy adjustment following the loss of a child. This applies to support from friends, family, families in similar situations, and professional health workers.

A large part of the participants in qualitative studies on cancer-bereaved parents have expressed the importance of staying connected to the deceased child in the adjustment of the loss (Barrera et al., 2009; Foster et al., 2011; Gerrish & Bailey, 2020; Proulx et al., 2016; Snaman et al., 2016b). General literature on bereaved parents has also shown that parents experience the continuation of the emotional bond with the deceased child as salutary (Foster & Gilmer, 2008; Klass, 1993), and a quantitative study indicate that the continued bond with the deceased child predicts post-traumatic growth (Albuquerque et al., 2018b). These studies indicate that the continuing bond with the deceased child is a central protective factor for cancer-bereaved parents, which may be understood as a protective inter-individual factor.

Recently, there has been increased interest in how partners coping style may affect each other's adjustments (Albuquerque et al., 2017, 2018a, 2018b; Bergstraesser et al., 2015; Stroebe et al., 2013). Albuquerque et al., (2017) found that the partner's loss orientation was related to lower levels of "meaning-made", while another study indicated that partners' communication about their stress and needs for emotional support may facilitate post-traumatic growth (Albuquerque et al., 2018b). Further, some found that sharing their grief and coping with the grief together helped bereaved parents work through their grief (Bergstraesser et al., 2015). These findings are supported by a study which suggests that parents who avoided to talk about the loss with their partners in order to protect their partner, actually increased the grief in both parents (Stroebe et al., 2013). Interestingly, one study examined reasons for not sharing grief with one's partner (Hooghe et al., 2018). Parents had several reasons for not sharing their grief, such as differences in grieving, grieving as a personal process, and the need for time off from the pain. Hooghe et al.'s finding may indicate that sharing one's grief is not exclusively a protective factor. Taken together, these studies indicate that the partner's coping style affects the bereaved parent's grief, and that sharing their grief mainly seems to be a protective factor.

### ***Situational Factors***

Circumstances of the disease period and death appear to affect the parents grieving and well-being. Sudden deaths, in which parents have not got the time to prepare for the death, seems to be a risk factor for developing complex grief reactions (Morris et al., 2019). Children with cancer often have a prolonged disease period, and one could assume that parents are more prepared for the eventual death of their child. However, studies suggest that some parents are not mentally prepared for the death of a cancerous child (Wiener et al., 2020), which could complicate the grieving process. Additionally, when children die at the

hospital, compared to children dying at home, there appears to be an increased risk of psychological problems (Goodenough et al., 2004). Other circumstances of the disease period, such as parent perception of medical care and the child's quality of life during the illness (McCarthy et al., 2010), symptom management, the child's pain, anxiety and anger (Van Der Geest et al., 2014) also seems to influence parents' long-term grief and increase symptoms of depression. Other situational factors might also influence parents' adjustment following loss, such as prior loss and economic situation (McCarthy et al., 2010). Thus, there are multiple circumstances of the disease period and death, as well as general situational factors that could affect parents' adjustment after the loss of their child due to cancer.

Some studies have found that the risk of psychological symptoms decreases with time after the death of the child. It has been shown that, for cancer-bereaved parents, the risk of anxiety and depression decreased over time, and was not higher compared to non-bereaved parents seven years after the loss of the child (Kreicbergs et al., 2004). Another study found that there was a higher likelihood that the cancer-bereaved parents had come to terms with their loss six years after the death of the child (Vegsund et al., 2019). Further, a decrease in PTSD-symptoms was found in mothers, but not fathers, over a five-year period (Ljungman et al., 2015). However, Ljungman et al. found higher PTSD-symptoms in both mothers and fathers five years after the child's death, compared to the general population. These results indicate that time may alleviate psychological symptoms for some parents, however, other parents still struggle with such symptoms several years after their child died.

### **Summary and aim**

In summary, research has shown a large variety in the adjustment of cancer-bereaved parents following the death of their child, having identified several intra-individual, inter-individual, and situational factors associated with the outcome of the grieving process. Among these, there are several protective factors, such as resilience, dual processing, social support, continuing bond, partners' adjustment, and perceived quality of health care. In addition, several risk factors have been identified, such as inflexible coping styles, isolation and loss of social environment, partner's loss orientation, and the child's pain and difficult emotions. These factors were identified mostly by qualitative studies, but some quantitative studies have also been conducted. However, the majority of the qualitative studies used small convenience samples. Thus, investigating this subject further in a larger and more representative sample can advance our understanding with respect to what makes working through the grief easier or more challenging.

Therefore, the aim of this study was to examine the grieving process in Norwegian cancer-bereaved parents, using a qualitative research design. The following research question was addressed:

- Which factors do cancer-bereaved parents experience as being helpful and hindering in the grieving process?

Exploring this question might identify new potential protective and risk factors or support already existing ones. More knowledge in this area can guide health care personnel to better help bereaved parents and decide on which parents to follow-up more closely after their child's death. It can also contribute with important knowledge in developing interventions with the aim to improve psychological outcome for cancer-bereaved parents.

## **Method**

### **Design**

This study is a retrospective cross-sectional Nationwide study, exploring cancer-bereaved parents' answers to two open-ended questions in a Norwegian questionnaire. The questionnaire was translated from a Swedish questionnaire that was developed to address parental experiences and psychological health after the loss of a child with cancer (Kreicbergs, 2004; Vegsund et al., 2018).

### **Participants**

The participants in the present study were cancer-bereaved parents ( $N = 162$ ) that had lost their child to cancer between January 2009 and December 2014. The descriptive and categorical variables of the sample are shown in Table 1. There were more mothers than fathers, and the majority of the parents had an education from college/university. Most participants were employed. The children were between one and 24 years old at the time of death, and the parents participated in the study two to eight years after their child's time of death. The majority of the participants were parents of the same child ( $n = 110, 67.9\%$ ). There was a fair gender balance of the deceased children, with 89 girls (54.9 %) and 73 boys (45.1 %).

**Table 1***Descriptive and categorical variables of the sample.*

Descriptive variables		<i>n</i> (%)		
		Total <i>N</i> = 162	Mothers 98 (60.5)	Fathers 64 (39.5)
Education	Gymnasium or less	63 (38.9)	34 (34.7)	29 (45.3)
	1 year of university/college	97 (59.9)	62 (63.3)	35 (54.7)
Marital status	Partner with the child's parent	133 (82.1)	78 (79.6)	55 (85.9)
	New partner	11 (6.8)	6 (6.1)	5 (7.8)
	Unmarried, living alone	18 (11.1)	14 (14.3)	4 (6.3)
Employment status	Working	150 (92.6)	86 (87.8)	64 (100)
	Out of work	10 (6.2)	10 (10.2)	0 (0.0)
Residence	Town/village	71 (43.8)	46 (46.9)	25 (39.1)
	City	90 (55.6)	52 (53.1)	38 (59.4)
Categorical variables		<i>M</i> ( <i>SD</i> )		
	Range	Total	Mothers	Fathers
Age of parents	31-69	51.50 (7.61)	50.43 (7.88)	53.14 (6.84)
Number of children			2.5 (1.0)	2.7 (0.9)
Age of child at time of death	1-24	14.46 (6.76)		
Years since death of child	2-8	6.0 (1.6)		

*Note:* Number of children includes the child that died of cancer.

### Procedure and recruitment

The data used in the present study are from the Norwegian national study "Factors contributing to mental health among siblings and parents after the loss of a child to cancer", lead by Mary-Elizabeth Bradley Eilertsen, which is part of the project "Health promotion – worthwhile? Reorienting the community health care services", lead by Toril Rannestad. The project was approved by the Regional committees for medical and health professional research (REK; reference number: 2014/1997/REK Midt).

Between 2009 and 2014, 246 children who had died of cancer were identified through the Cancer Registry of Norway and the Norwegian Cause of Death Registry. Through the Norwegian National Population Registry, 474 parents to these children were identified.



Inclusion criteria included that the parents lived in Norway, spoke and wrote Norwegian. In June 2017, an invitation letter with a consent form was sent to all 474 parents. A reminder was sent to the 214 parents that did not answer the first time. Of the 474 parents, 230 (48,5 %) gave written consent to participate in the study. Eleven of them withdrew the consent, and 57 of them did not return the questionnaire. In total, the response rate was 34,2 %, with 162 parents responding to the questionnaire.

### **Analysis**

Two open-ended questions were analysed using thematic analysis (Braun & Clarke, 2006). The first question was "What has helped you in your grief after the death of your child?". The second question was "Is there something in your child's disease period or death which has made your grief difficult to work through?". The approach of this study was based on a critic realist perspective (Patomäki & Wight, 2000) with a contextualist epistemology (Madill et al., 2000). While there are things that help and things that make grieving more complicated, the participants' interpretative resources and sociocultural meanings mediate their answer, which makes their answers based on their subjective versions of reality. Furthermore, the author of the present study had a semantic and inductive approach. However, one has to expect that the analysis was, to some degree, coloured by existing literature, as this is difficult to avoid.

The hand-written responses were read by the author two times, and then plotted into an electronic table for coding using Microsoft Excel. Each participants response was coded with preliminary codes which were refined after all the data had been coded. Next, the codes were placed together and organised in possible themes. At this point, two experienced supervisors (Eilertsen and Reinfjell) reviewed the codes and themes. Finally, the author and the supervisors (Eilertsen and Reinfjell) worked together to agree on the themes and sub-themes. The distribution of the themes in percentages are derived from the total amount of participants answering at least one of the open-ended questions.

### **Results**

A total of 91.4 % of the participants ( $n = 148$ ) answered at least one of the two questions examined in this study. The distribution of answers to the different questions are shown in table 2. There were slightly more mothers than fathers answering the open-ended questions. Most parents answered that they had worked through their grief, either a little or fairly much.

**Table 2**

*Distributions of answers to the open-ended questions and level of working through grief.*

		<i>n</i> (%)		
		Total	Mothers	Fathers
"What has helped you in your grief after the death of your child?"		143 (96.6)	89 (62.2)	54 (37.8)
"Is there something in your child's disease period or death which has made your grief difficult to work through?"		121 (81.8)	77 (63.6)	44 (36.4)
Worked through their grief	"Yes, a little"	89 (60.1)	58 (65.2)	31 (34.8)
	"Yes, fairly much"	55 (37.2)	31 (56.4)	24 (43.6)
	"Not at all"	4 (2.7)	4 (100)	0 (0.0)

*Note:* The percentages in the "Total" column are derived from  $n = 148$ , while the percentages in the "Mothers" and "Fathers" columns are derived from the corresponding "Total" column.

Almost one fourth of the parents answering the question "is there something in your child's disease period or death which has made your grief difficult to work through?" ( $n = 38$ ; 23.5%) answered "No", "nothing in particular" or "it's difficult either way", and two parents answered "Everything".

The answers from both questions were coded together, and the results gained more information on what the parents perceived as helpful than what they perceived as hindering the grieving. Three main themes with sub-themes were identified when analysing the answers:

1. Memories of the disease period and death
  - a. Acceptance
  - b. Painful memories
2. Going forward in life
  - a. Living everyday life
  - b. Living with grief

3. Relationships – a resource and a barrier
  - a. Social support as a resource
  - b. Lack of social support

### **Memories of the disease period and death**

The theme “Memories of the disease period and death” captures parents’ memories from the disease period and death, and how the parents relate to these memories differently. The theme encompasses both positive and painful memories, as well as looking back with acceptance and without regret, and looking back with complicated feelings and questions about how things could have turned out differently.

#### *Acceptance*

Remembering both painful and positive memories from the disease period and death and thinking back with acceptance was experienced as healing for some parents ( $n = 36$ ; 24.3%). Of these, 69.4% ( $n = 25$ ) were mothers and 30.6% ( $n = 11$ ) were fathers. This encompasses both events that made acceptance easier, such as no mistakes were made and the child had little pain, as well as choosing to let go and accept the things that happened. Perceiving the child’s care from health workers as good and supportive was also salutary for some parents. Factors about the disease and the cause of death was also helpful for some parents, such as the fact that their child had little pain, did not choose to die or die from a criminal act. Trusting that they as a family did everything in their power to aid the child was also perceived helpful: “[what helped was] thinking about the fact that we did as much as we could for him. We filled him with love and helped night and day”; “I regret nothing/have no guilt. I know that we did everything in our power for our son. We gave everything. Nobody can demand any more than that”; “We got to show her how much we appreciated her, and got to do many nice things together”. The relief that their child's pain was gone was also helpful for some parents in the grieving process. Some parents expressed how accepting the situation in spite of frustrating events helped them:

We have been realistic and understood that this happened. We chose not to use more energy on the things we can’t control. There have been frustrating and irritating episodes in the disease period – was the treatment and care good enough? It took a lot of energy while the child was alive. [We] chose to not focus on this, [as] we won’t get our child back.

### ***Painful memories***

Over a third of the parents ( $n = 59$ ; 39.9%) considered painful memories to be hindering the grieving process. Of these, 42 (71.2%) were mothers and 17 (28.8%) were fathers. The thought of the child's pain and not being able to take away that pain was tough for many parents: "The hardest part was probably to see the death anxiety of my daughter, and not being able to take it away"; "I can miss my girl, and in time I can live with that, but to think about what she went through the last weeks is painful"; "The fact that we had to see the severe pain he was in during the disease period and when he was dying. I have trouble sleeping at night, get flashbacks – horrible episodes where he screamed in pain has set in my memory, and makes it difficult to find peace". Some parents expressed that the painful memories were especially strong the first years: "The fact that she got so sick and lost function after function has been difficult to bear – it was like a movie that ran almost constantly the first years"; "The first year the thought of all the painful stuff he experienced went on and on in my head." Parents also mentioned different feelings complicating the grieving, like disappointment that there was nothing to do about the illness, guilt, bitterness, regrets, and doubt about the decisions made during illness. Many parents also expressed that complications and mistakes made by health care professionals made the grieving harder; "I think a lot about all the mistakes that were made during treatments and complications that could have been avoided."

### **Going forward in life**

This theme captures the focus on how life is now and the life ahead rather than looking at the past. It includes both returning to everyday life with work, leisure activities, caring for surviving children, handling extra loads and the fact that the grief and memories of the child is a part of life ahead.

### ***Living everyday life***

About one-third of the parents ( $n = 48$ ; 32.4%) expressed that different aspects of daily life and activities were helpful in the grieving process. Of these, 35 (72.9%) were mothers and 13 (27.1%) were fathers. Many parents mentioned activities such as work, physical activity, leisure activity, study and chores as helpful. Some parents elaborated their answer, claiming activities helpful because it made them look ahead and live life: "In the early days it was important to engage in some projects to focus on the life ahead and not backwards"; "To be able to live, laugh, experience, seek adrenaline in a positive way after a long and intense

disease period [helped]”; “Work and outdoor life. Dare to take life back.” Other parents expressed that activities helped them thinking about something else than the grief itself: “[what helped was] Going back to work quickly, just to get other thoughts”; “When you are at work you think a little about it, and then you think about other stuff regarding work.” Some parents also expressed the benefit of having other children that needed them, which gave them no other choice than to focus on life here and now and gave them reason to keep on living: “Remembering that the ones who still live (siblings) also matters makes it easier to focus on life going on”; “My biggest ‘help and therapy’ has been my little son, who has been the reason for getting up every single day, get out of the house and do all the ‘normal stuff’”; “I am very grateful that we had a surviving child when our sick child passed, life with the surviving child forced us to have a life right now.”

However, some parents ( $n = 19$ ; 12.8%) wrote about extra loads in their life that made the grieving more complicated, such as having troubles at work, getting back to everyday life too soon, lacking economic support for sick leave and family members who are struggling after the loss that needs them.

### ***Living with grief***

Another element in going forward was accepting grief as part of life, which more than half of the parents ( $n = 77$ ; 52.0%) expressed in some way. Of these, 50 (64.9%) were mothers and 27 (35.1%) were fathers. The parents communicated the importance of acknowledging that the grief will never pass, which meant that they have to learn how to live with their grief: “We have to – and want to – live with the grief and loss of the child”; “Learn to live with the loss and emptiness, because life goes on anyway.” They felt the child's presence in their life and found comfort in talking about and with the child. Another important aspect mentioned as helpful by some parents was frequent visits to the graveyard. Some parents mentioned the comfort in the belief that the child is in a better place and that they will see each other again. Many parents expressed that looking back at good memories with the child as well as the painful memories was salutary. Focusing on the positive and healthy aspects of life and being grateful for the life of their child was emphasised: “Good memories from the time we had together means a lot”.

Two mothers and two fathers (2.7%) had issues with the term “to have worked through the grief”. They claimed that one never entirely works through the grief and felt that working through the grief implies forgetting their child: “It [the grief] is with me every day – fortunately – and sometimes I think that working through the grief equals forgetting”; “To

have worked through the grief, I understand what it means, but it is about living with [the grief], going forward with [the grief]" Furthermore, they stated that the intensity of the grief shifts and gets milder with time: "The grief does not go away, but it changes with time. Then it is possible to carry it in the life forward, without having a constant, painful weight inside." Some parents ( $n = 20$ ; 13.5%) wrote that time helped them in their grieving. Nevertheless, some parents stated that the ache and missing of the child are just as intense, and sometimes even more intense with time. Learning about grief from health professionals, being open to their own grief, reflecting, writing and taking time for oneself was claimed helpful by parents.

### **Relationships – a resource and a barrier**

The theme "*relationships – a resource and a barrier*" encompasses that the experience of social support can facilitate better coping for the individual in their grieving process and at the same time relationships can also be seen as a barrier in the grieving process. Efficient social support was perceived helpful, while lack of social support or complicated relationships was perceived as hindering the grieving process.

### ***Social support as a resource***

More than two thirds of the parents ( $n = 108$ ; 73.0%) expressed that social support was helpful to them in the grieving process. The answers differed between some parents naming different sources of social support, and other parents writing about how social support had helped them, or the qualities of the support that they viewed as helpful. The most common source of social support was family, ( $n = 70$ , 47.3%), including partner, sibling, parents and surviving children. Of the parents viewing social support from family as helpful, 46 (65.7%) were mothers and 24 (34.3%) fathers. Other sources of social support the parents mentioned helpful was friends & co-workers ( $n = 52$ , 35.1 %), professional helpers & support groups ( $n = 39$ , 26.4 %), other bereaved parents ( $n = 9$ , 6.1 %) and pets ( $n = 5$ , 3.4 %). Qualities of the support that the respondents viewed restorative were the conversation, care, support, stability in relationships, understanding, shared experience: "Conversations with my wife and close family, the fact that friends ask questions, knowing that they remember what happened and is caring"; "Good friends and people around me who are patient and understands if I have a rough day"; "The best has been to talk to other people that have went through the same. We speak the same language." Some parents expressed the need to talk about the deceased child and viewed this as salutary: "Being together with friends have been important, and that they dare to talk about her"; "To tell my story to different health care personnel, family and

friends. Some processing every time we talk about her”. Learning about grief from health professionals was claimed helpful for several parents. They discovered that grieving is an individual process with no right or wrong way to grieve and that it can take different forms. Being met by professionals without perceptions of how one should act was expressed helpful: “The psychologist based the conversation on how I was feeling, not how I should be feeling.”

### ***Lack of social support***

Although many parents found relationships helpful in terms of social support, some of the parents ( $n = 31$ ; 20.9%) expressed that relationships were a barrier to the grieving process, either in the form of experiencing lack of support or having troublesome relationships. Of these, 35.5% ( $n = 11$ ) were fathers and 64.5% ( $n = 20$ ) were mothers. Some parents experienced less social support than they expected, both from family, friends and professional helpers; “We have many friends. But after the funeral it got really quiet. That was difficult and unexpected”; “The complicating factor is going a whole year without anyone offering professional help. There was nobody in the health care system that did anything, not even the general practitioner (GP). There should have been someone who understands you’re in shock after losing a child”. Some parents ( $n = 7$ ; 4.7%) experienced difficulties in their romantic relationships or breakups and viewed this as something that hindered the grieving process.

## **Discussion**

This study aimed to examine helpful and hindering factors for the grieving process in cancer-bereaved parents, using a qualitative design. Three main themes were identified, and each main theme was organised in two sub-themes. The first main theme was “Memories of the disease period and death”, with the sub-themes “acceptance” and “painful memories”. Acceptance of what happened and how it happened was important factors to help parents move on. On the other hand, holding on to painful memories made the grieving harder. The second main theme was named “Going forward in life”, including the sub-themes “Living everyday life” and “Living with grief”. Continuing life without the child’s physical presence, as well as keeping in mind that the grief and the child always will be a part of the parents’ life, was important helpful factors in this respect. The last and largest theme was named “Relationships – a resource and a barrier”, including the sub-themes “Social support as a resource” and “Lack of social support”. This theme stressed the importance of social support as a helpful factor, as well as the negative aspects of lacking social support as a hindering factor in the grieving process.

### **Memories of the Disease Period and Death**

Remembering both positive and negative memories of the disease period with an accepting attitude, were perceived as helpful for the grieving process of cancer-bereaved parents. Remembering memories of the disease period can be understood as a loss-oriented coping (Stroebe & Schut, 1999), and accepting what happened fits with the different models of meaning-making as a way of coping with stressful life-events (Neimeyer, 2019; Neimeyer et al., 2002; Park, 2010). Resilience has been suggested as an intra-individual protective factor in bereaved parents (Albuquerque et al., 2018b; Vegsund et al., 2019). Perception of self, a sub-component of resilience, involves the ability to trust one's decisions (Vegsund et al., 2019), and may be related to the ability to accept memories of the disease period. Several parents expressed that believing they as a family did everything they could for their child helped them move on, which is in line with Vegsund et al.'s study. These parents may have experienced post-traumatic growth, which has been associated with resilience (Albuquerque et al., 2018b). On the other hand, other parents experienced painful memories with a high degree of distress, especially when they could not stop thinking about these memories. This made the grieving process more difficult. One could interpret this as an expression of having too much loss-oriented coping, which has been related to poorer adjustment after the death of a child (Albuquerque et al., 2017). Rather, being able to shift between loss-oriented and restoration-oriented coping has been related to a more positive outcome following the loss of a child (Albuquerque et al., 2017), in line with the dual-process model of coping with losses (Stroebe & Schut, 1999). Interestingly, there were no clear gender difference in coping style in the present study, contrasting existing knowledge in this area (Alam et al., 2012; Stevenson et al., 2017). The current study had a larger sample than the previous studies, which may indicate that their findings are coincidental. In addition, Norway is known as a country where the equality movement has come a long way, and the results of the current study may be an effect of this. In summary, the results of the current study support intra-individual factors such as perception of self and a flexible coping style, as important helpful factors in the grieving process of cancer-bereaved parents.

Parents in the current study reported that perceiving the child's care from health professionals as supportive, helped the grieving process. For instance, knowing that the child received the best possible treatment possible was experienced as salutary, and thus made it easier to accept the things that had happened. In contrast, doubting medical decisions and being aware of mistakes that were made, led to more bitterness and regret, thus made accepting more difficult. Parents' perceptions of the quality of the medical treatment of their



child has also been related to adjustment following the death of their child in other studies (McCarthy et al., 2010; Hovén et al., 2020; Van Der Geest et al., 2014). Also, circumstances such as the child being in severe pain and distress made participants of the current study experience painful memories. In light of the meaning making model (Park, 2010), one could assume that perceptions of the child's care and severity of pain and distress in the children increase the discrepancy between the parents' situational meaning and global meaning, which in greater sense challenges the bereaved parents' coping resources. Some parents even reported PTSD-symptoms, such as years of flashbacks and sleep problems following a painful disease period. Bereaved parents are at risk of developing PTSD (Ljungman et al., 2015), and it would be plausible to hypothesize that experiencing one's child in severe pain might be a risk factor. Taken together, the quality of health care and degree of child suffering in the disease period, may be understood as situational factors, as well as intra-individual factors important for the outcome of the parents' adjustment following the death of their child.

### **Going Forward in Life**

Being able to get back into living a "normal" life with work and other daily activities seemed to help many parents, as it was reported by one third of the participants in the present study. It helped them stay in the present and look forward instead of being lost in the past. In light of the dual-process model, these factors seem to relate to a restoration-oriented coping style (Stroebe & Schut, 1999). It could also be interpreted as having "worked through" and "detached" from the loss, in line with Freud's theory (Archer, 2008). However, parents reported shifting between thinking about one's loss at work and thinking about work tasks in the present, indicating that the loss was still in their mind. Also, as previously shown, the results of this study showed the helpfulness in having positive memories from the disease period (i.e., not detaching completely from the deceased). Taken together, these results further support the positive effects of shifting between a loss-oriented and restoration-oriented coping style (Albuquerque et al., 2017).

However, circumstances of continuing normal life could also make grieving worse. Some parents reported increased distress of getting back to work too soon, having workplace conflict, lacking economic support from sick leave or having other struggling family members. One study suggest that grief processing can be more intense in the first months after the death of a child (Bonnano et al., 2005). Studies also indicate that there are individual differences in parents' grieving process (Lannen et al., 2008; Morris et al., 2019), which could explain why some parents were ready for work sooner than others. Other evidence has also

found that the economic situation of cancer-bereaved parents has been associated with prolonged grief and depressive symptoms (McCarthy et al., 2010). Thus, while being able to focus on other aspects of daily life might help cancer-bereaved parents cope with their loss, individual and situational factors might also seem to cause distress in a way that makes coping more difficult.

More than half of the participants in the present study reported that living with the grief was both necessary and important as a way to help moving on in life. They felt a comfort in both remembering positive and painful memories, and also to keep talking with the deceased child, as if she/he was still there. Being grateful for the time they had together was also helpful. These reflections seem to support the notion of continuing the emotional bond with the deceased as a way of healthy adjustment following loss (Field, 2008; Foster & Gilmer, 2008), which has been indicated as an important factor in several studies (Barrera et al., 2009; Foster et al., 2011; Gerrish & Bailey, 2020; Proulx et al., 2016; Snaman et al., 2016b). The parents may also be seen as having facilitated a meaning reconstruction (Neimeyer et al., 2002; Park, 2010) or post-traumatic growth (Calhoun et al., 2010), in the sense of accepting and integrating the loss experience in their life. Some parents even reported frustration with the term “having worked through their grief”, feeling that this term implied forgetting the child. These considerations further challenge the aim of detaching with the deceased in Freud’s theory of bereavement (Archer, 2008).

Some parents in the present study reported that the grief declined with time. Time since loss has also been found to be a helpful situational factor in other studies, such as a reduction in symptoms of anxiety and depression seven years after loss (Kreicbergs et al., 2004), having come to terms with their grief six years after loss (Vegsund et al., 2019), and having a reduction of PTSD-symptoms five-years after loss (Ljungman et al., 2015). However, what makes time helpful can be a question of debate. Does time itself heal wounds, or is it a more complicated process also involving both intra-individual and inter-individual factors? The latter seems likely, especially in light of the great individual variety in psychological adjustment following the death of a child, with some people struggling for years, developing complicated grief reactions (Lannen et al., 2008; Morris et al., 2019). Nevertheless, the evidence may suggest that grief takes time, even for the parents being able to adjust well to their loss.

### **Social Relationships – a Resource and a Barrier**

Over two-thirds of the participants of this study reported social support as helpful for the grieving process, making it the largest helpful factor. Support from family was considered especially important, and there was no clear gender difference in sources of social support, contrasting the study of Kreicbergs et al. (2007). Support from friends and health care professionals, as well as contact with other bereaved parents and pets was also a helpful factor for parents in the current study. This is in line with a large body of evidence suggesting that social support is a major protective factor for the adjustment of cancer-bereaved parents (Alam et al., 2012; Barrera et al., 2009; Kreicbergs et al., 2007; Snaman et al., 2016a, 2016b). On the other hand, participants of the present study reported lack of social support as a factor making the grief more difficult to handle. A lack of communication and isolation from friends and family have also been found to make the grieving more difficult in previous studies (Barrera et al., 2009). Interestingly, some participants experienced a high degree of social support to begin with after the death of their child, but that ended after the funeral. These parents seemed to experience the silence and lack of support as painful. This may underpin the importance of prolonged social support over time, instead of only for a short period after the loss.

While support from family seemed to be the most reported helpful factor for the grief process in the present study, other evidence found a significant negative correlation between family cohesion and parents having come to terms with their loss (Vegsund et al., 2019). In contrast, another study found social support of family members to be one of the most important protective factors (Kreicbergs et al., 2007). As family cohesion is characterised by strong emotional bonds between the family members, one may speculate that the experience of losing a child may cause severe disruption to these emotional ties, causing more distress for the parents. However, more exact explanations for why family cohesion may hinder the grieving process for some, and family support being helpful for others, merit further research.

### **Implications**

The findings of the present study may guide both practitioners and researchers in their field of work related to cancer-bereaved parents. It may also help practitioners look for factors identifying cancer-bereaved parents at risk for more distress, as well as parents with a more positive prognosis. Practitioners may also become more aware of which factors that are important to facilitate in helping parents work through their grief. For instance, encouraging parents to engage in flexible shifting between loss-oriented coping and restoration-oriented

coping might bear fruits, especially in parents with a predominant coping style in only one direction. Encouraging the parents to get back to a normal daily functioning, while both remembering past memories and continuing the bond with their deceased child, might also be helpful. However, the findings of the study implicate that some parents' distress increases if this process is rushed, implicating a customised approach for each parent. Further, parents with a limited social network or lack of social support should receive special attention, in light of the large body of evidence showing that most cancer-bereaved parents benefit strongly from social support. If parents experience limited support from their families and friends, helpers might encourage parents to seek social support in their network, getting help from professional counselling or meeting other bereaved parents. However, it should be underpinned that there is no "right" or "wrong" way to grieve, implicating that practitioners should not force different coping techniques on parents, even though some strategies or factors may be more empirically supported than others.

### **Strengths and limitations**

The results of this study add to the current knowledgebase on how cancer-bereaved parents adjust following the death of their child. Using a qualitative approach to analyse a large number of parents' open responses on helpful and hindering factors in their grieving process, is an innovative mix of quantitative and qualitative methods. The findings discovered important themes related to the participants' coping, as well as analysing how these were distributed in the sample, thus discovering which themes were more and less frequent. The data for the current study is nationwide including responses from parents from all over Norway, which increases the generalisability of the results. It is also the first study exploring this subject with respondents from Norway. These factors can be considered strengths of this study.

However, this study also has several limitations that needs to be addressed. First of all, it has a cross-sectional design and parents are asked to look back to what helped them or made it more difficult. Their responses could be influenced by many aspects (e.g., how they were feeling when they responded to the questionnaire), making the study at large risk of recall-bias. Therefore, the findings of this study should be reviewed with caution.

There are some limitations regarding the use of open-ended written responses in this study. Written responses yield less information than interviews, and the participants could choose not to answer the open-ended questions. The fact that some parents did not answer the open-ended questions is a concern regarding biased answers. The parents who chose to

answer the open-ended question might have some specific qualities, and information from the parents who did not answer the open-ended question may have altered the results. However, the possibility to include more participants in qualitative analysis of written responses strengthens the study. In addition, the answers were not influenced by an interviewer's presence or interests, which could make the answers less biased.

Although this was a nationwide study, there was a low response rate (34.8%). Therefore, many bereaved parents who were invited to participate did not partake in the study, which could mean that the sample is even more biased. There might be particular features in the group who chose not to participate in this study, such as a higher rate of parents not coping well with their loss and lack the energy to reply such a large questionnaire.

The question "Is there something in your child's disease period or death which has made your grief difficult to work through?" has several limitations. First of all, the question is closed, which resulted in many parents answering "no" to the question. Additionally, the question limits the parents' answers to factors about the disease period and death. However, many parents answered other factors outside of the disease period and death of the child (e.g., complicated relationships), which suggest that this question is too limiting. There is a possibility that some respondents have several ideas about what made the grieving more difficult but did not write about that because of the formulation of the question.

The gender balance between mothers and fathers in the whole sample and in the respondents answering the open-ended questions examined in this study was approximately one-third fathers and two-thirds mothers, which make this study somewhat biased towards the mother's views on what is helpful and challenging in the grieving process. Additionally, the study was conducted in a high-income country, which further limits the study's generalisability.

## **Conclusion**

The present study set out to examine cancer-bereaved parents' perceptions of factors helping or hindering the grieving process after the loss of their child, based on thematic analysis of open-ended responses from a large number of Norwegian parents. Three main themes were identified: (1) Memories of the disease period and death, including both the salutary process of accepting what happened, and painful memories making it difficult to move on; (2) Going forward in life, including both the helpfulness in getting on with daily life activities, as well as acknowledging that the grief will always be a part of life; and (3) Relationships – a resource and a barrier, including how social support helped the grieving

process, while difficult relationships and a lack of social support hindered the grieving process. The results support the perspective of going forward in life and at the same time accepting grief as a part of life, in contrast to the goal of “getting over” or “detaching” from the deceased. Both looking back at memories of the child and continuing the bond even after its death seems like important factors in making parents integrate the loss in their lives, and hence live on with their grief. In addition, social support seems to be a major helpful factor for bereaved parents, supporting existing empirical evidence. The findings of the present study can help health care professionals support cancer-bereaved parents to a larger degree, providing important insight into central factors influencing their grief process.

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