



An exploration of spousal caregivers' well-being after the death of their partners who were older cancer patients – A phenomenological approach

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ABSTRACT

Purpose: The aim of this study was to gain more insight into the psychosocial well-being of the recently bereaved spouses who took care of their partners with cancer.

Method: A qualitative study was developed, taking a phenomenological approach. Eleven former caregivers and spouses of patients who died of cancer at, or after, the age of 64, participated in individual in-depth interviews. Only caregivers who were bereaved for a minimum of three months and maximum of one year were interviewed. The analysis of the data was based on the Qualitative Analysis Guide of Leuven.

Results: The first moments of bereavement included feelings of disbelief, regret and relief. A feeling of being overwhelmed during this time was reported by some, others sought distraction from their grief. Loneliness, emotional fluctuations and a sense of appreciation for the support of loved ones were dominant themes. Also, gratitude and the importance of consolation played a role in the participants' well-being. When participants addressed the matter of moving forward in life, most explained how they wanted to keep the memories of their partner alive while rebuilding their lives.

Conclusions: The present study offers insight into the experiences of the bereaved spousal caregiver and highlights the need of social support during the bereavement period. All participants expressed loss-oriented and restoration-oriented coping strategies. Also, loneliness is considered a dominant feeling throughout the bereavement period. Social contact can ease these feelings of loneliness through providing either distraction or possibilities to share the burden. This paper emphasized the importance of improving access to healthcare professionals during bereavement.

1. Introduction

Being the caregiver of a dying loved one is complex and significantly impacts the caregiver's mental, physical, and social functioning. Caregiver burden - "a subjective experience that the individual perceives as stressful and occurs when an imbalance exists between caregiving demands and caregiver resources to cope with those demands" (Hsu et al., 2014, p 2927) - is therefore experienced by most caregivers. Providing care is often reported as stressful and difficult. Partners especially embrace the caregiver role, often with limited opportunity to do otherwise (Kim et al., 2008). Spousal caregiving also causes changes in caregivers' perceptions of their relationship: reciprocity of the relationship may decline, making the acts of helping more burdensome (Poulin et al., 2010; Pusa et al., 2012). However, helping others may improve caregivers' well-being. For instance, it may

increase levels of satisfaction and meaning in life (Kim et al., 2014). Caregiving can also be associated with many positive affects like companionship, fulfilment, personal growth, and enjoyment (Boerner et al., 2004; Dumont et al., 2008; Kim et al., 2008).

Although caregiving stress may contribute to caregivers' depressive symptoms (Kim et al., 2014), the level of social support received can reduce these depressive symptoms (Pusa et al., 2012). Caregivers who have limited social networks are therefore more vulnerable (Raveis, 2007). In addition, providing care is often time-consuming and may lead to a decrease in social network (Visser et al., 2004). However, when the support of healthcare professionals is received, caregiver burden is found to decrease (Gilbar and Ben-Zur, 2002; Pusa et al., 2012).

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1.1. Bereavement

Losing a spouse causes many changes in different domains of life. The remaining partner experiences the loss of a companionship, income, and the loss of identity as a partner (Gilbar and Ben-Zur, 2002). Many theories have been constructed, attempting to define bereavement. Traditional grief models view bereavement as a systematized process involving several stages (Boerner et al., 2015). In the last decade bereavement theorists have moved away from these models, given the limited support for the existence of these stages and the significant variation in the way grief is experienced (Bonanno et al., 2005). A current model describes bereavement as a dual process (Stroebe and Schut, 2010). It suggests a continued interaction between loss-oriented coping and restoration-oriented coping. In loss-oriented coping, the bereaved mainly look for the presence of the deceased or try to find ways to keep the deceased present (Boerner et al., 2015). People with an extreme focus on keeping this static past alive have been found to show lower well-being than people who construct a self-awareness apart from the deceased (Torges et al., 2008). Restoration-oriented coping mainly entails experimenting with new roles and trying to sustain a functional daily routine. If the bereaved person lingers in the restoration-oriented coping sphere, psychological difficulties can also occur, due to insufficient engagement with loss-oriented coping strategies (Madsen et al., 2019). The continued interaction between these two modes of coping is necessary to achieve adaptive coping (Boerner et al., 2015; Hooghe et al., 2018). As supported by several studies, bereavement can be seen as finding a balance between deep bereavement and moving forward in life, proceeding through different transitions (Holtslander et al., 2011; Madsen et al., 2019).

Adapting to bereavement can be seen as allowing oneself to give up various dreams and beliefs for the future, bearing with the absences of the person in the present, and acclimating to new roles (Torges et al., 2008). When this acceptance and life review is successful, people are more likely to establish personal growth and higher levels of well-being (Bonanno et al., 2005).

1.2. Bereavement after caregiving

Individuals' attitudes towards stressful life events depends on how they balance risk- and protective factors (Pusa et al., 2012). A prolonged stressful period of caregiving can reduce coping resources (Boerner et al., 2004). Caregivers who suffered a lot during caregiving are more at risk of lower mental health during bereavement (Trevino et al., 2015). When caregivers reported difficulties with caregiving, they were also more likely to develop post-loss depression (Boerner et al., 2004). Previous research also emphasized that a more intense spousal relationship, with more time spent together, may lead to more profound bereavement (Fujisawa et al., 2010; Moriarty et al., 2015).

Spousal caregivers often feel lonelier after the death of their partner due to the absence of the time-consuming caregiving. Caregivers have to find new activities and roles in their daily-life (Holtslander et al., 2011; Madsen et al., 2019; Schulz et al., 2008). Due to the exhausting nature of the caring relationship, caregivers of cancer patients sometimes report more relief than severe grief after the death of the patient (Bass and Bowman, 1990; Boerner et al., 2004; Pusa et al., 2012).

In case of cancer, death is often expected which can indicate that the bereavement process already starts beforehand (Gilbar and Ben-Zur, 2002). Expectation of bereavement is seen as a predictor for better acceptance of death (Fujisawa et al., 2010). In addition, the study of Dumont et al. (2008) highlighted the need of becoming aware of the imminent death which contributed to better adjustment during bereavement.

1.3. Aim of the study

Previous studies about bereavement after spousal caregiving mainly

rely on quantitative data (Boerner et al., 2004; Bonanno et al., 2005; Fujisawa et al., 2010; Moriarty et al., 2015; Trevino et al., 2015). Therefore, the experiences of the bereaved are less thoroughly investigated. Qualitative studies can give a deeper insight into the subjective experiences related to bereavement after caregiving and can potentially have great value for the practical field (Creswell, 2007). Comprehending spousal caregivers' experiences regarding the bereavement after the decease of the patient can help develop targeted support to the needs of these caregivers both before and after the death of their spouse. Therefore, the aim of this study was to gain more insight into the psychosocial well-being of the recently bereaved spouse who took care of his or her partner with cancer.

2. Method

2.1. Study design

This study took a phenomenological approach, by the principles of Edmund Husserl (Bailey, 2013). This approach matched closely the aim of the study, which focused on close analysis of lived experiences of the spousal caregivers (Starks and Trinidad, 2007). The qualitative data was obtained through in-depth interviews. This study used 'Consolidated criteria for REporting Qualitative research' (COREQ) (Tong et al., 2007). This COREQ method contains a process of writing and rewriting to clarify meaning, in line with his phenomenological approach.

2.2. Participant selection

Participants were the former spousal caregivers of patients with cancer who died at, or after, the age of 65 years. In line with previous research (e.g., Francis et al., 2016; Gilbar and Ben-Zur, 2002; Holtslander et al., 2011), only caregivers who were bereaved for a minimum of three months and a maximum of one year were included in this study. To obtain various experiences, purposive sampling was used to find a mix of several participant's characteristics: gender, duration of the caregiving, time between their partners' death and the interview, type of cancer and place of death.

Participants were recruited through psychologists or social workers working with cancer patients or their caregivers affiliated to UZ Leuven (a university hospital in Belgium), and through the pastoral service connected to UZ Leuven. These professionals gave potential participants an information letter, including the researcher's contact details and more information about the study. After obtaining written informed consent of the participant, the interview was planned at the participant's preferred location, for example at their home. This study was approved by the Research Ethics Committee of the UZ/KU Leuven (MP006010).

2.3. Data collection

The interview questions were constantly revised until consensus between the researchers was reached. A test interview was conducted to improve the interview questions and to refine the researcher's interview techniques. The interview covered two major aspects: the caregiving and the bereavement process. In this paper, we will focus on the bereavement process. We made use of a small topic list drawn up in consultation with the research team (i.e., the co-authors). Each interview commenced with the start of the caregiving experience by asking: How do you experience the loss of your partner? The interviewer followed the narrative of the experiences brought forward by the informal caregiver as much as possible. Sometimes the researcher asked for elaboration on certain topics or prompted the informal caregiver to recount in more detail how they experienced things or when things were not clear. Audiotaped interviews were transcribed verbatim. In addition, field notes were made during the interview. The data

collected during interviews were anonymized. All interviews were conducted by one researcher (EVH), mentored by experienced qualitative researchers. A state of not knowing and open questions were applied by the interviewer, in line with the phenomenological approach. Data collection continued until data saturation was attained, meaning that conducting additional interviews no longer provided new insights.

2.4. Data analysis

The analysis of the data was based on the Qualitative Analysis Guide of Leuven (Dierckx de Casterle et al., 2012), a comprehensive, systematic, theory-based and practical guide optimizing the quality and trustworthiness of the article. The analysis was done by two researchers independently but with mutual agreement after each step (a nurse and final year master student of Science in Sexology, EVH, and a post-doctoral researcher in Medical Education and Primary Care, SP). The researchers did not only focus on comparisons of coding but also on different perceptions and readings of the data. Data saturation was achieved when no new themes were found in an interview by two dependent researchers (EVH & SP).

The inductive coding process consisted of two steps: (1) a thorough preparation of the coding process, in which the researchers first read and reread the interviews, made a narrative report, and a conceptual interview scheme which helped to increase a conceptual understanding of the data as a whole; (2) the actual coding process, in which each line of text was coded independently by the two researchers. The coding process was guided by a list of codes, which organised the descriptive and conceptual themes within a tree structure with different levels. This list was created within collaboration and mutual agreement of the two researchers.

3. Results

Data saturation was reached after 11 interviews. The interviews had an average length of 62 min (range 34–94 min) and were performed between November 2018 and February 2019. The participants lost their spouses between 3 and 12 months before the interview (an average of 7 months) due to various types of cancer: Kähler's disease, and brain-, intestinal-, kidney-, esophagus-, liver-, pancreas-, and prostate cancer. Participants took intensive care of their ill partner during 6 months–10 years, with an average of 2 years. Their average age was 76 years, ranging between 67 and 85 years. Of the 11 participants, 7 were women (63,64%).

Participants' well-being after their partners' death related to three major themes: (1) the first moments of bereavement, (2) grief in progress, and (3) moving on in life.

3.1. The first moments of bereavement

Participants felt disbelief in this first period after their partners' death. They were angry and sad about how the disease and the subsequent death of their partner could have happened. Some participants felt regret about how quickly the partner died or about certain decisions they made.

"I have now bought a lighter [car] model. And every time I get into that car, it is just like ... that I did something wrong ... Because he said I had to make sure I had a good solid car." (Participant 2, Female, 70 years old)

For all participants the first few days were very busy due to the many issues that had to be dealt with and the many visitors. The majority of the participants experienced this as overwhelming and difficult. Nevertheless, some participants also perceived this busyness as a distraction from their grief and sadness.

Participants were also frequently thinking about the last moments

with their partner, which was accompanied by a variety of different feelings. The presence of love and being able to say goodbye to their partner gave them consolation. Nearly all participants felt contentment with fulfilling their partners' wishes, e.g. about the funeral.

Some participants felt relieved after the bereavement as their partner did not have to suffer anymore. Additionally, several participants were also relieved that they had their rest and freedom back, as most participants perceived the caregiving as exhausting, both emotionally and physically. Also, the lack of sleep during the caregiving period had a negative influence on the physical and emotional well-being of the participants.

3.2. Grief in progress

A bit later after their partners' death, participants' well-being related to consolation, gratitude, loneliness, fear, emotional fluctuations, and consolidating support.

All participants experienced mixed feelings when confronted with the absence and memories of their partner. Although they missed their partner in nearly everything they did, participants also felt consolation and contentment when thinking about their partner. They were grateful for their long relationship and the love they felt for each other.

"I consider myself lucky to have known her for so long" (Participant 8, Male, 80 years old)

Nevertheless, loneliness was experienced by all participants after bereavement but also already before the partners' death. The care they provided to their partner brought with it high responsibilities and was accompanied by a lot of new tasks. In addition, the majority of the participants explained how they had to sacrifice certain hobbies due to the caregiving. Their life was completely devoted to the care of their partner.

"You are being lived. You live on automatic pilot." (Participant 3, Female, 77 years old)

Participants expressed having difficulties with the confrontation of the partners' absence and also the absence of the time-consuming caregiving. The house felt empty for them and activities were not experienced in the same way as before. Moreover, some participants already experienced loss of connection with their partner during the caregiving period. While some participants experienced a strengthening of their relationship during caregiving, some also explained the loss of meaningful communication with their partner. The main subject of their conversations became the disease which resulted in the participants' reluctance to talk about their own concerns. This made participants already feel lonely during the caregiving period, which continued in the bereavement period. Furthermore, some participants mentioned fear of cancer due to their partners' experiences.

"I am also a bit of a worrier now, now with my throat [that hurts]. The doctor said, 'I see nothing amiss'. Is it cancer? I do not believe it, but you still walk around with those thoughts." (Participant 5, Male, 87 years old)

Participants also mentioned their emotional fluctuations during the grief process. They expressed how memories could sometimes lead to moments of intense sadness, and on other moments consolation. Participants highlighted that these emotions could change quickly.

"I can be very happy and then suddenly, 10 minutes later, I can cry." (Participant 1, Female, 77 years old)

Furthermore, participants received a lot of support during the bereavement period, especially from family, friends, neighbours, psychologists, activities, household and family assistance, fellow sufferers, and pet animals. Participants gained courage, friendship and consolation from the support. They felt less isolated in this situation and could share the burden of grief with them.

“My oldest grandson was waiting for me ... That moved me. Otherwise my husband was always with me. He [grandson] must have thought ‘I am going to meet my grandmother halfway, then she will not be alone’.” (Participant 1, Female, 77 years old)

Having conversations about grief helped some participants to accept the death of their loved one. Nevertheless, not all participants expressed the desire to talk about their grief. Some participants explained how they avoided a confrontation with people who did not know about the decease yet. Still, talking to neighbours and participating in hobbies gave them a distraction from their severe sorrow. Participants also expressed how the weather had an influence on their well-being. The cold winter weather made them feel lonelier, as a result of being more alone inside their house.

Family was for all participants an important aspect of their support network. However, some participants tried to suppress their emotions for their family. Others explained how they did not want to be a burden for their family as they were afraid that their family felt obliged to take care of them.

“I am not going to do that to my children ... if I let myself go, I will not do anything anymore ... I would not want to be an additional burden for my children because I let myself go.” (Participant 8, Male, 80 years old)

Also, participants expressed that they tried to be distracted through activities or visits from family and friends. Some participants tried to avoid having conversations about their partners' death while others sought such conversations.

“You do not actively try to have that conversation either ... then you get emotional ... That's why I avoid that conversation.” (Participant 10, Male, 71 years old)

Furthermore, participants explained how they were confronted with the fact that life continued. Given that participants noticed that other people went through the grief period more quickly than themselves, it made them feel lonelier and less understood by others.

“I thought life would stop, but life just goes on. It is accompanied by a lot of pain, but it goes on.” (Participant 11, Female, 67 years old)

Participants expressed how their network reduced during this bereavement phase. On the one hand, participants mentioned how the professional support disappeared after the partners' bereavement.

“Firstly, the nurses stopped visiting ... He got a physiotherapist at home, also he did not visit anymore. The family doctor did not come anymore. So my social life of the last 2 years was suddenly gone. That was my social life, I had nothing more.” (Participant 2, Female, 70 years old)

On the other hand, participants also expressed having less friends as a result of losing their partner. Some people did not visit the participants anymore, while others did visit but could not talk about the grief. Therefore, the participants did not feel the need to continue those friendships. Although most participants did not mention this as a distress, it was felt as a reduction of their support network.

3.3. Moving on in life

Participants felt the need to keep memories of their partner alive. They did not want to move their partners' personal belongings, and they felt the need to continue their habits or the partners' habits as this made them feel closer to them. The desire for the partners' presence was mentioned by all participants. They mentioned that they still saw their partner, for example, sitting in the living room or talking to them in their dreams.

“Sometimes I think ‘he is inside [the house]’. But that is no longer possible. Although I wish it was.” (Participant 1, Female, 77 years old)

This presence was felt through the tangible remains of their loved

ones, e.g. their necklace or photograph. This was experienced as something that gave the participants courage. Participants also felt the loss of their partners' practical assistance. Participants, mainly women, explained how their partner always took care of the financial, administrative, and technical matters. Dealing with these tasks by themselves created an additional burden for the bereaved caregivers. However, they felt proud of themselves when they were able to solve problems without their partner. This gave them confidence that they could manage by themselves. Rebuilding their lives without their partner was a challenge for all participants. Learning how to be alone was experienced as one of the main difficulties.

“I cannot stand being alone ... Before, I always had someone, someone to say something to, but now I come in and it is just as if the walls are coming towards you.” (Participant 9, Female, 85 years old)

Participants wanted to move past their sadness without forgetting their partner, trying to accept their partners' death.

“I am learning to accept it [the loss] ... we have to move on, I will not forget you, but I cannot cry all day.” (Participant 8, Male, 80 years old)

Participants tried to put their situation into perspective by comparing themselves to others. They expressed that others have to go through a similar process too or even experience a worse situation than theirs.

Some participants mentioned how they had different expectations of this period after the decease. While some expected to feel more burdensome, others expected to have accepted their partner's death much sooner. These different expectations were accompanied with respectively contentment and disappointment.

“I thought it would have improved by now ... Everyone says that it is normal, but it has already been ... about 5 months.” (Participant 5, Male, 87 years old)

A few participants also expressed feeling changed through the disease trajectory of their partner. They indicated being less frightened of death and to take life 1 day at the time.

4. Discussion

In-depth interviews have revealed interpersonal differences in experiences of caregivers who recently lost their partner due to cancer. While describing the first days after the loss, participants strongly emphasized the busyness of their days. This was experienced as overwhelming for some, while others experienced it as a distraction. During the bereavement process, participants noticed both negative feelings, such as sadness, disbelief, regret, and positive feelings, such as contentment, gratitude, and relief. In addition, all participants mentioned loneliness. They highlighted support from their social network as an important factor for their well-being. Moreover, emotional fluctuations were considered to have a daily role in their life. They were trying to keep the memories of their partners alive through tangible remains, while being confronted with the fact that life goes on.

All participants in this study experienced loss-oriented and restoration-oriented experiences during bereavement, as explained in the model of [Stroebe and Schut \(2010\)](#). The emotional fluctuations that participants described can thus be considered as a normal aspect of the bereavement process, on the basis of the dual process model of coping with bereavement ([Holtslander et al., 2011](#); [Hooghe et al., 2018](#); [Madsen et al., 2019](#); [Stroebe and Schut, 2010](#)).

However, some differences were found between certain phases in the bereavement process. This study showed that there was variation in the perception of busyness during the first days after their partners' death. Most participants experienced it as overwhelming, which is in line with previous research ([Dumont et al., 2008](#); [Madsen et al., 2019](#)). Other participants experienced this busyness as a distraction from their

deep sorrow. In line with the model of [Stroebe and Schut \(2010\)](#), distraction from grief can be seen as an indication of restoration-oriented coping strategies.

Also, participants gained courage, friendship and consolation during bereavement from their social network. As shown by previous research ([Holtlander et al., 2011](#); [Torges et al., 2008](#)), social support is important through the process of finding balance, as it offers consolation and strength to cope with loss. Whereas some participants used their network to talk about their grief, others were seeking distraction through their social contacts. Overall, participants felt less lonely when they shared the burden of grief with others.

Loneliness was experienced by all participants and can be considered as one of the most prominent feelings regarding caregivers' well-being. Participants were confronted with the absence of the deceased and a reduced social network during bereavement. Due to the time-consuming caregiving, the absence of the partner and his or her healthcare professionals became more pronounced. As supported by the study of [Schulz et al. \(2008\)](#), the confrontation with the absence of the time-consuming caregiving can make caregivers feel lonelier. Previous research stressed that loneliness is a dominant feeling during deep bereavement after caregiving ([Madsen et al., 2019](#)).

In addition, some participants had more difficulties with accepting their partners' death than others. Previous research highlighted that participants who experienced a deep connection with their partner throughout the caring process, have more difficulties to adjust during bereavement ([Boerner et al., 2004](#)).

Nevertheless, some bereaved caregivers in this study reported feelings of relief after the death of their partner. In line with previous research ([Pusa et al., 2012](#)), participants highlighted that they felt relieved because of the absence of the exhausting caregiving tasks after their partners' decease.

4.1. Strengths & limitations

It was a strength of this study that all interviews were conducted by one interviewer, which limits the variation in the interviewing techniques. Another strength is found in the collaborative process used to analyse the results. The wide variation between participants can be seen as another strength of this study. Both male and female participants, who took care of their partners with different types of cancer, were included in this study. Although variation between participants is found, participants in this study mainly expressed positive experiences when asked about their partner relationship prior to the disease. It is possible that grief experiences would be different when a less positive relationship was expressed. Therefore, it could be a limitation that only informal caregivers with a good relationship with the patient were included in this study. Furthermore, participants were only recruited through psychologists, social workers and pastoral services affiliated to hospitals. It can be seen as a limitation of the study, that only caregivers who already found their way to professional help were included to the study. Future research should determine if the findings of this study would be similar if participants would be recruited through other organisations. Another limitation of the study was related to the phenomenological approach of the study. We have tried to write down the experiences of the informal caregivers as rich and complete as possible in their own words. Based on this, we have tried to keep our own interpretation to a minimal level by using a collaborative process. However, the narrative reports have not been proofread by the caregivers themselves, as a result of which the researchers' interpretation may have crept in. In this study, one participant did not consent to use the audio recording of the interview. Nevertheless, he consented to use the written data from the interview.

4.2. Clinical implications

This study emphasized the importance of social support during

caregiving and bereavement. As shown by the study of [Trevino et al. \(2015\)](#), support from healthcare professionals can result in better bereavement adjustment. This study highlighted the different perceptions bereaved caregivers can have of this support. Bereaved caregivers seek to share their burden, as well as distraction from their grief through their social contacts. Although healthcare mainly focuses on the caregiving process, nurses and other health care professionals can also provide support during the bereavement process. This can be achieved through a brief contact after the patients' decease with possibilities for targeted referral. Additionally, support from healthcare professionals can reduce the caregivers' feelings of loneliness. If more attention would be paid to the risk of loneliness and support would be offered, better adjustment to the new circumstances may be realised. Nurses, who are close to the caregiver, are in the best position to determine these risks and provide the support they require. By improving access to healthcare professionals during bereavement, bereaved caregivers' loneliness can be reduced.

5. Conclusion

This study highlighted prominent feelings of bereaved caregivers and their need of social support during the bereavement process. Loneliness is considered to be a dominant feeling due to the absence of the time-consuming caregiving and decreased availability of healthcare professionals. Social contact can ease these feelings of loneliness through providing either distraction or possibilities to share the burden. This study emphasizes the importance of facilitating access to support from healthcare professionals during bereavement. Bereavement adjustment might be enhanced, for instance, through brief moments of contact between the healthcare professional and the spousal caregiver.

CRedit authorship contribution statement

E. Van Hout: Visualization, Writing - original draft, Data curation, Investigation, Formal analysis, Validation, Methodology. **S. Peters:** Writing - review & editing, Formal analysis, Validation, Methodology. **L. Jansen:** Project administration, Writing - review & editing, Resources, Conceptualization. **P. Rober:** Writing - review & editing. **M. van den Akker:** Supervision, Funding acquisition, Writing - review & editing.

Declaration of competing interest

The authors have declared no conflict of interests.

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