



Walking a fine line: An exploration of the experience of finding balance for older persons bereaved after caregiving for a spouse with advanced cancer

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A B S T R A C T

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Purpose of the Research: During the past decade, research regarding cancer patients has become more prevalent, however research regarding the needs of their family caregivers is limited. The purpose of this study was to explore the ways in which caregivers, who survive the loss of their spouse to cancer, find balance in their lives.

Methods and Sample: A constructivist grounded theory approach was undertaken which included the analysis of in depth interviews, journal entries and the researcher's field notes and memos. Interviews were conducted with 10 bereaved caregivers (7- females, 3-males) ranging in age from 66 to 83 years old. The data included 21 interviews and 8 journals.

Key Results: For bereaved caregivers "walking a fine line" emerged as a major process, balancing between "deep grieving" and "moving forward" in order to successfully create a new life without their partner. The main concern of the participants was "losing control" of balance. The emergence of these processes reveals the importance of addressing the bereaved caregivers' need to find balance within their new lives.

Conclusions: The findings of this study highlight the unique needs of bereaved caregivers who have lost a spouse to cancer, and provides a basis for ongoing research focused on assessment and intervention. Further research is needed to determine whether the process of finding balance is similar in other groups of caregivers who are bereaved.

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Introduction

Bereaved family caregivers are considered to be an important part of the trajectory of cancer survivorship, as their lives have been and will continue to be affected by the cancer experience (Kim and Given, 2008). Cancer is a leading cause of death throughout the world (World Health Organization [WHO], 2009) and many family caregivers will face bereavement as a result of cancer deaths which are steadily increasing in proportion to an aging population (Canadian Cancer Society/National Cancer Institute of Canada, 2009). Family caregivers of cancer patients are often elderly themselves and frequently experience an intense trajectory of events during caregiving; ranging from symptom management, to steep declines at the end of the patient's life (Lunney et al., 2003). For the caregivers, this results in both physical and emotional strain (Kim and Schulz, 2008). Although providing support for bereaved

family members is included in international guidelines (WHO, 2002), the needs of family caregivers *after* the death of the patient have been mostly neglected in both practice and research.

Older adults have unique needs during bereavement, which may predispose them to many problems including increased mortality and morbidity (Kowalski and Bondmass, 2008; Stroebe et al., 2007). Finding balance in their completely changed lives is essential for bereaved caregivers as they navigate their way through coping with their grief and new life circumstances within a complex psychosocial context (Holtslander and Duggleby, 2010). In order to explore how older adults who are bereaved after caregiving understand and find balance during bereavement, the authors undertook a grounded theory exploration. To improve the quality of life and positive outcomes for these cancer survivors, it is key to understand the experience of finding balance for older persons who are bereaved following caregiving for a spouse who has died of cancer.

Background

A review of the research literature regarding bereaved caregivers revealed many challenges including intense grief and acute

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distress while facing a lack of support (Dumont et al., 2008; Ferrario et al., 2004). Specific aspects of their social context played a key role including caregiver age, health, social supports, the setting and circumstances of the death, and the length of caregiving (Addington-Hall and Karlson, 2000; Schulz et al., 2001). A number of studies revealed that hope is an important psychosocial resource that bereaved caregivers may utilize in order to face bereavement (Borneman et al., 2002; Herth, 1993; Holtslander et al., 2005). However, without the ability to find balance, the older caregiver may have difficulties in finding hope, and therefore, in experiencing positive outcomes during bereavement. In a study by Holtslander and Duggleby (2009), the bereaved caregiver participants defined finding balance as an important process to begin dealing with many negative and overwhelmingly difficult emotions and experiences.

Very little is known about the experience of finding balance for the bereaved family caregiver but it does seem to be an important process at the end of life. Several grounded theory studies have investigated “balance” in patients and their caregivers. In one study, patients with HIV/AIDS described a daily effort to balance hope, hopelessness, and despair (Kylmä et al., 2003). Balancing between hope and despair was an important finding in another study of 15 participants going through diagnosis on a gastroenterology ward (Giske and Artinian, 2008). Similarly, Thulesius et al. (2003) examined 57 caregivers, including health care staff in end of life cancer care and concluded that balancing is an important process in problem solving and in health care.

The process of coping with bereavement was described by Stroebe and Schut (1999) in their Dual Process Model. This model identifies two types of stressors, loss and restoration-oriented, and the dynamic, regulatory coping process of oscillation which shows the grieving individual at times confronts, at other times, avoids the different tasks of grieving. Caserta and Lund (2007) developed a 22-item Inventory of Daily Widowed Life to measure the oscillation between loss-orientation (LO) and restoration-orientation (RO). It seems that finding balance during bereavement would be an important step in coping with the many challenges experienced by bereaved family caregivers, and this has not been explored from a grounded theory perspective before. For the bereaved caregiver, finding balance is essential to enable them to navigate through rebuilding their lives. They must struggle to create their new identity while incorporating the experiences of the past, including caregiving, the environment of the present and the direction of the future. Hence, the overall purpose of this grounded theory study was to explore the experiences and processes of finding balance from the perspective of older bereaved caregivers of partners who had terminal cancer. Specifically, the aims were to: a) provide a conceptual overview of the experience and processes of finding balance for these participants; b) describe these definitions and processes within a social context; and c) construct a substantive theory of finding balance for this population. Originality of this study has been confirmed through a review of the literature, which revealed that finding balance has not been studied from the perspective of the bereaved spousal caregiver using the same methodology.

Method

Design

Constructivist grounded theory was chosen as it is well-suited for revealing complex processes within a social context, while acknowledging subjectivity and the authors' roles in collecting and interpreting the data (Charmaz, 2006). In depth interviews, field notes and written information from participant diaries were utilized to gather data. Analysis was based on deriving concepts,

conceptual categories, and identifying relationships between categories to produce an understanding of fundamental social processes. This form of analysis allows for the development of a substantive theory that is grounded in the lived experience of the participants.

Participants were gathered through purposive sampling using pre-established recruitment criteria including a range of ages over 60, a variety of caregiving experiences, and various support situations. This study reports on the interview data, as well as the data gathered through the journaling process, to construct an overall theory for finding balance.

Sample

The inclusion criteria consisted of the following requirements, men and women (a) aged 60 years of age and older; (b) who resided with and provided care for a spouse with terminal cancer who died within the last year; (c) English speaking; and (d) freely consenting to be a participant in a study about finding balance in bereavement. Participants who were unable or unwilling to talk to a nurse researcher were not included in the study.

Purposive and theoretical sampling strategies were used to reach saturation. Saturation was defined as theoretical completeness, when the data collected were rich and in depth and no new properties of the categories were being gained (Charmaz, 2006). Theoretical sampling narrowed the focus of the follow-up interviews to the emerging theory. Follow-up interviews were conducted, asking the participants about the processes and categories to fully saturate the properties of the emerging theory. Participants were asked to complete a daily journal after the first interview, which encouraged deeper insights into their daily lives, and provided a rich way to gather ideas to explore at the follow-up interviews.

Ten older adults, ranging in age from 66 to 83 years old participated in the study. Details about the participants, including demographic data, length of caregiving, and months of bereavement are contained in Table 1. Twenty-one interviews were completed and eight journals were collected and included in the data. Three participants were interviewed three times for confirmation of the emerging theory. Two participants were not willing to write in the journal provided and could be considered as contrast cases as they were having difficulty finding balance and expressing their feelings and thoughts in writing. However, the experiences of these participants were integrated into the emerging theory, adding depth and an important source of variation.

Procedures

This study was reviewed and approved by an institutional ethics review board. In addition, the local health region provided operational approval. Participants were recruited by the coordinator of volunteers from palliative care services and then, if they agreed, were contacted by the researchers. A written, informed consent was obtained by the nurse researcher prior to data collection. Participants had the opportunity to ask any questions before, during and after the interview process. In addition, participants were informed that their names would be removed from all given responses and journal entries and the results would be reported in a group format.

Data collection consisted of: (a) the completion of a demographic form which addressed questions such as age, gender and diagnosis of the spouse; (b) in depth, face to face, open-ended, audio taped interviews; (c) the completion of a journal over 2 weeks; and (d) the researchers' field notes and memos. The interviews took place in the participant's homes, in a small city in

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