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Exploring Aging-Related Stress Among Older Spousal Caregivers

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Abstract

The goal of this study was to explore aging-related stress among older spousal caregivers providing hospice care for an older adult with cancer. Cases were selected from an ongoing randomized controlled trial that involved audiorecorded visits with caregivers over four different time points. Recordings consisted of caregivers discussing caregiving problems and ways they attempted to cope. Four caregiver cases comprising 16 audiorecordings were qualitatively analyzed for aging-related stress during caregiving. Caregiving stress primarily involved the patients' cognitive deficits. The caregiving experience also made older caregivers aware of their own aging and physical limitations, heightened self-imposed expectations to fulfill their role as spouse, and led them to consider their own mortality. This study informs development of caregiver interventions aimed at addressing the reciprocal challenge of caregiving and aging.

An increasing number of older cancer patients are receiving care at home from an informal caregiver who is likely to be an older adult and spouse (American Cancer Society, 2013; Given & Grant, 2012). The reciprocal nature of the illness experience between patient and family caregiver exists among older spouses, where there is increased mortality risk as a result of caregiving burden (van Ryn et al., 2011). Caregiver burden has been found to be associated with more advanced cancer, elevated patient distress, higher caregiving demands, and a lack of caregiver resources, all of which characterize geriatric oncology care (van Ryn et al., 2011; Weitzner, Haley, & Chen, 2000). Although the care needs of geriatric oncology

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patients have been well documented, little attention has been paid to older spousal caregivers who often provide day-to-day oversight and care.

Older spousal caregivers provide more extensive and comprehensive care, maintain the caregiving role longer, experience more severe adjustment demands on lifestyle, and report greater burden and personal strain than younger spouses or other caregivers (Daly, Douglas, Lipson, & Foley, 2009; Haley, 2003; Hauser & Kramer, 2004). In addition to having an increased risk of depression (Haley, LaMonde, Han, Burton, & Schonwetter, 2003), older caregivers are more likely to have physical problems and a lack of financial and social resources (Covinsky et al., 2003). Cancer patients and their caregivers are least satisfied with prognosis information and information about pain management (Hannon et al., 2013), yet older spousal caregivers report that the demands of caregiving activity include providing emotional support and managing patient behavioral problems (Park et al., 2013). Currently, there are no clear interventions that address the caregiving role in light of aging-related comorbidities and functional changes (Given & Grant, 2012). With little known about aging-related stressors during caregiving, a case study approach was used to describe specific caregiving issues for older spousal caregivers of cancer patients receiving hospice care.

METHOD

The current study population was drawn from a larger ongoing randomized clinical trial aimed at demonstrating the feasibility of a problem-solving intervention for hospice caregivers. The study is informed by the Nezu and D’Zurilla problem-solving therapy framework (Nezu & D’Zurilla, 1989; Nezu, Nezu, & Perri, 1989), which is built on an approach labeled ADAPT (*attitude, define, alternatives, predict, try*), designed as a cognitive-behavioral intervention aiming to improve problem solving and coping skills. The study was conducted in two urban hospice programs in the western United States. Hospice caregivers were randomly assigned to either an attention control group or one of the two intervention groups where caregivers receive the ADAPT intervention face-to-face or via video. The intervention protocol consisted of three intervention visits made between Days 5 and 18 of the hospice admission, in addition to a brief exit interview and 40-day postintervention follow up. We selected cases from the larger study that consisted of caregivers who were 65 or older, providing care to a spouse 65 or older with cancer, and enrolled in the intervention group. The study was approved by the supporting university’s institutional review board.

The first session consisted of the first step of ADAPT, “attitude,” which encouraged caregivers to adopt a positive orientation to problem solving. The second session addressed steps two and three of ADAPT, “define” and “alternatives,” to define factors associated with the problem before setting realistic goals and help caregivers be creative in generating a list of alternative approaches to problem solving. The third session consisted of steps four and five of ADAPT, “predict” and “try,” asking caregivers to predict the consequences of each alternative to select an effective solution plan and prompting them to implement a solution plan to solve the problem. Finally, caregivers participated in an exit interview about their

perceptions of the intervention. The intervention discussions and exit interviews were audiorecorded and serve as study data.

Data Analysis

First, we listened to recorded intervention discussions and exit interviews and transcribed caregiver statements related to aging, including self-recognition of life span changes, and age-related changes and problems, such as lifestyle changes, as a result of deconditioning, chronic diseases, or other primary causes, and health concerns for them or their spouse. Next, transcript excerpts were inductively analyzed using a process of theme analysis (Creswell, 1998). Given that the goal of this exploratory study was to describe aspects of aging-related stress for older spousal caregivers, cases were combined and open coding of the excerpts was used to suggest themes. To establish validity, the data were independently coded by two individuals and discussed among members of the research team to resolve differences (Creswell, 1998).

RESULTS

At the time of analysis, six cases were identified from the larger study. However, two older caregivers were not spouses, and thus were excluded from the study. Overall, four cases were included, each with three audiorecorded intervention visits that were conducted face-to-face and an exit interview (a total of 16 audiorecordings). Two of these caregivers were recently bereaved at the time of the study. The average intervention visit was 37 minutes, and the average exit interview was 12 minutes. Mean patient age was 85.25, and mean caregiver age was 82. Three of the four caregivers were wives caring for their husbands, and all but one patient lived with their spouse (Table).

Cases depicted that caregiving stress primarily involved the patients' cognitive deficiencies rather than physical decline. Compromised due to disease or aging-related dementia, older caregivers reported that their spouses were easily confused and would not follow directions. Walter, a 96-year-old caregiver explained that his wife would get "ticked off" because "she doesn't understand what's happening to her.... It takes her mind sometimes." Eliza, who had been providing care for her 90-year-old husband for more than 3 years, admitted that her husband "doesn't really comprehend what hospice is all about" because his "short-term memory is gone." Memory loss and dementia were discussed as factors that created a more stressful environment for these older caregivers. Maive, a bereaved caregiver whose husband was diagnosed with lung cancer and brain tumors, explained that her husband didn't "know what they diagnosed and there's no way I could help him through that, and that really, really bothered me."

All four cases highlighted the complexity of decision making about patient placement in geriatric caregiving situations. Determining whether the patient should remain at home forced older spousal caregivers to question their ability to provide care, which complemented or contradicted recommendations from family and health care professionals. Uncertainty about quality of care was prominent for all caregivers, especially for Maive, who opted to move her husband to an assisted living facility. She felt responsible for not only moving him to the facility, but for taking "him out of this house," explaining that she

“didn’t want to make that decision.” Caregiver cases illustrated few options for older caregivers, and caregivers talked about few choices when it came to making decisions.

All of the caregivers talked about the challenge of addressing patient care needs while simultaneously experiencing declines in their own health. Challenges to meeting their spouses’ care needs were confounded by their own aging process, which was accelerated by caregiving.

Three of the four caregiver cases involved spousal care lasting for more than 3 years, and caregivers acknowledged that caregiving limitations were associated with their own aging. When asked to list an obstacle to care provision, Walter said, “my own health condition.” Cases depicted financial constraints that created limited care opportunities, heightening caregiver concern about the cost of care and challenges to long-term caregiving.

In all four caregiver cases, couples had been married for more than 20 years, and personal values about caregiving stemmed from their long-standing role as a married partner. In each case, spousal caregivers reflected on their own caregiving efforts and had a hard time accepting less-than-perfect performance or their failure to measure up to self-constructed expectations.

In every case, caregivers shared their thoughts on death, with some caregivers struggling more than others to accept their spouses’ death or their own inevitable death. Two caregivers talked about death as the end to suffering and in regard to their spouses’ pain from the prolonged death from cancer, which sometimes manifested in discussions about suicide. Caregivers also talked about their thoughts about a prolonged dying process, and described how they wanted to end their spouses’ pain. References to a prolonged cancer death included both its comparison to dying unexpectedly and the inability to be prepared for death.

DISCUSSION

Although this is an exploratory study of selected cases, limited by a lack of diversity within the sample, it provides a longitudinal view of caregiving among four older spousal caregivers of hospice cancer patients. The cases analyzed suggest that older spousal caregivers experience distinct aging-related stress during caregiving. Although we do not know if the patients in this study had been diagnosed with Alzheimer’s disease or had an underlying dementia, cognitive deficiencies created additional stress for older spousal caregivers. Caregiving for different diagnoses can yield varying experiences, and geriatric syndromes occurring among older cancer patients in addition to disease progression may create higher burden for older spousal caregivers. Unlike most oncology caregiving research that has identified education, communication, and information with providers as deficient yet needed for caregiving (Cagle & Kovacs, 2011), older spousal caregivers in this study were mostly concerned with their own ability to provide care.

Although previous research has shown that geriatric oncology patients lack knowledge about their medications and lack practices for safe medication use (Si, Koo, Poon, & Chew, 2012), none of the caregivers in this study reported problems with pain medication management or

administration. Rather, caregivers described their own psychological pain from observing the suffering of their spouse and descriptions centered on the patients' existential and psychological pain. Pain management has previously been found to be problematic among hospice cancer patients (Mayahara, 2011), yet older spousal caregivers may have differing needs than younger caregivers when it comes to pain management.

The coexistence of system alterations and comorbidities can lead to reduced functionality that makes it difficult for older patients to adapt to stress (Bozzetti, 2011). Caregiving stress was similarly portrayed in these four cases by caregivers who worried that their own aging would impede their ability to provide quality care. The negative impact of the caregiving role on their own mental and physical health concerned older caregivers in the current study. Older patients often experience sensory deficits, cognitive impairment, and functional deficits, yet there has been little research to explore these issues among caregivers.

CLINICAL IMPLICATIONS

Findings from the current study caution providers to reflect on their own caregiver assessments and practices when providing care. Attention should be given to the age of the patient and the caregiver when developing care plans and discharge directions. All aspects of the caregiving situation should be accounted for, including physical and psychological factors. An interdisciplinary team of providers is necessary to provide quality geriatric care to patients and caregivers, and future research should include assessment of older spousal caregivers to ensure that quality care can be provided in the home. Understanding the factors that contribute to caregiver burden for older adults caring for geriatric oncology patients can inform the development of interventions targeting in-home care settings, such as hospice. Special considerations for older adult spousal caregivers could lower caregiving burden and increase awareness of geriatric principles in hospice care.

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TABLE

Summary of Caregiver and Patient Characteristics

Characteristic	Caregivers (<i>n</i> = 4)	Patients (<i>n</i> = 4)
Mean age (years)	82	85.25
	<i>n</i> (%)	
Sex		
Female	3 (75)	1 (25)
Male	1 (25)	3 (75)
Race		
Caucasian	4 (100)	4 (100)
Education		
High school/GED equivalent	1 (25)	
Some college/trade school	2 (50)	
Graduate/professional degree	1 (25)	
Employment		
Full time	1 (25)	
Retired	3 (75)	
Patient residence		
Private residence with caregiver		3 (75)
Assisted living facility		1 (25)
Length of time providing care		
2 to 5 months	1 (25)	
3 years	3 (75)	
Amount of care provided		
11 to 20 hours per week	2 (50)	
>20 hours per week	2 (50)	

Note. GED = general educational development.