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# Caregiving at the end of life: Perspectives from spousal caregivers and care recipients

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## ABSTRACT

*Objective:* The purpose of this study is to examine the perspectives of both the spousal caregiver and care recipient on the caregiving experience in home-based palliative care.

*Methods:* A qualitative research strategy involving home-based face-to-face interviews with older palliative care patients and their spousal caregivers was used to examine the caregiving experience.

*Results:* Ten spousal caregivers and care recipient dyads participated in the study. Most informal caregivers viewed caregiving as an extension of the family relationship where caregiving responsibilities evolved over time. Spousal caregivers identified many negative reactions to caregiving, such as fatigue or weariness, depression, anger and sadness, financial stresses, and lack of time. Care recipients acknowledged the emotional and financial strain and expressed concern for their spouses. Both caregivers and care recipients were appreciative of home care services although they identified the need for additional services. They also identified difficulties in communication with formal providers and poor coordination of care among the various services. Both caregivers and care recipients disclosed some challenges with informal supports, but on the whole felt that their presence was positive. Additional positive aspects of caregiving reported by spouses included strengthened relationship with their spouse and discovering emotional strength and physical abilities in managing care.

*Significance of results:* Health care and social service professionals need to recognize and understand both caregiver and care recipient perspectives if they are to successfully meet the needs of both members of the dyad.

**KEYWORDS:** End-of-life care, Family caregivers, Care recipients, Qualitative interviews, Home-based palliative care

## INTRODUCTION

Discussions about terminally ill patients and their families often focus on how to maintain people in their own homes (Stajduhar & Davies, 1998; Ross

et al., 2002). Because the primary carer of a terminally ill person is often a family member, it is important to understand the impact of caregiving on their lives (Addington-Hall & McCarthy, 1995; Payne et al., 1999). Several studies have documented the burden for family members who are often ill prepared for the level of care required by a terminally ill person. The resultant burden can have significant psychological, physical, and finan-

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cial consequences for family caregivers (George & Gwyther, 1986; Bowles et al., 2000; Aranda & Hayman-White, 2001; Wennman-Larsen & Tishelman, 2002; Hauser & Kramer, 2004; Waldrop et al., 2005).

Although an essential principle of palliative care is that the patient and his or her family comprise the unit of care (Ferris et al., 2002), the majority of studies on this topic often neglected to examine both perspectives of the caregiving experience. Lyons et al. (2002), who compared these two viewpoints, found that caregivers often reported higher levels of caregiving difficulties and lower amounts of support than care recipients. Relatively little has been written about care recipients' views about the caregiving experience, as it has been generally assumed that caregiving has a positive impact on the health of the care recipient. There is some evidence that the caregiving experience can have negative mental health implications for the care recipient in situations where the caregiver offers too much unnecessary help and not enough necessary help (Lehman et al., 1986; Thompson et al., 1989).

The purpose of this study is to examine the perspectives of both the spousal caregiver and care recipient on the end-of-life caregiving experience in home-based palliative care. The findings can provide valuable information to help in the planning and development of community-based programs tailored to improve the caregiving experience for both caregiver and care recipient.

## METHOD

### Study Design and Participants

A qualitative research strategy involving home-based face-to-face interviews separately with palliative care patients and their spousal caregivers was used to examine the caregiving experience. Inclusion criteria were that the care recipient be 50 years of age or older, be receiving home-based palliative care, and that the spousal caregiver and care recipient could communicate proficiently in English and provide informed consent. Participants were drawn from a larger population of caregivers who had participated in a study that examined care of the terminally ill in the community (Care of the Seriously Ill in the Community) in south-central Ontario, Canada (Brazil et al., 2005). Study participants were recruited over a 6-month period in 2001. Ethics approval for this study was obtained from St. Joseph's Healthcare, Hamilton, Ontario, Canada.

### Participant Characteristics

Half of the 44 caregivers who expressed an interest in participating in the home interviews declined to participate due to fatigue and caregiving responsibilities, five care recipients had died by the time the household was contacted by the project coordinator, and 5 caregivers were lost to follow-up. Of the 12 caregiver/care recipient dyads who participated in the home interviews, two were excluded from this analysis because the primary informal caregiver was not a spouse but an adult child.

The majority of spousal caregivers were female ( $n = 7$ ). The group ranged in age from 58 to 87 years (mean age = 70.3 years). Seven of the care recipients were male and all had a diagnosis of cancer and ranged in age from 60 to 88 years (mean age = 73.7 years). On average, care recipients received 4.6 services. The most commonly used services among the participants were in-home nursing ( $n = 9$ ), followed by religious support ( $n = 6$ ) and occupational therapy ( $n = 6$ ).

### Data Collection

Family caregivers who participated in a telephone interview on caregiving were invited to participate in a caregiver/care recipient home-based interview. Caregivers who expressed an interest and gave their permission to be contacted were called by the project coordinator, who explained the study and scheduled a home interview.

Two parallel versions of the interview guide were developed for the spousal caregivers and care recipients. Topics of the semistructured interview included perceptions on (1) formal services (what worked well, what did not work well); (2) informal supports (who provided what type of assistance, what type of support was most appreciated); and (3) the spousal caregiving experience (what aspects of the experience were most satisfying, most difficult). Prior to conducting the interviews, interview schedules had been pilot tested with two caregiver/care recipient dyads recruited through a local hospice. Pilot testing had led to revisions to the protocol and interview questions. Two trained members of the research team conducted the home interviews in the dyad's home. Audiotaped interviews were completed separately by both caregiver and care recipient using the parallel interview guides.

### Data Analysis

Audiotapes of each interview were transcribed to create verbatim written accounts. To preserve participant confidentiality and anonymity, all identi-

ying information captured on tape was removed from the transcripts. A summary of each interview was made by the interviewer and mailed to the study participants for feedback. Comments were mailed back to the study investigators. Any changes or additions made by interviewees were added to the computerized version of the transcript.

Two members of the research team who did not attend the home interviews independently read each transcript before coding the data. Interviews were coded based on a preliminary codebook that had been developed on the basis of a literature review. The coding template was updated as the interview data were coded. After independently reviewing the coded passages, the two reviewers compared their findings to reach consensus on the coding differences. Caregiver and care recipient interviews were analyzed separately.

To support the interpretations drawn from the interviews, short examples or typical statements (quotes from participants) are included in the text. Sources of these quotations are identified with a letter representing the caregiver (CG) or care recipient (CR) and the number corresponding to dyad (1–10). Some of these quotes were edited minimally to preserve authenticity while ensuring readability.

## RESULTS

### Perspectives on Caregiving

Five themes on the home-based palliative caregiving experience were identified: positive aspects of the caregiving experience, negative aspects of the caregiving experience, spousal relationship, formal supports, and informal supports. In certain cases, subthemes were identified within the major themes. Each will be described in turn.

### Positive Aspects of the Caregiving Experience

#### *Caregiving Mastery*

The majority of the caregivers reported that they felt competent and confident to take care of their spouses independently: “I can handle anything. Any situation that comes up. I’ve been through all of them” [CG10]. Many female caregivers felt that it was their natural role to be a caregiver and to look after their spouse: “You go back for 63 years and you get used to it” [CG12]. Male caregivers reported that they were able to successfully handle housekeeping duties: “I surprised myself that I could do all these things. I made some mistakes with cooking [but am] learning quickly” [CG5].

Many care recipients confirmed the effectiveness of their caregiver in providing care for them: “She’s able to deal with it, wants to deal with it, and knows how to deal with it” [CR9]. Similarly, another care recipient voiced his deep appreciation for his wife: “When I first took sick, I couldn’t do nothing for myself . . . My wife cleansed me, did everything for me” [CR3].

### Negative Aspects of the Caregiving Experience

#### *Physical Strain*

The most commonly reported physical strains experienced by caregivers were fatigue (“I’m just so tired I just want to sleep. I feel kind of weary” [CG1]) and physical burdens of lifting (“Thank goodness I don’t have to do the lifting now” [CG3]). Care recipients reported that they were concerned about how the work of caregiving was having a negative toll on their spouses: “I worry that she’s working too hard. She looks after me like a baby and it’s just a little too much for her” [CR12].

#### *Emotional Strain*

Generally, most caregivers found it difficult to witness the state to which their spouses had deteriorated: “Everything is a struggle for him, and I hate to see him having a hard time” [CG11]. Other caregivers felt angry and expressed difficulties in realizing how their lives had been completely transformed: “It was overwhelming that one day your life is normal, the next day it’s not” [CG6]. Depression in the care receiver was a commonly cited strain on the caregiver: “It’s been strenuous. . . . You have to cope with his [CR3] depression” [CG3]. Caregivers also expressed their own feelings of depression: “You sort of get down sometimes when you’re all alone and alone with your thoughts” [CG5]. Many care recipients also expressed concerns about the current and future emotional state of their spouses: “My biggest concern is what [CG7] will have to go through when I’m gone. . . . These tears are not for me. So it’s what’s [CG7] is going to have to go through and what my kids are going to have to go through that bothers me” [CR7].

#### *Restrictions on Time*

Caregivers voiced concerns regarding the lack of time they had to fulfill their daily activities plus caregiving duties: “He [CR11] has so many doctors’ appointments and it’s a lot—it takes up a lot of time” [CG11]. One care recipient expressed con-

cerns about the lack of time that his caregiver had due to providing care for him: “Her [CG9] mother’s still alive and she’s 93, so she’s [CG9] got enough on her plate without having me to worry about too” [CR9].

### *Financial Strain*

Caregivers noted that the costs of medical equipment and drugs were considerable expenses. Some of them explained that they had difficulties coping with the costs: “You feel like you’re drowning sometimes” [CG7]. One care recipient acknowledged great frustrations and similar difficulties in dealing with the high costs of medical equipment: “But \$600 for a cushion—come on guys give me a break, we’re sick, we can’t afford those kinds of expenses in order to be comfortable, it’s sickening” [CR7]. Later on, the care recipient also noted that “the cost of being sick is enough to make you sick, it’s the cost of getting well [that] is almost prohibitive” [CR7].

### **Spousal Relationship**

Almost all caregivers revealed important insights into their relationships with their spouses. Many caregivers felt that the caregiving experience had brought them closer to their spouses: “Just going through the awareness of what’s happening to you, facing death, talking about the times that we’ve had together, how we’ve grown together” [CG9]. Most caregivers noted that good communication was an essential part of their successful relationship with their care recipients; the ability to openly discuss various issues was important in order for caregivers and care recipients to work together: “We have a good communication so when he can’t, he just tells me what he can’t do and then we work together” [CG1]. This openness and frank dialogue were also seen to play a significant role in the decision-making process for many couples: “I ask him [what] he wants so he’s always included in everything we discuss” [CG1]. Several care recipients confirmed how the caregiving experience had brought them closer to their spouses: “We’ve shared a lot of experience just in the last 3 months in this house. I think we’ve come to understand that I’m dying” [CR9]. Communication also seemed to be an important constituent of the caregiver–care recipient relationship in the perspectives of the care recipient: “We both agreed that we were going to try and see if it worked out. And it has, there’s nothing that we regret having done” [CR10].

## **Formal Supports**

### *Positive Aspects of Formal Supports*

All caregivers expressed gratitude and appreciation for the services that they had received: “The service right from day one was just fantastic” [CG6]. Good communication with formal support workers was observed to play an important role in shaping a positive perception of formal supports for most caregivers because it enabled caregivers and care recipients to ask questions, to be informed, and to have their concerns addressed: “He [the palliative care doctor] takes time with patients and listens to them where most people don’t, where most doctors don’t” [CG1]. It was commonly reported that caregivers felt that it was important to have continuous care (i.e., the care or service is delivered by the same person throughout the caregiving experience): “It’s been the same [care] all the way through which is really nice because then, they’re [home service workers] almost like friends now” [CG7].

Similar to the caregivers, all care recipients acknowledged how helpful and supportive formal services had been: “I’m so grateful that there are those things in the community that can support us at home” [CR10]. Care recipients also found that communication with their health care providers was important: “He [the doctor] tells you like it is. He doesn’t sugarcoat it and that’s good because you know exactly where you stand” [CR7]. Continuous care by the same individual(s) was also acknowledged by care recipients to be a positive aspect of formal supports: “I didn’t have to go from one person to another” [CR6].

### *Negative Aspects of Formal Supports*

Some caregivers reported that formal providers did not listen to their needs: “They [OT] had presumed that we would need a certain kind of bench which we didn’t, and they wouldn’t listen to me” [CG6]. Other caregivers were unable to ask their questions: “Even though I have the Cancer Centre, unfortunately it’s been a very bad experience generally. . . . My questions generally really aren’t answered very well” [CG1]. Caregivers often reported that the services and care they were receiving was fragmented. It was often reported that service workers were not aware of what other service workers had done; the information was not getting passed along: “It just seems like we’re chopping it all up and nobody knows what anybody’s doing and you don’t work as a team” [CR1]. Another caregiver remarked: “The only thing is it’s been very erratic in the person. For 3 weeks in a row, we get three different people” [CG6].



The lack of communication between the care recipients and their health care providers was cited to be a major problem: “The doctors don’t listen to you. They are more interested in making your body well and it doesn’t matter how sick you feel” [CR5]. Some care recipients perceived that the service that they had received was not well coordinated and continuous: “They [nurses] write it down but the report in the end doesn’t go to the hospital, and from the hospital the reports doesn’t go to the VON [community nursing agency]” [CR5]. Another care recipient found that the nurses were insensitive while speaking to her: “They told me that I was a cancer patient and I said well the doctor didn’t tell me that. . . . It was, to tell you the truth, quite upsetting” [CR2].

## Informal Supports

### *Positive Aspects of Informal Supports*

All care recipients expressed how informal supports had a positive influence on their lives. As one care recipient noted: “The people do want to help. They do want to come out and, for my benefit not for theirs” [CR9]. Even though informal supports were not easily accessible in a physical sense, caregivers were able to receive their support through other means: “My family hasn’t been physically involved but, phonewise they’re phoning different times to see how things are going” [CG6].

Care recipients recognized the importance of informal supports for their caregivers, as it enabled their caregivers to voice their concerns, fears and frustrations: “She [CR6’s neighbor] would tell him things that happened to her and different feelings she had which I think was good for my husband sharing with her” [CR6]. Similar to the responses of the caregivers, care recipients also reported that they had friends, family, and neighbors that they could call upon, even if they did not require it: “If I told him that I needed him [CR2’s son] he would be here in 5 minutes” [CR2].

### *Negative Aspects of Informal Supports*

The most commonly cited concern regarding informal supports was the overwhelming, exhausting support that caregivers received: “A lot of telephone contact. As a matter of fact it really gets to be too much. . . . It wears you down” [CG7]. The unavailability and lack of regular support from family members was another concern for caregivers: “It’s difficult because they’re young people and they are working full time so it’s hard to corner them” [CG7].

Another problem was the inability of family members to be sensitive to the emotional needs of the caregiver and care recipient: “It’s just emotionally they’re [CG7’s son and his wife] very different. . . . And they’re too prayerful, I mean I believe in prayer and we need all we can get but you don’t like the preaching all the time” [CG9]. It was noted in our interviews that caregivers reported difficulties in asking for assistance from friends and extended family: “I don’t want to burden my children . . . you know with our own personal problems” [CG5].

Several care recipients expressed negative perspectives regarding the presence of informal supports during the caregiving experience. For one caregiver, the problem was due to the lack of friends, as they had all previously passed away before him: “But as you get older you become more lonely. . . . You haven’t as many friends because they’re gone” [CR12]. Similarly, another caregiver voiced frustration over the lack of face-to-face support from her children: “They supported me in one way—okay, they phoned—but they never came. . . . I felt that was the hardest part” [CR5]. Similar to the perspectives of caregivers, too much support was cited as an issue for one care recipient: “I had about 29 [visitors] in one day and they had to cut the visitors off because it wasn’t doing me any good” [CR6].

## DISCUSSION

By capturing the thoughts of spousal caregivers and their critically ill care recipients to discuss their caregiving/care receiving experiences, we can gain insight into what the impact home-based palliative care has on caregivers and care recipients. Most informal caregivers viewed caregiving as an extension of the family relationship, where caregiving responsibilities evolved over time. Nonetheless, caregivers could easily disclose unexpected aspects of the experience.

Spousal caregivers identified many of the negative reactions to caregiving reported elsewhere in the literature, such as fatigue or weariness, depression, anger and sadness, financial stresses, and lack of time (Bowles et al., 2000; Ross et al., 2002; Wennman-Larsen & Tishelman, 2002; Hauser & Kramer, 2004; Waldrop et al., 2005). Care recipients acknowledged the emotional and financial strain that their spouses were under, expressing concern for their well-being. In particular, care recipients reported concern over the lack of emotional support for their spouses or the difficulties that their caregivers encountered while caregiving.

These findings suggest that this group of caregivers would benefit from interventions that ad-

dress the physical tasks of caregiving, such as personal support workers through home care services. Both caregivers and care recipients were appreciative of the services that they received in the home. However, both parties identified the need for additional services, difficulties in communication with formal providers, and poor coordination of care among services as problems they had faced.

Informal supports were observed to be a positive influence for both caregivers and care recipients. This observation is consistent with the research literature that has noted the importance of extended family and friends in the caregiving experience (Emanuel et al., 1999; McSkimming et al., 1999; Block, 2001; Waldrop et al., 2005). It is noteworthy that caregivers in our study disclosed some challenges with informal supports such as the excessive presence of support, which resulted in a loss of time, or supports being inappropriate or unhelpful. Spousal caregivers also reported that friends and family were not adequately prepared to deal with a terminal illness and thus, may have had great difficulties in interacting with care recipients.

The unique aspect of this article was our intent to capture the positive aspects of caregiving as well as the burdens from the perspectives of both care receivers and their spousal caregivers. In this study, participants reported that their experience strengthened their relationship with their spouse due to the increased time spent together and shared decision making they experienced. Spousal caregivers also reported discovering emotional strength and physical abilities they had while managing the care of a family member. These findings correspond with other studies that have noted similar caregiver reports (Stajduhar, 2003; Rabow et al., 2004)

In this study, we also identified the difficulty of recruiting family dyads into palliative care research. Many caregivers declined to participate due to the challenges of caregiving they were experiencing. Of those who did participate in our study, interviewers had to be sensitive to interview fatigue. Even though our study sample most likely represents a select group, the information gathered in the interviews provides insight on the caregiver and recipient perspective on home-based palliative care.

An important goal of the present study was to explore home-based palliative care from the perspective of the spousal caregiver and care recipient. Health care and social service professionals need to recognize and understand both caregiver and care recipient perspectives if they are to successfully meet the needs of both members of the dyad.

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