

# Giving support and getting help: Informal caregivers' experiences with palliative care services

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## ABSTRACT

*Objective:* Palliative care services have made significant contributions to those needing end-of-life care, but the effect of these services on informal caregivers is less clear. This article reviews the literature and examines the influences of palliative care services on caregivers of people who are dying of cancer, HIV-related illnesses, and illnesses of later life.

*Methods:* Based on questions that we developed from the literature review, we conducted six focus groups in Toronto, Thunder Bay, and Ottawa, Canada, with informal caregivers about their experiences with caregiving and with palliative care services.

*Results:* We outline the major themes relating to the 42 focus group participants' experiences of giving support and getting help.

*Significance of results:* Our findings help us better understand the common concerns of caregivers of terminally ill seniors, people with HIV/AIDS, and people with cancer. The article discusses the implications of participants' experiences for palliative care service providers.

**KEYWORDS:** Caregivers, Support, Palliative care

## INTRODUCTION

Informal caregivers, sometimes referred to as family or unpaid caregivers, play an indispensable role in providing in-home care for people with advanced life-threatening illnesses (Hicks, 1988; Baines et al., 1991; Attias-Donfut, 1995; Baltes, 1996). Informal caregivers who are caring for a loved one receiving palliative care services experience significant psychosocial, physical, and economic stresses. It has been suggested that the emotional needs of family caregivers often exceed those of the patients (Grunfeld et al., 1997). Although the role of the family in the patient's treatment is critically important, the family as a whole is seldom considered as the unit

of care within research on palliative care (Knapp & DelCampo, 1995), in spite of the fact that a major reason for admission of community hospice clients to the hospital is exhaustion of the primary caregiver (Bramwell et al., 1995). Researchers are now beginning to focus more attention on the effects of providing support to caregivers who are caring for their family members, partners, or friends who are dying.

The literature identifies a number of issues that are specific to particular groups of caregivers. For example, palliative care issues for elderly patients and the needs of their families differ in a number of ways from those of younger patients. Caregivers of elderly people must deal with a blend of geriatric and disease-specific symptoms. Age-related illnesses, such as Alzheimer's disease, present the patient and their family caregivers with a complicated variety of concerns requiring an integrated

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care plan that attends to both the needs of the family and the elderly patient (Moore, 1997). Because of the subtlety of the progression of Alzheimer's disease, caregivers often find themselves gradually allocating increased amounts of time and energy to the care of their loved ones (Boykin & Winland-Brown, 1995). Intervention provided to spouses of patients with Alzheimer's disease was effective in reducing the need for spouses to place the patients in nursing homes (Ferris & Mittelman, 1996). Enhancing long-term social support can reduce depression in caregivers of spouses with Alzheimer's disease (Mittelman et al., 1995). Caregivers whose family member received support from a hospice indicated significantly less worry than caregivers of posthospitalized older persons (Kirschling et al., 1994).

Caregivers of people dying of HIV-related illnesses share many common needs and concerns with caregivers of people with other illnesses, but their experiences are unique in a number of ways. Atkins and Amenta (1991) found that families of people with AIDS have a significantly greater accumulation of stress, more rules prohibiting emotional expression, lower trust levels, and more illness anxiety than families with other life-threatening illnesses. Also, these families tend to have significantly fewer people in their social networks, which, in turn, creates more stress. The duration of the illness and multiple losses associated with it may impede the caregiver's ability to effectively engage in the grief process, thus differentiating it from other illnesses (Walker et al., 1996). The stigma associated with AIDS can contribute additional stress. Many informal caregivers of people with end-stage HIV diseases are gay men (Turner & Catania, 1997). The caregiver himself may be HIV-positive, which can complicate the caregiving relationship (Folkman et al., 1996). Providing care and support to one's partner with AIDS may have adverse effects on the caregiver's psychological and physical health (Smith, 1994; Lobb, 1995). With the great many changes that occur during the course of an HIV-related illness, relationships between patients, families, friends, and lovers may become strained (Fisher et al., 1994). A needs assessment of informal caregivers of persons with HIV or AIDS found that the most important needs reported were to be listened to, to share experiences with other informal caregivers, to be prepared for the death of the person with HIV/AIDS (PWA) or to deal with death, and to receive support in home care (Perreault et al., 1994).

Caregivers of people dying of cancer face a number of specific issues. Blanchard et al. (1997) described that caregivers expressed fear of cancer and its spread, and struggled with helping their loved

one deal with the emotional ramifications of the disease. Hull (1990) studied the concerns that families meet as they care for their dying relative in an oncology hospice home care program. Three general concerns were noted by the caregivers: patient symptoms, interactions with others, and concerns for self, namely absence of time for oneself and lack of time to be alone. The most stressful concern related to changes in the patient's mental status over time. Miaskowski et al. (1997) argued that the amount of pain experienced by the patient adversely affects the mood states of caregivers, particularly their level of depression and anxiety. Davis-Ali et al. (1993) found that cancer patients receive significantly more social support than did their spouses. A significant correlation has been found between a longer time in palliative care and lower family anxiety, indicating the beneficial effect of this service on family caregivers (Higginson & Priest, 1996). The literature has also noted that caregivers' well-being and quality of life are influenced by the type of support they receive. Kramer (1996) found that women whose spouses have been cared for in a hospice experienced less grief than women whose spouses did not have hospice care. All this suggests that there is a need for expanded attention to the idea of cancer as a "family disease" with a special emphasis on the unique, but often neglected, experience of spouses of adult cancer patients.

Beyond the specific concerns relating to the provision of informal care to people dying of diseases of later life, HIV/AIDS, and cancer that were identified in the literature, caregivers share a number of common needs with regard to support, communication, and information. In this article, we will examine the common experiences and concerns of caregivers in providing care in the home and in receiving formal support services. We draw on data collected in six focus groups. As will be seen, our respondents identified a number of common concerns that cut across the focus groups, particularly as it relates to their experience of receiving formal support services. The article concludes with a discussion of how service providers can better respond to the needs of informal caregivers.

## METHODS

We focus our attention in the following on how support services might have been more helpful to informal caregivers in facing the day-to-day realities of caring for a loved one. We conducted a series of six focus groups with caregivers in Ontario, Canada. In Thunder Bay, we conducted a focus group for caregivers of people who were dying or had died of cancer, for caregivers of people who had died of

HIV-related illnesses, and one group for caregivers of people who died of later life illnesses. In Toronto, there was a focus group for those who cared for people who had died of AIDS. In Ottawa, there was a group for people who had cared for those who died or were dying of cancer and a group who cared for people who had died or were dying of illnesses related to later life. We recruited our respondents with the assistance of eight health and social service agencies in Thunder Bay, Toronto, and Ottawa. Some of the agencies circulated an information sheet about the study, whereas others played a more active recruitment role by directly contacting current or former clients. As a result, the study participants can be characterized as having reasonably positive and close connections with the agency and its workers. Clients who experienced more problematic relationships with the agencies are likely not included in our sample; the same could be said for those clients whose ties were more tenuous or short-lived. One might expect, as a result, that the participants might be expected to give a relatively positive account of their dealings with the agencies. Still, as will be seen below, participants offered a range of criticism of the services they received.

In total, we spoke to 42 people who were the primary caregivers for their husbands, wives, partners, mothers, fathers, brothers, cousins, and friends. In addition, four people wanted to participate in these focus groups but were unable to do so. Two were unable to attend the group meeting because of time conflicts. One caregiver could not leave his wife unattended to participate in a focus group. The husband of another participant died within the past month and, although she wanted to share her experiences, she did not feel ready to discuss them in front of a group of people. We interviewed these four caregivers individually. Each participant was offered an honorarium of \$25 to compensate for their time and incidental expenses associated with their participation in the study.

The focus groups and interviews were conducted by the researchers. A discussion guide provided general direction for the focus groups, but as much as possible, we tried to keep the interactions informal and conversational. Discussion between participants was encouraged. The general questions that guided our focus groups included the following: How did you find out about the palliative care services you used? What supports were available to you before you received palliative services? How did the palliative services help you in providing the care your family member required? In what ways were the services supportive to you personally? What kinds of service gaps might you identify? What other services would have been helpful to

you? What kinds of follow-up services were available or might have been helpful? Are there special circumstances in caring for older people/people with cancer/people with HIV who are dying? Could palliative care services address these special circumstances?

With the permission of participants, focus group discussions were audio-taped. Participants were assured that the tapes would remain in the possession of the researchers and destroyed upon completion of the study. They were also told that the information they provided would be confidential. The audio tapes were transcribed verbatim and analyzed to identify the major themes that emerged from the discussions. Names and identifying information were deleted or changed to protect the identity of participants. The specific concerns they raised were not fed directly back to the referring organizations, although agencies were given a copy of the final report. The project received the approval of the McMaster University Committee on Ethics of Research on Human Subjects.

## GIVING SUPPORT: THE CAREGIVING EXPERIENCE

Several common themes emerged from our discussions that cut across all six focus groups. Although they may take a specific form with particular illnesses, the themes of overwhelming demands of providing care, the social isolation that comes with caregiving, the difficulties of negotiating care, and the financial costs of providing in-home care were shared by participants in all six groups.

### Overwhelming Demands

Once the decision to care for their family member was made, respondents faced extraordinary demands. Many were working full-time while providing care. Many had children to raise or parents to support, along with all of the details of their own lives to take care of. The caregiving demands often felt incessant, particularly as the dying person became increasingly ill. It was often difficult to leave the house to run errands, because it meant that the sick family member would be left unattended or unsupervised. Several participants in one group agreed with a woman who observed: "It's just like having a baby, you could never leave." The demands could become all-consuming. Alzheimer's disease was noted by several caregivers as particularly difficult to cope with due to the symptoms of the disease. One woman caring for her husband with Alzheimer's disease said:

I had to occupy him. This was the worst part of it. I found that I had no life. I finally didn't think of anything else at all but Alzheimer's. Everybody was giving me papers to read and all this, and I said, "I don't need this. I'm living it." He's not worried about anything. I do. I'm worried every hour. I'm the one who seems to be sick.

Nighttime can be especially stressful for caregivers. Often the caregiver was unable to sleep throughout the night. As one daughter caring for her mother who had Alzheimer's Disease stated:

My mother had her days and nights mixed up. The nights were tough. You had two or three hours of sleep, if that. You often had breakfast at three o'clock because that was when she was hungry and she slept quite a bit during the day. But I had to take early retirement in order to survive and eventually I worked part-time. It was hard. And nighttime . . . no one wants to come at night to help you out.

Dementia due to Alzheimer's disease or to HIV often requires the caregiver to closely monitor and supervise their loved ones because they presented a danger to themselves or to others. One partner of a man with HIV described how he needed to take more control of his lover's life: "There were a lot of situations where he was putting himself in danger. At that point, I had to be very, very, very strict. I had to know exactly who came, who he was calling, things like that. He was very, very angry with me . . . He didn't love me anymore. He had lost mental capacity, and he saw me as his enemy who kept trying to stop him from doing what he really wanted to do."

Some caregivers found that their daily patterns in the home were disturbed when providing care at the home. Such disruptions made it difficult to carry on with everyday living: "After a year, I just couldn't do it. She would go to bed at six or six-thirty at night and I couldn't. So at five or six o'clock in the morning, she'd be knocking at the door, 'Are you all right?'—'Yes, mother'". Many caregivers, especially those caring for seniors with some form of dementia, suggested that it was almost an impossibility to care for the family member at home: "I would encourage people who have Alzheimer's patients to put them in a home because it's very hard to take care of them. Very hard. Even to eat, they're slow to eat. Even your own eating is disturbed, your whole life is disturbed." Focus group participants often felt they had to do everything: "I did it all. I did the shopping, I did the cleaning, I did

the laundry, I paid his bills, I supported him emotionally as much as I could. Plus, I was working full-time." These demands meant considerable sacrifice and personal cost. As one woman who was caring for a friend dying of cancer stated: "I gave up my job for her, my life for her, really, for three years . . . so I didn't have the energy to look after myself because I was so concerned for her." Work demands were particularly difficult to negotiate with caregiving responsibilities, if for no other reason than that it required that the caregivers absent themselves from the home for relatively long stretches of time:

I was sneaking in and out of work. My immediate boss knew, but nobody else knew. I was missing meetings. I was coming in late, sneaking out at lunch time, making sure that he was okay. I took a day at a time, but I was exhausted when it was all over.

Many of these caregivers were dealing with this situation of providing care for a loved one while, at the same time, providing care for other members of their family. This dual responsibility of providing care contributed considerably to their sense of being overwhelmed. As one woman who cared for her husband who had cancer for 15 years stated: "I thought I was losing my mind. My life was being destroyed by him dying on me. I thought I was going to disappoint everybody, including my kids." Even when other family members shared the responsibility for caregiving, it did not mean that the demands on participants lessened. The extra help often simply meant that they were freed up to tend to other chores and responsibilities. While clearly exhausting, in some ways, the relentless demands often seem to be what got the participants through the day: "You just do it. You do what you have to do. There is no time to think about what could happen tomorrow or the next day or a month down the road. You simply wake up and think: 'There is a doctor's appointment today'." Given these kinds of demands and pressures, it is little wonder that participants spoke of often feeling physically and emotionally exhausted:

What was the worst part of the whole situation? It's not that I was exhausted physically, because you can be, obviously. Or not having a moment to myself or not being able to just go for a walk for two hours without feeling guilty about it. The worst part was how emotionally drained I was.

Adding to caregivers' exhaustion and feelings of being overwhelmed was the need to perform some

of the tasks of paid caregivers. Participants often felt that professional workers thought that family caregivers knew more than they actually did. One woman caring for a husband with cancer was strongly encouraged to give him intramuscular injections so that the registered nurse did not have to come to the house to do this: "But, the bottom line is that it was added pressure for me to have to give those needles . . . especially when I realized that the nurse's aides were not qualified to give them." One man who cared for his brother noted, "It's like starting a new job. They assume that you know everything." As a result, they did not receive the support and education that they felt they really needed, increasing their sense of stress and anxiety.

### Social Isolation

Caregiving responsibilities often take priority over other social obligations, leading many participants to feel isolated from others. Caregivers generally felt they did not have the time or the energy to invest in friendships—relationships that might otherwise nurture or rejuvenate them. Participants' sense of isolation seemed to relate to a number of factors. First, it often felt awkward to talk about serious illness and death. This helped to create distance from others, and it sometimes made conversation difficult, even with the ailing family member. One parent described some of the difficulties her family experienced when her son was diagnosed with AIDS: "I knew he was sick. Something was the matter, but he wouldn't tell us . . . You try to talk to him, and he doesn't want to make you feel bad." Other times, the isolation was related to the unwillingness or inability of others to assist with caregiving. One man explained that it was easier for him to care for his partner without assistance from the family than to deal with the tensions and stresses that characterized these relationships:

I had no family support. Zero. The family, they were loving people and accepting from day one of our relationship, but I think the ethnic background . . . I got to a point where the emotions were running constantly. I didn't really need them around to upset me. So I would say, "No, I'm fine. Don't worry about us. If we need help, I'll call you."

Several focus group participants stressed that other people cannot truly understand their situation unless they have cared for a seriously ill friend or family member themselves.

### Negotiating Care

An issue identified by several participants was a tension that developed with regard to whether they should make use of formal service providers. Several participants recalled that they wanted paid assistance, but the person to whom they were providing care rejected the idea of formal services, such as Homecare or visiting nursing care. Paid caregivers were often seen by the sick family member as an unwanted intrusion. One woman who was caring for a close friend with AIDS recalled: "My problem was not that [help] wasn't available. I could have had it for him 24 hours a day any day I wanted. The problem was that he didn't want it . . . He wouldn't have Homecare. He didn't want people running around his apartment. He didn't want strangers cleaning." Other participants echoed this experience and talked about how difficult it was to insist on arranging for paid help when their family member did not want strangers in the house. Respondents also spoke of often having to mediate between paid caregivers and their family member: "The visiting nurse, he just hated her. I'd say, 'Please, she's just checking your blood pressure.' He didn't want to have a worker to come to sit with him or read to him or make him lunch. He would not allow that. That was not done." Another participant recalled, with some humor, how his brother kept firing paid caregivers because he did not like having them around: "My brother would keep firing the nurses. He'd say, 'You can go now.' He'd shut the door, and then we'd get a phone call saying 'your brother's kicked [us] out.' And this went on for a month. It was funny, you had to laugh about it." The end result of such tensions, however, was that caregivers were required to take on more of the practical work, like cleaning and shopping. Providing more control to the dying individual was one of the important reasons for ensuring that he or she was cared for at home, yet in this regard, the needs and desires of the ailing family member conflicted with their own. This had implications for their relationship with their dying family member or friend:

Finally, all I was doing was cleaning and shopping, and trying to get him to eat, and doing laundry, and errands. There was no time for us to sit down for half an hour to just enjoy each other. I said, "I can't do both. You make up your mind. You either let me get somebody in here to at least do the cleaning and the laundry. That way I can spend some time with you." It was shattering, because there was no time to spend with him. I was exhausted and he was exhausted by the time I'd be finished, so he finally agreed.

## Financial Costs

A number of focus group participants spoke of the direct and indirect financial costs of informal caregiving. Many spoke of how difficult they found it to juggle their responsibilities at work with those at home, and several quit their paid employment to be at home more often. One man explained:

I quit my job and went on social assistance for two years because I just couldn't work. And my brother didn't want me to work. I didn't want to have to leave him. I wanted to be with him, that's how I coped. And my mum sold the house. It was just a huge financial drain, but not a bad one at all, but it was a strain on money.

This respondent's family was not the only one that sold their home because of their caregiving responsibilities. One mother who lived in a different city than her ill son sold her home, not because she needed the money, but because she needed to be closer to provide care: "I told the real estate agent that I didn't want my condominium to sit on the market. The real estate market at the time was 'dead' but I said that I wanted it to move. We ended up selling in about two weeks, so I was off the hook." Because this respondent needed to sell her home quickly, she ended up selling it for a low price in a bad real estate market, so it probably ended up costing her thousands of dollars.

Trying to negotiate financial resources from governments and private companies often increased the stress load for caregivers. Caregivers felt they were often caught up in an unnecessary bureaucratic process at a time when they were exhausted from providing day-to-day care. The process of applying for sick benefits and disability benefits for the dying person and for other assistance such as Employment Insurance was often traumatic in itself: "They make you feel like you're begging for money . . . it's a very degrading process that you have to go through." A woman caring for her husband with cancer felt fortunate that her husband's insurance company responded favorably as her own insurance company balked at covering some services:

I was allowed one shift in a twenty-four-hour period through Homecare and I was advised to get the night shift so that would give me respite that I could sleep. Anything else above that, I had to go through private insurance, and it did turn out that I needed twenty-four hour assistance with him. I don't know how, if I hadn't had private insurance, I would have coped financially.

The government . . . should sit down and speak with the insurance companies and force them, in a way, to cover the nurses' aides' costs because we are paying premiums to those insurances and when it comes time to pay out, all of the sudden, you start reading in between the lines and you find that there's a lot of things they don't or won't cover and I don't think they should be allowed to get away with that.

Some caregivers are forced into early retirement or have to take a significant amount of time off work. A daughter caring for her mother commented on the lack of financial aid to caregivers:

We also have (jobs), many of us are taking vacation days, we're taking holidays . . . We give pregnancy leave, we give paternal leave for the father to bond with his child, but when at the other end of the spectrum, when people are dying, why don't we give caregiver relief?

Caregivers receive no compensation when they take time off work or decide not to seek work. Decisions to leave work for periods of time can impact future career development and future earning power. Early retirement has implications for pension income for one's retirement years. Thus, the costs of caregiving can be long-term, lasting well beyond the death of the family member. Participants were very aware of how money was being saved in the health care system. They were glad that they were able to be there for their loved one, but many were resentful that "the system" was obviously cutting costs and saving money without providing much support in return. A woman who cared for her husband raised the question: "Did I not save the government a lot of money by keeping my husband at home? Why couldn't I apply for some kind of a benefit from the government?"

## DISCUSSION: INFORMAL CAREGIVING AND FORMAL SUPPORT

The experience of providing care to a dying loved one is a demanding and often overwhelming one. Our focus group participants described the many practical tasks and emotional concerns for which they were responsible. Participants described their experiences with formal palliative and support services in largely positive and appreciative terms. These services were described in words like "essential," "critical," or "indispensable." Many remembered the kindness of particular nurses, doctors, social workers, psychologists, home care workers and hospice workers; small gestures of care and

concern were clearly important to them during the difficult period surrounding the death of their loved one. At the same time, participants were critical of the formal caregiving system in a number of ways. With few exceptions, health care professionals focused their attention on their dying family member, leaving the caregiver with little emotional support. Caregivers were often not provided resources, such as financial assistance, information about the course of illness or about available services, connections to peer supports, or a core of consistent service providers. Although participants acknowledged that they could have used more support, the issue of primary importance for them was getting better care for their loved one. In fact, it was difficult to get their views about what would have been helpful to them as caregivers. Helping caregivers recognize and attend to their own needs is an important issue given that exhaustion is a leading reason why family members need to seek out formal services.

Health care professionals need to consider the psychological needs of caregivers and to address them with concrete and realistic interventions. Caregivers need information, support, and encouragement to maintain hope and a positive attitude so that they can continue the caregiving that they want to do. Uncertainty about what to expect through the course of illness creates unnecessary anxiety. Knowing what to expect helps them plan for the future and normalizes many of their feelings and experiences. Although they had been provided with helpful information about the illness at the time of diagnosis, participants felt that it would have been helpful to have information about the services and supports available to them as caregivers. Health care workers can help the family anticipate their needs, to discuss the possibility of conflict, and to mediate a mutually agreeable plan of care. Informal caregivers should be made aware of the issues they may face during their loved one's life-threatening illness and what educational and support services are available in their community. They might be provided with a "caregiver package" of information about these programs and resources soon after diagnosis, before they reach a crisis. A number of participants said they would have valued support and information from someone who has gone through a similar situation themselves. Caregivers would also have benefited had workers given them permission and encouragement to seek support services.

Participants indicated they would have benefited from efforts to help them coordinate the numerous services they received. Almost everyone complained about how frequently they needed to train and supervise new health care workers. This

responsibility often falls to them at a time when they already felt exhausted and confused about the service options. Several felt overwhelmed by the large numbers of people coming in and out of their lives. The designation of a "primary" worker for each person who is receiving palliative care services would have been helpful. This worker could assist with coordinating other care providers and advocating for services, because it is often difficult for family members to confront or challenge paid workers if they feel the care for their loved one is inadequate. Family caregivers are sometimes asked to administer medications or use medical technology for which they feel they are poorly prepared. Although they found it difficult to refuse such requests, these tasks served to increase their feelings of anxiety and stress and created the possibility of improper care to the patient. If caregivers are asked to take on such tasks, health care workers must provide adequate education and ongoing support to ensure adequate medical care for their loved one who is dying and to minimize caregiver anxiety and stress.

Finally, participants identified a number of broad policy issues. They worried about the quality of care in hospitals and nursing homes as a result of the many changes that the health care system is experiencing. Informal caregiving comes with significant direct and indirect financial costs. Caregivers who leave their home or place of employment to provide care to their family member or friend should be eligible to apply for financial assistance to help defray the costs they incurred. Fortunately, a number of jurisdictions in North America are changing policies to include such measures as caregiver tax credits, revising Employment Insurance benefit eligibility to include family leave, and permitting penalty-free withdrawals from registered retirement savings plans.

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