

PAPER

“I didn't want to be in charge and yet I was”: Bereaved caregivers' accounts of providing home care for family members with advanced cancer

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Abstract

Objective: To describe bereaved caregivers' experiences of providing care at home for patients with advanced cancer, while interacting with home care services.

Methods: Caregivers of patients who had completed a 4-month randomized controlled trial of early palliative care versus standard oncology care were recruited 6 months to 5 years after the patient's death. All patients except one (control) had eventually received palliative care. In semi-structured interviews, participants were asked about their experiences of caregiving. Grounded theory guided all aspects of the study.

Results: Sixty-one bereaved caregivers (30 intervention, 31 control) were interviewed, including spouses (33), adult children (19), and other family (9). There were no differences in themes between control and intervention groups. The core category of *Taking charge* encompassed caregivers' assumption of active roles in care, often in the face of inadequate formal support. There were 4 interrelated subcategories: (1) *Navigating the system*—navigating the complexities of the home care system to access resources and supports; (2) *Engaging with professional caregivers*—interacting with visiting personnel to advocate for consistency and quality of care; (3) *Preparing for death*—seeking out information about what to expect at the end of life; and (4) *Managing after death*—managing multiple administrative responsibilities in the emotionally charged period following death.

Conclusions: Caregivers were often thrust into assuming control in order to compensate for deficiencies in formal palliative home care services. Policies, quality indicators, and guidelines are needed to ensure the provision of comprehensive, interdisciplinary home palliative care.

KEYWORDS

cancer, family caregivers, home care, oncology, palliative care, qualitative research

1 | INTRODUCTION

Caregivers are required to take on multiple responsibilities relating to the physical, psychological, social, and practical aspects of patient care,¹ often resulting in distress, burden, and reduced quality of life.^{2–4}

The provision of formal home care services may diminish the distress and burden of these responsibilities and improve quality of care.^{5,6} However, few studies have considered the contextual influences on home-based family caregiving at the end of life, and how it may be

shaped by professional support.^{7–9} Bereaved caregivers are able to reflect on the experiences they have had as the main care providers and provide important insights on how home care services may be improved. However, few studies have focused on the unique perspectives of bereaved caregivers.¹⁰

The present qualitative study was conducted with bereaved caregivers of patients with advanced cancer who had completed a 4-month cluster-randomized controlled trial of early outpatient palliative care versus standard oncology care. The intervention included monthly

visits to a palliative care clinic for 4 months and 24-hour on-call access to the palliative care team. Those receiving standard care could be referred to palliative care upon request. This trial demonstrated benefits of early palliative care in improving patients' quality of life, symptom control, and satisfaction with care.¹¹ For caregivers, there was improvement in satisfaction with care, but no significant difference in quality of life.¹² After the 4-month trial, almost all patients in both trial groups (96%) received some form of palliative care before death.

In the current study, we analyzed qualitative interviews with bereaved family caregivers about their encounters with the home care system. Our objective was to describe the experience of providing informal care at home for patients with advanced cancer, from the perspective of bereaved caregivers. Specifically, we examined the processes by which caregivers participate in home care and how they draw on formal supports in order to manage care of their family member.

2 | METHODS

2.1 | Methodology

Grounded theory methods consist of "systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves."¹³ Although grounded theory has several traditions,¹³⁻¹⁵ all employ the method of constantly comparing data to explore variations and similarities, form categories, and produce theory.¹⁶ The theoretical underpinning of our study was based on the constructivist conception that theories are constructed by researchers out of subjective accounts by participants rather than "discovered" out of the data.¹³ Our methodology was based on that of Corbin and Strauss,¹⁵ who espouse the development of an overarching "core category" that ties together the other categories.

2.2 | Setting

The study took place at the Princess Margaret Cancer Centre, a comprehensive cancer center in Toronto, Ontario, Canada. As part of the methodology of the randomized controlled trial, home care services were discussed with all patients in the intervention group and those accepting were referred; such referrals could also be made by the oncology team for patients in either trial group. Both groups had access to the same home care services, which are funded by the Ministry of Health in Ontario and were not tailored for the trial.

In Ontario, home care services for patients with or without cancer are provided through regionally organized Community Care Access Centres (CCACs) that arrange services including visiting staff (nurses, personal support workers, etc.), equipment, and a drug benefit program. The range of services is based on estimated prognosis and performance status, as is the amount of home care provided (typically 1 to 4 hours weekly).¹⁷ Initially, a nurse may visit weekly to monitor symptoms; later in the illness, personal support workers offer help with everyday care. In urgent situations, 24-hour support may be arranged for 1 or 2 days pending admission to a residential hospice.

CCAC services do not include physician support; rather local palliative care physicians have formed groups that provide home visits and work in collaboration with CCAC staff and family physicians.¹⁷ As few family physicians in Ontario provide home palliative care, particularly in urban centres,¹⁸ these palliative care physicians provide most of the medically related palliative home care in Toronto, including 24-hour on-call coverage.

2.3 | Participants and data collection

Participants were bereaved caregivers of adults with advanced cancer who had participated in the trial and were approached by mail and/or telephone 1 to 5 years after the patient's death.¹¹ Eligibility criteria for the current study included being identified as a primary caregiver by the patient or in the hospital electronic patient record; 18 years or older; and able to speak and read English. All bereaved caregivers were also participating in a larger quantitative study of bereavement outcomes (in progress). Initial purposive sampling for qualitative interviews was conducted aiming for diversity in Quality of Dying and Death questionnaire scores,¹⁹ trial arm, age (younger or older than 60 years), and sex; theoretical sampling of data followed once the study was underway.¹⁵

Audio-recorded semi-structured interviews, lasting 1 to 2 hours, were conducted by trained members of the research team (NS, AP, BH, JK) over the telephone ($n = 26$), in a private office ($n = 34$) or at the caregiver's residence ($n = 1$), from April 2012 to March 2015. An interview guide, developed by the authors, included open-ended questions about the experience of providing care at home and the support that was received; the guide was revised during the study based on the content of previous interviews. Written informed consent was obtained before conducting the interviews. A professional transcriptionist transcribed all interviews, which were anonymized and verified for accuracy by research staff. The study was approved by the University Health Network Research Ethics Board (REB number 06-0525-CE).

2.4 | Data analysis

NVivo qualitative data analysis software (Version 10, QSR International Pty Ltd., 2012) was used to store and manage the data. Coding involved a constant comparison approach, where early themes were verified systematically through multiple data searches.^{14,20} Final themes were conceptualized and refined until a core category emerged from the analysis and theoretical saturation was achieved.¹⁵ To promote trustworthiness, investigators discussed transcripts, emerging codes, field notes, and quotation context during weekly meetings.^{15,21,22}

3 | RESULTS

For the 61 bereaved caregivers interviewed (30 intervention, 31 control), the median age was 60 years, 72% (44/61) were female, and 54% (33/61) were spouses (Table 1). Of the patients associated with these caregivers, all except one (control) eventually received some form of palliative care, and 48% (29/61) were seen by a home palliative care physician. Seventy-seven percent (47/61) received formal home

TABLE 1 Characteristics of participants

Characteristics	Total N = 61 N (%)	Intervention, N = 30 N (%)	Control, N = 31 N (%)
Age, mean (SD) in years	59 (12.6)	58.3 (12.9)	59.7 (12.4)
Age, median (range) in years	60 (29-85)	59.5 (30-85)	60 (29-84)
Female sex	44 (72.1)	23 (76.7)	21 (67.7)
Patient's primary tumor site			
Gastrointestinal	21 (34.4)	9 (30)	12 (38.7)
Lung	12 (19.7)	9 (30)	3 (9.7)
Gynecological	11 (18)	3 (10)	8 (25.8)
Breast	10 (16.4)	5 (16.7)	5 (16.1)
Genitourinary	7 (11.5)	4 (13.3)	3 (9.7)
Ethnicity			
European	56 (91.8)	27 (90)	29 (93.5)
Other ^a	4 (6.6)	2 (6.7)	2 (6.5)
Education completed			
College/university/vocational/trade school	47 (77)	25 (83.3)	22 (71)
High school	12 (19.7)	5 (16.7)	7 (22.6)
Less than high school	2 (3.3)	0	2 (6.5)
Employment			
Employed	31 (50.8)	16 (53.3)	15 (48.4)
Retired	24 (39.3)	11 (36.7)	13 (41.9)
Unemployed	4 (6.6)	2 (6.7)	2 (6.5)
On disability	2 (3.3)	1 (3.3)	1 (3.2)
Annual household income >\$60 000	37 (60.7)	20 (66.7)	17 (54.8)
Marital status			
Widowed	30 (49.2)	14 (46.7)	16 (51.6)
Married/common-law	24 (39.3)	12 (40)	12 (38.7)
Separated/divorced	5 (8.2)	3 (10)	2 (6.5)
Single	2 (3.3)	1 (3.3)	1 (3.2)
Relationship to patient			
Spouse/common-law partner	33 (54.1)	14 (46.7)	19 (61.3)
Son/daughter	19 (31.1)	10 (33.3)	9 (29)
Sibling	4 (6.6)	2 (6.7)	2 (6.5)
Parent	3 (4.9)	2 (6.7)	1 (3.2)
Other family ^b	2 (3.3)	2 (6.7)	0
Years from DOD to questionnaire completion, mean (SD)	3.2 (0.8)	3.3 (0.8)	3 (0.9)
Received home care nursing	47 (77)	25 (83.3)	22 (71)
Received palliative care before death	60 (98.4)	30 (100)	30 (96.8)
Received care from a home PC physician	29 (47.5)	16 (53)	13 (42)
Location of patient's death			
Palliative care unit	23 (37.7)	10 (33.3)	13 (41.9)
Home	21 (34.4)	11 (36.7)	10 (32.3)
Hospice	9 (14.8)	3 (10)	6 (19.4)
Medical ward bed	4 (6.6)	3 (10)	1 (3.2)
Long-term care facility/nursing home	2 (3.3)	2 (6.7)	0
Emergency department	2 (3.3)	1 (3.3)	1 (3.2)

^aOther ethnicity includes those who identified as East/Southeast Asian, South Asian, Canadian, or mixed ethnicity.

^bOther family includes sister-in-law and girlfriend.

Data are missing for 1 caregiver in the intervention group for Ethnicity, and for 1 caregiver each in the intervention and control groups for Annual household income. Abbreviations: DOD, date of death; PC, palliative care; SD, standard deviation.

care services and the themes presented relate to this subset. The mean time from patient death to the interview was 3.2 years, with 57 interviews (93%) occurring 3 to 5 years after death.

The results of the analysis describe caregivers' experiences of providing and overseeing care at home and their interactions and negotiations with professionals while doing so. There were no differences in

themes related to trial group. As well, we compared data from interviews in the second and third year after the patient's death to those done in the fourth and fifth year; we found remarkably consistent accounts, with no thematic differences. The core category of *Taking charge* encompassed caregivers' assumption of active roles in care at home, in the face of what was often perceived as inadequate formal support. There were 4 interrelated subcategories: (1) *Navigating the system*—navigating the complexities of the home care system to access resources and supports; (2) *Engaging with professional caregivers*—interacting with visiting personnel to advocate for consistency and quality of care; (3) *Preparing for death*—seeking out information about what to expect at the end of life; and (4) *Managing after death*—managing multiple administrative responsibilities in the emotionally charged period following death.

3.1 | Taking charge

The theme of *taking charge* was the central category that encompassed all other themes. Participants described their central role in coordinating all aspects of home care and making important decisions, often with what they perceived as inadequate information and support. This was not necessarily a role that they were comfortable with. Rather, they often felt thrust into this role without adequate resources to fulfill its expectations. The complexities of overseeing care and the weight of these responsibilities were challenging to manage, leading to mental and physical exhaustion.

I became a 'take charge' person. I've often said this, that there's a tremendous gap for the major caregiver that wants to know everything... [T]hese caregivers that look after their husbands and whomever, or wives, they don't know what's going on. They are just being pushed through the system (C633I [Caregiver 633, Intervention group]).

I don't think I realized that I would be the one basically in charge. Although there would be support from the palliative care doctor, the palliative care team, from CCAC, you were the one that was there, as it were, 24 hours a day, trying to make those decisions about medications, and painkillers, and feeding and drinking. I think that certainly took quite a big toll on me I think over that last three months. (C081C [Caregiver 81, Control group]).

It's funny, I know I wanted someone there maybe just to take charge; maybe that was it. I didn't want to really be in charge and yet I was. I mean you do what you have to do, but it would have been nice to just sort of, someone else make the decisions. (C031I)

This core category encompasses 4 inter-related sub-categories, described below.

3.2 | Navigating the system

Caregivers stated that they felt compelled to navigate the home care system in assertive ways to access resources and support. Many

described the challenges of taking on this complex task without training or prior knowledge of the system, which they found had inadequacies in coordination and communication:

I will tell you that it's a morass to try and work through the various providers. Everyone tries very hard to be helpful, but the system is difficult to negotiate... I spent a lot of time on the phone trying to figure out what could be done, where to get it done, etc. (C144I)

The communication with the homecare people and us was bad. I had to be the initiator of all discussions. At a time when your wife is dying and you want to be with her, that is not good. (C151I)

Caregivers described several navigation strategies, such as making demands, speaking to higher levels of administration, and sending back improper equipment. This detracted from spending time with their family member:

So I spent a lot of time like, I guess unnecessarily or whatever trying to contact homecare... and trying to get all the right equipment. [I]nstead of investing all this energy..., I would just say try to spend the two weeks with her at the hospital and you know, maximize the time that I have with her or whatever, right? (C076I).

Much of the navigation work undertaken by caregivers was devoted to pursuing formal therapeutic support. Caregivers would negotiate for visiting staff they felt comfortable with, and, at times, refused entry of staff perceived as unhelpful:

It took a lot of work to organize all the various people who were coming and going... you had to stay on top of them—Some of them delivered what they said and some of them didn't. (C435C).

3.3 | Engaging with professional caregivers

Caregivers described the importance of interactions with professional caregivers to obtain practical, informational, and therapeutic support “so we can take control” (C031I). Formal support helped to instill a sense of reassurance, while relieving some of the pressure to take charge:

Let's face it, I haven't got a clue. I know when something's wrong, but I don't know necessarily what to do, or how to handle it or what the next step should be. (C587C).

Because you know, the nurses would put things in perspective. [B]oth [patient] and I would see things and we'd get a little scared. The nurses come in and help her... all sorts of things and with her medications. It was very, very helpful, and they're very caring people. (C034C).

Home care services were structured in a way that did not always allow consistent care by the same personal support worker or nurse, or consistency in the quality of care provided: (“some of them were

wonderful, some of them were hellish.” [C114I]) This caused distress for caregivers and patients:

There was a different one every day pretty well... It was hard for me because I had to deal with a different personality each time” (C001I).

For a man who was very proud, to have all these different people, never seeing the same person come and poke him and try and feed him and change him and all that, it was very humiliating for my dad, very, very humiliating. (C015C)

Because support provided by the CCAC program was often perceived as inconsistent, unreliable, and/or insufficient, those who had the means often hired private support.

I was getting some nursing help but that was not sufficient. I didn't get enough hours from these people. It came to the point that she needed someone to be 24 hours a day. I couldn't, so I had to, I hired nursing help. Lucky I could afford that... (C167I)

Those who could not afford private help often felt they needed to provide more support than they were comfortable with: “I couldn't do it all. CCAC needs more resources.” (C314C), “... it basically throws all that heavy nursing on family members” (C-269C). For some, this lack of support resulted in admissions at the end of life.

[Patient] was supportive of me. When he knew the end was coming, he... said, “I need to go in the hospital because I can't do this to my wife anymore.” [crying] Because even though they claim there's support through Community Care, they were basically useless. (C310C)

So by the end [four days before death in the hospital], I remember the last night that I looked after [patient] at home, it probably took me three hours to get her to bed. ... I remember thinking, God, I can't do this. I'm out of steam. (C435C)

Caregivers described the value of being seen by the same professional providing care at home from the initial evaluation to a home death. This was usually the case for physicians, but not for nurses or personal support workers. When it did occur, it was greatly appreciated.

It was the same [personal support workers] basically, which was wonderful. I can't tell you how important that was for [patient]. (C171C)

[Nurse] was the first person to evaluate him. She kept all the records. Every time she came in, she'd update the records... She was actually there with me when he took his last breath. That was a comfort. (C587C).

3.4 | Preparing for death

Those caregivers who had planned for a death at home described the need to prepare and to understand in advance what this would entail.

As most had never witnessed a death, they appreciated detailed explanations from health care providers about how the dying process would unfold; if this did not occur, they sought out information independently:

[Home palliative care physician] sat me down at one point, I think the last visit before she died, and he walked me through and was able to tell me. He told me what I might expect and... the best thing to do, how to react. That was invaluable. (C144I).

Well, [home palliative care physician] told us exactly what was happening with her and what to expect. We would have a meeting once a week and he would tell us if her condition had worsened... and what we could probably expect in the next few days.... The last time we had a family meeting, he said she's pretty well towards the end and it could happen any time. (C059C)

I had some idea of what to do. But I'm not sure that there was any clear instructions given to me as to how to handle those last few days. I think I actually ended up looking on the internet for a document to explain well, what is the dying process? What actually are the stages in which someone dies in this situation? (C081C)

Health care professionals were rarely at the bedside at the moment of death. When this occurred, it was generally by chance but was greatly appreciated (“It was just a coincidence... I'm so glad [nurse] was with me” [C587C]). More often, the palliative care physician or nurse would debrief with the caregiver after the death, which was also seen as helpful:

It was quite traumatic, the death. I wasn't expecting that. I was expecting him to be... just not breathe any more. It was very hard.... I called [palliative care physician]. I remember him talking to me and also his resident that was with him.... I think the most helpful thing was to be able to talk to someone who'd actually seen this many, many times, obviously. (C462I).

3.5 | Managing after death

Death was followed by an emotionally charged time, when caregivers needed to attend to multiple administrative duties. Caregivers described going “into function mode” (C109I), performing tasks such as connecting with the home care team to pronounce death, informing family members, and making funeral arrangements. These involved interactions with both health care professionals and the funeral home:

I think I was very business-like and efficient. I phoned the physician who I was supposed to call and made all the arrangements and—The coroner came and gave me the certificate. The arrangements were made, already premade with funeral home so they came—all the mechanics were done efficiently. Everything was prearranged. (C167I)

Emotionally it was very, very difficult that morning and then we had to call the funeral home. We had to call the palliative care doctor to come in and pronounce her and we had to call the funeral home. It was just that the whole day was just a day of organizing. (C034C)

Some characterized the period following death as disorganized and rushed, while others stated that tasks went smoothly as a result of their own planning and the support of health care providers.

He'd been in a bit of coma for two or three days. It was very much expected. Then we called the palliative care doctor who came in and signed the death certificate which needs to be signed. I'd made all the arrangements I guess when he went into a coma. (C428I).

Caregivers appreciated it when home palliative care providers were proactive in providing assistance with administrative duties after death. This removed pressure from them in the initiation of multiple pressing and often confusing responsibilities at this time and allowed them to grieve.

When [son] called him to tell him that [patient] had died, he [home palliative care physician] came over straight away to sign the death certificate and that. The process was easy if one can say that. From a point of view where I didn't have to push for anything.... there was no pressure on me. And so as I say, it was a difficult time but it was made very easy by those who helped. (C331C).

4 | CONCLUSIONS

Our results outline the processes by which family caregivers participate in home care for patients with advanced cancer, while encountering constraints in the formal delivery of home care services. This study illuminates the multifaceted ways in which caregivers feel compelled to take charge of care as death approaches. It also highlights gaps that may be improved upon, both in the support of caregivers and in the provision of home palliative care services.

Caregivers' described being thrust into a situation of needing to assume responsibility for crucial tasks, without feeling adequately prepared. Due to assumptions that home is the ideal place of death²³ and pressure on hospitals to curtail length of stay, family caregivers may feel "pressured" to provide care at home,²⁴ while lacking appropriate resources. Caregivers take on increasingly complex duties, including managing and administering medications,²⁵ without sufficient support and training. Admission to hospital occurred in those without sufficient support, corroborating evidence from previous studies.^{26,27} Most interventions for caregivers have focused on identifying and relieving emotional distress,^{9,28} rather than on educating, enabling, and supporting caregivers.^{29,30} The present study may inform the development of interventions that train caregivers not only in providing care, but also in navigating administrative complexities, and articulating their needs to health care professionals.

The need to assume control for multiple responsibilities resulted not only from the complex needs of patients with advanced cancer, but also in response to deficiencies in the delivery, organization, and coordination of home care services. Areas of care that were valued, but often not actualized, were consistency of home care providers; accessibility of staff; nursing and personal support for patients that matched the degree of need; and an efficient system that anticipated needs, rather than requiring constant intervention initiated by the caregiver. Although community-based palliative care services may allow patients to remain at home and curtail hospital costs,³¹ an adequate investment is necessary to allow sufficient support for patients and caregivers, including 24-hour support.^{32,33} Our study also highlights the need for better preparation and supports for caregivers in the period immediately following death, which may avert bereavement-related distress.³⁴

Caregivers' frank comments contrast with the generally positive reports on satisfaction surveys,³⁵ underlining the importance of qualitative research in this area. The consistency of these comments among participants, in the intervention and control groups of the trial, also contrasts with positive accounts of patients and caregivers in the intervention group while receiving early outpatient care in the palliative care clinic.³⁶ In contrast to the latter study, the focus of the current study was later in the disease course, by which time almost all participants in both groups had received some form of palliative care. Moreover, unlike care provided in the clinic, which was a core component of the early palliative care intervention, home care services represented an ancillary component, which was not protocolized.¹¹ This might have played a role in the lack of impact of the intervention on the home care experience and on caregiver quality of life.¹² Future palliative care trials of early palliative care should aim to include community care in the formal intervention.

4.1 | Limitations

The main limitations for this qualitative study relate to sampling and recall bias. Participants were predominantly English speaking and well-educated, with a moderate income. All patients for whom care was provided had been enrolled in a trial, and their characteristics (and those of their caregivers) may have differed from those who did not participate. Our research was conducted in a comprehensive cancer center with access to palliative care consultations and home care services. The findings may have limited transferability to settings with more restricted resources.

Recall bias is also pertinent, as the time from bereavement to interview was 1 to 5 years. This range was due to the fact that this study was undertaken when the related randomized controlled trial was complete; because recruitment for the trial occurred over several years, patients recruited earliest had died years before the qualitative study began. Although interview content and themes were remarkably consistent despite variation in time from death to interview, recall bias is nonetheless an important limitation due to the length of elapsed time.

4.2 | Clinical implications and conclusions

Our study contributes to an understanding of the elements of support that enable caregivers to provide care at home. Interventions for

caregivers should include help with navigating the complexities of the health care system; advocating for their own needs as well as for those of their family member; understanding what to expect at the end of life; and preparing in advance for tasks after death. In addition, changes are required in the home care system. These include better coordination of care; improved communication of health care professionals with each other and with caregivers; consistency, accessibility and responsiveness among those providing care; and equitable access to adequate and timely support.

In conclusion, caregivers contribute importantly to home care, but often receive inadequate formal support. The results from this study may be used to inform the development of interventions to support caregivers, as well as the establishment of policies, quality indicators and guidelines for the provision of comprehensive, interdisciplinary home palliative care.

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CONFLICT OF INTEREST STATEMENT

None declared.

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