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ORIGINAL ARTICLE

Caring at home until death: enabled determination

Carole A. Robinson[1] · **Joan L. Bottorff**[2] · **Erin McFee**[3] · **Laura J. Bissell**[4] · **Gillian Fyles**[5]

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Abstract

Purpose The importance of family caregivers in providing palliative care at home and in supporting a home death is well supported. Gaining a better understanding of what enables palliative family caregivers to continue caring at home for their family members until death is critical to providing direction for more effective support. The purpose of the study was to describe the experiences of bereaved family caregivers whose terminally ill family members with advanced cancer were successful in achieving a desired home death.

Method A qualitative interpretive descriptive approach was used. Data were collected using semi-structured, audio-recorded interviews conducted in-person or via telephone in addition to field notes and reflective journaling. The study took place in British Columbia, Canada, and included 29 bereaved adult family caregivers who had provided care for a family member with advanced cancer and experienced a home death.

Results Four themes captured the experience of caring at home until death: context of providing care, supportive antecedents to providing care, determination to provide care at home, and enabled determination. Factors that enabled determination to achieve a home death included initiation of formal palliative care, asking for and receiving help, augmented care, relief or respite, and making the healthcare system work for the ill person.

Conclusions Clarifying caregiving goals and supporting the factors that enable caregiver determination appear to be critical in enhancing the likelihood of a desired home death.

Keywords Family caregivers · Lay carers · Home death

Introduction

In Canada, home is considered the preferred place to die [1–4] and is associated with better overall quality of death [5–7]. Families of individuals who die in their preferred location are significantly more likely to be satisfied with their loved one's end-of-life care and quality of death [8]. Although deaths outside the hospital setting in Canada accounted for 35.4% of total deaths across the country in 2012 [9], the majority of expected deaths still occur in hospital or residential care facilities [10].

✉ Carole A. Robinson
Carole.robinson@ubc.ca

Joan L. Bottorff
Joan.bottorff@ubc.ca

Erin McFee
erin.mcfee@alumni.ubc.ca

Laura J. Bissell
Laura.bissell@ubc.ca

Gillian Fyles
gfyles@bccancer.bc.ca

[1] School of Nursing, University of British Columbia, ART 132, 1147 Research Road, Kelowna, BC V1V 1V7, Canada
[2] School of Nursing, University of British Columbia, ART 223A, 1147 Research Road, Kelowna, BC V1V 1V7, Canada
[3] School of Nursing, University of British Columbia, Kelowna, BC, Canada
[4] College of Graduate Studies, University of British Columbia, EME 2121, 1137 Alumni Avenue, Kelowna, BC V1V 1V7, Canada
[5] British Columbia Cancer Agency, Sindi Ahluwalia Hawkins Centre for the Southern Interior, 399 Royal Avenue, Kelowna, BC V1Y 5L3, Canada

A primary family caregiver (FCG) is essential to providing end-of-life care at home [11–13]. Estimates suggest that FCGs are responsible for 75 to 90% of palliative care provided at home [11]. Individuals who are supported at home by a specialist palliative care team are more likely to achieve a desired home death [7, 14]; however, the majority of Canadians do not have access to such care [15]. The provision of end-of-life care by a FCG is complex and challenging as well as rewarding [16–26]. FCGs experience significant lifestyle changes, decline in physical and emotional health, and financial burden [23, 24]. Determining effective supports remains a vital research priority [27].

We conducted a study of FCGs who were not able to achieve a desired home death [28]. In addition to previously identified caregiving challenges, we found when FCGs promised to care at home until death, it constrained them from considering other options even when their personal resources were depleted. In addition, these FCGs were reluctant to ask for help because they were afraid that care would be taken out of their hands. When they became overwhelmed, FCGs sought professional assistance and complied with directives to bring their ill family members to hospital or hospice for care. The ill family members never returned home. Inadvertently, the promise of a home death was broken and the bereaved FCGs suffered profound guilt and despair. This study highlighted the critical importance of timely and effective support and the consequences when it is absent.

Researchers have begun to describe factors that contribute to FCGs' ability to provide their loved ones with the home death experience they desire. Successful FCGs were characterized by a desire to maintain a sense of control in the caregiving situation and to provide privacy and a feeling of normalcy for their family member [26]; maintained open communication with and between healthcare providers to ensure continuity of care and the comfort and dignity of the dying person [29]; maintained a flexible positive attitude toward caregiving while drawing their own strength from the strength of the dying person [25]; and found the burden of caregiving to be more manageable when additional FCGs were involved [6, 30, 31]. While the literature provides some important general insights, a better understanding of the factors that contribute to FCG success in achieving a home death is needed to provide direction for effective support. The purpose of this research was to describe the experiences of bereaved FCGs who were successful in providing their family members, who were terminally ill with advanced cancer, with a desired home death.

Method

An interpretive descriptive design [32] was employed. This inductive approach focuses on participants' experiences from their own perspective enabling researchers to generate a meaningful interpretation that provides direction for optimizing quality of care [32, 33]. The study was approved by the University Behavioral Research Ethics Board.

Participants

Recruitment occurred through media releases, including notices in local newspapers, FCG support groups, and hospice and cancer organizations. In addition, a radio interview regarding the project generated interest. For the purpose of this study, FCGs were defined as the person providing the majority of emotional and/or physical care to the terminally ill person and was inclusive of family members and close friends. Inclusion criteria were (1) English-speaking adults aged 19 years or older who provided care to a family member with advanced cancer at home, (2) death occurred at home, and (3) FCGs were bereaved for no less than 6 months [34]. A $25 gift certificate was provided as a token of appreciation. The final sample included 29 bereaved FCGs (Table 1).

Data collection

Semi-structured, audio-recorded interviews were conducted in person or by phone depending on the location and preference of the participant. Open-ended questions focused on caregiving experiences, decision-making processes, and the impact of caring at home until death. Participants completed a short demographic questionnaire. The Brief Grief Questionnaire (BGQ) was used as a screen for complicated grief [35]. This tool is a reliable indicator of the need for further clinical assessment (Cronbach's alpha range of 0.75–0.82) [35–37]. All participants had a BGQ score indicating they were unlikely to be at high risk for complicated grief, which was supported by their interview accounts. Field notes and reflective journaling were used to contextualize data and enhance reflexivity [38]. Participants were offered a list of regional resources and psychological supports. Each participant received a follow-up phone call within 48 h of their interview to inquire about emotional difficulties and need for support. None of the participants required referral.

Data analysis

Interviews were transcribed verbatim and accuracy checked. Data collection and constant comparative analysis occurred synchronously [38]. Three team members (CR, JB, LB) independently read transcripts to identify codes that captured distinct aspects of the caregiving experience. These codes were compared and contrasted within

Table 1 Description of family caregivers

FCG	Number
Gender	Women—19
	Men—10
Year of birth of FCG	Range: 1922–1981
Marital status	Married/common-law/widowed/divorced/separated—28
	Single, never married—1
Education	High school—5
	Post-secondary (including university and technical/non-university education)—24
FCG report of own health	Excellent—7
	Very good—12
	Good—5
	Fair—5
Relationship to the dying person	Spouse/partner—16
	Child—5
	Parent—5
	Other relation—3
FCG proximity to the dying person	In the same home as your family member/friend—21
	In the same community as your family member/friend—3
	Other—5
Duration of caregiving	Range: 1 week–16 years
	Mean: 20 months
Hours per week of caregiving	Minimum: 2 h/week
	Maximum: 168 h/week
	Mean: 109 h/week
Main caregiving tasks FCG performed (could choose more than one)	Home maintenance (inside and/or outside)—26
	Car maintenance—14
	Grocery shopping—24
	Cooking—25
	Taking care of pets—11
	Home changes for safety (e.g., installing wheelchair ramps, grab bars for bathroom, etc.)—17
	Operating special equipment (e.g., hospital bed, commode, wheelchair, etc.)—23
	Personal care (e.g., bathing, toileting, transferring in and out of bed, wound care and dressing, etc.)—26
	Pain control—26
	Symptom management (e.g., nausea, vomiting, confusion, trouble swallowing, etc.)—23
	Knowing the signs and symptoms of a problem that requires medical attention—24
	Giving medications and keeping a record—25
	Transportation to and from healthcare appointments—26
	Keeping your family member/friend active and exercising—18
	Doing enjoyable things with your family member/friend—26
	Financial affairs (e.g., bills, banking, etc.)—22
	Legal affairs (e.g., power of attorney, wills, representation agreement, etc.)—20
	Other activities—10

and between interviews to identify patterns and relationships in the data, thus creating a coding framework. When the coding framework became stable, all transcripts were entered into NVivo 9.0. Then, data coded to each node were analyzed by three team members (CR, JB, EM) to elicit patterns, variations, and dimensions of the FCGs' experience that contributed to achieving a home death [32, 39].

Results

The main themes represented in FCGs' experiences of caring at home until death were context of providing care, supportive antecedents to providing care, determination to provide care at home, and enabled determination.

The context of providing care

The circumstances of caregiving for the participants in the current study did not differ significantly from those of caregivers in previous studies [22, 28]. The focus was on comfort for the ill family member, and the FCGs were willing to do whatever was required to meet the needs of the ill person. Because FCGs were intensely committed to providing excellent care, they fervently searched for and synthesize information, made keen observations, engaged in creative problem solving, and took a position of vigilant advocacy for the ill person.

The experience of being "on 24/7" was common as were symptom management challenges and crises, and demands associated with multiple co-occurring life events. As one FCG said, it felt "like a plague of locusts." Not surprisingly, sleep disturbance accompanied by profound fatigue was common. However, direct observations from paid providers that the FCG needed help were sometimes viewed as judgmental rather than caring.

> Even when the palliative care nurse said to me, "I think it is time for you to have help," I objected. That was in the last week of (name)'s life. I said, "No, I have looked after him all along. I am going to continue to look after him." So, when she hit me with this, I was almost a bit resentful.

All participants struggled with lack of coordination and continuity of care from healthcare providers. At times, even well-intentioned support was overwhelming because it added responsibilities, such as when new home care staff needed repeated education and supervision. These experiences prompted some FCGs to refuse further assistance. As one participant said, "We just did it ourselves."

FCGs acknowledged that caregiving was challenging and a few had times where they wondered about continuing. But, when support was put in place, care continued at home. In fact, participants reported that the time of intense caregiving was relatively short and manageable. The period of intense caregiving often began with the realization that the ill person was dying, and the perception that it was short did not seem related to the actual duration of caregiving. Providing care did not push these FCGs beyond the edge of their personal resources.

Supportive antecedents to providing Care at Home

Common to reports of the experiences of other caregivers [22, 28], the FCGs in this study undertook caregiving without question or forethought about the commitment they were making. However, several important antecedents appeared to set these FCGs up to successfully achieve a home death. Many participants had previous experience with caregiving, death and dying, or counseling, which supported them in taking up the caregiving role. An understanding of such things as what illness progression entailed, decisions that might be faced, elements of care that would be required, how to facilitate communication, and how to provide care seemed unique to this group.

Determination to provide Care at Home

The FCGs were absolutely determined to provide care at home and were committed to care as long as possible.

> You can do it, if your heart and soul are in it. You would do the same thing I am doing. I am not a martyr, I am not anything great… I am doing what I want to do, which is caring for my husband.

Not unlike other caregivers [22, 28], these FCGs explained their determination to care at home as a relational commitment that rested in love, respect, obligation, or giving back to someone who had given them so much and as a way to honor their ill family member's wishes. Often, determination to care at home was initiated or solidified by a negative experience with the healthcare system and thereby shaped by a desire to protect the ill person from hospitalization and pleas not be taken to hospital.

Unlike caregivers that made promises to care at home until death [28], these FCGs were committed to care at home for as long as possible, including the possibility of death at home. This acted as a positive influence on the experience by allowing room for considering options.

Enabled determination

Recognizing that FCG determination to provide palliative care at home, while important, is not sufficient to enable a desired home death [28], we sought to identify critical factors that aided these FCGs in achieving a home death. Five factors were identified as enabling caregivers' determination and each is described below.

Initiation of formal palliative care. Participants reported that initiation of palliative care services enabled caregiving. Four important things came with formal palliative care: system recognition of them as caregivers, access to a highly qualified team, better coordination of care, and the availability of a program of resources. System recognition involved attention to the FCG, acknowledgment of the critical work of caregiving, and concern for their needs as caregivers. Skilled nurses assisted with assessing, identifying, and meeting needs.

> So, she [nurse] said to me I think you need a bed bar, I am going to bring one tomorrow….That was probably one of the best things that happened to us, because he felt that he was more able to get himself up.

Getting the right assistance at the right time was immensely helpful for FCGs who had been persevering on their own. Caregivers felt relieved when "things just started to appear," like a hospital bed. They had someone else thinking with them, which took some of the pressure off. Even small things made a big difference. Coordination and continuity of services was crucial.

Asking for and receiving help. Although in previous studies [22, 28] caregivers reported reluctance to ask for help because they were afraid that paid providers would judge them negatively and care would be taken out of their hands, this group of FCGs did not hesitate to ask for help. Help mustered during a crisis or potential turning point was critical to carrying on at home. Providers occasionally went beyond expectations by securing a needed resource rather than simply identifying the need and leaving the work of pursuing the solution with the FCG. This enabled FCGs to meet their goal of staying close to the ill person and, at the same time, providing excellent care.

Augmented care. Care that was augmented by the ill person, as well as family and friends, was also an enabling factor. While some FCGs lived alone with the ill person, none cared alone without support. Many of the participants reported having friends who were healthcare professionals who played a pivotal role in filling health system gaps. These friends offered information about illness progression and ways to meet caregiving needs, anticipatory guidance, assistance with problem solving, suggested resources, and emotional accompaniment.

Care was also augmented by family members who helped primarily with instrumental tasks like building a wheelchair ramp. In addition, FCGs talked about the critical support they received from the ill person. They identified the importance of the ill person accepting rather than fighting care and contributing to care by doing as much as possible for themselves or calling in additional family support. The positive influence of both a sense of humor and gratitude were noted. When the ill person appreciated the work of the FCG, it was a powerful influence. Whereas some caregivers have been reported feeling alone in their caregiving even when palliative support was in place [28], the FCGs in this study reported feeling accompanied.

Relief or respite. Many participants commented on the importance of getting a break, whether it was to attend a meeting outside the home or the ability to sleep in and re-charge on a weekend. Family members were key to the primary FCG having respite at home, which was the preferred site of care. Respite provided effective relief if it occurred when the FCG needed it and had confidence that the ill person was in good hands. When paid providers provided respite in the home, this was often unsuccessful because they required supervision and were limited in what they could do.

Respite outside the home was not desired by some caregivers and not successful for others: "I didn't go through all this with him…to put him in respite." Some participants who used respite outside the home experienced unmanageable requirements for bookings months in advance and system failure, such as poor care or lack of communication, so they removed their family member from care.

Making the health care system work for the ill person. The final factor was making the healthcare system work for the ill person rather than orienting care to work for the system. Some participants reported "doing battle" with the system to get what their ill family member needed. Others took the "just say no" approach. This was a startlingly different approach than that taken by FCGs in a previous study who complied with directives to bring their ill member to hospital or to hospice, which meant they did not accomplish a desired home death [28]. In contrast, the FCGs in the current study reported multiple instances where, instead of conforming to what the system wanted of them, including leaving home for care, they said "no, that will not work." As one participant explained:

> I needed to be able to get up and have a shower, brush my teeth without having to worry about him falling. So once I changed my [community care] hours around, had the family come on the weekend, and instead of respite, short breaks during the week….That was huge, to be able to sit and have a shower, cup of coffee…before getting into that busy place.

Another FCG gave this example of what happened after her father slid to the floor:

> The ambulance people came in and they are excellent….They said "We think we should take him to the hospital." I looked at [father] and said "Do you want to go to the hospital?" And he said no, so…we…continue[d at home].

Another FCG, after careful observation, altered medications that were not supporting the goals of caregiving.

> I kept making notes when I was giving [the medication] and…the reaction [agitation] for a period of over 20 hours. I finally said, no, I am not going to do that….anymore. We were…starting to lose some of the more lucid moments…not allowing some of those intimate kind of…moments of cognitive ability.

Caregivers stood up to provider judgments, suggested alternatives, and were able to continue providing care; the ill persons remained at home, and essential assistance was obtained. This speaks to the clarity, competence, confidence, and advocacy of the FCGs in this study.

In summary, multiple factors contributed to FCGs' ability to enact their determination to care for their ill person at home. These participants believed they had done their best for their ill family members and all but one reported they would do it again.

Limitations

The participants were highly educated, which may have contributed to their success in caring at home until death. Although this study was conducted in Canada where palliative care falls under the scope of a publicly funded healthcare system, variations exist in the provision of palliative care services (e.g., between urban and rural dwellers). However, the findings may not be generalizable to settings where government-funded home care programs are not available.

Conclusions

Critical factors that enable caregiving until death at home were identified in this study.

None of the FCGs experienced an ideal situation where all enabling factors were in place. All experienced significant challenges, but with some of the enabling factors in place, were able to persevere in their determination. If attention were paid to supporting each of the enabling factors as shown in Table 2, our data support the assertion that death at home may be more feasible. The key seems to be recognition that FCGs are central to people being able to live and die with advanced cancer at home. Palliative care providers have identified the importance of patient and family goals of care in medical decision making. Equally important are *goals of caregiving*. When FCGs' goals are clarified and provider care aligns with those goals, then dying at home is enabled. However, even for these FCGs who were successful in achieving a home death, we heard many stories of how providers did not recognize them, did not recognize their work or the importance of their work, and at times, interfered with the accomplishment of their caregiving goals. For many, successful caring at home occurred in spite of health system failures. Assistance and resources to support FCGs need to be offered in respectful, uncompromising ways to avoid undermining FCGs' work and determination. This requires a partnership relationship explicitly built on reciprocal trust [40] that is inclusive of comprehensive assessment and support of friend and family involvement in care. Managing at home was a joint endeavor between the FCG and the person dying of cancer. This too requires recognition and support. Dying at home takes a compassionate community and while professional providers are critical, we are only one piece of the picture. We are called to carefully find our fit rather than requiring the family and their network of support to march to our tune.

Table 2 Enabled determination

Enabling factors	Enabling aspects	Ways to strengthen enabling factor
Initiation of formal palliative care	• System recognition of them as caregivers • Access to a highly qualified team • Coordination of care • Availability of a program of resources	• Clear identification of all available services and supports • Role clarity of various providers • Improved coordination, integration and continuity of services
Asking for and receiving help	• Timely and effective support particularly during crises or turning points • Anticipatory identification of needed resources	• Acknowledgment of the work of caregiving • Identification of goals of caregiving • Explicit alignment with FCGs to support goals of caregiving • Information provided in ways that acknowledged the demands of caregiving and critical role of FCGs • Improved continuity of provider assistance
Augmented care	• Friends and family members available to fill health system gaps and support FCG • Contributions to supporting FCG caregiving by ill person	• Identification and recognition of augmented care • Support of augmented care when needed, e.g., enabling ill person to do as much as possible
Relief or respite	• In-home respite care provided by family or others with knowledge of ill person and ability to meet needs	• Paid respite providers who do not require supervision and are not limited in the care they can provide
Making the system work for the ill person	• Being a strong patient advocate by contesting unhelpful provider judgments or using a just "say no" approach • Being clear about what is needed to provide excellent care at home	• Putting patient needs first—rather than system needs • Listening to FCGs and engaging in collaborative problem solving • Aligning with goals of caregiving

The importance of comprehensive, coordinated, and integrated palliative services in the home cannot be underestimated. Indeed, evidence supports the contention that palliative care increases the odds of dying at home [41]. This does not always require specialist palliative care but it does require palliative expertise. There is desperate need to improve the provision of palliative care and the need will only increase [15]. Despite the predominant strategy of focusing day-by-day that was taken up by most of the FCGs, when skilled palliative providers anticipated need and had resources in place in advance, just-in-time support was enabled. Further, assisting FCGs to "work the system" was important for caregiving well and for bereavement [42].

These findings point to the need to maximize the effectiveness of existing palliative care services through early initiation and orientation to *both* patient and FCG needs in order to better support care at home. One way to enable FCG-directed care is through the systematic integration of targeted interventions, such as the Carer Support Needs Assessment Tool [43], within routine care. This tool addresses both FCG support needs and their ability to provide care; it enabled nurses to develop effective relationships with empowered FCGs [43]. Other tools such as the Family Caregiver Decision guide show clinical promise [44, 45]. While it is not possible to estimate the cost implications of using these strategies to strengthen the provision of palliative care services, there is growing evidence that effective home-based palliative care is less costly than other alternatives [46]. Furthermore, FCGs need to provide excellent palliative care and there are serious, long-term consequences when this is not possible [22, 28]; they must be invited out of the shadows and into a collaborative partnership [40].

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Compliance with ethical standards

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