Examining the Perspectives of Family Members Involved in the Delivery of Palliative Care at Home

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Abstract / This ethnographic study examined the social context of home-based palliative caregiving. Data were composed of observation field notes, interviews, and textual documents, and were analyzed using constant comparative methods. Findings show that home-based palliative caregiving resulted in life-enriching experiences for many caregivers. However, assumptions about dying at home and health care re-forms resulted in some caregivers feeling “pressured” to provide home care, and consequently, left them feeling their obligations to care were exploited by the health care system. Shifts toward providing care closer to home not only changed caregivers, but also changed the home setting where palliative care was provided. Findings indicate a need for interventions designed to improve support for caregivers at home, and to explore how assumptions influence and sometimes drive the provision of home health care.

Résumé / Cette étude de nature ethnographique s’est penchée sur le contexte social entourant la prestation des soins palliatifs à domicile. Les données utilisées comprenaient des observations et des notes prises sur le terrain, des interviews, de même que des documents qui ont été analysés selon des méthodes comparatives constantes. Les résultats de l’étude démontrent que pour plusieurs soignants le fait de pouvoir prodiguer les soins palliatifs à domicile a été une expérience enrichissante. Cependant, les réformes de la santé, tout comme les présupposés entourant la mort à domicile ont fait en sorte que certains soignants ont senti qu’il s’exerçait une pression sur eux afin qu’ils dispensent les soins à domicile et conséquemment que cette obligation de soigner un des leurs avait été exploitée par le système de santé. Ce déplacement des soins palliatifs de l’hôpital vers la maison a non seulement changé la vie des soignants, mais également le milieu familial où les soins étaient maintenant dispensés. Les résultats de l’étude démontrent la nécessité d’établir des modes d’interventions pour soutenir les soignants naturels tout comme on devra faire une réflexion plus poussée sur la façon dont les présupposés influent et, quelques fois, servent à justifier la notion de soins palliatifs à domicile.

INTRODUCTION

Family caregiving is a prominent issue in Canadian society (1). Irrespective of whether a country has a universal, comprehensive health care system, such as Canada’s, estimates suggest that between 75% and 85% of all caregiving occurs in the home and is provided by unpaid family members (2,3). Family caregiving has gained attention in the last decade, as the Canadian health care system struggled to meet the demands of an aging population and an increase in the prevalence of cancer and other life-threatening conditions (4,5). At the same time, reduction of health care budgets and closure of hospital beds have placed increased pressure on community-based care. Canadians are becoming increasingly reliant on home care as more people die at home or spend a large portion of their illness in the home setting (6,7).

Calls to enhance home care services for the dying have been echoed across the country. Yet, many claim health care systems have been largely unresponsive to the needs of family caregivers (8–10). Research suggests that burdens associated with caregiving greatly exceed family members’ capacity to cope (10), highlighting physical, psychosocial, and financial risks to assuming the caregiver role (11–16). The social context of our modern society also produces challenges for families. Migration of family members away from the home, smaller families, and changing household structures mean there may be fewer people to support those dying at home in the future (1,17,18).

The impetus to provide care at home is growing as a result of the need to curtail health care costs, and to provide a more therapeutic milieu in which dying and death can occur (19,20). While there are specific benefits to family members who provide palliative care (21–24), studies examining family caregiver experiences tend to focus on individual descriptions, with less attention paid to structures and processes that may shape caregivers’ experiences. The purpose of this study was, therefore, to describe the experiences of family members who provide home-based palliative care and to situate these
a broader context (25,26). The primary sample was comprised of 12 dying patients, 13 family members who were providing care for them, and 47 caregivers who had previously provided care at home to a dying person. The secondary sample was comprised of health care providers (HCPs) (n=28) and administrators (n=10). Caregivers (and patients) were recruited by letters of invitation distributed to them by HCPs and by advertisements in local newsletters. HCPs were recruited through presentations. Letters of invitation were used to recruit administrators. Purposive sampling (27), a form of non-probability sampling, was used to guide selection of all participants. Demographic characteristics of the 60 caregiver participants are given in Table 1.

### Data Collection

Data included participant observation field notes, interviews, and documents (e.g., news stories, policy statements, government reports) pertaining to family caregiving and home care that had been published in Canada between 1990 and 2000. After obtaining informed consent, 130 hours of observation (28,29) were conducted in the homes of 13 palliative caregivers. Field notes (30) were written to document observations and were validated with caregivers to ensure accurate interpretation of events. Open-ended interviews (31) were also conducted to augment observation data. In total, 92 people participated in either a one-to-one or focus group interview (Table 2).

### Interview guides were developed for each participant group, but interviews remained open to exploring variations in participant experiences. For instance, caregiver interviews began with an open-ended prompt such as, “Tell me how you came to be a caregiver”. As the interviews progressed, questions became more specific, focusing, for example, on factors influencing the decision to provide palliative home care, the rewards and challenges resulting from that decision, and questions related to caregivers’ experiences within a broader context. This paper presents an overview of research findings. Detailed findings will be reported in forthcoming papers.

### METHODS

Ethnography was the methodology used for this study, because it uses research methods aimed at understanding individual experiences within

<table>
<thead>
<tr>
<th>Table 1 / DEMOGRAPHIC PROFILE OF FAMILY CAREGIVER PARTICIPANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years):</strong> mean = 58 range = 25–85</td>
</tr>
<tr>
<td><strong>Education</strong></td>
</tr>
<tr>
<td>elementary/primary only</td>
</tr>
<tr>
<td>attended or graduated high school</td>
</tr>
<tr>
<td>attended or graduated college or trade school</td>
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<tr>
<td>attended or graduated university</td>
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<tr>
<td><strong>Employment Status at Time of Caregiving</strong></td>
</tr>
<tr>
<td>working full-time</td>
</tr>
<tr>
<td>working part-time</td>
</tr>
<tr>
<td>took leave of absence to provide care</td>
</tr>
<tr>
<td>unemployed</td>
</tr>
<tr>
<td>retired</td>
</tr>
<tr>
<td><strong>Relationship to Dying Person</strong></td>
</tr>
<tr>
<td>wife</td>
</tr>
<tr>
<td>husband</td>
</tr>
<tr>
<td>daughter</td>
</tr>
<tr>
<td>son</td>
</tr>
<tr>
<td>daughter-in-law</td>
</tr>
<tr>
<td>partner in same sex relationship</td>
</tr>
<tr>
<td>mother</td>
</tr>
<tr>
<td>sister</td>
</tr>
<tr>
<td><strong>Living Arrangements</strong></td>
</tr>
<tr>
<td>shared household with patient</td>
</tr>
<tr>
<td>lived independent of patient</td>
</tr>
<tr>
<td>moved from permanent residence to share household</td>
</tr>
<tr>
<td><strong>Annual Income at Time of Caregiving</strong></td>
</tr>
<tr>
<td>&lt;$20,000 CDN</td>
</tr>
<tr>
<td>$20,000–$39,999</td>
</tr>
<tr>
<td>$40,000–$59,999</td>
</tr>
<tr>
<td>$60,000–$79,999</td>
</tr>
<tr>
<td><strong>Patient Diagnosis</strong></td>
</tr>
<tr>
<td>cancer</td>
</tr>
<tr>
<td>AIDS</td>
</tr>
<tr>
<td>end stage cardiac</td>
</tr>
<tr>
<td>ALS</td>
</tr>
<tr>
<td>other</td>
</tr>
<tr>
<td><strong>Location of Patient Death</strong></td>
</tr>
<tr>
<td>home</td>
</tr>
<tr>
<td>hospice inpatient unit</td>
</tr>
<tr>
<td>acute care hospital</td>
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<tr>
<td>long term care facility</td>
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<tr>
<td><strong>Number of Years Since Caregiving</strong></td>
</tr>
<tr>
<td>&lt;1 year</td>
</tr>
<tr>
<td>1–3 years</td>
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<tr>
<td>4–10 years</td>
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<tr>
<td>11–20 years</td>
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<tr>
<td>&gt;20 years</td>
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- Location of death was counted only for family members who had previously provided care. Thirteen of the 60 caregivers were providing care at the time of the study.
- Number of years since caregiving is recorded only for the 47 caregivers who had previously provided care.

<table>
<thead>
<tr>
<th>Table 2 / PARTICIPATION IN INTERVIEWS BY PARTICIPANT TYPE</th>
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<tbody>
<tr>
<td><strong>Category</strong></td>
</tr>
<tr>
<td>family caregivers: active</td>
</tr>
<tr>
<td>family caregivers: previous</td>
</tr>
<tr>
<td>health care providers</td>
</tr>
<tr>
<td>administrators</td>
</tr>
<tr>
<td><strong>Total</strong></td>
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* Although 13 caregivers participated, only 10 participated in an interview. Caregivers were given the option to participate in an interview, observation, or both.
experiences with formal health care systems. A first round of interviews with half the study population led to the development of a conceptual scheme that was validated and extended through a second round of interviews with the remainder of the sample and through further observations with caregivers. Focus group interviews (32) were also conducted with two groups of home care nurses and one group of home support workers. Interviews lasted between 60 and 180 minutes. With few exceptions, interviews were tape-recorded and transcribed. Most caregivers were interviewed separately from the family unit.

Data Analysis

Analysis was concurrent with data collection. Analysis began immediately following the first interview and episode of observation, and proceeded by reading a hard copy of data to get a sense of the whole (26,33). Data were then coded using the computer software package NVivo™ (34) to highlight key categories and areas requiring clarification. To validate findings and account for potential investigator bias, almost half the caregiver participants were asked to respond to the evolving analysis and evaluate its relevance. Triangulation, another way to establish validity and reliability in qualitative research (35), was also employed, using data from different sources and by using various data generating procedures. Meetings with research assistants (who interviewed several participants) were held to discuss emerging findings and to provide the investigator with the opportunity to check her interpretations. Findings and conclusions were also independently reviewed by five academics, as this work made up the investigator’s dissertation research. The second round of interviews and observations with caregivers also validated findings, since such “member checks” assist in establishing data credibility and trustworthiness (35).

RESULTS

This study resulted in a contextualized picture of the experience of family members who provide palliative care at home. An overview of findings is presented to describe how caregivers made the decision to provide home care and what factors influenced their decisions. Living with the decision was life-enriching for many caregivers, but was also challenging, leading some caregivers to change their decisions about home care. The context of community-based care, including health care reforms, and assumptions about dying at home also influenced caregivers’ experiences.

Deciding to Provide Home Palliative Care

There was significant variability in how caregivers made their decisions to provide home care.

- Some made snap decisions, giving little consideration to the implications. Providing care at home was “something I hadn’t really thought about, I just had to do it”.
- Other caregivers made indifferent decisions, whereby they sometimes felt they had little choice but agreed based on the wishes of the patient, even though the caregivers themselves were ambivalent.
- Still other caregivers made negotiated decisions, whereby they openly discussed the decision with the patient and reached a mutual agreement.

The decision to provide home care was most commonly in the form of a promise the caregiver made to the patient. This promise was influenced by a desire to support the patient’s wish to be at home, and by a belief that privacy and self-determination could be maintained at home. A primary motivator for home care was caregivers’ and patients’ previous negative experiences with acute hospital care. Notwithstanding favourable feedback, caregivers were mostly critical of hospital care, describing it as depersonalized, paternalistic, and rule-based. Caregivers differentiated acute care wards from palliative care wards and said acute care was like “entering the war zone”, where caregivers and patients had to “fight” for quality health care. When negative experiences occurred, this often resulted in caregivers making a promise to “never take [the patient] back there [hospital].”

Living as a Palliative Caregiver

Living with the decision to provide care at home was life-enriching for many caregivers. Caregiving provided opportunities for reciprocity, finding meaning in the situation, and for spending time with the patient. This experience allowed some caregivers to learn about themselves and the patient in new ways, and helped them accept their impending loss, work through grief, and recognize the life-affirming aspects of the experience:

I would have had a lot harder time letting her go and accepting that she was gone if I hadn’t had that time with her [at home]. Not just the caregiving, but the grieving process. It’s not something that you would ever want to go through but it’s still one of the most life-affirming things that I’ve ever been through. It gives you a perspective that life does go by and time does go by, and
you're not here indefinitely....So it still definitely
has an effect on my life.

Caregivers describing life-enriching experiences felt prepared, were able to anticipate the needs of and had previously shared a good relationship with the patient, were well supported by home HCPs, had the time and financial resources to commit to caregiving, and negotiated the decision with the patient to provide home care.

Caregiving was also draining. Despite the support provided by HCPs, many caregivers said their experience was exhausting, difficult to recover from, and required both financial and personal sacrifice. Some caregivers said they felt "tied down" and "stuck", and began to see their role as a "job". While caregiving provided opportunities to demonstrate commitment to the patient, some caregivers felt their sacrifices were minimized:

If I hear one more person saying how wonderful I am to be doing this [providing care at home], I think I'm going to scream.

Many caregivers remarked on how their homes and family relationships changed as a result of providing home care. By necessity, the home environment was often turned into a hospital-like setting, filled with equipment and supplies. Maintaining privacy, intimacy, and self-determination—hallmarks of a normal home life—was difficult when the home was taken over by medical equipment and home HCPs. Invasions of privacy were a major problem for caregivers who struggled to adjust to the numbers of different HCPs coming into their homes. Home visits from HCPs, deliveries of medical equipment, onsite pharmacy services, and emergency care were all provided at home and sometimes left caregivers feeling "pushed aside". At the same time, caregivers acknowledged they could not have kept their promises without the help provided to them.

Many caregivers reinvented themselves to become "nurse-caregivers" by assuming responsibilities for the patient's personal care, assessing symptoms, planning and coordinating care, monitoring the patient's health status, and mediating family tensions. While some caregivers took considerable pride in this role, stating caregiving was a "final gift" they could give to the patient, others said assuming this role meant they had little time to devote to maintaining their core identities as wives, husbands, mothers, fathers, daughters, or sons, and this produced changes in family relationships. For instance, a young woman caring for her father, who refused outside help, "battled" over lifting techniques each time she moved him from the bed to the commode. Reflecting on her experiences, she said she relinquished her role as a daughter as she became the person inflicting unpleasant procedures on her father. She wondered whether the hospital might have provided a better care option:

It came to us having to fight all the time, instead of spending my time saying goodbye to him. All that [caregiving] gets in the way. Like the fact that he was mad at me because I was the one inflicting all of this stuff on him. That gets in the way....When he was in the hospital, I could just be there and support him and help him and have more of a comforting type of relationship....I guess your role changes [when you are at home]. Because instead of your job being to just sit there, spend time with him, comfort him, and hold their hand, suddenly your job is to look after their pain, their nourishment, their bodily functions. So, you feel like you don't really know what exactly it is you should be.

Changing the Decision

Some caregivers could not continue to provide home care. When caregiving became overly burdensome, these caregivers had the patient admitted to hospital. Some caregivers could only make this decision when the patient became unconscious, because they were unable to break their promise to the patient to care for them at home. Other caregivers felt they had deceived the patient, letting them think they were only going to hospital for a few days. Changing the decision or "breaking the promise" made caregivers feel extremely guilty; they felt they failed the patient because they were unable to grant the patient's wish to be at home. An HCP recommended early intervention to help caregivers recognize potential difficulties, and suggested that this might minimize the guilt caregivers feel when they reverse their decision:

Some of the things I see that are distressing are the promises that people make to keep him or her at home. You know, they say, "We promised we'd keep her at home." And now, you know, they're desperately guilty because the person can't stay home. I often say to them, "You know, circumstances change." I think, when we meet families and we ask them where they would like them to die and they say home, we should probably say to them, "Fine, but circumstances change and if it changes, you shouldn't feel guilty." We should start at that point in saying to them, "you don't have to feel guilty," because it's too darn late to do that to them afterwards. We should be saying to them, early on, that problems may arise which make this impossible for you to carry out and you must not feel guilty about it.
Context of Community-Based Care

Reforms in health care delivery influenced home-based palliative caregiving. At the time of this study, the health care setting was in the process of regionalizing services, with the goal of shifting services closer to home to enhance continuity of care. Achieving continuity of care, however, was difficult for caregivers and they experienced discontinuity, with health care agencies parcelling out specific functions. Although caregivers appreciated the help they received, many indicated that communication between agencies contributed to discontinuity:

I don't want to say I didn't appreciate the help we got, because I did. But nobody seemed to be talking to each other....It was the same questions over and over again, and it just seemed that one didn't know what the other was doing....At first we were with the cancer agency and, when we moved over to palliative care, it just seemed like one group didn’t communicate with the other....When we went home, well, that was another story. There were reams of people coming in and out, all asking the same stuff, and you get tired of that after a while....The system certainly broke down in our case, and I think there are just too many branches and they don’t all get together.

Changes in the health care system aimed at maintaining people at home also shaped caregivers' experiences. Some caregivers, unable to cope, could not get access to inpatient beds because none were available. Some caregivers felt they had to prove they were in need of help, sometimes using the emergency department as a point of entry into the system. Once the patient was in acute care, some caregivers felt pressured to take their family member home. HCPs and administrators also felt pressured to discharge patients, and acknowledged they may have unintentionally transferred this pressure to caregivers to take the patient home.

Caregivers were also influenced by reforms in community care, particularly with home support. For instance, restructuring of home support resulted in some caregivers losing familiar home support workers they trusted. Policy changes to accommodate provincial standards for home support resulted in reduced numbers of subsidized home support hours for families. A retired woman, receiving a small pension, expressed her concern when she was told that her home support services were being reduced:

I was told if he wasn't dead before November 1st that I wouldn't have any more home support hours left....If he's not dead before November 1st, I don't know what I'll do.

In such situations, caregivers felt exploited by the health care system.

Assumptions Influencing Caregivers

Findings suggest four assumptions influenced these caregivers’ experiences. First, access to quality palliative care is generally assumed, because provinces are required to observe the principle of accessibility under the Canada Health Act (36). However, some caregivers were unable to afford the costs of home care, or felt they could provide only substandard care because they could not afford needed medications and supplies. For example, some caregivers held back on purchasing analgesics because they could not afford them. According to HCPs, promises to care are often made before it is realized how much it will cost. These costs limit access to quality care, particularly for double-income-dependent families, as this home care nurse explained:

Often we'll get [families] who have heavy mortgages...I had two people on care who were dying of breast cancer who had three or four children....The husband was trying to work full time. They had a mortgage, they had to pay for their medications, and they had to pay for bandages, home support, plus they didn't have the income of the person who was ill....So, what do you do for adequate home care? They just can't afford it and sometimes they just can't do it [facilitate a home death].

When cost became an issue, caregivers were thankful when others "stepped in to help", otherwise, they might not have been able to keep their promise to care for the patient at home:

We were very fortunate to have a neighbour that was with the social services and she got him [son] on to welfare because he wasn't earning at the time. And without that, I think we would have been broke because with that, all his drugs were paid for....and while he was in the hospital, they were paid for, but when he was an outpatient....Oh, it would have been terrible. It would have been terrible because we were both retired and we have our property but we don't have a lot of cash...it would have actually been crippling...we couldn't have afforded to keep him at home.

Second, inherent in some discussions about home care for the dying is an implicit assumption that caregivers choose to provide home care. Yet, caregiving stemmed more from an obligation to uphold the wishes of the patient than from the caregivers' ability to choose. Choice of location of care was often between the home and hospital but, given caregivers' previ-
ous experiences with acute care, many felt they had little choice but to provide home care. Sometimes caregivers' and patients' wishes did not coincide, leaving some caregivers feeling their needs took second place to the needs of the patient:

He [husband] didn't even think about how this [caregiving at home] would impact me. He just said, "You can do it, the girls [daughters] will help you". I was saying to him, the girls have jobs and children and they can't always be around. It was really hard for me...I'd just go upstairs and cry...He just wanted to be here [at home] and that was that. It didn't matter that I wasn't sleeping or eating or anything. So I just became indifferent to the whole thing and did what I had to do.

Even though palliative care principles espouse the patient and family together as the unit of care, these findings suggest patient choice may sometimes override the choices of their family members.

Another assumption influencing caregivers' experiences was that home care would afford better quality care for patients and families. Many caregivers described the benefits of being at home, explaining, for example, the importance of maintaining family life, as this interview segment with a dying patient illustrates:

Researcher: Can you tell me about what being at home means to you?

Patient: Well, yeah. I don't want to go to any institutions. Hell with that. I want to stay home.

Researcher: Tell me about why that is.

Patient: Well, [wife] wouldn't be there and I've got two sons who I wouldn't see as often and I just like being here. I've got everything that I need here. What other reason could I give? There's no place like home I guess...They're [grandchildren] so great. They come to see me and climb right up here [on the bed] and tell me stories about school and stuff. I don't know, we just have a routine here. It just seems like the best place to be.

Patients and caregivers also described how biomedical influences shaped their experiences. For instance, notwithstanding the excellent care received from HCPs, some caregivers struggled for control over their home environment, and felt devalued and as though their roles had been usurped. Caregivers said some HCPs took it upon themselves to decide what was best for the patient, and the caregivers felt the knowledge gained from their caregiving experience was minimized:

When they came to our home [the hospice nurses and counsellors]...I'm not saying all of them did this, but...I had to put my Mom in front of her [the counsellor] with my Dad because it was like my Mom didn't exist. Constantly. And my Mom would be sitting there and she'd say, "Can you talk to me too? I can hear everything you're saying. I know you're talking about me." It was completely disrespectful. I said on a number of occasions when they were talking to me, "I would like to include my Mother in this conversation. She can hear us anyway. We are talking about her and making decisions about her care. I would like to involve her." But they did it constantly. I think part of it was because of the drugs and they just thought that she had a really hard time understanding things, so it would have to be repeated again and again, and they found it just easier to talk to a family member. But at the same time...her eyes were closed, but she could hear us. And she was really offended by that...Just because she's sick, doesn't mean she's not a person.

In contrast, some caregivers had "wonderful experiences", when they felt supported and respected, and during which HCPs became "part of the family". Caregivers were appreciative when they encountered HCPs who understood their experiences and respected their expertise.

Finally, most caregivers entered caregiving with the assumption that home constituted the ideal location for palliative care. Several factors reinforced this assumption. Caregivers commented on how dying and death were depicted in the media, and implied these portrayals contributed to their initial assumptions. Others said their assumptions were based on a cultural movement that promoted the benefits of dying at home. One caregiver said the idea of dying at home was "the newest best thing", saying it had been "idealized and glamorized, and you're made to feel almost guilty if you don't do it". Some caregivers and HCPs theorized home care for the dying was seen by health care agencies as ideal because of its potential to reduce health care costs. And, sometimes, HCPs' and administrators' strong philosophical beliefs about dying at home unknowingly influenced their interactions with caregivers, as this interview segment with a HCP illustrates:

I remember one family I worked with, and they wanted their loved one admitted [to the hospital]. They asked me "What would you do if it was your father?" And I said, "Well, I'll tell you what I did when it was my mother. I took a leave of absence and I just stayed with her." And they just looked one to the other and said, "Oh, we can't afford to do that." And I said, "I couldn't afford not to."

Many caregivers commented on how these assumptions and interactions made them feel they could not live up to societal and health care system expectations that the patient would be cared for at home.
DISCUSSION

These findings must be considered within the limits of the study design. The study occurred in one region in western Canada and, while home services share similarities across the country, local context may have influenced the findings and, therefore, may not provide a complete representation of caregivers’ experiences across settings or jurisdictions. Furthermore, this study occurred in the midst of community care reforms which may also have influenced caregivers’ experiences. Only English-speaking persons participated. Thus, cultural differences were not explored in this study. Nevertheless, several findings emerge that have implications for practice and research.

The decision by family members to adopt the caregiving role is often depicted in palliative care philosophy as a choice (37). However, findings from this study, like those of Aranda and Peerson (37), suggest caregiver choice is complex. Caregivers who made snap or indifferent decisions often felt they had little choice and were ambivalent about home care but wanted to uphold the patient’s wishes. Caregiver decisions were often made out of a sense of obligation to the patient or through force of circumstance—inpatient beds were unavailable or previous hospital experiences eliminated hospital care as an option. Many caregivers’ lives were enriched by the experience but, in some instances, promises to care created difficulties, especially when caregivers were unable to keep their promises or felt stuck in the caregiving role. Studies have shown that family members often place patient wishes before their own (38,39). While some caregivers may willingly put their own needs aside, the findings of this study suggest the circumstances surrounding such choices can be problematic when societal expectations or the absence of reasonable alternatives exist. Interventions designed to enhance caregiver choice could help to ensure caregivers’ needs are equally considered. For instance, HCPs could facilitate communication between family caregivers and patients early in the disease trajectory, in order to set mutual goals and expectations of care, and to increase patient understanding of the family caregiver burden associated with home care. Families are more satisfied with palliative care when HCPs take an active role in preparing them for the future (40). Action to improve hospital care is also needed, so patients and caregivers see it as a legitimate choice. While the dehumanizing aspects of hospital care for the dying have been documented previously (41–43), the manner in which hospital staff act toward the patient and family can greatly improve hospital experiences (44). Development of alternate institutions, such as hospices, could also increase care options and mitigate pressures that some caregivers feel because of acute care downsizing.

Home is often associated with comfort and privacy; a place where we are at liberty to be ourselves (3,45). This study’s findings suggest home and family relationships change when home becomes the site for health care provision. Most notably, caregivers were distressed by the numbers of different HCPs coming into their home and were concerned about preserving their core identity within the family. Other authors have stressed the challenges family members face when health care is shifted to the home (10,46–48). Although the consequences of providing home health care are relatively under-researched (6), and studies examining the organization, delivery, and outcomes of home care are needed, this study found caregivers’ (and patients’) experiences might be improved by reducing the numbers of HCPs entering the home, and by improving communications among health care agencies responsible for home palliative care delivery. Streamlining services to reduce additional personnel entering the home and scheduling home visits to allow families private time could help reduce the burdens associated with multiple HCPs entering the home. At the same time, professional service hours may need to be increased (with consistent HCPs) for family members who desire this, so they can maintain their core identity, and spend quality time with the patient relating to them as a spouse, child, parent, and so on. HCPs also need to be reminded that the home is family territory. Caregivers who viewed HCPs as “strangers” or who felt “pushed aside” often felt they and their homes were disrespected and their expertise minimized. Some home care research has shown relationships between family and professional caregivers are more exploitative than collaborative (49). Education to sensitize HCPs could help them work toward developing respectful and collaborative relationships with family caregivers. HCPs can also educate caregivers, assisting them in understanding changes that will occur in the home environment because of home care. Such education could help normalize the experience and prepare caregivers for impending changes.

Findings illustrate how health care reforms can influence family caregivers. Some caregivers felt exploited or pressured to keep the patient
home as a result of reforms. HCPs and administrators also felt pressured to discharge patients from hospital. Health care reform is now part of the landscape of Canadian health care. Some authors have voiced a need to examine the effects of health care reform on the nature, quality, and provision of health care (10,50,51), but little investigation of the effects of such reforms on the provision of home palliative care has been conducted. Further studies in different jurisdictions are needed to validate findings from this study and determine the extent to which reforms are affecting family members who provide home care.

Findings also suggest assumptions can influence caregivers' experiences. For example, many caregivers assumed (prior to their caregiving) that home was the ideal setting for dying and death. However, this assumption was challenged as caregivers went through their experience and came to realize home care is not always ideal. Many studies confirm the beneficial nature of providing palliative care at home (21,52–54) and this study supports previous findings. This study, with others (37,55), also calls attention to the need to examine how assumptions may influence the experience of caregivers and drive home-care provision. Family members who are led to believe home care will afford greater quality of care than alternate care settings may make decisions based on unrealistic expectations. Further research with larger samples is needed to more fully examine assumptions underpinning care at home. At the same time, promoting a critical consciousness about the effect on family members who provide home care is needed to create more thoughtful ways of viewing home care and the role family members play in it.

This study's findings extend understanding about the important and beneficial nature of home-based palliative caregiving. They also illustrate the difficulties caregivers face when palliative care is provided at home. Palliative care philosophy maintains the patient and family together make up the unit of care (56). Putting this philosophy into effect means continual commitment to ensuring both patients and their family caregivers are at the centre of care.

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