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What is This?
Variations in and factors influencing family members’ decisions for palliative home care

Kelli I Stajduhar Centre on Aging, University of Victoria and Vancouver Island Health Authority, Victoria, BC and Betty Davies University of California San Francisco School of Nursing, San Francisco

The purpose of this paper is to describe the variations in and factors influencing family members’ decisions to provide home-based palliative care. Findings were part of a larger ethnographic study examining the social context of home-based palliative caregiving. Data from participant observations and in-depth interviews with family members (n = 13) providing care to a palliative patient at home, interviews with bereaved family members (n = 47) and interviews with health care providers (n = 25) were subjected to constant comparative analysis. Findings indicate decisions were characterized by three types. Some caregivers made uninformed decisions, giving little consideration to the implications of their decisions. Others made indifferent decisions, whereby they reluctantly agreed to provide care at home, and still others negotiated decisions for home care with the dying person. Decisions were influenced by three factors: fulfilling a promise to the patient to be cared for at home, desiring to maintain a ‘normal family life’ and having previous negative encounters with institutional care. Findings suggest interventions are needed to better prepare caregivers for their role, enhance caregivers’ choice in the decision-making process, improve care for the dying in hospital, and consider the development of alternate options for care.  

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Key words: decision making; family caregiving; home care; palliative care

Introduction

It is increasingly evident that family members play an important role in the provision of home health care. In Canada, more than one in eight adult men and women over the age of 15 provide care to people at home with chronic health conditions or life-threatening illnesses and calls to support dying patients and their families through the enhancement of home health care services have been widely advocated. Dying at home is thought to embrace what Gomas says ‘is most noble in medicine: sometimes curing, always relieving, supporting right to the end!’ (p. 45). Indeed, dying at home has been considered ideal when defining a good death.

The conditions needed to effectively support dying at home are well established: a desire for home care on the part of the patient and family, the availability of more than one caregiver and access to skilled palliative care providers. Feasibility of dying at home also depends on the financial ability of the family, the extent of functional disability of the patient, and whether physical symptoms can be adequately controlled at home.

Understanding the conditions that enhance the dying-at-home experience is important given the belief that dying patients and their families, if given a choice, prefer care to occur at home. Studies have reported between 40 and 80% of patients expressing a preference for dying at home, because home often represents a place of comfort and security. Decisions and preferences for location of care, however, may vary between patients and their family members. Keizer et al. found a large majority (80%) of family caregivers believed inpatient palliative care offered the best quality of life and death, even for patients who had resisted admission to a palliative care setting. Hinton has similarly shown that, as the patient’s disease progresses, caregivers often prefer hospital care and some caregivers have considerable misgivings about providing palliative care at home.

Recognition is growing that the decision for home care has a profound effect on family members because of the burdens and distress that can be associated with palliative caregiving. Family members may be ambivalent about providing home care but often do so based on the wishes of the dying person and sometimes feel they have little choice in the decision-making process. For example, a national survey to establish an in-depth profile of family caregivers across Canada found that over 50% of caregivers perceived they had no choice in caring for their disabled or ill family member.
Consequently, the family's perspective is clearly important given the implications this decision has for family members who ultimately provide the majority of physical and emotional support. To better understand the perspectives of family members, an ethnographic study examining the social context of home-based palliative caregiving was conducted. An overview of this study has been previously published. The purpose of this paper is to describe, from the perspectives of family caregivers and health care providers, the variations in and factors influencing family members' decisions for palliative home care.

Methods

Ethnographic methodology was used to guide this study. Ethnography is concerned with describing, in a detailed way, the point of view of the study participants and commonly uses qualitative approaches to reach this goal. There are several features to this methodology, but at its core, ethnography involves participation in the 'everyday' setting, using participant observation and interviews as a primary means of data collection.

Consistent with ethnographic approaches, purposive sampling, a form of nonprobability sampling, was used to select participants. For the purposes of this paper, data were drawn from the primary sample comprised of 13 family members who were actively providing care to a palliative patient at home and 47 bereaved family members. The secondary sample was comprised of 25 health care providers (HCPs). To ensure maximum variation in the sample and, therefore, in participants' experiences, every attempt was made to include female and male participants, family members who were caring for (or who had cared for) a spouse, parent, or friend, and caregivers who had a range of experiences (i.e., caregiving experiences that were going well/not well). Maximum variation in the HCP sample was similarly sought by including participants from different disciplines who had worked in health care for varying lengths of time. Demographic characteristics of the primary sample are presented in Table 1 and the secondary sample in Table 2.

Data collection

Upon obtaining ethics approval and informed consent, data were collected by participant observation and in-depth interviewing. In total, 130 hours of observation was conducted by the primary author (KS) in 13 homes where family members were caring for a palliative patient. Observational methods in qualitative research take many forms from complete participant to complete observer roles. The primary author undertook this study as an observer-as-participant, whereby her research role was publicly acknowledged at the outset of, and throughout, the study, and through which she negotiated some

<table>
<thead>
<tr>
<th>Table 1 Demographics by type of family caregiver</th>
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<tr>
<td>Variable</td>
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<td>Age in years</td>
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<td>Retired</td>
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<td>Relationship to the dying person</td>
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<td>Wife</td>
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<td>Husband</td>
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<td>relationship</td>
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<td>Mother</td>
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<td>Sister</td>
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<td>Living arrangements</td>
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<td>Shared household with patient</td>
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<td>Lived independently of patient</td>
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<td>Moved from permanent place of residence to provide care</td>
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<td>Patient diagnosis</td>
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<td>End stage cardiac disease</td>
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<td>ALS</td>
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<td>Other</td>
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<td>Location of patient death&lt;sup&gt;a&lt;/sup&gt;</td>
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<td>Home</td>
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<td>Hospice inpatient unit</td>
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<td>Acute care hospital</td>
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<td>Long term care facility</td>
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<td>Number of years since caregiving&lt;sup&gt;b&lt;/sup&gt;</td>
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<td>&lt;1 year</td>
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<td>11–20 years</td>
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<sup>a</sup> Location of patient death was not recorded for active caregivers.

<sup>b</sup> Number of years since caregiving was only recorded for bereaved family caregivers.
limited work responsibilities with family caregivers (e.g., house cleaning, preparing meals).

Initially, observations occurred with five family members over a three-month period. Following preliminary analysis of observational fieldnotes that were recorded based on the observations with these family members, subsequent observations occurred over an eight-month period in an additional eight homes in order to extend the analysis and validate evolving interpretations. Observations occurred on weekdays, weekends, and during daytime, evening and night hours. Taking direction from Emerson and colleagues, observations focused on key events or incidents that were occurring in the home. The primary goals of the observations were to: a) observe family caregiving; b) understand the nature of caregivers’ experiences; and c) understand how the context of the health care system influenced these experiences. Observational data was supplemented with informal conversations with family caregivers during the observations. These conversations were recorded in fieldnotes to clarify and validate what was being observed in the home setting.

To augment observational data, in-depth, open-ended interviews were also conducted. Although 13 caregivers who were providing palliative home care participated in the observations, only ten participated in a formal, in-depth interview because the remaining three caregivers lost their family member during the study period and were too distressed to participate. In addition to these caregivers, an additional 47 bereaved family members participated in a one-to-one interview. Of the 25 HCPs interviewed, 13 participated in a one-to-one interview and 12 participated in focus group interviews.

Interview guides were constructed for each group but the interviews remained open to allow for exploration of varying experiences. Similar to the process of conducting observations, an initial round of interviews with approximately half of the total caregiver and HCP sample was conducted. These initial interviews (and observations with family members) were used to create a beginning understanding of the home caregiving experience. A second round of interviews and observations with the remaining sample were used to validate and extend understandings of the data. In most cases, only one in-depth interview was conducted with each participant. In instances where clarification or validation was required, follow-up telephone interviews occurred. With few exceptions, all interviews were audiotaped and transcribed verbatim.

Data analysis

A constant comparative analysis was completed on data generated from observations and interviews. As such, analysis occurred concurrently with data collection. Initially, data from observational fieldnotes and interview transcripts were read over several times to identify recurring themes and illustrative examples from the data. Preliminary concepts and themes were then developed and used to categorize and illustrate examples from the data. As data continued to be collected and reviewed, coding categories were revised and refined until a preliminary conceptual scheme was devised. At this point, concepts, categories and themes were incorporated into the second round of interviews and observations to check for descriptive and interpretive validity. All coded data were entered into a computer software package used for managing and organizing qualitative data so that data could be compared, linked and contrasted. Because this research comprised the primary author’s (KS) dissertation research, principal responsibility for analysis was assumed by the primary author. To account for any potential investigator bias, almost half of the family caregiver and HCP participants were asked to evaluate the emerging analysis and all participants were invited to respond to a summary of the preliminary findings. In addition, a committee of five academics independently reviewed the results and conclusions of the study.

Findings

Data reported here are part of a larger ethnographic study investigating the social, historical, political, economic and ideological structures and processes that play a role in shaping family members’ experiences with providing palliative care at home. This paper focuses on one aspect on the study findings, namely, the variations in family members’ decisions for palliative home care and
the factors that influenced their decision making. Findings are supported by verbatim passages from the data.

**Variations in family members' decisions for palliative home care**

Decisions for palliative home care varied amongst family members. Although the decision-making process was unique for each individual family member and family situation and was influenced by many factors, there was some commonality in how these caregivers constructed their decisions; they made uninformed decisions, indifferent decisions and negotiated decisions.

**Uninformed decisions.** Of the 60 family members who participated in either observations and/or interviews, 22 described situations where they had given little consideration to the implications of their decision. As one daughter said in a conversation during observations: 'I made the decision just like that... There was never any question or thought that went into it. I just didn’t know what I was getting into.' Such decisions were commonly made early in the patient’s disease trajectory or when the patient was imminently dying. Early decisions typically occurred when the patient was in hospital and when hospital care was perceived as unfavourable. Unsatisfactory hospital experiences often led patients to ask their family member to take them home and family members were obliged to do so even if they were unaware of what they were getting into. Uninformed decisions also occurred when the patient was imminently dying and expressed a desire for a home death. In these situations, some of these caregivers made the decision for home care because they believed an ‘end was in sight’ and their caregiving time would be short; they did not consider what would happen if caregiving became prolonged.

All of the caregivers who described making uninformed decisions said that they felt both unprepared for the caregiving role and uninformed about what to expect. At least half of the caregiver participants mentioned that unrealistic and romanticized portrayals of dying at home in the media led them to believe that the experience would be a positive one. Portrayals in the media led this 36-year-old daughter to believe that dying at home would be a peaceful experience, but she later discovered the implications of her uninformed decision when she was caring for her father in his home:

> I had no idea. I’ve been watching too much TV... I’m appalled at the fantasy world that we see all around us, how unrealistically we view this kind of death [at home]. I just had no idea what I was in for. If I had known, maybe I wouldn’t have been quite so forthcoming about making that promise [to care for him at home]. It all sounds nice when we first talked about it like, ‘Oh yes, it would be nice to have him at home, that’s so much better, so peaceful’. Other people said to us, ‘Oh, it will be so much nicer if he is in his own bed’. And I thought, yes it will. But it’s like you’re from the movies. And when it’s really happening, you think, oh my God, this is horrendous. It’s not at all what I expected.

Interviews with HCPs confirmed that family members are often unaware of what they are getting into when they make the decision to provide palliative home care. Even when information is provided to family members, HCPs said that some caregivers find it difficult to fully understand how caregiving will personally affect them. A few of the caregivers who were interviewed indicated advanced preparation would have frightened and prevented them from selecting home care, an experience that generated considerable pride and accomplishment. Most caregivers, however, wished they had been better prepared. One employed caregiver believed that it was impossible to make fully informed decisions without having adequate information in advance:

> I didn’t really have the information that I needed at that time to make a decision... Because you’re making a decision [about dying at home] that wasn’t an informed choice... And by the time you have all the information and you realize that maybe that wasn’t the best choice, it’s too late... That’s why I think the decision should be made and the information should be provided earlier.

Some of the caregivers recommended that practical suggestions for and books about caregiving would have helped them to prepare, as would have the opportunity to discuss the pros and cons of their decision with HCPs early in the disease trajectory. At the same time, caregivers and HCPs acknowledged that knowing the exact time and way to provide preparatory information is not always clear because each family has different needs and copes with information in different ways. Focus group interviews with HCPs having expertise in home care for the dying emphasized caregiving involves periods of continual adjustment where information is best provided at ‘transition’ points. According to these providers, this ensures that caregivers receive the information they need when they need it as this hospice counsellor indicated:

> In the beginning of the terminal phase, there’s going to be a need for information about this [caregiving] to help them make a good decision about care at home..... But many people aren’t there. They’re not. I can talk about it, but they don’t hear it... So, at that point in time, you can’t give them a lot of information that’s coming down the road in ten days. You need to kind of do it today and maybe in the near future, but you can’t go too far in most cases..... You have to be
able to figure out their transition points to be able to understand when they need the information.

**Indifferent decisions.** Like family caregivers who made uninformed decisions, those who made indifferent decisions also felt unprepared for the caregiving role. The distinction between an uninformed decision and an indifferent decision was characterized by situations where caregivers felt they had little choice in the decision for home care. Of the 60 family caregiver participants, 29 described situations where they perceived themselves to have little choice in the decision-making process. Indifferent decisions commonly occurred when the caregiver had already been providing care at home and plans for ongoing care were being discussed. The patient's needs and wishes often drove decisions with caregivers giving little consideration to their own needs. Even in the interviews and observations, almost all of the caregivers were hesitant to speak of their needs and indeed, when asked if they had felt forced or pressured into the decision, most of the caregivers who were actively providing care at the time of the study said they were uncomfortable with labelling their decisions in this way because they did not want to say anything that they perceived might make the dying patient feel that they were a burden. One of these caregivers was more forthcoming, describing how she sometimes felt 'tied down' and 'stuck' in caring for her husband and how her feelings seemed to stem from not having choices in her own life:

C: I do feel really tied down... Like sometimes I wish I was on another planet. But I am tied down. There's no question about it... My girlfriend called to say that they just got back from a month away and I said, 'Oh, isn't that lovely'.

R: Do you ever feel envious about that?
C: Oh, absolutely. Absolutely. It's not that I would go away, but it's just that she has the choice and I haven't got a choice. Not having the option really bothers me more than the fact that I'm not exercising it.

Sometimes, caregivers' and patients' preferences for home care did not coincide; patients assumed family members would be willing to provide care as this bereaved sister suggested:

She [my sister] said to me, 'You can care for me, you know, I want to die at home.' And I thought, 'You must be seriously joking.' I said to her, 'Well, I did say that I would look after you, but you are too unwell and you cannot be looked after at home'... She thought that I could handle this and do this but I couldn't... I was talking with her [on the phone] and she slammed the phone down... She was pretty angry at me... So what can you do?... You've got no choice really. You can live with the guilt of not doing what they want or you can just do it and deal with it... So that's what I did.

Interviews and focus groups with HCPs confirmed caregivers' decisions are often dependent on the preferences of the dying family member. In their desire to be supportive, caregivers often reluctantly agree to provide care thinking only of the needs of the dying person, as this physician suggested:

Most of the patients that I see want to stay at home. Probably some of the caregivers want them to as well but not necessarily because they want it. They'll often say, 'Well, my Dad really wants to stay here, but we don't know if we can take this'. The client usually drives the decision, saying that they want to stay at home. Then I think the family tends to support that decision. But there is some ambivalence.

Many HCPs noted caregivers' reluctance stems from a lack of awareness of available help. When aware, caregivers often reconsider their decisions, as this palliative care nurse suggested:

Sometimes they've [caregivers] made a decision that they just couldn't possibly care for this person at home. They don't see any alternatives. Then sometimes we arrive on the scene and show that things can be done, particularly for people at home, to make them more comfortable and to make things work a lot better for them. Then they will go, 'Oh yeah, I guess we can stay at home now and you're going to help us do that'. So, a lot of people I find change their minds.

However, some HCPs theorized caregivers' reluctance might also be a 'sign of trying to exercise choice', acknowledging that offering options for assistance was necessary but that this could also place added pressure on caregivers, especially when they and the patient disagreed on the location for care. Interestingly, caregivers who described making indifferent decisions were often those whose loved one had died. These caregivers admitted it would have been difficult for them to reflect on their own needs when they were actively providing care because they felt they had to maintain an attitude of optimism for the patient rather than thinking about themselves or their needs.

**Negotiated decisions.** Negotiated decisions for home care typically occurred when caregivers and patients were able to openly talk about dying and had done so throughout the disease trajectory. The nine caregiver participants who described situations in which they felt that they and the patient had come to a mutually agreed upon decision about palliative home care all said that their ability to make a negotiated decision resulted from
previous negotiated decision-making processes that characterized their relationship with the patient before the patient became ill. Making a negotiated decision, according to these caregivers, involved ensuring that both the caregivers' and patients' needs were considered as this interview with a bereaved daughter implied:

My Father wanted to talk to me about his going home. He asked me, 'What do you think about me coming to your home?' I said, 'We want to look after you at home' but he thought it would be too much work. I told him that we [the family] would all chip in but he was concerned that there was no room at my house and I said to him, 'What do you mean there's no room, you can have a whole bedroom'. But then he said, 'Well what if I die in that bed, would it ruin the bed for you?' And I said, 'No, in fact, it will endear the bed to me'. But we went through this kind of negotiation all along the way. I was lucky that my Dad was so open about it.

These caregivers, while being able to openly talk about dying and death with the patient, appreciated when HCPs facilitated discussions about decisions for palliative home care. A son, caring for his dying mother at the time of the study explained that he was unsure of how to broach the subject of where his mother wanted to die. During one of the observations in the home, he told the home care nurse that he was unsure if he was 'up to the task' [of providing home care] but that he did not know how to talk with his mother about how he was feeling. In a subsequent interview, the son explained how the nurse facilitated a negotiated decision-making process:

She [the nurse] just helped us lay it all out on the table. What my worries were. What her [mother] worries were and she [the nurse] was able to address all of our concerns.... My mother wanted to be at home but I needed her to know that I had limits to what I could do.... And the nurse helped us to see that this was kind of a back and forth process and that the decision didn't have to be a final decision. So, in the end, we both felt good about her being at home .... We still do.

Provider participants maintained that caregivers who are able to engage in a negotiated decision-making process with the patient are much better able to cope with providing care at home. Some of the providers suggested that caregivers who are unable to come to a mutually agreed upon decision and who feel ambivalent about providing home care have much more difficulty during the bereavement period. A hospice counsellor theorized that caregivers who are unable to make negotiated decisions experience lasting memories that complicate their grief:

I've seen people in bereavement where the struggle for them is their memory of the last day, the last few weeks. Their memory and their view of that isn't around, we were at home, the family could all be there and that kind of stuff. It was all about the dying in the bedroom.... And people can have a difficult time moving away from that. They can't remember the good times in their life, just the dying part with the symptoms and being in the bedroom. I think it complicates their grief.... They just focus on, 'This is what is in my day dreams and this is what is in my night dreams'. And I don't think that happens so much in families where they went into the idea of care at home with a really wise decision of what they were getting into, and it was a mutual decision rather than something that they promised or felt obliged to do.

Caregivers who negotiated decisions seemed more prepared and coped better with home caregiving than those who made uninformed or indifferent decisions. In contrast, caregivers who made uninformed decisions typically did not consider the implications and felt overwhelmed by the responsibilities of caregiving, particularly when it became prolonged. Caregivers who made indifferent decisions tended to minimize their needs, deferring to the needs of the patient. For some, temporarily placing their needs aside was a final gift they gave to the patient and something caregivers would do again in similar circumstances. For others, feelings of envy and resentment surfaced and these feelings coloured their perceptions; they were not sure they would engage in caregiving again if placed in a similar situation.

Factors influencing family members' decisions for palliative home care
Regardless of the types of decisions made, three major factors influenced family members' decisions for palliative home care: 1) a promise caregivers made to the dying person to care for them at home; 2) the caregivers' desire to have the dying person in an environment where a 'normal life' could be maintained; and 3) a desire to avoid institutional care.

Making promises to care. Promises to care were most often made out of a sense of duty or obligation stemming from the caregiver's desire to respect the patient's wishes to be cared for at home. One wife's promise was tied to the commitment of her marital vows; providing care at home gave her a sense of pride in knowing that she was able to fulfill her vows:

It was a promise I made to him.... I said to my husband, 'I'll look after you'. And that's what I did. To me that was part of our vows to one another.... For better or for worse. I felt so good that I could do this for him. It was quite a sense of accomplishment.
HCPs also described the accomplishment many caregivers experienced, highlighting that even while exhausted, many caregivers coped with the demands placed on them:

When a person has made a promise and they’ve been able to hold to their promise, they feel some kind of accomplishment. They feel like a champion you know? They’ve fulfilled the promise and that really helps them feel good about themselves. However, it may have done a lot of damage to them in terms of them feeling completely exhausted. But people do cope because we provide them with a lot of support. It always amazes me to see how well people cope…. There is an amazing number of people that do it really well naturally.

Despite these benefits, the promise to care created a high degree of distress for many caregivers. Caregivers who were challenged by the daily demands of caregiving sometimes regretted their promises. One woman caring for her husband with cancer described the consequences of making and then having to break the promise:

That [promise] came back to haunt me in those last couple of weeks…. When it got too much, almost the last conversation I had with my husband was about trying to force him into palliative care. Trying to convince him that this was best. How do you think that made me feel? That was terrible. That was a guilt trip that you couldn’t believe…. That’s the worst feeling, because you have promised. You feel so guilty. You feel like a failure, as though you are letting this person down. You’ve had to renege on your promise to let him stay at home. It’s awful. You’re basically saying, ‘Sorry, I’m too weak, I’m giving up’. And that’s exactly how I felt.

Many caregivers were determined to maintain their promises even when the situation was disproportionately burdensome. While some caregivers seemed to cope well in these situations and derived a sense of achievement, others felt guilty when they could no longer cope and felt they had failed to uphold the patient’s wish to be at home.

Maintaining normalcy. Caregivers’ decisions were also influenced by their desire to maintain a ‘normal life’ for themselves and for the patient. They welcomed being with the dying person and were eager to participate in family events, be in familiar surroundings, and have control over the home environment. Being at home provided opportunities for privacy where intimate exchanges occurred and where family life was maintained. Determining meal times, rest times and visiting times made caregivers feel in control of a situation where they often felt ‘out of control and helpless to do anything’. Providers agreed that family members (and patients) often seek control and that the provision of care at home provides an opportunity to accomplish this:

There is an element of control. When people are at home we teach family members to do everything and they’re in charge of everything…. Then they go into the hospital and we take that away from them…. It’s all up to somebody else…. So I think it’s not only that people want to be at home for their space and their privacy, but because they also have some measure of control or they’re delegating that control to their family member.

For many caregivers, the need for this control arose from their previous experiences with institutionalized health care.

Institutionalized health care practices. Negative experiences with institutional care, most notably acute care, was a primary motivator for caregivers deciding to care for the patient at home. While some caregivers spoke positively about acute hospital care, the majority of caregivers described it as depersonalized and paternalistic. Many caregivers said they were treated ‘like a number’ even though they hoped for individualized care. For example, some caregivers felt humiliated by seeing their confused family members restrained and physically exposed on a hospital ward. Others found it difficult when their requests for help were minimized, especially in situations where the patients’ symptoms got ‘out of control’. Still others were surprised at the approaches of some hospital staff as this daughter reflected:

I remember one morning that I went down and asked the staff, ‘Where’s mom’s food?’ I went back a second time to ask and I suppose they thought I was being a nuisance. The doctor came storming out and he said, ‘What do you think this is, the Hilton?’ After he left, Mom finally got a kind of bashed up banana. But he [the doctor] was ticked off. It was like he was saying, ‘How dare you’. Like, ‘We’re not here just to serve you’. I mean, all we asked for was food.

Caregivers’ negative experiences with institutional care reduced their confidence in hospital-based providers. These caregivers described having to ‘fight’ for quality health care for the patient. One bereaved caregiver described fighting for adequate pain control for her dying mother and explained that, while her threats prompted swift reactions, the experience made her behave in ways that were unsettling and prompted her to arrange to discharge her mother from the hospital against the advice of HCPs:
She [the nurse] told me she didn’t have time. I told her, “The situation’s gotten out of control. You’re in charge, you’re the one who’s supposed to get it back into control so do it.”… And she just said, I don’t have time. I said to her, “Well do you have time for when I call the ambulance to take her home?” And I won’t take her directly home. I’ll stop at the news station. She [the nurse] went down the hall and got the needle and knocked my Mother out… I brought her home after that even though they told me that she would be dead in three days and that what I really needed was rest. They advised me not to [take her home], but what choice did I have? I don’t really blame the nurses. They really didn’t have time… But that’s what it turned me into… I didn’t even kill spiders but I had to fight every step of the way for her… I didn’t have a choice but to take her home.

Other caregivers had positive experiences with hospital staff. They appreciated the help and advice received from nursing staff and were thankful when nurses ‘went the extra mile’, particularly when plans for home care were being made:

Everything was put in place for us…. The hospital was really supportive…. They even gave us things, because when you’re taking someone home you’re faced with all of this and you don’t know what you need. And they [the nurses] said, ‘Well we’re not supposed to do this but here, take some of these pads and a urinal’ and stuff like that…. They asked if we had kids and could they go down to the Red Cross loan cupboard and [get equipment] so our kids chipped in. But, it was just advice like that that was really helpful.

At the same time, caregivers acknowledged that workloads prevented nurses from providing quality health care; many caregivers felt they could provide better care at home. One caregiver, who had previously been a registered nurse, reminisced about how the health care system used to be:

The patient doesn’t get the care they used to get. Maybe they’re short staffed but in my opinion, a nurse is not like nurses in the olden days. They used to take care of patients. There were more nurses. Here, you ring a bell and wait until doomsday before you see somebody. The system is rotten. I can’t blame the nurses…. There is just not enough of them to go around. I mean, you can die in the hospital all right but I don’t think it is very dignified. You are a number. So, needless to say, we didn’t want that [dying in the hospital].

Caregivers’ decisions were also influenced by the hierarchical and rule-based structure of the hospital system. They perceived hospital systems as not allowing for privacy or for creating environments that were conducive to dying. Hospital rules, for example, did not allow patients to smoke, a habit many were unwilling to give up. Other caregivers asserted a focus on cure and rehabilitation in acute care placed unrealistic expectations on patients. The home setting allowed caregivers to ‘dance my dance rather than having to dance my dance according to the hospital’s protocols and procedures’. Caregivers often contrasted hospital systems with inpatient hospice settings, indicating that hospice care may be better equipped to provide personalized support that takes into account the individual needs of both patients and caregivers:

When he was in the hospital he was just like another number…. You know, you would get your treatment and then they’d [hospital staff] say, ‘see you later’. There was no sort of nurturing support…. Whereas you would go to hospice and a counsellor would meet you and people would ask you, ‘How’s it going?’ Not just with my Dad but with me. It was a totally different situation…. It was a lot more open and there were fewer rules that you had to follow.

However, several HCPs indicated hospice beds were in short supply and that this limited the choices for family members who were providing home care.

Previous experiences with acute care played a major role in influencing caregivers’ decisions and made them determined to keep their promises. Some caregivers believed they could provide a better quality of care in the home than professional providers could in the hospital. At the same time, caregivers indicated they might have viewed institutional care as a welcome alternative to home care if the care system was flexible, personalized and open to family involvement in care. If a hospice bed had been available to them, some caregivers indicated they would have considered this care option.

**Discussion**

Dying patients’ participation in decision making at the end of life has received considerable attention. Less is known about how family members make decisions, particularly about how they come to adopt the palliative caregiving role. Findings from this study indicate caregivers’ decisions vary, suggesting decision making about home-based palliative care occurs in different ways. Caregivers who made uninformed decisions typically did not consider the implications of their decisions and often felt unprepared for their roles. Caregivers who made indifferent decisions also felt unprepared, often placed their own needs aside, and felt they had little or no choice in the decision for home care. Caregivers who made negotiated decisions seemed to cope better with
caregiving, felt they had a choice in the decision-making process and, in general, were more satisfied with their decisions.

Previous research has shown that caregivers often negate their needs and instead, focus solely on meeting the needs of the dying. Because of their intense involvement in the provision of care to the patient, caregivers may not identify themselves as persons in legitimate need of help and may not be perceived as needing support by the health care system. Caregivers in this study often did not think of themselves as the target of intervention and this was reinforced in situations where patients assumed that family members would care for them. That some patients' and caregivers' wishes did not coincide is an important finding given that much of the literature implies decisions for home care are based on both patient and family preference. While not meaning to exclude family members from the decisions, it is possible the emphasis on patient decision making at the end of life has served to minimize the importance of caregivers' perspectives. Bereaved caregivers were particularly vocal about their perceived lack of choice whereas those providing care at the time of the study were much more reluctant to discuss their decisions because of their need to remain optimistic in supporting the patient. This implies that caregivers may engage in mechanisms to protect the patient, including concealing how they actually feel at the time of caregiving. Harding and Higginson found caregivers are often ambivalent about expressing their needs in relation to the caregiving situation. As such, even if they are in need of help, caregivers may be reluctant or unable to express their own needs because of the need to honour the wishes of the dying person. The observation that bereaved caregivers were more willing to talk about their lack of choices than those who were actively providing care may also suggest that perspectives about providing care at home may change over time. For instance, although not the focus of this study, it is possible that as caregivers move through the caregiving process, decisions for home care may change. Longitudinal studies that track family caregiver preferences over time may help to elucidate potential changes in their decision-making processes.

Others have described how family members feel unprepared for the caregiving role. Findings suggest caregivers may also feel unprepared to make decisions about providing palliative home care. Making an informed decision implies an individual has been given the necessary information upon which to base the decisions. In health care, the evidence for informed decision making is typically represented by the documentation of consent. In family caregiving, however, little discussion focuses on whether family members consent to provide care at home. Usually, consent is assumed because family members are already providing care. The decision to provide care at home often results in caregivers having to drastically shift their lives to fulfil obligations to care for the patient; consequently, caregivers should be given opportunities to fully understand the likely benefits and burdens of their decisions. Just as preparatory information plays a key role in assisting patients to make informed decisions, palliative caregivers also need information to assist them in decision making. Although it may not always be possible to achieve a fully informed consent in situations where family members feel obligated to care or where they are unable to understand the implications of their decisions, informed consent, supported by ongoing dialogue with the patient and family may help patients and their caregivers to move toward negotiated decision making.

Given that negotiated decisions seemed to result in better outcomes for these caregivers, consideration should be given to the types of strategies that can guide HCPs in their attempts to assist families in making negotiated decisions. Some scholars have argued that accommodation and mediation of all legitimate interests (patient and caregiver) ought to be considered when thinking about decisions regarding end-of-life care at home. When working with caregiving families, for example, HCPs could mediate discussions with the aim of coming to a mutually acceptable accommodation or compromise about decisions for home care. Such a strategy could assist caregivers and patients with understanding each other's perspectives and may open up dialogue toward ensuring that caregivers' needs are considered alongside the patients' needs. Indeed, discussions with patients and caregivers would ideally be initiated by HCPs early in the disease trajectory so that caregivers and patients are aware that promises to care might change as the disease progresses. Although dying at home may be a laudable goal, counselling patients and families at the outset that plans for dying at home should be considered provisional may give family members a kind of 'moral escape hatch' (p. 21) that may help reduce the guilt associated with breaking the promise to provide care at home.

Some caregivers felt they had little choice in decisions for home care. This situation is of concern, particularly when the decision is motivated by caregivers' perceptions that hospital care is inadequate. Characterized by paternalistic approaches and a tendency to depersonalize and decontextualize the experiences of families in palliative care, hospital care was seen as a last resort for some of these caregivers. Some did not view hospital care as an option at all, even when caregiving became overly burdensome. Research has long demonstrated the problematic nature of dying in hospital. Although studies do not explicitly link hospital experiences with caregivers' decisions, authors have hypothesized a
connection between the two, and this study supports those contentions. Given that a large proportion of people do and will continue to receive end-of-life care in hospital settings, ongoing attention should be given to improving hospital care so that caregivers see it as a legitimate choice. Additionally, expansion of alternate care options, such as well designed hospices, could also provide a meaningful alternative to home care. Some of these caregivers indicated that they and the patient would have considered such an option had it been available to them. Offering a range of options such as support in the home, inpatient hospice care, day care and respite care, for example, would help to alleviate situations where caregivers feel they have limited choice. Caregivers who lack any decent alternatives between the hospital and home may be placed in positions where they are forced to opt for home care even if their own health and wellbeing are seriously compromised as a result.

Conclusion

Regardless of where care is provided, the modern hospice palliative care movement has sought to ensure dying patients and their family members are actively involved in decisions that affect them. In palliative care, the decision to adopt the caregiver role has been depicted as a choice. Findings from this study suggest caregivers may not always have a choice about the location of palliative care and their decision is influenced by a myriad of factors. While it is true that many caregivers derive significant benefits by fulfilling their obligations to care for the dying, the decision to provide care can result in significant consequences for caregivers. Increasing the numbers of people dying at home has been the focus of many government policy directions. While an admirable aim, it is possible, as Addington-Hall and Karlsen argue, that this aim may, at times, be in conflict with supporting the people who provide the large majority of care for the dying – the family members. Family members and entire families are affected by the illness experience. Given the complexity of the home care environment when palliative care is provided there and given that each family shares a history that determines, to a large extent, how family members will cope with the physical and emotional demands of home care, there can be no universal 'rule' to determine whose choices ought to be respected when decisions for palliative home care are made. However, in the context of the home, where decisions have immense impact on family caregivers, consideration of caregivers' needs ought to be central to the decision-making process.

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