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What family caregivers learn when providing care at the end of life: A qualitative secondary analysis of multiple datasets

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ABSTRACT

Objective: Although growing numbers of family members provide end-of-life care for dying persons, caregivers frequently report lacking essential information, knowledge, and skills. This analysis explicates what family members learn during the process of providing end-of-life care.

Method: Four qualitative interview studies of family caregivers to those at the end of life ($n = 156$) formed the basis of a secondary data analysis.

Results: Thematic and cross-comparative analyses found three general kinds of learning that were described—knowledge about: (1) the situation and the illness (including what to expect), (2) how to provide care, and (3) how to access help. Learning gaps, preferences, and potential inequities were identified. Further, in some instances, participant talk about "learning" appears to reflect a meaning-making process that helps them accept their situation, as suggested by the phrase "I have *had* to learn."

Significance of Results: Findings can inform the development of individualized educational programs and interventions for family caregivers.

KEYWORDS: Family caregiving, Palliative care, End of life, Qualitative secondary analysis, Education

INTRODUCTION

As ever-increasing numbers of family members take on the responsibility of providing care at the end of life, there is a growing need to evaluate caregiver learning needs and processes. For instance, neoliberal restructuring of Canadian healthcare over the past two decades has embraced families as the primary care providers, shifting care from government back to families (Chappell & Penning, 2005). Families find themselves managing tasks, such as administering medication, that were once the domain of health professionals (Schumacher et al., 2000). This role can involve considerable stress and anxiety at an already extremely stressful and emotionally challenging time. In addition, family members must also learn how, when, and where to access help in their role; they must learn what to expect in the disease trajectory, how to identify symptoms, and so on.

In this study, we explore family members' descriptions of what they learned during the process of providing care to a dying person, which informs our discussion of areas and strategies for improving these learning experiences. We conducted a secondary analysis of data from four qualitative interview studies with family caregivers to those at the end of life ($n = 156$).

Existing research tends to focus on the educational needs of health professionals; in terms of family caregivers (FCGs), there is a focus on disease- and diagnosis-related learning, leaving a gap in inductive research on FCG learning, particularly regarding

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end-of-life care (Thielemann, 2000). In general, the research suggests that some disease-related information is needed and desired by FCGs, albeit with individual variation (Harrington et al., 1996; Rees & Bath, 2000; Thielemann, 2000; Fukui, 2004; Parker et al., 2007). This information includes gaining knowledge about the disease, prognosis, and treatment, and helps FCGs to provide care and manage uncertainty (Hardwick & Lawson, 1995; Rose, 1999; Friedrichsen, 2003). Disease-related information should be delivered several times in the most comprehensible way possible (Grahn & Danielson, 1996), and understanding must be constantly assessed (Rose, 1999; Friedrichsen, 2003; Parker et al., 2007). Research with FCGs caring for patients with nonterminal conditions indicates repeated provision of information at multiple timepoints (Hardwick & Lawson, 1995) and follow-up verification of understanding (Hardwick & Lawson, 1995; Smith et al., 1998).

Care-related learning can include cognitive, psychomotor, and affective knowledge and skills. FCGs for dying persons tend to express knowledge and learning gaps and needs regarding the management of symptoms, pain, and medication (Fukui, 2004; Docherty et al., 2008; Funk et al., 2010). They also desire information on physical techniques and skills of care (Thielemann, 2000; Parker et al., 2007), including addressing patients' psychological needs (Fukui 2004; Parker et al., 2007), maintaining patient autonomy (Steele & Fitch, 1996), and responding to emergencies (Parker et al., 2007), as well as coping with care provision (e.g., self-care: Fukui, 2004; Parker et al., 2007). Care-related learning needs may increase as the illness progresses (Parker et al., 2007); however, Wilkins and colleagues (2009) found that interest in caregiver skill training was independent of whether tasks were currently being performed. Care-related learning and problem solving needs may also be specific to medical requirements and the challenges of particular diseases and conditions (Smith et al., 1994; 1998; Silver et al., 2004).

To a lesser extent, research has identified that FCGs also express needs for information about available sources of help (Thielemann, 2000; Parker et al., 2007), including equipment (Harrington et al., 1996). Indeed, FCGs "often find it challenging to navigate the system and access services due to a lack of knowledge about how the system actually works, what services and resources are available to them, and how to access these services" (Brookman et al., 2011, p.24). For instance, Canadian studies (Crooks et al., 2007; Giesbrecht et al., 2009) demonstrated a lack of awareness among FCGs' of the national workplace leave program available to FCGs caring for those at the end of life. In another study (Wilkes et al., 2000), information about available resources helped FCGs feel empowered and in control.

Overall, there is a lack of inductive research on caregiver learning, and what is available tends to focus on specific needs for disease- and treatment-related information, in contrast to more instruction-intensive learning needs (such as how to provide care). In this secondary qualitative analysis of data from four samples of FCGs providing end-of-life support, we explored how family members describe what they learned when they provided care, informing future considerations of how to better foster and support these learning experiences.

METHOD

Qualitative secondary analysis involves reanalyzing preexisting primary data to investigate new questions (Heaton, 2004) so as to maximize data to their fullest use and minimize further intrusion and research fatigue (Glaser & Strauss, 1967; Hyman, 1972; Bernard et al., 1986). Our approach "transcends the focus of the primary study from which the data were derived, examining new empirical, theoretical, or methodological questions" (Heaton, 2004, p.38). We combined data from multiple samples of FCGs at the level of analysis; this can enhance the range and variability of individuals and settings from which to identify overarching commonalities. We did not use a formal triangulation process (e.g., with convergence or dissonance coding and assessment, as in Farmer et al., 2006), nor was our purpose to validate or crosscheck findings between different samples or sources of data (Patton, 1999).

Data were assessed for their fit for inclusion in this analysis—that is, whether they provided information to address the new research questions (Dale et al., 1988; Stewart & Kamins, 1993; Heaton, 2004). To mitigate the risk of misrepresentation when reanalysis is removed from the context of the original research (Thorne, 1998), the primary datasets were all studies led by the second author, who was "thoroughly familiar with the original datasets," research processes, and contexts, and "with the reports of findings made in relation to those data" (p. 553). The first author was familiar with and had previously analyzed three of the four datasets.

Participants in all datasets were 18 years of age and older, resided in one Western Canadian province, spoke English, and provided end-of-life support to a family member. A total of 156 interviews were used in these analyses, including 42 current and 114 bereaved FCGs. Face-to-face qualitative interviews were conducted and audiotaped with each participant and transcribed verbatim. Publications cited below provide further details on study methodologies.

The first dataset was from an ethnographic study examining the social context of dying at home and included interviews with a purposive nonrandom sample of 13 current and 47 bereaved FCGs who provided homebased palliative care (Stajduhar, 2003; Stajduhar & Davies, 2005). Participants were recruited via advertising in newspapers and through local hospice organizations. They were asked about how they came to be a caregiver and how they experienced the challenges and rewards. The second dataset was from a qualitative study of a purposive sample of 26 FCGs who cared for a dying family member at home (Funk & Stajduhar, 2011; Funk et al., 2011). FCGs were recruited though a health agency from a list of patients deceased within the last 3–6 months who had been enrolled in palliative home care. Eligible participants had lost a family member within the past 3–12 months who had received home care nursing services. Participants were asked about their access to home nursing care services and their relationships with home care nursing. The third dataset was from a qualitative study of 24 bereaved family members of a patient who had a terminal condition and died in an inpatient setting (Stajduhar et al., 2011; Funk et al., 2012). Participants were recruited from a larger sample of 388 respondents to a mailed questionnaire study of perceptions of end-of-life care quality (Stajduhar et al., 2010). Eligible family members were the primary contact person for a relative/friend who had died in the previous 3–6 months in an inpatient setting. Participants were asked to describe and evaluate their experience with the end-of-life care received by the deceased person and describe examples and aspects of care important to them. The fourth dataset was from a qualitative study of 29 current and 17 bereaved family members who provided care to someone with cancer at the end of life (Stajduhar et al., 2008*a*; 2008b). Eligible FCGs were providing care at home to an adult diagnosed with advanced cancer. Participants were recruited by healthcare providers. In-person interviews focused on questions about caregiver coping and identifying the features that FCGs believed had influenced their coping.

Transcripts were combined into an overarching dataset within NVivo 8.0. After reading through interviews to identify relevant talk about learning or knowing (defined broadly), we produced summaries of the relevant content on learning within each interview, considered in tabular form against descriptive data for each participant. This informed the development of codes identifying talk about learning, knowing, and gaps and preferences in this regard. Codes were applied to the data by the first author. Findings within each code were compared and contrasted and were used to generate descriptive thematic categories, presented below.

RESULTS

Our analysis focused on identifying what family caregivers learn in the process of providing support for a dying person, including but not restricted to what FCGs state they want or need to learn. FCGs spoke of three general kinds of learning: about the situation/illness, including what to expect; learning what to do (how to provide care); and learning how to access help from the healthcare system and others. A fourth kind of learning was also identified that was primarily affective or attitudinal in nature, focused on self-discovery and personal development; this learning reflected a more active and ongoing meaning-making process.

Learning About What Happened, and What to Expect

Learning about the situation entailed learning what is happening to the patient and what to expect in the future. This was a key concern for many participants—and for some, a gap or unmet need. FCGs desired medical information about the nature of the illness and its prognosis as well as information about care and treatment decisions made by healthcare providers. One FCG described the reassurance connected to information when a hospital nurse conveyed to her and the patient exactly what she was going to do in terms of managing his pain at night. Participants described developing personal skills in this regard, such as interpreting medical information. For instance, one participant noted that, through the process of caregiving, “I’ve learned a fair bit about the science or the directions that cancer can go and some of the treatments for it, and what their effects are.”

Family members tended to report more negative or stressful experiences when they perceived a lack of adequate information regarding the patient’s condition, hospital treatments or policies, symptom management, side effects, or medications. For example, one FCG was upset because the patient had been enduring a high level of pain until the hospital “suddenly came up with this drug” that he presumed had been “held back”: “If you’re not educated and you’ve never been through this, you don’t know that [certain medications] exist.” FCGs appeared particularly dissatisfied when information and instruction were not offered through expected channels (e.g., from healthcare professionals) at preferred times. For example, one FCG was disappointed that hospital staff did not inform her about what was happening, what they were doing, or when the patient might be discharged:

> It was like nobody wanted to talk to me or tell me anything or sort of say how bad it was until I think it was about a week before Christmas. One of them finally said to me, “he’s never coming out of here so” (. . .) I think I could have been better prepared with that sort of information if they would have said, “We believe it’s this, and this is what is causing it, and this is what we can or cannot do.”

Another FCG was frustrated with incomplete explanations from the home care nurse (HCN) about the side effects of morphine: “I don’t feel like I had been told, ‘we’re going to start with this, but it’s probably going to change, and your mother, by the way, is going to lose all coherence.’ ”

Learning what to expect and what could happen in the future was for many seen as crucial to prepare oneself emotionally and practically for possible scenarios. This included learning about potential physical, mental, and emotional changes for the patient. Learning about the likely trajectory was strongly desired, although many acknowledged difficulties in prognostication. Many FCGs also learned and/or wanted to learn about how to detect the signs and symptoms of imminent death, or what to expect from the healthcare system in terms of institutional policies (e.g., visiting hours), and what would occur after the death. As one FCG stated, “I can handle anything if I know what is coming.” Another FCG described a social worker who provided her a “fantastic” caregiving book that helped her become aware of, and accept, the patient’s lack of appetite as a normal part of the illness. The book also provided information, using nonmedical terminology, about signs and symptoms at the end of life. Written materials (handouts, books, internet resources) generally could be helpful in providing supplementary information, but are perhaps ideal when targeted to the specific concerns of the FCG.

Several participants recommended that FCGs be given more information sooner about what to expect, in some cases even before a terminal diagnosis is given. For example, one FCG noted, “When something first happens, when a person first has a stroke (. . .) go to the people, sit with the person who’s going to be the caregiver, tell them what [they should] expect, how it’s going to affect them.” One FCG suggested that, even if a visit from home care nursing was not possible right away after hospital discharge, “maybe that’s when you should get the binder and do some reading and get yourself a little bit more prepared before things are happening so fast.” In part, some of the focus on advance information connects to participants’ concerns with learning to accept and comprehend the situation and the terminal diagnosis (i.e., affective learning). Another FCG appreciated a book they received from the hospice about grief, but noted, “Had I read it maybe two months before, [it] might have prepared me a little bit better when I was caring for my mom and physically watching her in the dying process.”

Occasionally, a family member expressed that they did not want to know the trajectory, or wished they had not known. One FCG explained that, although her daughter searched the internet for information about what to expect, she herself did not want to prepare herself in this way, because, based on her prior experience, things often take their own course different from “what the pages say” (or what professionals say)—so, “I was just taking it as it came.” Another FCG referred to the palliative care manual she received as a useful overview: “It warns you about what’s going to happen later on in the illness, so it’s not such a surprise.” However, when reading about the latter stages of illness she “had to stop” as it was too “graphic,” suggesting she read it at a time when she was feeling fragile and “did not want to think about my mom ever being in that condition, which we knew was the inevitable.” For similar reasons, some FCGs expressed not wanting (and/or being unable to process) this kind of information until later in the trajectory. For instance, one FCG appreciated the HCN’s approach of “gradual revelation,” not revealing all the information at the beginning (giving medication, injections, etc.), which the participant felt would have intimidated her, but it was needed by the caregiver throughout the progression of the care recipient’s illness.

Learning What to Do and How to Do It

FCGs spoke of learning how to provide care to and assist the patient both at home and within inpatient settings. This included cognitive learning (i.e., knowing what to do and how), psychomotor learning (regarding the hands-on provision of care), and skill development (organization, research, troubleshooting and problem solving, household management). It can also entail affective learning, such as learning how to manage one’s relationship with the care recipient and respect their autonomy, as well as how to manage personal emotions and the stress of care provision. Other FCGs spoke of learning generally about the experience of care provision (e.g., what it is like to provide care), including challenges, emotions, and long-term impacts, as well as the grieving process.

Of particular concern in care provision was learning about medications and pain management, as evidenced by the dominance of statements about this topic, and references to the challenges and uncertainty involved. Participants described learning how to administer medications (e.g., I.V.s, needles, patches) as well as how much, and which medications to give at what times (including "breakthrough" doses). They learned about the purposes of medications and how to recognize side effects, to assess effectiveness, to manage the balance between pain relief and side effects, and to make dose adjustments accordingly. Being responsible for, and learning about, pain management could generate stress and fear because of the uncertainty and lack of knowledge often involved. As one FCG described, "When [the patient] is in a lot of pain, it's much harder on me because I don't know how to handle it exactly. I know (. . .) what they tell me I can give her, but if it doesn't help very much, it's a bit difficult." Others were afraid of doing something wrong that might harm the care recipient or believed that medications would be better managed by healthcare professionals.

Beyond pain and medication management, FCGs spoke of learning and/or wanting to learn about how to monitor and effectively respond to and minimize patient symptoms such as nausea and vomiting, digestive issues, hallucination, excessive phlegm or breathing issues, anxiety, depression, and anger. They learned how to diagnose problems or potential problems involved in the patient's condition. Further, they described learning a range of personal care tasks and skills (those with previous caregiving experience focused less on these aspects). These included: feeding and hydration (e.g., deciding what food to give and how to administer food and liquids, when to give up feeding, tube feeding); bathing and washing, toileting (bedpan procedures, dealing with patient incontinence, monitoring bowel condition, giving enemas); and managing, cleaning, and changing colostomies, urostomies, and ileostomies.

Some FCGs were concerned with how to move, lift, and transfer the care recipient (including changing them, or the sheets, while they were in bed) in a way that was easiest and prevented patient discomfort. Less common, but also mentioned, was learning about managing the care recipient's physical surroundings to promote comfort; changing dressings and wound care (including recognizing and monitoring bed sores); taking and reading blood pressure; monitoring blood sugar levels; dealing with infections; and managing and monitoring equipment such as a Hemovac or oxygen machine. Some FCGs described learning and/or wanting to learn about what they should do after the patient dies (e.g., cleaning the body, who to contact).

As noted in the first section, FCGs often recommended that they be given more information sooner about what to expect. In part, this was to better understand what they might need to do, and when. Some participants in particular took issue with the lack of practical information and advice about the hands-on provision of care in terms of distributed materials from health agencies. For example, one FCG stated that the HCNs "had given me all these bizarre little things saying how to be a caregiver; you have to take care of yourself; and go to a spa and all this—what a useless thing! Give me a book that tells me how to do what I have to do."

However, in some cases information given in advance can lead some FCGs to overfocus on planning, which as one participant noted, can have its downside:

> I'm always looking forward to that next step—what if, what if. The hospice doctor tells us he could just go in a coma anytime now, so I'm thinking, "if he's in a coma, he needs these soakers on his bed." (. . .) And I don't know what next I'm going to have to get into, like the lift for going to the washroom. You're constantly planning for tomorrow, whereas we should live for today.

Learning How to get Help

FCGs also spoke of learning how to access services, support, and information from healthcare providers and within the healthcare system. This includes primarily cognitive learning (e.g., information) as well as learning to rely on others, ask for help, effectively communicate and negotiate with healthcare providers, and advocate within the system (e.g., affective learning and skill development). This was a challenging learning curve and/or learning gap for many participants who spoke about this topic. FCGs learned about what public and/or private services are available (e.g., home care, home support, respite, hospice, as well as mobile labs or home visiting physicians), contact information, how much they might cost, and what procedures and eligibility requirements are entailed. For instance, one FCG described how the HCN instructed her to ask for help from her family and gave her suggestions and contact information about available resources, and suggested she ask her family doctor to convince the patient to help himself: "She helped me figure out ways so that I wasn't so burdened with so much stuff."

FCGs spoke about finding out what was available and how to access it, and also about learning (or wanting/needing to learn) when to ask for help and from whom (e.g., when not to call 911 for emergencies); and about available complimentary therapies for the patient; as well as what equipment, supplies, and modifications might be needed to make care provision easier or more effective (and how to access them). For instance, one FCG, frustrated by a lack of guidance about needed supplies during the care experience, explained, “Looking back now, I can count all the things that you need to have” when providing end-of-life care at home, such as “rubber gloves or latex gloves when you’re helping somebody in the bathroom, things like a washbasin or a nice sterile bucket if you need to do any bathing or cleaning, baby wipes,” and personal products to deal with incontinence.

Negotiating through and within healthcare systems was another area of participant learning. FCGs pointed out difficulties negotiating within the healthcare system (e.g., filling out government forms, institutional placement processes). One FCG spoke of the challenges involved in learning about the operation of the assisted living system and how to fill out forms: “Who to contact is very difficult—who to talk to and get a straight answer.” Another described care work as involving knowing strategies of “working within the system” (e.g., discovering sources of funding). One mother of a son with cerebral palsy described how, over time and with the guidance of a social worker, she figured out what she needed (such as respite at night) and how to set it up and find funding. A few FCGs described learning about “system shortcuts”—for instance, one spoke of learning that she could call the fire department for help when the care recipient (who was considerably overweight) fell down; another spoke of learning that she could call the ambulance to ensure quicker service and shorter waits at the hospital.

Participants similarly recounted learning (and the importance of learning) how to effectively communicate with healthcare providers, including being specific in describing patient symptoms and conveying needed information to those who make service decisions. One FCG was disappointed that she had not been told about the criteria that HCNs employ to make service decisions so that she would know what was important to tell them, and therefore could have been able to access the level of help she needed. In order to access help, participants also described learning “what questions” and which providers to ask. For instance, one FCG explained how they learned which staff in the hospital they could approach to ask for a glass of water for the care recipient. Another FCG spoke about the initial difficulty in identifying staff (because they no longer wear uniforms to distinguish their roles) and then gradually “figuring out” who to ask for help in the hospital by getting to know them. Some participants learned how to ask for help from others. For instance, one FCG explained: “I learned in the illness of my son, to open every door, every door. I don’t shy away. I go to the top places if it comes to advice and explanations.”

Attitudinal Learning as Meaning Making

In some cases, participants’ reports about attitudinal learning appeared to reflect an ongoing effort to convince or remind themselves of something they were struggling to achieve or accept in order to cope with their situation, as in the phrase, “I have *had* to learn.” For instance, one FCG with a terminally ill child referred to “what [my husband] and I had to do was learn to teach ourselves to accept that death was coming—because it’s not acceptable to a parent.” Such learning experiences were characterized as difficult, as they might be counterintuitive to the participant’s normal or usual responses or reactions; indeed, learning these lessons could be an ongoing struggle. FCGs described learning through reflection on negative experiences or challenges of care provision, as well as reminding or talking to themselves. This represents primarily a self-initiated kind of affective learning almost synonymous with coping, the result of ongoing reflection about experience, though sometimes “prodded” or guided by others (indeed, potentially more than participants acknowledged).

As an example, learning to ask for and accept help from others appeared to equate with becoming comfortable with this process, especially where the participant was previously quite independent. One FCG expressed how she needed to learn to ask for help, which was contrary to her usual independent style: “So it’s not a good way to be. I’ve got to get over that. I think gradually I’m learning a little bit.” Others spoke of learning to accept the fact of the impending death and terminal diagnosis (and that there was no “magic bullet” solution) and learning to manage and sometimes hide their emotions (especially in front of the patient). As an example of the latter, one FCG described learning not to take her husband’s anger personally: “I’ve learned to accept the fact that it’s the illness.” Another FCG spoke of trying to counteract her tendency to get emotionally swept up with empathy, which was unproductive for her caregiving role: “I had to severely talk to myself quite often because that wasn’t healthy. I used to say, ‘if you’re going to do this then you’re going to make yourself sick. If you’re going to make yourself sick you can’t do it.’ So you spend a lot of time talking to yourself.”

Learning to respect the patient’s decisions and autonomy was also noted, as with one FCG describing learning how to adjust her own “pushy” type of personality with regard to feeding the care recipient: “I have had to learn to back off. I’ve had to learn to, if he doesn't feel like eating for two days, okay, back off and take it as that." As a further example, one FCG stated, "You as caregiver think you can do a better job of it than anybody else (. . .) you want the patient to have some control of choices, right? We are so controlling. People are controlling. As a caregiver it doesn't fly so well. That's a learning process."

Participants also described learning to recognize their capacities and limits. One FCG spoke of learning what he is capable of (e.g., "I can deal with certain situations") but also his limits (e.g., referring to a scale, "You expect you can do 10; in reality you can do 5. But you don't find out your limit is 5 until you try to do 7"). One FCG spoke of how she ignored the advice of others to take care of herself until "one day I lost my cool about some silly little thing and I realized, you're right—time to get away."

Others described their processes of learning to cope (e.g., taking one day at a time, being nonjudgmental, and learning to identify the positive aspects of care provision). One FCG spoke of learning the "life lesson" of patience through providing care, adding, "I have a lot more patience now." Another FCG drew on her spiritual beliefs to aid her affective learning: "I quit feeling that it's up to me whether she lives or dies. I only recently came to that. Part of the reason is the realization that I am not God, and I don't get to decide. It's not in my hands."

DISCUSSION

Our study is unique in its examination of caregiver learning outside the confines of disease-related caregiver education research. A secondary analysis of four datasets of family caregivers enabled us to examine how family members describe the learning involved in providing care to a person with a terminal illness.

As is well established in the existing literature (e.g., Rees & Bath, 2000; Thielemann, 2000; Fukui, 2004; Parker et al., 2007), our analysis confirmed that understanding the nature and trajectory of a patient's illness is important for FCGs and, for some, represented a gap or unmet need, with implications for their level of stress and preparedness. Participants spoke of educating themselves about unfamiliar medical terminology and information, which for some was particularly challenging (and highlights potential inequalities based on literacy levels). Given the charged emotional context surrounding terminal diagnoses, there may be problems with information comprehension, interpretation, and recall (Hardwick & Lawson, 1995).

This analysis also highlights two other important caregiver learning needs that may go unrecognized. First, FCGs emphasized learning what to do and how to provide care and support, including hands-on provision of personal care and psychosocial and relational aspects of care. Many stressed the need for more practical "how-to" information. Learning how to administer medications and provide pain management generated particular insecurity and anxiety. In the absence of information or instruction, family members may learn through "trial and error," or in a reactive way after a crisis has occurred (Stajduhar et al., 2013).

Likewise, learning how to get help often presented a difficult learning curve. FCGs expressed a need to learn not only what services were available, when such assistance could be requested, and from whom. Learning how to communicate their needs successfully to healthcare providers was another important issue. Those with prior professional or personal experience with caregiving and navigating the healthcare system had an advantage, while FCGs without such preexisting knowledge or skills were less able to access help (Dixon-Woods, et al., 2006; Stajduhar et al., 2013). This highlights a potential inequity of access to service and resources between caregivers. In some cases, a system navigator support role may be warranted (Manderson et al., 2012), which might help enhance caregiver well-being (Colombo et al., 2011).

An additional unexpected finding from our study highlights the link between affective or attitudinal learning and FCG coping. Learning to accept the diagnosis, to be comfortable asking for help, and to take things "one day at a time" represent ways in which FCGs can manage caregiving challenges. Indeed, some FCGs may actively strive for interpretations of their experience that help them cope with challenges (Hudson, 2004). Though attitudinal change may be important, the extent to which this can be promoted through intervention is unclear. For many participants, this was an individualized process involving an active and ongoing process of experience and reflection as participants sought to interpret their experiences and describe their reactions to those experiences. Nonetheless, acknowledging the role of this form of learning fosters a better understanding of the nature of the caregiving experience.

There are various educational programs and interventions for FCGs, but few are assessed rigorously or target care for palliative care patients—especially provision of physical care (Caress et al., 2009). Overall, there appears to be at least moderate evidence that such interventions can improve caregiver outcomes, including self-efficacy (Beauchamp et al., 2005), coping/reduced stress (Robinson et al., 1998), perceived competence (Devor & Renvall, 2008), ability and knowledge (Sorensen et al., 2002), and skills (e.g., Hepburn et al., 2003). The most effective interventions should focus not only on the passive dissemination of information but also draw on the principles of effective learning to provide in-depth and active learning opportunities, including time for discussion, modeling and demonstration, role-playing, active practice, and application of knowledge (Bucher et al., 1999; Gallagher-Thompson et al., 2000; Pinquart & Sorensen, 2006). Whether such programs can be easily incorporated into the everyday practices of healthcare professionals in interactions with family caregivers remains unknown, and would likely depend on ongoing structural and organizational support (e.g., resources) to allow adequate time for supporting FCG learning needs. Other modes or sources of delivery could also be explored.

In some instances, a few FCGs did not want certain kinds of information at all, whether because of emotional readiness, involvement preferences, or because of the unpredictability of the situation. Preferences for, and receptivity to, written or verbal information also varied, with some preferring one over another or at different times in the trajectory, and others preferring both, so long as the written materials addressed their specific caregiving concerns. Given the many complexities and challenges of the learning context and preferences, addressing learning needs requires an individualized approach throughout the illness trajectory that FCGs need and desire (Stajduhar et al., 2013). Ongoing assessments should address whether FCGs themselves want particular aspects of information or skills training. Decisions as to how much they want to learn and be involved in care provision should be made by FCGs themselves, once they are informed about their options.

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