Family Members Providing Home-Based Palliative Care to Older Adults: The Enactment of Multiple Roles*

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RÉSUMÉ

L'espérance de vie des Canadiens s'accroît et, de ce fait, les maladies chroniques (Santé Canada, 2002) exigeant des soins en fin de vie (Fisher, Ross, & MacLean, 2000). La recherche est limitée sur le processus visant à établir la multiplicité des rôles pour les membres de la famille dispensant des soins palliatifs à domicile. En se fondant sur une étude ethnographique plus vaste des relations client-famille-fournisseur de soins palliatifs à domicile (Ward-Griffin & McWilliam, 2004), la présente analyse secondaire visait à évaluer l'adoption de multiples rôles par les membres de la famille dispensant des soins palliatifs à domicile aux aînés souffrant de cancer avancé. Les membres de la famille étaient d'avis que les attentes envers eux étaient nombreuses lors de la dispensation des soins, mais qu'on ne répondait pas à leurs attentes en matière de services. Jouer des rôles multiples était décrit par trois thèmes interreliés : équilibre des charges, établissement de nouvelles priorités, et évolution. Les réponses positives et négatives en matière de santé découlaient des tentatives de minimiser la santé personnelle tout en maintenant simultanément la santé. Les « véritables » soins de santé dans une perspective familiale étaient absents, mais devraient devenir l'un des objectifs des professionnels de la santé dispensant des soins de santé en fin de vie.

ABSTRACT

Canadians are experiencing increased life expectancy and chronic illness requiring end-of-life care. There is limited research on the multiple roles for family members providing home-based palliative care. Based on a larger ethnographic study of client-family-provider relationships in home-based palliative care, this qualitative secondary analysis explores the enactment of multiple roles for family members providing home-based palliative care to seniors with advanced cancer. Family members had multiple expectations to provide care but felt their expectations of services were unmet. The process of enacting multiple roles was depicted by three interrelated themes: balancing, re-prioritizing, and evolving. Positive and negative health responses resulted from attempts to minimize personal health while simultaneously maintaining health. ''True'' family-centred care was found to be lacking, but should be a goal of health professionals involved in end-of-life care.

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Canada and developed countries worldwide are experiencing an overall increase in life expectancy and a growing senior population. The number of Canadians aged 65 years or older in 2001 was 492,000, and the population in this age group is expected to increase to 2.5 million in 2056, or 5.8 per cent of the total population (Statistics Canada, 2006). Consequently, more people are experiencing chronic illness in old age (Statistics Canada) requiring end-of-life care (Fisher, Ross, & MacLean, 2000; Ross, MacLean, Cain, Sellick, & Fisher, 2001). Along with these changing demographic trends, health-care reforms that have resulted in increased demands on community-based programs and services, shorter hospital stays, and health-care cutbacks (Armstrong & Armstrong, 2004; Ward-Griffin & Marshall, 2003; Ward-Griffin & McKeever, 2000) have placed greater reliance on family members to provide care for older adults within the home (Fast & Keating, 2000; Ward-Griffin, 2004; Ward-Griffin & Marshall)

Cutbacks to Canadian community health care in the 1990s resulted in shifting care from full-time health-care professionals to unpaid family members (Armstrong, 2002). Close family members such as spouses or adult daughters provide the majority of care to older adults with chronic illness (Armstrong & Armstrong, 2004; Given & Given, 1998; Ross, MacLean, & Fisher, 2002), and are more likely to adopt the role of family caregiver, despite the fact that this role is unwanted and unexpected for some (Given & Given). However, the health-care needs of family members providing care have been overlooked as the clients' needs are given priority (Given & Given; Grbich, Parker, & Maddocks, 2001).

Palliative care has become a health-care priority (Fisher et al., 2000) and is intended to provide care for clients who are experiencing a life-threatening illness and their family members, ensuring that physical, psychological, and spiritual needs are addressed (Fisher at al.; Ross et al., 2001). However, the traditional nuclear family is no longer a societal norm (Armstrong & Armstrong, 2004). Family roles have changed, making it more likely that members must assume multiple roles, such as simultaneously providing child care and parental care (Fast & Keating, 2000). Although societal gender role ideologies continue to reinforce the notion that women are ''natural'' providers of unpaid care (Armstrong & Armstrong), and the gendered division of familial labour remains (Fast & Keating), both men and women are participating in paid and unpaid work. Therefore it is necessary to consider the interaction of multiple life roles, including employment and gender role expectations of family members providing palliative care within the home.

Reforms to the health-care system, coupled with an aging population and an increased demand for end-of-life care, highlight the importance of addressing the perceptions and experiences of family members who provide home-based palliative care. The purpose of this qualitative secondary analysis was to explore the multiple roles and health experiences of family members providing home-based palliative care to seniors with advanced cancer.

Literature Review

The empirical literature focusing on home-based palliative care falls into three general areas: predisposing factors of the provision of home-based care, the process of enacting multiple roles, and outcomes for family members providing care. The research is derived predominantly from Canada; however, studies from other countries are also included.

Predisposing Factors of the Provision of Home-Based Care

Predisposing factors that influence the decision to provide care within the home include the expectation of family members, a sense of obligation, and gender. A common finding in the literature is the shift in care from formal care providers to unpaid family members in the home (Richardson, 2002; Ward-Griffin & Marshall, 2003; Ward-Griffin & McKeever, 2000), illustrating the expectation of family members to provide care. Family members have also been asked to perform ''medical'' tasks in the home (Ross et al., 2001; Ward-Griffin & Marshall; Ward-Griffin & McKeever), including the administration of injections and wound care.

The relationship between the family member and care recipient has also been found to influence the decision to provide care. Researchers have found that maternal feelings, love, and family ties are important factors for women providing care to the elderly or mentally ill (Guberman, Maheu, & Maille, 1992). Family members reported feeling morally obligated to provide care in the home, leaving them little choice (Guberman et al., 1992; Stajduhar, 2003) as they attempted to respect their relative's wishes (Stajduhar & Davies, 2005).

The provision of familial paid and unpaid work is influenced by the social and historical context of gender and class positions during life (McMullin, 2005). Employed women providing care for an elderly relative in this Canadian study spent more time caregiving, performed more tasks, and had increased care responsibilities than men. In comparison, Neal, Ingersoll-Dayton, and Starrels (1997) found no differences in the specific care tasks between male and female participants in the United States. However, Fast, Forbes, and Keating (1999) found differences in care tasks between men and women through analysis of Statistic Canada's 1996 General Social Survey data on social supports. These findings suggest that gender role norms and expectations for men and women should be further examined to understand their influence on family members enacting multiple roles, including the provision of end-of-life care.

Process of Enacting Roles

The process of family members enacting roles while providing care within the home has been briefly examined in the literature using qualitative methods. In a study of women providing care for relatives of all ages, using grounded theory, Wuest (2001) identified ''precarious ordering'' as a process for managing the competing and changing demands of caring. Three interdependent strategies were used to create order: setting boundaries, negotiating, and repatterning care. However, ordering was precarious, dynamic, and recurring as these strategies resulted in new competing demands while old demands continued to change.

Negotiating boundaries is a common theme in the family caregiving literature. In an ethnographic study, the boundaries separating formal and informal care were continuously negotiated and crossed by community nurses and family members, with continuous transfer of caring work from nurses to family (Ward-Griffin & Marshall, 2003; Ward-Griffin & McKeever, 2000). Family members negotiated boundaries and were viewed in different roles: helper, co-worker with the nurse, worker, or patient. In findings similar to these, Ross et al. (2001) found that female family members providing home-based palliative care used negotiation to ensure that professionals provided quality care for their relatives. Moreover, family members in this study functioned as intermediaries between the care recipient and the formal caregiver, directing and managing care. Finally, the blurring of boundaries between professional and personal caregiving roles was found among health professionals who provided care for elderly relatives in the home (Ward-Griffin, 2004; Ward-Griffin, Brown, Vandervoort, McNair, & Dashnay, 2005), and for female Australian nurses who provided care for older adults (Gattuso & Bevan, 2000). Clearly, it is important to take into account the influence of employment on the caregiver role and the overlapping role boundaries for those who provide care in the personal and professional domains.

The balance of work and other responsibilities along with caregiving among family members providing care to a relative is another common finding in the literature. ''Juggling work'' consisted of coordination, negotiation, and mediation, where women made accommodations in caregiving, family, employment, and their personal and social lives to maintain balance (Guberman & Maheu, 1999). Similar findings were reported for family members providing care at the end of life (Ross et al., 2001).

The process of assuming multiple role identities was described in a Canadian ethnographic study examining the social context of end-of-life caregiving (Stajduhar, 2003). Family members providing home-based care ''reinvented themselves'' and assumed the role of ''nurse-caregiver'', although they were not educated as nurses, performing personal care, assessing and monitoring health, and planning and coordinating care. Some family members viewed this role with pride, while others stated they had less time for the roles of spouse, parent, or child. Although this research examined the process of family members enacting multiple roles in addition to the caregiver role, few studies have examined this process within home-based palliative care.

Outcomes of Providing Home-Based Care

Outcomes of providing home-based palliative care included tiredness, loneliness, frustration, and fear (Grbich et al., 2001), increased psychological distress and strain (Payne, Smith, & Dean, 1999), and anxiety and burden (Harding, Higginson, & Donaldson, 2003). In addition, high levels of depression were found in employed family members providing cancer care (Given et al., 2004). The interruption of usual activities for family members providing end-of-life care in the home was also a common finding (Brazil, Bedard, Willison, & Hode, 2003; Cameron, Franche, Cheung, & Stewart, 2002; Denham, 1999; Payne et al.), and was linked to increased distress (Cameron et al.) and caregiver burden (Brazil et al.). These findings may be associated with balancing other role expectations and responsibilities. Conversely, family members providing end-of-life care have also reported positive outcomes (Grbich et al.; Koop & Strang, 2003), including finding meaning, spending time with loved ones, and accepting the coming death (Stajduhar, 2003). Deriving meaning from caregiving has been positively associated with self-esteem and negatively related to depression (Noonan & Tennstedt, 1997). These findings take into consideration the positive outcomes from adopting the caregiver role that may mediate negative outcomes for family members who provide care.

Most studies tend to focus on family members in the caregiver role, although some research has examined the health outcomes of family members who have multiple roles. However, the majority of this research has not occurred within the context of end-of-life care. Heightened feelings of strain relating to the new caregiver role and increased negative affect were found in individuals simultaneously occupying multiple roles such as employee and parent in the United States (Kim, Baker, Spillers, & Willisch, 2006). Alcock, Danbrook, Walker, and Hunt (1998) found role strain resulted from balancing multiple responsibilities in and outside the home, and in role reversal. Increased stress and decreased importance in wife and employee roles were experienced by women providing home-based parental care (Norton, Stephens, Martire, Townsend, & Gupta, 2002). Additionally, women who reported conflict between their parental caregiver role and one other role tended to have fewer socioeconomic resources and older children, and cared for parents with greater needs (Stephens, Townsend, Martire, & Druley, 2001). Similarly, it has been found that nurses and social workers who provided care to elderly relatives were at a higher risk for psychological distress, poor health, and decreased well-being when their financial resources and social supports were taxed or stressed (Ward-Griffin et al., 2005). Moreover, overload was reported by women with multiple roles such as parent and worker while providing parental care (Murphy et al., 1997). However, higher resentment was found for those with fewer roles other than caregiver, specifically those who had left the workforce to provide care, or participants with no partner. Life satisfaction in this study was higher in partnered and employed participants.

Schumacher, Stewart, and Archbold (2007) found the perceived quality of the relationship between the family member providing care and the individual with cancer assisted in protecting the family member experiencing high demands when the perceived readiness and preparedness to provide care was high. However, when the perceived quality of the relationship and preparedness were low, there was a greater risk for mood disturbance, even when low demands were experienced. Other studies have also demonstrated that distress levels did not appear to be affected by the acquisition or loss of the caregiver role for middle-aged women providing parental care (Dautzenberg, Diederiks, Philipsen, & Tan, 1999). Additional roles were not found to increase distress levels or caregiver role strain. However, contradictory findings of increased distress in participants who experienced heavy caregiving demands that interfered with their social and personal lives were found. Similarly, family members providing a high level of assistance found that other life roles contributed to burden, although occupying additional roles was positively associated with increased well-being (Stoller & Pugliesi, 1989). Conflicting findings were also found for older adults in the United Kingdom occupying multiple roles (Glaser, Evandrou, & Tomassini, 2005). Simultaneous participation in the employee and caregiver roles did not appear to be associated with poor health, although mixed results were found between caregiving and health in this sample. These mixed findings highlight the need for more research on health experiences of family members occupying multiple roles, especially within the context of home-based care at the end of life, as little research has been conducted in this area.

In conclusion, prior research has explored factors influencing the provision of home-based care, the process of enacting multiple roles, and the related health outcomes for family members providing care in the home. Although investigations in home-based care continue to focus on family members in the caregiver role, they rarely examine other social roles. More research is needed to understand this process in home-based palliative care, the interaction of multiple roles, and the resulting health effects. Therefore the aim of the current study is to begin to address these gaps in the literature.

Purpose and Research Questions

The purpose of this interpretive secondary analysis using an ethnographic perspective was to explore the roles experienced by family members providing home-based palliative care to seniors with advanced cancer. The research questions for this secondary analysis were,

- How do family members providing home-based palliative care experience multiple roles?
- What contextual factors constitute the enactment of multiple roles in home-based palliative care?
- What are the health experiences for family members who occupy multiple roles, including the provision of home-based palliative care?

Methodology

Qualitative secondary analysis was utilized for this study, therefore an overview of the original study from which the data were initially obtained will first be discussed.

Original Study Overview

A longitudinal ethnographic approach was used to explore client-family-nurse relationships in the daily world of home-based palliative care (Ward-Griffin & McWilliam, 2004). A purposeful sample of four groups or triads each consisted of a client aged 60 years and over with advanced cancer, his or her identified family caregiver, and visiting home-care nurse. The family participants' relationship to the client consisted of 2 female spouses, 1 male spouse, and 1 daughter, with an average age of 57 years, ranging from 50 to 65 years during data collection. The average age of the clients was 70 years, ranging from 67 to 75 years. Family members had completed 1 to 7 years of post-secondary education, with annual income ranging from $20,000 to $79,000. The 3 female family members were employed, either full-time, part-time, or casual. The male family member was retired.

Multiple, individual in-depth interviews occurred approximately every 4 weeks, for a total of three to five audio-taped interviews with each of the 4 family member participants (Ward-Griffin & McWilliam, 2004). Family members were chosen as the focus based on the primary author's interest, and to contend with the large scope of the original study data. A semi-structured interview guide was used, and field notes including observations were recorded after each interview and followed a guided format (Morse & Field, 1995). The field notes included data on the location of the interview, description of the environment, content of the interview, nonverbal behaviour, and preliminary insights, interpretations, beginning analysis, and working hypotheses (Ward-Griffin & McWilliam). All interview and field note data were transcribed, reviewed, and edited as soon as possible after each interview. Using the guidelines of Lofland and Lofland (1995), independent analyses were compared and combined during research team meetings, allowing for the exploration and expansion of themes and patterns.

Qualitative Secondary Analysis

Qualitative secondary analysis using the ethnographic interview and field note data was chosen to explore the roles experienced by family members providing home-based palliative care to seniors with advanced cancer. Various types of qualitative secondary analysis have been suggested (Heaton, 2004), and include in-depth focus on aspects not covered in the original study, re-analysis to verify original interpretations, and combination of data for comparison. Supra-analysis of qualitative data (Heaton) was used for this study, as new questions were asked beyond the purpose of the original study. A subset of the 16 family participant transcripts and accompanying field notes from the original study were examined.

Secondary analysis is sensitive to the potential burdens placed on participants, as research is conducted without requiring recruitment of additional participants (Sandelowski, 1997; Szabo & Strang, 1997). The use of secondary analysis in this study ensured that family members who provide end-of-life care and who live in a highly sensitive and emotionally charged environment did not have to participate further in this study. Thus available data were effectively utilized.

The identified limitations of qualitative secondary analysis must also be mentioned, as they relate to the use of a data set not generated by this primary researcher (Hinds, Vogel, & Clarke-Steffen, 1997; Szabo & Strang, 1997). While there was a good fit between the available data and new research questions, distance between the collection of the original data set and the secondary analysis is a potential threat in the interpretation of findings, as the researcher was unable to clarify data with the participants (Thorne, 1998). The primary researcher served as project coordinator for the original study, and became familiar with the data collection and analysis methods used. Moreover, the lead investigator from the original study served as thesis supervisor for the secondary analysis, which ensured communication between the original study and current study (Szabo & Strang).

Data Analysis

Salient words, phrases, and sentences that captured the essence of the meaning were underlined, and the audiotaped interviews were listened to, resulting in data immersion. Analysis began with initial coding, where the data were condensed and organized into categories, followed by focused coding, which builds on the initial codes by elaborating on a select few, and discarding those considered less descriptive or useful (Lofland, Snow, Anderson, & Lofland, 2005). Memos describing the coding categories, interconnections, and the research experience were kept to assist the developing analysis.

Findings

Four family members who provided care for their relative at the end of life participated in the original study, with pseudonyms chosen for each. Alice, age 58, provided care for her husband while also working full-time as a health-care provider in long-term care. She had trained as a nurse in her native country but chose to not pursue registration upon coming to Canada. Emma, age 50, also provided care for her husband, choosing to work only on a casual basis during this time. Fred, age 65, was retired and provided care for his wife. Alice, age 56, provided care for her mother while working part-time as a community-based personal support worker (PSW).

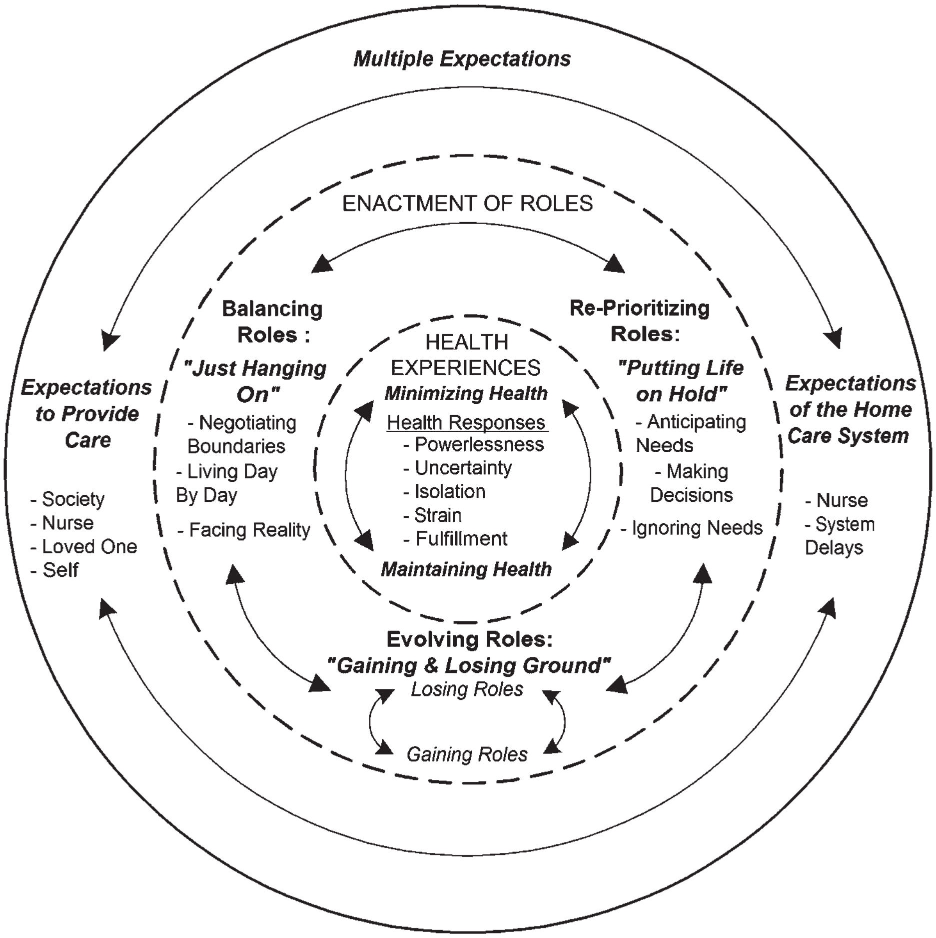

Figure 1: Enactment of multiple roles for family members providing home-based palliative care

Analysis of the interview and field-note data revealed the context of home-based care and the multiple expectations that surrounded the experiences of family members providing palliative care to an elderly relative. The family members' enactment of roles occurred within that context, described by the themes of balancing roles, re-prioritizing roles, and evolving roles. Finally, the health experiences for the family members were located within the centre of their overall palliative-care provision (see Figure 1).

Multiple Expectations of the Family Member

Family members experienced multiple expectations, which formed the context of home-based palliative care. Competing demands and tension occurred between the expectations of the family members to provide care and their unmet expectations of the home care system. They struggled to cope with the contradictory expectations they encountered while providing care in the home for their dying relative.

Expectations to Provide Care

Gender role expectations of the family members appeared to influence the adoption of the caregiver role. Traditional societal gender roles and norms reinforced the ideology that women are "natural" care providers in the home for these participants. The participants shared similar views and beliefs about women and caregiving. Anne had also observed that women, often a daughter, are expected to assume the caregiver role, typically on their own. Similarly, Fred experienced change in his spousal role by adopting the caregiver role and assuming responsibility for other domestic tasks. He described these roles as unfamiliar to him because his wife previously managed those responsibilities in the home. Emma stated,

> I've always been very motherly.... I think it's just something, a nature thing.... I don't know where I learned to be a caregiver. I think a mother, for the most part, has to have a little bit of that just built into her, because that's what you do.

Expectations of family members to provide palliative care were also held by health-care providers.

According to the family members, the nurses were busy, conservation of resources was necessary, and they believed others required more nursing services than their relative. Family members provided the majority of the care, while the nurse was viewed as a helper. As a result of the perceived heavy workloads of nurses, participants reported that they were expected to perform nursing tasks in the home such as the administration of medications. Fred was initially afraid to administer pain injections to his wife:

> [Learning to administer injections] . . . was . . . hammered in my head by the doctors and [nurse] . . . don't be afraid to give that needle you're not going to overdose her.

Participants felt the care recipient also expected them to provide care and shared a desire to follow their wishes, keep promises, and reciprocate care.

> [Admission to palliative care unit] has never been a question . . . I've always known that Bill did not want to end up in a hospital for anything.. . . I've always known that, and I have always said that I would be here.. . . You do what you say you're going to do. (Emma)

Finally, the participants held expectations of themselves to provide care for their family member and to meet their care-related wishes. These feelings of obligation reinforced the expectations of others for the family members to assume the caregiver role, often citing that they had little choice.

> But if . . . you are put in that situation [of providing care], you just deal with it, you don't have a choice. So you just handle it. (Emma)

The family members' comments implied that a close interpersonal relationship with their relative also contributed to and reinforced their expectations to provide care.

> For the most part Bill's happier if I'm with him taking care of him . . . . So I try to see to it that that's the way of it most of the time. (Emma)

Expectations of the Home Care System

While others held expectations of the family members to provide care, the family members held their own expectations of the nurse and of the home care system. They expected the nurses to arrive on time for visits and to inform them if visits needed to be rescheduled, be respectful, and provide treatment fairly and appropriately. Family members experienced dissatisfaction when their expectations of the home care system were unmet, and they responded with anger and frustration. Fred became upset when the nurse did not visit on two consecutive weekends.

> I was . . . enraged that they didn't call and let me know . . . they weren't coming [to visit on the weekend].. . . I called roughly half an hour after they were supposed to be here, and . . . we weren't even on their list for the day.. . . That made me upset.

As a former sales representative, Fred valued keeping appointments, being on time, and rescheduling appointments as necessary. Thus, his trust in the nurse and home care system was compromised by numerous unmet expectations. Furthermore, many family members were disappointed in the health care system and experienced delays, including failure of the health care system to diagnose cancer earlier, as annual physicals had been completed and treatment for symptoms had been sought. Examples of failure to provide testing and a timely transfer to hospital for admission were also shared. Overall, it appeared the family members had been conditioned to have few or no expectations of the home care system.

> I don't blame [the nurse] for [visits not occurring]. . . . The system broke down. (Fred)

However, when care and services were available and received in a timely manner as the family member's condition deteriorated, satisfaction and trust in the system were expressed. Having the same nurse visit consistently was valued, as it facilitated the formation of a bond between the client, family, and nurse. Emma stated,

> It is nice to [be] dealing on a one to one . . . with the same [nurse] because then they have a better idea of what was going on the week before and the week before that.

Furthermore, family members appreciated nurses who monitored their relative's health status, ensured medications were prepared, and functioned as a liaison with the physician.

Gender and age were also influencing factors. Fred was a retired senior and most vocal with expressions of displeasure and experienced contradictions throughout his experience with the nurse. He valued her abilities to manage medical tasks in the home, but was also upset that many of his other expectations surrounding home visits were not met. As a result, he had a tenuous relationship with the visiting nurse. In contrast, Emma and the nurse were close in age. She was satisfied with the delivery of care and shared a bond with the nurse, valuing her expertise, knowledge, and friendship.

> You do . . . develop some kind of a bond when you're seeing someone all the time.. . . [The nurse]

> listen[s] to my thoughts . . . and we . . . work things out together.

In summary, differences in the expression of satisfaction and dissatisfaction were influenced by gender, age, employment experience, personal values and beliefs, and the relationship with the nurse.

Enactment of Roles

The multiple expectations experienced by family members to provide care influenced the dynamic process of role enactment, which was captured within three interrelated themes: balancing roles, re-prioritizing roles, and evolving roles. Ongoing tension was also encountered as the family members simultaneously experienced balancing, re-prioritization, and evolution of their roles.

Balancing Roles: "Just Hanging On"

Family members attempted to meet the multiple expectations they encountered. They described their experiences as "just hanging on".

> I do think about . . . how long I will be able to manage.. . . If it comes to the point where I have to take some time off work in order to . . . cope if he gets worse . . . that's what I'll have to do.. . . I don't think there will be too many options then, it's a matter of survival. (Alice)

The family members endeavoured to balance their life roles with the following strategies: negotiating boundaries, living day by day, and facing reality.

Negotiating Boundaries

Negotiating boundaries between roles as a family caregiver and professional caregiver occurred for the participants who provided care in the home and the workplace. Anne shared perceptions that were influenced by her experience as a PSW, increasing her awareness of the negative consequences for family members who provided home-based palliative care, such as physical and emotional stress. These participants had a different perspective and understanding of palliative care, and struggled to maintain separation between their caregiving and family roles, which resulted in tension. Anne declared,

> It's a . . . balancing act. How much do I offer my help, how much do I stand back? . . . I don't want to be there a lot because I want to let her family see her. . . . You don't want to hover . . . because . . . I've seen it happen with some of my clients.

Physical boundaries were often created, which assisted in separating their personal and professional caregiving roles. For instance, Alice found it easier to be absent when the nurse was visiting rather than be present and not involved with her husband's care.

> I found it a little difficult to stay in the background [when the nurse was visiting] . . . because I'm involved in nursing and . . . I'm used to being front line and giving the care, so it's just a little bit tough to be in the background.

The impression she had from the nurse was that the care was intended for her husband only.

> I guess the impression I got was that they came to attend to John's needs and that was it, so . . . I would just get out of the way.

She ultimately made the decision to hospitalize her husband at the end of his life, as this allowed her to resume her role as wife, not caregiver.

Anne also reported the need to separate her caregiver role from her daughter role, but continued to draw on her knowledge from the workplace, acknowledging there were some things she did not want to share, or a line she did not want to cross. Her professional experience exposed her to the provision of home-based palliative care, but stated it only partially prepared her for the caregiver role. Anne wanted to remain the daughter and strived to maintain separate boundaries between these two roles.

> This is my mother, this isn't a client. So I will be there for her, but I don't really want to do [the] personal care.. . . I want to be the daughter.. . . I'll be doing, I'll be helping.. . . That's me.. . . I've been there until almost the very end and I know it's not exactly a picnic.

Living Day by Day

The family members attempted to live "one day at a time" in order to cope with the challenges they were facing. Each day was different and depended on their relative's condition. Ultimately, the family members felt unable to plan for the future.

> I have no idea how I'm coping.. . . I just don't know, I just try to get through each day . . . and hope the world doesn't fall apart around me. (Emma)

To manage the complexity of their daily lives it was necessary to "go with the flow". Being prepared was beneficial, but the unexpected could occur and would be managed. Interpersonal values and beliefs also influenced their desire to connect with their relative and make the most of their remaining time daily. Opportunities to spend time together to share, ask questions, and listen to her mother's wisdom was especially important for Anne.

Facing Reality

The family members reported they had to "face the reality" that their relatives were dying, in order to manage their life roles. Enjoying their remaining time with their relative and maintaining their own well-being assisted them in being organized and prepared for the death. However, family and friends did not always respond in the same manner as the family member, contributing to the struggles and challenges faced during this time.

> For my own sanity I have to face reality . . . if I didn't I'd be living in a fairyland and . . . that would collapse.. . . [Friends] don't want to hear what is happening . . . they ask how he is, but they don't really want to know . . . how I feel about it or anything because then they have to deal with it. (Emma)

Re-Prioritizing Roles: "Putting Life on Hold"

A second theme in family members' enactment of roles was re-prioritizing roles. This process was informed by the expectations and values of the family members that surrounded their role enactment. New roles were assumed, such as family caregiver, and were given more priority at various times. Other roles were given less priority, such as the employee role. In this process, family members stopped some activities and put their lives on hold, having to "take stock" of the situation. As Emma stated, "Well, you would have to be prepared to put your own life on hold, to realize that your first and main priority is your spouse or whoever you're taking care of." Essentially, their relative and caregiving became their main focus. Prioritization was expected both internally and externally, leaving little choice for the family member in making decisions about the type and degree of care.

> When this is all over, I'll somehow work it all out. But at the moment I have to stay focused here. There's not much you can do. (Emma)

> [My wife] does want to be at home.. . . We both would . . . she also agrees that . . . it's tougher at home on me.. . . I don't think about that so much. I think of where she wants to be that would make her happiest and would have the best care. (Fred)

According to the participants, the nurse encouraged and reinforced the family members to adopt the caregiver role, and functioned in an assistive capacity to the family. The strength of the interpersonal relationship between family member and relative also shaped the re-prioritization. Positive relationships often led the family member to prioritize the role of caregiver over other roles.

The re-prioritization of roles included sub-themes: anticipating needs, making decisions, and ignoring needs.

Anticipating Needs

Family members anticipated that their relatives' needs would change and require increased care, resulting in prioritization of the caregiver role. For example, participants realized the health status of their relative could decline and change quickly, increasing their caregiving demands.

> The time will come where I'm probably going to have to have somebody come in once in awhile because I am going to be at a point where I won't be able to go out for even an hour to do groceries . . . if there's not someone here. (Emma)

Making Decisions

Family members continued to make decisions about care provision. For instance, Anne wanted to meet her mother's wishes and assist her mother in decision making. She would be ready to step in if needed. Some family members had numerous factors to consider when making decisions, while others had fewer. These factors included flexibility of employment, available support for the family member and relative, and the dying individual's health status. Emma said that she had few choices when she stopped working.

> [I'm] not [working] much.. . . One day it might be okay and one day it might not.. . . People . . . want you to work every day.. . . They don't want you to have to call 2 or 3 days in a row . . . so basically it's just here [at home].. . . I was working for a little while when he first took ill and I was in constant worry about whether he had remembered to take his medication . . . hoping he didn't go too far and things like that. It was just very stressful.

Ignoring Needs

Consequences of prioritizing the caregiver role included reducing participation in other personal activities. Typical responses if away from the home were constant worry, concern, and shopping only for basic necessities.

> You just can't think about those other [activities you used to enjoy].. . .. You may think of them but you can't do them.. . . What you have to do is here mainly. (Fred)

Priority was ensuring their relative was not home alone. Even if someone was with their relative, family members felt pressured to return home quickly. For example, Fred would leave his wife only if he had given her pain medication by injection to ensure her comfort while he was away for short periods of time.

Evolving Roles: "Gaining and Losing Ground"

Evolution of roles was a final theme in the changing nature of family members' roles. Certain roles would "shrink" while others would "expand" for the participants at different times, as depicted in the dialectical sub-themes of gaining and losing roles.

Gaining Roles

Within the evolution of roles, family members adopted new roles, where caregiving was most prominent. Continuous change occurred within the caregiver role. If their relative was perceived to be in poor health, the caregiver role would "expand", while improved health resulted in "shrinking" of the caregiver role. Spousal responsibilities that had previously been shared now became the main responsibility of the family member providing care. For example, during times of poor health the family member would often be responsible for grocery shopping, banking, cooking, along with working and motivating their relative. Fred stated that because his wife "can do nothing", he must do everything. Emma said,

> I've always known . . . how [Bill] would want things, so that's not been difficult. . . . The finances [have] been difficult. . . . I still haven't gotten a complete grasp on it, but I'm getting better. . . . I'm going to have to figure this out anyway.

Other roles in the family members' lives also expanded, such as the mother, grandmother, and sister roles for Anne. She became aware of the significance these roles would assume following her mother's death. She would become the "grown-up" and accept the responsibility of helping her family address problems. However, Anne wanted to be viewed as a different person, not the family matriarch as her mother had been.

> I'm not my mother. I don't have the same personality. So if anybody expects me to become my mother and take over all these things, they're gonna get a surprise. . . . That's not me. . . . We're different people. . . . [That's] a concern of mine . . . I'll be the . . . matriarch. . . . I don't think I'm ready to grow up that much yet.

Losing Roles

Family members prepared themselves for the eventual loss of current roles, which shrank over time, and the loss of roles following the inevitable death. Fred discussed the loss of spousal activities such as spending time with his wife and making spontaneous plans for the day. Anne discussed coming to terms with the realization that her daughter role would cease to exist when her mother died, as both her and her husband's parents would be gone. Emma experienced changes to her life since adopting the caregiver role:

> I've worked and I've been a mother . . . [and] had the freedom to still be the kid. . . . It was never taken away from me. . . . How do you play the grown-up? It's not an easy role. . . . [It's] a different perspective . . . [figuring] out how everything gets done.

Health Experiences

Family members' health experiences were central to their overall care provision experience and were concurrently managed along with the enactment of roles, informed by the provision of home-based palliative care. Tension occurred as they attempted to maintain personal health while minimizing their health needs. This dialectic relationship occurred particularly when family members prioritized the caregiver role.

Minimizing Health

A predominant theme for family members was minimizing their personal health simultaneously and needs as they attempted to make their personal needs invisible to those around them. When speaking with friends, Alice stated, "By the time they get around to asking me how I am, I'm just fine." The family members worked hard to be the "best" caregiver, privately and publicly, with no time to think of their own needs.

> [My stresses and concerns] are not important. They are important, but they are not the main priority . . . Bill is. . . . I keep focused on that . . . that's what I have to do. . . . I'm no good to him if I fall apart or I get sick or anything else. (Emma)

Family members voiced the belief that other people experienced worse situations, and ignored their emotions "that tend to get in the way" (Anne). Awareness of personal feelings and needs was shared, but their own health was deemed less important because caregiving occupied most of their time. For example, Fred said he would change his regular doctor's appointment if someone was unable to stay with his wife. It was apparent the family members' time and efforts were directed towards providing care and minimizing personal physical and emotional needs. Minimizing health needs can also be considered a strategy used by family members while putting their lives on hold.

Maintaining Health

At the same time, the family members valued maintaining personal health, but this was of greater importance for participants providing care in both the home and workplace. Alice stated,

> I'm thinking and wondering . . . what effect it's having on my physical as well as emotional self and just trying to keep it balanced and not let it get me down.

Alice experienced physical benefits such as decreased fatigue, and emotional benefits from making the decision to address her health by increasing her exercise. Anne was told by her doctor to provide less physical care because of her own health concerns, but she was willing to provide more care for her mother if required. Family members realized it was important to maintain their personal health as they continued to prioritize the caregiving role. Thus, maintaining health was informed by their pre-existing health, current coping abilities, and personal health values and beliefs.

Health Responses

Health responses were situated within the dialectic of minimizing health and maintaining health while providing home-based palliative care. Feelings such as powerlessness, uncertainty, isolation, strain, and fulfillment were experienced by the family members.

Powerlessness

Powerlessness was experienced frequently because family members were expected to assume the caregiver role, as there was very little choice to provide care. Family members in this study felt powerless in their caregiving activities and because some of their expectations of the home care system were unmet. When they experienced constraints within the home care system they were unsure with whom to share their anger and frustration. This was demonstrated by Fred, who felt that his expectations of the nurse and home care services were unmet when nursing or doctor's visits were not made to the home. Fred was concerned that his wife's care would suffer if he did not "hold his tongue" about his displeasure, and believed his concerns would not result in change to the system.

> It helps a . . . bit [to talk about it] but . . . [the problem is] still there . . . [and I] want to do something about it. It's just finding the right avenue or the right road to take.. . . In the back of your mind you're saying . . . nothing is going to happen anyway.

Uncertainty

Uncertainty was experienced as participants were unable to make plans. Coping with the inability to predict disease progression, and the effects on their relatives and themselves were identified concerns. Anne stated,

> We have no idea . . . how she's going to progress, or digress . . . because she's . . . not going to get any better.. . . It may . . . stand still for awhile, but that's the uncertainty.

Uncertainty was also experienced by the family members in the caregiving role, as they felt unsure if they were providing the "best" care. Concerns included proper management of physical symptoms and feeling they were "missing something". Fred stated, "There's nobody there to tell me whether I'm doing a good job or not."

Isolation

Isolation from family, friends, and other sources of support was experienced, as most participants felt "overlooked". Little support was perceived to be available as friends would inquire about their relative before asking about the family member. Some family members felt alone because they had limited contact with friends. Alice found it tiring to entertain along with her other responsibilities, such as caregiving. Emma also experienced decreased interaction with friends.

> I'm not getting any calls . . . [to] go to lunch . . . [or] do you need a break? . . . I know you're not supposed to feel like you should.. . . But once in awhile it hits me.. . . I'm just feeling down and depressed . . . because I have never . . . expected anything from anybody if I do [things] for them, but a phone call would have been nice.

Strain

Some family members reported feeling overwhelmed with many stressors or strains that included watching their relative's health decline and completing tasks at home. New physical and emotional health experiences were highlighted such as fatigue, insomnia, increased blood pressure, and depression. Alice said she often felt too tired to leave the house during her time off from work, and described a physical and mental struggle.

Community services and resources were not readily accessible to all participants. Hospice programs were offered during daytime weekday hours, conflicting with Alice's work schedule. She needed to switch with a co-worker in order to attend; however, she realized there would be benefits from making use of the available services.

> I would prefer not to be working . . . at all . . . for the time being. I think that would probably afford me the opportunity to maybe take advantage . . . of the programs offered.. . . It would be less stressful.. . . Right now it's just work, and work. (Alice)

Loss of income, leading to financial difficulty, was a prominent concern, compounding the strain. Alice felt unable to ask for time off to attend available hospice programs because of loss of income. One family had suffered the loss of two incomes from the individual with cancer and the spouse after the diagnosis. Although the physician encouraged nursing home placement for Fred's wife, financial feasibility was a concern.

Prior health conditions also challenged family members and affected their everyday living. Alice experienced a flare-up of a previous back condition, altering her ability to work and participate in daily exercise that she had found beneficial. Fred experienced increased sleep disruptions during this time as well. Although Anne was told by her doctor to provide less physical care for her mother to protect her own health, she was willing to provide more care for her mother if needed.

Fulfilment

Although study findings portrayed a negative experience for the family members who provided end-of-life care, all participants found that this experience improved their relationship with their relative. Fred explained,

> I love her more each day.... [Our] relationship's basically the same, maybe deeper.... She waits for me to come [visit in hospital] and I can't wait to get there. I like to spend as much time as possible there.... I find it hard to concentrate on anything else ... away from there.

Previously challenging relationships evolved into closer relationships during this experience. Family members described a ''better understanding'' of one another, sharing feelings, and growing closer, resulting in an improved relationship.

Receiving social support from close friends and other family members was appreciated and contributed to feelings of fulfilment. Positive relationships were formed by some with the visiting nurse, who provided emotional and physical support for them and their relative, and was considered a friend. The presence of these fulfilling, supportive relationships assisted the family members in offsetting the demands of assuming multiple roles in home-based end-of-life care.

Implications for Practice

The findings of this research afford several insights. First, they demonstrate that the day-to-day experiences of family members simultaneously providing home-based palliative care for an older adult is a complex, dynamic process of enacting multiple roles. Within this process, the family members experienced balancing, re-prioritization, and evolution of their roles. Consistent with the findings of others (Guberman & Maheu, 1999; Wuest, 2001), all participants struggled to maintain balance between the social roles in their lives while continuing to provide end-of-life care. Nurses and other health-care professionals involved in home care can assist family members in balancing their roles by identifying the multiple roles family members occupy and informing the family member of available resources and supports. The family member in partnership with the nurse can then decide which resources are relevant. The appropriateness of downloading care to the family member should also be questioned, as some individuals may have numerous roles that would limit their ability to provide care. Moreover, family members who were also paid caregivers experienced a blurring of boundaries between their personal and professional roles. This finding, supported by others (Gattuso & Bevan, 2000; Ward-Griffin, 2004; Ward-Griffin et al., 2005), suggests that nurses should also consider the employment of the family member in order to meet the needs of all involved and not simply reinforce the caregiver role.

While attempting to balance their roles, the participants also experienced re-prioritization of their roles, predominantly the increasing prominence of the caregiver role. They felt there was little choice in prioritizing the caregiver role, and that finding was supported by the literature (Guberman et al., 1992; Stajduhar, 2003; Stajduhar & Davies, 2005). As the caregiver role became more prominent, the individuals participated less in personal activities and ignored their own needs. Similar findings of interruption to usual activities have also been found (Brazil et al., 2003; Cameron et al., 2002; Denham, 1999; Payne et al., 1999).

In addition, roles evolved as some roles ''shrank'' while others ''expanded'' for family members. Continuous change occurred within the caregiver role, which appeared to be closely related to the health of the older adult with cancer. The participants also experienced the gradual loss of certain roles, such as the spousal or child role, as their experience of providing care continued, similar to findings by Stajduhar (2003). The changing nature of family members' roles suggests that they should have the right to modify their involvement in care (CCC-CCAN, 2005) as their needs and roles change.

In addition, the findings indicate there are numerous expectations of the family members, but there is little appreciation of the family members' expectations of home-care services. Differing expectations of care from the perspective of home-care service-providers and recipients of care have been found in the literature (Woodward, Abelson, Tedford, & Hutchison, 2004). Understanding and addressing the mutual expectations placed on the family member and the expectations the family member holds are vital for all involved in providing end-of-life care to older adults. The family members in this study had unmet expectations, resulting in feelings of anger and frustration. Participants expected the nurse to be on time, to be treated fairly, and to receive services in a timely manner, along with a desire for consistency of care providers, as found in prior research (Woodward et al.). Services failed to meet their needs, including miscommunication between family and nurse, and a lack of continuity with health care professionals. However, investigations have shown that family members providing home-based care valued continuity with care providers (Ross et al., 2001; Ward-Griffin & McKeever, 2000; Woodward et al.), and felt overwhelmed when interacting with many health care professionals (Ross et al.).

Home care policies and procedures should ensure that communication is maintained among the family, nurse, and case manager, and continuity in care-providers is optimized. Expectations of the client and family member should be discussed during the assessment and subsequent visits (CCC-CCAN, 2005). Arranging appointments in advance is one strategy that would prevent families and clients from waiting and worrying about missed appointments. The demands family members encounter may be different as the client's care needs and illness change over time, and should be assessed at regular intervals (Glajchen, 2004). In the current study, the caregiver role was new for many of the participants and they felt uncertain about their abilities as caregiver at times. Family members have reported benefits from receiving preparatory information relating to care provision (Hudson, Aranda, & Hayman-White, 2005). Consequently, health care professionals can support family members by providing information and positive feedback about their ability and skills in providing care, without unduly adding to their responsibilities.

As well, study findings demonstrate the health outcomes relating to the enactment of multiple roles. Although the family members felt dissatisfied and let down by the system and nursing services at times, they also experienced fulfilment in their lives from their relationships with their relatives, family, friends, and nurses. Developing a close bond with a nurse and having supportive family were considered assets and helped to offset the negative aspects of providing home-based palliative care for the family members. These relationships provided them with the support and energy to continue in the caregiver role. Previous research has also demonstrated the beneficial effects of supportive relationships (Dautzenberg et al., 1999; Stoller & Pugliesi, 1989), and positive outcomes from providing home-based palliative care (Cohen et al., 2006; Grbich et al., 2001; Stajduhar, 2003). Therefore it is necessary to highlight the benefits of positive relationships and the availability of support from various sources in home-based palliative care, which will carry family members through this experience. The study found that the overall experience of providing home-based palliative care tends to be negative for many family members. Nurses and other health-care professionals should be prepared to assist the family and alleviate some of these undesirable experiences. Therefore recognizing the importance of family relationships, encouraging this form of support, and altering their practice accordingly is vital for health care professionals working in home-based settings providing palliative care.

Finally, study findings suggest that "true" family-centred care is currently not a normative practice in home-based palliative care, although there are standards and guidelines that encourages this form of practice (CHNAC, 2003; RNAO, 2002, 2006). Participants valued the nurses' abilities to manage medical aspects of their relative's illness; however, family members rarely considered the nurse to be in a position to address needs other than those of their dying relative. Health care professionals need to ensure that their actions and intentions are communicated accurately to the family. Family-centred care that considers family members as part of the focus of care rather than just the caregiver should be made available, especially when family members are expected to provide the majority of care in the home. This type of care may be a challenge for health care professionals and require changes in their daily practice. The Best Practice Guideline "Supporting and Strengthening Families through Expected and Unexpected Life Events" (RNAO, 2002, 2006) provides specific strategies to provide "true" family-centred care. It is necessary to ensure that there are supports to make this goal feasible. Individual, community, and societal perspectives surrounding care approaches and issues at the end of life should be clarified (Ross et al., 2002). In addition, it is necessary to lobby all levels of government and policy makers on the development and implementation of strategies and policies to assist and protect those who provide care in the home, such as the "Framework for a Canadian Caregiving Strategy" put forward by the Canadian Coalition on Caregivers (CCC-CCAN, 2005). For instance, initiating flexible work arrangements (Ward-Griffin, 2004) and supportive work environments (Ward-Griffin et al., 2005) for family members providing care can assist those who are also employed. Therefore it is necessary for nurses and other home care service providers to promote family-centred care and advocate for the changes and modifications to public policy that reflect the needs of families at the end of life.

Similar to other studies (Richardson, 2002; Ward-Griffin & Marshall, 2003; Ward-Griffin & McKeever, 2000), multiple expectations of the family members to provide care were found in this secondary analysis. The participants felt they had little choice but to assume the caregiver role for their dying family member. Important questions must be asked of the health care system and of the expectations placed on family members. Home may not be the best location for some who are dying and for their families. Some individuals may be willing and ready to accept the caregiver role when provided with the necessary knowledge, tools, and support, but others may not. Assessing the appropriateness of the home as the location of care for a family unit, and ensuring that family members understand the benefits and burdens of providing care (Stajduhar & Davies, 2005) is necessary before initiating home care services for a client and the family at the end of life. For example, one daughter providing care for her mother and in the workplace attempted to maintain separation between these two roles in her life, similar to findings by Gattuso and Bevan (2000). Therefore, the care expectations of the entire family need to be identified and supported by health care professionals involved in their care.

Implications for Further Research

Although this secondary analysis has provided an interpretive perspective focusing on family members enacting multiple roles while providing home-based palliative care, further research is needed to address some of the limitations. Participants who previously had a positive relationship may have been more likely to volunteer for the original study. This may have influenced the findings surrounding fulfilment and the quality of the relationship between the client, family member, and others. Interpersonal relationships in this study were found to influence the role enactment for family members, as participants shared close relationships with their dying relative and tended to prioritize the caregiver role. However, the data did not explain role enactment for those who did not share close interpersonal relationships. Therefore research should attempt to incorporate participants with differing interpersonal relationships to understand better their influence on the enactment of roles. The family members in this study were relatively young compared to their relative for whom they were providing care and were well-educated. In addition, two of the family members worked in health care, and that influenced their understanding of care provision at the end of life. These factors may also contribute to their experience of providing care and their potential access to available resources. Future research should include family members of all ages who are providing end-of-life care to examine similarities and differences in their experiences. Further research is also needed to examine the enactment of multiple roles in palliative care for older adults focusing on chronic illnesses other than cancer, as this experience may be different for those who have lived with chronic illness for many years. Research could examine the enactment of multiple roles for family members providing home-based care for individuals who are not at the end of life. These findings could then be compared with the current findings. The process of enacting multiple roles could also be examined from the perspectives of clients and nurses, as it is important to include the experiences of all individuals who occupy numerous social roles. The client's and nurse's perspectives of the family member's roles also merit attention, as it is necessary to determine their understanding of this process and the impact on their experience.

Investigations should also explore questions about the appropriateness of expecting family members to provide home-based palliative care. Do family members fully understand the extent of the commitment they are making and the ramifications of a death in the home? The duration of time during which family members provide care should also be addressed, as the effects on health may change during extended periods of caregiving. Therefore, there are numerous avenues for future research focusing on home-based palliative care, with the goal of promoting the health of clients and their family members at the end of life.

Conclusion

The findings of this interpretive secondary analysis revealed the experiences of family members providing home-based palliative care to seniors with advanced cancer, where family members enacted multiple roles. Multiple expectations to provide care and unmet expectations of the home care system shaped the family members' experiences. The enactment of roles for the participants occurred within that context, where the main themes were balancing roles, re-prioritizing roles, and evolving roles. Health experiences of the family members were located at the centre of their experience, illustrating how they attempted to minimize their health and simultaneously maintain it. The result was both positive and negative health responses. The family members' experiences were tension-laden as they attempted to contend with the conflict surrounding the numerous expectations they encountered, while simultaneously experiencing the enactment of roles and coping with their health experiences.

The findings revealed that family members struggled to enact their multiple roles along with that of caregiver. Supportive relationships with other family, friends, and the visiting nurse assisted family members during this time and contributed to feelings of fulfilment. Unmet expectations of care provision and challenges with home-care services resulted in frustration and anger. Home care professionals could further adopt the existing standards for practice to become truly family-centred, viewing both the individual with an illness and the family member as the client. Responsibility is with those in decision-making positions such as practitioners, administrators, educators, and policy makers to increase awareness on the provision of family-centred care, to implement appropriate changes, and ultimately optimize the health of all involved in end-of-life care.

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CCC-CCAN. See Canadian Caregiver Coalition.

CHNAC. See Community Health Nurses Association of Canada

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