Uncovering the Meaning of Home Care Using an Arts-Based and Qualitative Approach*

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RÉSUMÉ

Le besoin de soins à domicile s'accroît au Canada, mais on sait peu de l'expérience de soins à domicile de clients et de leurs familles. Découvrir le sens de l'expérience de soins à domicile est une étape importante vers le développement de la compréhension et la sensibilisation du public. Nous avons exploré les expériences de soins à domicile en utilisant des méthodes axées sur les arts et des entretiens individuels avec 11 participants (un client et 10 aidants naturels). Les participants ont débattu les nombreuses façons de soins à domicile et de la famille et comment ceux-ci ont affecté leur vie, comment ils ont fait face à ces effets, leurs expériences dans les hôpitaux ou les résidences-services, et les aspects de l'expérience de soins à domicile qu'ils aimaient ou n'aimaient pas. Les participants ont convenu que les soins à domicile ont facilité une meilleure qualité de vie pour les familles et les clients, bien qu'ils reconnaissent certains défis avec eux. Les résultats artistiques produites par les participants ont facilité le dialogue de l'entrevue et ont favorisé la compréhension des thèmes clés de la recherche par l'équipe.

ABSTRACT

The need for home care is increasing in Canada, yet little is known about the home care experience of clients and their families. Uncovering the meaning of the home care experience is an important step towards developing understanding and public awareness. We explored the experiences of home care using arts-based methods and individual interviews with 11 participants (one client and 10 family caregivers). Participants discussed the numerous ways formal home care and family caregiving affected their lives, how they coped with these effects, their experiences in hospitals or assisted living facilities, and aspects of the home care experience they liked or disliked. Participants agreed that home care facilitated a better quality of life for families and clients, although they acknowledged some challenges with it. The artistic outputs produced by participants facilitated interview dialogue and fostered understanding of key themes within the research team.

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Introduction

Home care includes an array of services encompassing maintenance, curative, end-of-life, and rehabilitative care; home support services and support for family caregivers; and health promotion and teaching provided to people in their own home (Canadian Home Care Association, 2013). Home care is increasing across Canada, as many clients – most of whom are older adults – choose to remain at home with support from family caregivers and home health care teams (Canadian Home Care Association, 2013). Canada has experienced large growth in its elderly population in recent decades (Special Senate Committee on Aging, 2009; World Health Organization, 2002), and as such, home care is becoming an essential health care service. Home care is a key strategy to reduce overall health system costs and meet client needs (Canadian Institute for Health Information, 2010; Fraser & Strang, 2004; Williams et al., 2009); however, the increased demand for services often exceeds the resources available for home care provision.

To identify gaps in home care service, there is a need for research into what the home care experience is like for families and clients. Although there is a growing body of research about home care in general, little is known about the experience of home care from the recipient's, or family caregiver's, perspectives. The very nature of home care, provided within intimate "home" spaces, makes that knowledge particularly difficult to uncover. Care received in the home is not as visible as care in other settings is (for example, in hospitals, long-term care facilities, and clinics). It is difficult to imagine what we do not experience, let alone that which we do not see. Research into the home care experience will help increase public awareness and help policy makers make better decisions regarding home care.

To date, home care research has focused heavily on issues around caregiver burden, privacy in the home, access and use of health care services, decisions to remain in the home, and elements that affect quality of home care service (such as relationships between home care nurses and clients, the nature of the home care process, and the impact of home care services on family dynamics and coping) (Cho, 2005; Cooper & Urquhart, 2005; Devlin & McIlfatrick, 2010; Gomes & Higginson, 2006; Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Magnusson, Severinsson, & Lützén, 2002; Piat, Ricard, Sabetti, & Beauvais, 2007; Santos Salas, 2006). Research focusing on the home care experience and its meaning for clients and families has primarily centred on elements of the palliative home care experience, such as the meaning of hope, quality of life, and the meaning of home itself (Benzin, Norberg, & Saveman, 2001; Bowden & Bliss, 2008; Melin-Johansson, Ödling, Axelsson, & Danielson, 2008; Williams, 2004). However, understanding the experience of palliation in home care is only one of many important components in understanding the broader home care experience. Understanding experiences from the perspective of clients and families beyond palliative care may include those living with dementia, auto-immune disorders, and multiple chronic conditions to name a few.

Various methodological approaches have been used previously to explore phenomena of relevance to the home care experience. Commonly employed methods include phenomenology, case study, and grounded theory. These have been used to explore the phenomena of caregiver burden, chronic illness, and quality of life (Fitzsimons et al., 2007; Genoud & Weller, 2008; Lau, Machizawa, & Doi, 2012; Liddy et al., 2008; Lin & Lu, 2005; Ornstein, Smith, & Boal, 2009; Rothera et al., 2008). Ethnographic methods have also been used (Fraser, Estabrooks, Allen, & Strang, 2010); however, arts-based approaches to investigate these phenomena and the experience of home care from the client and family perspective have thus far not been applied. Arts-based methods have the ability to allow clients and family members to share their experiences in ways other than the usual spoken word (Archibald, Scott, & Hartling, 2013; Fraser & al Sayah, 2011). Arts-based methods may allow clients and family members to express deeply troublesome, emotional, or profound experiences that are difficult to express in words (Fraser & al Sayah, 2011).

In this study, we attempted to uncover the meaning of providing and receiving home care from the perspectives of clients and families by means of a unique approach: a combination of artistic and traditional interview methods. The use of arts-based methods as knowledge production tools in health research is connected to the increased use of qualitative research to uncover meaning and content unattainable through quantitative work (Furman, 2006; Oliffe & Bottorff, 2007). Researchers (e.g., Bagnoli, 2009) believe that arts-based methods can access insights, experiences, and emotions about particular phenomena that more-traditional methods fail to accurately or comprehensively investigate. In this case, we wanted to apply the arts to help participants express aspects of their home care experiences that previously they may not have been able to verbally communicate. Accordingly, a group of participants also created artwork for this study that represented aspects of their home care experience, and helped us gain a deeper understanding of what home care meant to them when we reviewed the artwork with them.

Methods

We received ethical approval for this study from the health research ethics board from the institution where the principal investigator (PI) is employed.

All participants agreed to have their artwork published in whole or in part.

Participants

The initial inclusion criteria for study participants included being a client or family member of a client receiving home care and having a willingness to create a literary (e.g., poem or prose) or visual piece of art (e.g., painting, drawing, or fibre art). We used a convenience sample of nine women and two men recruited through home care programs, service provider agencies, and the PI's home care network using posters, letters, and emails. Participants ranged in age from 32 to 86; three were married; three, widowed; and five, single. All participants lived in urban Albertan communities. Six were adult children of a client receiving home care, three were clients' spouses, one was a client's sister, and one was a client. The spouses and three adult children lived with a client receiving home care, and the two remaining daughters lived near a client and visited the home regularly to provide care (one of whom had initially lived with her parents when her mother had a stroke and required home care). Two of the spouses in this study were caring for the same client (father/father-in-law), and two participants were sisters caring for their elderly mother, one of whom lived with their mother.

The clients had a wide variety of chronic and palliative conditions, and many had multiple health problems; six of the clients were frail older adults with chronic medical conditions. All interviewees described their family member's ability to complete daily activities as either "fair" or "poor". All clients required regular and ongoing help with the completion of basic activities of daily living (ADL) such as dressing, bathing, and ambulation. All clients also required assistance with their instrumental activities of daily living (IADL) (for example, banking, preparing meals, managing medication, and shopping). One client in the study was self-directive in her care, but required significant hands-on care and assistance for ADLs and IADLs.

Data Collection

We used in-depth interviews and artwork to collect data. We asked participants to identify their artistic medium of choice when they agreed to participate, and they completed the artwork before the interview. In the interviews, we explored participants' home care experiences and discussed their artwork, its meaning, and why they created what they did. Generating artwork became somewhat of a barrier to recruitment as participants wanted to share their story but were reluctant to produce art. Consequently, and following revised ethics approval, we broadened the inclusion criteria and accepted participants for interviews only. We recognized this as appropriate because these participants were willing to share their experiences of home care through interviews but were not comfortable with alternative forms of data collection, such as using arts-based approaches. In total, six participants created seven pieces of artwork in addition to participating in an interview.

On hearing about the study, participants contacted the PI. Once deemed eligible, the participant confirmed the artwork they would create within the next two to three months. The PI agreed to follow up and schedule an interview in three months' time if there had been no other contact with the participant. We conducted interviews either in the participant's home or in a small, private meeting room near the PI's office. Interview length ranged from 45–75 minutes with an average length of 60 minutes. All interviews were audiotaped and transcribed verbatim. The interviews focused on the experience of receiving home care, which also included the experience of providing home care within the family unit. For those who created artwork, the latter part of the interview focused on the production of the artwork and how it represented home care from the participants' perspectives. The full data set included 11 interviews and seven pieces of participant-generated art (one participant created two art pieces): a wall quilt, a drawing, a story, three poems, and one short story.

Data Analysis

Interpretive description (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004) guided our approach to uncover the shared meaning of home care from the perspectives of study participants. We transcribed the interviews and transferred them to QSR International's NVivo software for data management. Because NVivo also supports photos and documents, we photographed all visual artwork and scanned literary (poetry or prose) artwork, then transferred these to NVivo. Analysis began after the first three interviews and took place iteratively with data collection throughout the study. We initially reviewed the interview text and artwork several times to gain a sense of the text as a whole (Sandelowski, 1995). We looked for patterns in the data before coding or conceptualizing themes from both the interview transcripts and the visual or textual art. We engaged in a rigorous dialectic process which involved developing theoretical concepts, examining text and artwork, and exploring emerging patterns. We treated all interview data as well as visual and textual artwork as the dataset. We performed data collection and analyses until we were not hearing anything new from study participants. Consistent with the logic of interpretive description and on the basis of an understanding that, theoretically, an infinite variation of participant experiences is possible, we resist claiming that theoretical saturation has been reached in this study.

Findings

Study participants shared their experiences of negotiating the health care system and adjusting to changes in their loved one's health status, changing family situations, and the impact of receiving home care on their lives. Participants' experiences of receiving formal home care were intimately linked to their experiences of illness and debilitation, and the associated impact that illness and debilitation had on their lives. In this way, each theme uncovered through this study told the interconnected story of negotiating illness and receiving home care.

We identified six predominant themes throughout participants' stories and artwork: (a) the effects of caregiving, (b) coping with caregiving, (c) accessing home care services, (d) working the system, (e) formal caregiver qualities and relationships, and (f) living with home care. Each theme consisted of sub-themes as noted in Table 1. These themes included both the family caregivers' experience of caregiving as well as the effect that formal home care services (for instance, nurses and caregivers who visit the home) had on participants' lives.

Table 1: Themes and sub-themes

Theme 1: The effects of caregiving
Sub-theme: Physical effects of caregiving
Sub-theme: Emotional effects of caregiving
Sub-theme: Social effects of caregiving
Sub-theme: Financial effects of caregiving

Theme 2: Coping with caregiving
Sub-theme: Mitigating effects
Sub-theme: Attitude and activities
Sub-theme: Coming to acceptance
Sub-theme: Creative problem solving
Sub-theme: Continuing their pattern of living

Theme 3: Accessing home care services
Sub-theme: Uncovering information—no easy task
Sub-theme: Arranging services and equipment

Theme 4: Working the system
Sub-theme: A caring – but limited – health care system
Sub-theme: The need for advocacy

Theme 5: Formal caregiver qualities and relationships
Sub-theme: Capability
Sub-theme: Consistency
Sub-theme: Reliability
Sub-theme: Compassion
Sub-theme: Personality fit

Theme 6: Living with home care

Effects of Caregiving

Caregiving affected many aspects of participants' daily lives. Many participants commented on how far-ranging and in-depth this impact was, but they were committed to making home care work. Caregiving effects were physical, emotional, social, and financial.

Physical Effects of Caregiving. The effects of caregiving took their toll on the physical well-being of study participants. Family caregivers frequently talked of losing sleep and the resulting exhaustion, which was more pronounced if caring for someone who required assistance during the night. Caregivers sometimes maneuvered equipment or transported immobile clients, which could be physically demanding or even dangerous. If caregivers had a disability or illness themselves, they felt these physical strains even more. In fact, the exhaustion experienced as a caregiver could be so extreme that one participant said their loved one's hospitalization might be the only option for a much-needed respite period. This theme is captured in the following caregiver quote:

> *"But I will admit that there was a point that the last New Year's Day, I woke up and I thought to myself, 'Oh here we go, year three of an indefinite sentence.'"*

Emotional Effects of Caregiving. Study participants gave up much of their own free time to take care of their loved ones. This often came at the expense of time spent with their families and was often very stressful. Family caregivers took on any number of roles, such as chauffeur, cook, nurse, accountant, gardener, maid, and advocate in both the legal and health care systems. They also spent a great deal of time researching their loved one's health problems so they could give appropriate care. Some caregivers even gave up their formal paid jobs or moved in with their loved one to create more caregiving time. Many participants mentioned that the amount of time dedicated to caregiving sometimes became too intense, and many approached the point where they could not handle it anymore. As two caregivers stated:

> *"The impact is far more so than just the preparation of meals, looking after laundry, and that kind of thing. It affects absolutely everything about your day-to-day procedures."*
>
> *"I don't think it's reasonable to expect somebody to be on call, giving full-time care 24 hours a day for six days a week, and 20 hours [laughs] a day for the rest of it. And that's what it was. "*

This was further illustrated in a drawing one participant made of a heart with a hand in the centre. For this participant, the heart-and-hand imagery represented two interrelated and essential components of caregiving: the hands, which are needed for providing physical care, and the heart, which captures the love and connection seen as essential to caregiving work. In another piece, a caregiver created a wall quilt of a yin/yang symbol. One side was represented with beautifully sewn, even stitches with bright colors. The caregiver said that was how she presented to the world. One rarely saw the opposing side which was represented with haphazard, uneven, dark colors. She said that was how she felt on the inside – an emotional wreck, everything in turmoil. Some days it was all she could do to "keep it together" on the inside so she could deal with the situation.

Clients and caregivers had to adjust to new people coming in to provide care through the home care program; this circumstance intruded on their privacy and limited their freedom. Many participants acknowledged some anxiety, sadness, and resentment at having strangers (home care personnel) come into their home to provide a client with what is sometimes very intimate care. One client indicated that she felt a great deal of anxiety when a new person came to the house because she did not know if they would be capable of taking care of her. Family caregivers found it difficult to watch home care personnel come in and invade their loved one's privacy. Some paralleled accepting home care with accepting their loved one's loss of independence, which they said was depressing. Some participants found ways to mitigate these problems; we will discuss these under the "coping with caregiving" theme. Participants' experiences of this intrusion are captured in the following caregiver quotes:

> *"[Formal home care] was an intrusion to my life really. It was a very great help, but I tell you very honestly, I was not looking forward to the person ringing the doorbell in the morning and sort of intruding into our lives."*
>
> *"I would submit that if you asked anybody who'd been doing it for more than six months, what do they miss more than anything else? Freedom and privacy."*

Caregivers expressed the view that witnessing their loved one's health deteriorate was emotionally difficult. One participant said she felt bitter and angry at the world that her mother had had a stroke at a young age; she felt that was not fair and should not have happened. Participants caring for a parent often mentioned that they found the resulting role reversals quite sad. An excerpt from a caregiver's poem describes this new relationship and the emotion accompanying it:

> "Now I lead her and her guide dog
> down the avenue and onto buses,
> read her mail aloud as she once intoned
> storybooks at bedtime.
> …
> Stubborn, she holds her credentials
> as life-giver high, even as I dish out her food,
> and I listen, good girl again, as I guide her feet
> into her shoes and spell out conversation
> on the palm of her hand,
> tears burning behind my eyes
> which see for the two of us
> on this sunset-flooded journey."

Dealing with their loved one's attitudes and mental states also had an emotional impact on caregivers. Clients were often depressed about their situation, and sometimes resisted formal care either in whole or in part. This increased pressure on family caregivers because they had to persuade their loved one to accept outside care or feel an increased burden to provide that care themselves. Depression among loved ones also depressed or frustrated their family caregivers.

Although study participants experienced some emotional lows during their caregiving, they also experienced some emotional highs. Participants described spending time with their loved one during their loved one's final years in a positive way, and were often proud that they were able to care for them in such a significant way. One caregiver said her siblings were sometimes jealous of her caregiving duties, because she got to spend more time with her mother and would have more memories of her than did the siblings. Another reflected on the humour she shared with her husband, and described – with much emotion – the love they felt for one another ("*And at night … he always says how much he loves me*").

In creating a wall quilt, one participant said she was able to express the loss she was experiencing as her life partner *"was being taken from me and the overwhelming sadness of watching his decline"*. In the accompanying interview, she reflected on creating the piece as a journey. Through the interview she shared how she did not set out to create the specific piece, but as it came together she told us that she knew it was enabling her to express her profound feelings – something she may not otherwise have been able to do.

Social Effects of Caregiving. Clients and family caregivers became more restricted in where they could go, resulting in a loss of social life for both. Some clients were so restricted that their family caregivers were the only people they saw on a daily basis. Some caregivers' outings were restricted to the grocery store or work. In these cases particularly, visits and phone calls from friends, family, and neighbours supported their spirits and kept them in touch with the outside world. However, sometimes these "informal support groups" frustrated, rather than supported, the caregivers. For instance, one caregiver complained about friends who repeatedly reminded her to take care of herself, yet never offered any help. This was captured in the following caregiver quotes:

> *"Take care of yourself," she said sternly. I knew what was coming as I have heard it so often: "Because, if something happens to you, what will happen to [your husband]?"*
>
> *"She turned and went on her way, thinking she had done her good deed for the day. It's funny how the people who lecture the caregiver about taking care of self are the least likely to offer assistance."* (excerpt from literary art)

There are different social boundaries between family caregivers and their loved ones than there are between formal caregivers and their clients. Clients were more likely to push relational boundaries when relationships were very close, such as parent-child or husband-wife relationships. One caregiver said her husband would complain more with her than he would ever do with a formal caregiver. Another indicated that her infirm mother would barrage her at the door with questions about her day, but she needed to decompress from work first before responding.

Financial Effects of Caregiving. Participants did not talk about the financial effects of caregiving often, but the subject did come up. Some caregivers spoke of relocating or renovating their loved one's home to provide safer care for them, and reflected on their satisfaction in being financially able to do this. However, there were also those who assumed they could not afford more-formal home care or did not want to pay for it, and so resisted getting it. One participant reflected on her parking costs and how she would appreciate some financial assistance for the additional doctor's appointments and hospital visits she made. Many participants made resentful comments about family caregivers not getting paid anything, despite all they did.

Coping with Caregiving

Caregivers coped with caregiving and the disruption that home care brought into their lives in various ways. This included strategies to mitigate caregiving and maintain balance in their lives, foster a good attitude, take physical breaks, and keep up personal interests and activities.

Mitigating Effects. At times, caregivers found ways to mitigate the stressors of caregiving. Many of these strategies can be thought of as ways to balance the caregiver's need for independence and individuality against the demands of being a caregiver. For example, participants tried to balance the time they dedicated to caregiving and the time they needed for themselves. One way they accomplished this was to set specific boundaries between their loved ones and themselves. Learning to say "no" to some of their loved one's requests was essential to maintaining some personal space. Spousal caregiver/client dyads found the need to carve out distinctions between husband-and-wife relationship time and caregiver–care receiver time. One participant who needed a few minutes after work to herself had to verbally request this of her loved one, and through this encounter recalled learning "the art of negotiating". As well, all of the participants appreciated the time away from caregiving that friends, other family members, and formal home care provided. Some caregivers had formal home care come at night, so they could sleep without interruption. Many mentioned that, without formal home care and their "informal support groups", they would have become burned out.

Attitude and Activities. Participating caregivers spoke of needing a positive attitude to help them cope with their loved one's depression, and told us how they accomplished this. One caregiver got a family dog, resulting in much tension release and better bonding between caregiver and client. She also found small escapes in knitting, sewing, shopping, playing piano, and journaling, which helped her stay positive. Another participant spoke of the emotional release she felt in quilting. Her relationship with her husband (the care recipient) was suffering under the strain of illness and his unwillingness to discuss it, so she found creative outlets a relief.

Coming to Acceptance. Witnessing a loved one's health deteriorate was sad for all participants; however, accepting their loved one's conditions as permanent provided peace of mind for some participants. One participant's poetry captured the gradual process of accepting health deterioration, through powerful imagery of a tearful and "sunset-flooded journey". This imagery functioned as a catalyst during the interview process, opening up space for discussing the emotional components of acceptance. Acceptance also made participants more willing to accept outside help, which eased their caregiving burdens. As one caregiver expressed it:

> *"And I think we've also learnt too that … [the client's health status] isn't gonna change and we just have to accept it. I think a lot of times at the beginning you know … this shouldn't have happened and mom's gonna get better … whereas now we've kinda learnt that, that we have to accept it."*

Creative Problem Solving. Participants often talked about being problem solvers, and that it was important for them to take on one problem at a time to avoid getting overwhelmed. They tried not to worry about what could happen tomorrow or how they would solve problems that had not yet occurred. One caregiver tried not to worry about things she could not control, such as her loved one's choices, or what might happen while she was out. Creativity also helped with problem solving. One caregiver found unique ways to puree food so it retained its flavour. Another created an IV stand using coat hangers and other household items. One caregiver expressed this as a pragmatic and necessary approach:

> *"You just have to – you see a problem and you solve that problem, you move on to the next problem and you solve that problem."*

Continuing Their Pattern of Living. Caregivers took pains to try to keep life much like it was before home care began. They ensured that their loved one kept up as many enjoyable habits as possible, and tried to take care of themselves, too. One caregiver said her client told her, "*Let me do as much as I can, 'til I can't.*" Another client enjoyed cooking for people, and although she required help with it, her daughter let her do as much of it as possible, which kept both their spirits up. Family caregivers also tried to make formal home care visits less intrusive to their loved one's privacy and freedom, which helped caregivers deal with their own emotional difficulty in witnessing the loss of these. Caregivers performed some of the more intimate caregiving duties (like bathing), so home care personnel would not have to. One caregiver kept her mother's medication in the living room, so home care would not have to enter the bathroom (a private space).

Despite all these strategies, coping with the stress of caregiving was not easy. When describing her artwork to us, one caregiving participant made the following remarks, illustrating the difficulty she had in achieving balance:

> *"That this yin-yang, that used to be a whole, is coming apart … one half is me and one half is my husband. One half is me and how it's staying in control to get through this situation with my husband, and the other half is me internally falling apart because you always – I keep it together on the outside, but inside it falls apart."*

In another excerpt from poetry, a caregiver called herself "stretched," and wrote, "*Zen – wanting this, quiet, calm, can this ever happen – who can help balance*." Many participants echoed this sentiment. One caregiver likened herself to a balancing scale: her needs on one side and her caregiving demands on the other. Participants worked hard to make sure that scale did not tip.

Accessing Home Care Services

Once accessed, many participants stated that home care services were fantastic. Notably however, participants said that finding information about home care in the beginning felt unnecessarily – even intentionally – difficult. We will discuss these difficulties more under the subthemes of "arranging services and equipment" and "uncovering information" respectively.

Uncovering Information: No Easy Task. Many participants said that their case managers were often not very forthcoming with information on home care services. They thought it was by chance or accident when they found out about certain services. As one caregiver expressed it:

> *"In terms of the support they provide, incredible. But the thing is, they don't tell you what they can offer."*

For instance, one caregiver spoke of taking her terminally ill husband on painful cab rides to have lab work done, until one day a technician casually commented that at-home lab collection services were available. Another caregiver (whose husband was also terminally ill) found out too late that she could have had more-qualified home care personnel help her with his IV drip at night. No one had told her that she could have had a night nurse – who could manage an IV – instead of a health care aide. As a result, she missed out on a great deal of much-needed rest. Many other caregivers commented about being so in the dark that they did not even know the right questions to ask to find out what services they could have.

Family caregivers employed many approaches to find out more about home care. For example, family caregivers researched home care extensively, joined caregiver support groups, read caregiver pamphlets and magazines they found in hospital waiting rooms, and reached out to knowledgeable friends and family in the health field. There was overall agreement throughout the interviews that health care workers, and in particular, home care workers, should proactively give caregivers and clients information on what services are available.

Arranging Services and Equipment. Once they knew how to get in touch with home care services and ask the right questions, most participants agreed that the services they received were great. Some caregivers indicated that they had excellent case managers who quickly put the right services in place. One caregiver in particular raved about his case manager who gave him information on how to access government-funded equipment for his paralyzed wife.

Ironically, however, participants felt that sometimes the same home care personnel who should have been easing their burdens also became the roadblocks to service. For instance, one caregiver spoke of her case manager's reluctance to provide a hospital bed for her bedridden, terminally ill husband. She felt she had to continually pester her case manager to get her husband proper care and equipment, which she believed was completely opposite to how home care should work. Participants also had some problems with inconsistent, unreliable, and uncaring home care personnel, which we discuss in the "formal caregiver qualities and relationships" theme.

Working the System

This theme is related to the "Accessing home care services" theme, except it encompasses people's experiences with the health care system in general. In this theme, we explore participants' experiences in hospitals, assisted-living facilities, and other health care settings (excluding home care services). In the first sub-theme, entitled "a caring – but limited – health care system", we relate some of the study participants' experiences with this system. In the second sub-theme, entitled "the importance of advocacy", we discuss how participants dealt with and navigated their way through the health care system.

A Caring – but Limited – Health Care System. Participants mostly agreed that although the "system" itself had a number of caring individuals, there was a lack of resources available. Participants used many services across the health care system, because their care requirements were not solely met within the home care program. One participant voiced annoyance at the lack of equipment in emergency services, meaning they could not move his paralyzed wife to the right department. Other participants dealt with physicians on rotation who were unfamiliar with their loved one's background, sometimes resulting in the wrong medication being prescribed. A client indicated that she spent extra hours in the emergency department because hospital staff had not advised her on how to properly care for her tracheotomy at home. Even those participants with health care backgrounds found it difficult to obtain information on their loved one's health condition and needs. As one participant aptly stated:

> *"And also there needs to be more education, I think, because I did spend many hours in doctor's offices and in emergencies for things that we probably could have handled at home or with a home care person if I had been more aware."* (Client)

Other experiences with the system were more negative. One participant voiced her horror at the inattentive staff during a short stay at an assisted-living facility. She described her loved one as being stripped of dignity when the staff had neither the time nor the compassion to properly dress patients or clean their bed sheets in a timely manner.

The Need for Advocacy. Participants also talked of their success in finally leaving the "system" (referring to in-patient care in this context) and achieving their goal of caring at home. They agreed that advocating for their loved ones was necessary to accomplish this. They knew when their loved ones were not properly looked after, and made valiant efforts to correct this when it arose, often running into reticent health care workers. Participants researched their loved one's needs and talked to as many health care workers as possible for advice on how to leave the "system" and bring their loved one home. This was captured in an excerpt from one caregiver's literary art:

> *"I love you enough to research your condition and your medications and to pester the doctors and pharmacists for answers. Because I love you, I continue to seek answers that will improve your quality of life."*

Participants who were caregivers often expressed worry about people in the health care system who did not have a family caregiver or friend advocating for them. They wondered how many patients in facilities were not receiving proper care, because they had to rely solely on an over-burdened health care system. As one caregiver stated:

> *"So we learned how to operate in the medical system and God help anybody who's in there on their own because they're just at the mercy of a caring but not understanding administration."*

Formal Caregiver Qualities and Relationships

The theme of caregiver qualities and relationships to care recipients was expressed by one caregiver who stated, "*It takes a certain kind of person to be a caregiver …*". This theme captures the good and bad experiences that participants had with formal caregivers, and the qualities that affected these experiences. These qualities are reflected in the five sub-themes of capability, consistency, reliability, compassion, and personality fit.

Capability. If a formal caregiver demonstrated that they had the appropriate clinical knowledge to take care of a client's health needs, it eased participants' anxiety. Although a few participants spoke of formal caregivers who lacked the appropriate clinical skills for their situation, most were generally satisfied with their caregivers' skill level. However, they also noted that having clinical skills was a small part of what they needed, and that other personal qualities at times were more important.

Consistency. Participants voiced frustration at frequently having different caregivers sent to them. Every time a new caregiver came to the house, participants would have to familiarize them with their loved one's needs. As new caregivers were frequently encountered, participants also found it difficult to establish the necessary trust between caregiver and client.

The importance of trust was expressed by one caregiver when she said:

> *"Yes, we have a care aide come in for a short while on weekday mornings, but if it is someone new, [my husband] doesn't trust her enough to let her clean him up."*

Reliability. In addition to having constantly rotating home care staff, participants also had to deal with caregivers who did not show up at all. Formal caregivers were sometimes late, or could not gain access to the house, despite having instructions on how to do so. Alternatively, reliable caregivers made participants' days much easier to plan, and eased their anxiety. As one participant put it, "*For me, reliability is number one*."

Compassion. Even if a formal caregiver had the aforementioned qualities, if they did not display compassion, participants did not think they were effective caregivers. This combination was valued but uncommonly found. As one caregiver stated:

> *"Knowledgeable and compassionate … those people are very rare. You know?"*

Participants described compassionate caregivers as supportive, patient, kind, and understanding. They took the time to find out how their clients and their families were doing, what their health problems were, and asked them questions in a tactful and non-intrusive manner. Compassionate caregivers tried not to be too invasive when entering private spaces in the home, and demonstrated respect for their clients and their client's property. One client stated that if a caregiver smiled, made light conversation, and was friendly, it eased her anxiety a great deal. She wondered if conversational skills and compassion could be taught to caregivers. In contrast to this, however, were caregivers who burned food or did not bother to throw away disposable gloves after use. Participants believed that home care personnel were often over-booked and rushed through their jobs. Such behaviours made participants believe that these personnel were not really concerned about the loved ones for whom they were providing care.

Another study participant illustrated the difference compassion and consistency can make. She was irritated with the many different home care nurses or case managers who came to assess her terminally ill husband, and repeatedly asked the same questions on pain level and depression. She disliked their insistent use of the 1–10 scale to rate his pain and felt this approach was overly clinical, distancing, and unnecessary. This was especially so after they had witnessed a very experienced home care nurse come in and discern her husband's pain level through expert observation and communication. It was not the use of the pain rating scale that was upsetting; it was that the pain scale was the only method some nurses used, instead of engaging in a more holistic conversation.

Personality Fit. Participants valued caregivers with personalities that complemented that of their loved one. The qualities that made up this good "fit" were different for each client. One participant spoke of her happiness in finding a gentle, soft-spoken caregiver for her mother, who herself was gentle and soft-spoken. Another participant said her husband was very intellectual, and would not respect a caregiver who was not intellectual enough to converse with him in a manner he enjoyed. Other participants needed a caregiver with a forceful personality to properly care for their stubborn, elderly loved one.

One participating family had finally found a caregiver whose personality and compassion suited them well. The following excerpt from a study participant's poems brings to light the importance of finding a suitable formal caregiver:

> "Some caregivers would bring comfort,
> And provide much needed support,
> Some never hesitated to stay,
> Encouraging Mom to smile every day.
> Together we grew and we have learned to cope,
> Together we have strength and hope.
> A special and compassionate caregiver now to stay,
> Once again, Mom has a smile every day."
> (Caregiver, excerpt from poetry)

The overall personality of the clients also affected their willingness or reluctance to accept formal home care workers. Those who were natural socializers were more likely to welcome formal home care. One caregiver's loved one viewed the formal home care visits as opportunities to socialize, and saw the home care workers as her "little friends". More-withdrawn clients, however, avoided socializing. One caregiver's loved one was so private he would refuse most care until she got home to give it; this was his way of avoiding interaction with the formal caregiver.

Living with Home Care

In this theme, we discuss the general meaning of home care to clients and their families in the context of their lives. All participants agreed that home care services made their lives better, even though they acknowledged the challenges it brought. It was recognized that home care services allowed them to stay at home and maintain as high a quality of life as possible. For example:

> *"I sort of went from being very anxious about how I'm going to manage life with a trach to feeling much more comfortable and confident that life can carry on almost as it was, not quite, but closer to what it was."* (Client)

Participants agreed that home was the best place for them and their loved ones. Staying at home meant being surrounded by the comfort of home, fewer long waits in health clinics, and avoiding lonely hours in facility living. Although illness necessarily limited their independence and privacy, home care allowed them greater freedom than living in a facility would have. The importance of home was expressed by participants as:

> *"And for my husband, being at home was the best possible place for him to be. It was even better for me."* (Caregiver)
>
> *"[Home care] makes your life, the client's life, better and it's more flexible for them – certainly is, and it means the world as far as their own health situation goes."* (Client)

Study participants valued home care services so much that they often said it should have more funding and support, so services could be expanded and workers paid more. They also believed that there was not enough public awareness of what home care was and what services it offered. This was captured in the following quotes:

> *"There needs to be more caregivers with the pay that reflects what they do."* (Caregiver)
>
> *"It's better with home care. I think it could be better yet. Maybe if we had more home care."* (Caregiver)
>
> *"And I think there should be more funding and more awareness around the issue, and perhaps more supports in place, if possible for people."* (Caregiver)
>
> *"General public, I don't think has a real good concept of home care. I think they feel that home, whatever situation you're in, that you can call up home care and home care is going to be able to do everything."* (Client)

Discussion

Artwork and interviews conveyed a comprehensive and unique story about the home care experience. While the overarching themes of this study seemed to compete for prominence, it was clear to us that – at least from the participants' point of view – home care is about improving clients' quality of life and providing peace of mind for family caregivers. Nevertheless, the study revealed shortcomings in home care service that warrant improvement.

Home Care Services Are Appreciated and Helpful, but Family Caregivers Need More Support

All study participants were committed to making their home care experience a success. This was influenced by their self-reported negative experiences in hospitals or assisted-living facilities, and through their understanding that home care was the best option for them. However, caregiving is stressful, and strains family caregivers' physical and emotional health (Gottlieb & Wolfe, 2002; Papastavrou, Charalambous, Tsangari, & Karayiannis, 2012; Stajduhar, 2003). Formal home care provided a welcome relief to family caregivers, and eased some familial stress. Although the study participants acknowledged challenges associated with home care, they understood it was not home care that initially caused this turmoil, but rather the underlying illness or infirmity that brought about the need for it in the first place. They found some peace and happiness in knowing they were caring for their loved one in the best way possible, and acknowledged that formal home care services augmented their efforts.

Unfortunately, because of their negative experiences with the health care system, family caregivers may feel pressured into caring, before they are ready, for a client at home (Stajduhar, 2003). Compounding this problem is the lack of support family caregivers encounter when leaving a hospital or facility (Plank, Mazzoni, & Cavada, 2012). Many participants did not know how to access home care services, or even that home care existed. This resulted in family caregivers taking on extraordinary caregiving responsibilities (at least initially). Professionals in the health care system, whether in home care or part of the larger health system, are not always forthcoming with information. Although this may be unintentional, in our study this contributed to caregivers' impression that the "system" expected that as long as they *could* do the caregiving, then they *should* do it, whether or not they felt capable.

Not only do family caregivers need more information and home care support in the transition from hospital to home, but they also need further assistance in all stages of the caregiving experience (Cameron, Naglie, Silver, & Gignac, 2012). We agree with study participants that people working in health care, and in particular, home care, should proactively give caregivers and clients information on what services are available. Having to obtain this information independently adds an unnecessary burden to already over-burdened caregivers, and can reduce the quality of care clients receive.

When discussing the financial effects of caregiving, some study participants assumed they could not afford additional home care services. This illustrates the extant misinformation about home care, given there is no charge for government home care in the study's jurisdiction. However, there is merit to participants' frustrations that family caregivers do not receive financial support. In Canada, there is often a financial hardship when one takes on a caregiving role. Emanuel, Fairclough, Slutsman, and Emanuel (2000) and Jacobs, Dumont, Turcotte, and Anderson (2011) reported household income losses of more than 10 per cent, placing less affluent families in vulnerable positions. Participants expressed resentment when discussing the lack of financial support they received, and the perceived lack of awareness for all they do. Such concerns warrant further attention. Specifically, decision makers should investigate policy changes that could make a positive difference for clients and caregivers.

Finding a Healthy Balance is Essential to Making Home Care a Success

Home care depends on family caregivers. We found that in cases where caregivers were not able to achieve some balance in their lives and effectively cope with the burden of caregiving, it hampered their ability to make home care, as a care option, work in their lives. Many of the coping mechanisms and strategies that our study participants employed corroborate results evident from other studies on the caregiving experience and include trying to stay positive, having good support systems (through extended family or friends), developing problem-solving skills, setting boundaries, and accepting the client's condition (Gottlieb & Wolfe, 2002; Kneebone & Martin, 2003; Proot et al., 2003). As well, Cameron, Franche, Cheung, and Stewart (2002) reported that increased lifestyle disturbance leads to increased emotional distress for family caregivers. To ameliorate this, family caregivers in our study tried to keep life as much like it was before home care, and formal home care helped them achieve this. This was especially true of caregivers of clients who required round-the-clock caregiving or nightly support. Without nightly home care, family caregivers' sleep loss and exhaustion can exacerbate depression and health problems, and lower the quality of their relationship with the home care recipient (Hearson, McClement, McMillan, & Harlos, 2011).

Overall, participating caregivers learned to cultivate an immense appreciation for even small amounts of time spent on non-caregiving tasks. They appreciated the little things in life far more than before their caregiving days; they reveled in their morning coffee alone, or a few quiet minutes of reading or knitting. Even days at work were a relief from caregiving, and they greatly appreciated those who allowed them this respite (through formal home care and the assistance of friends and family).

The Importance of Healthy Relationships

Caregivers and clients need a "relationship free from conflicts" (Plank et al., 2012). All study participants cared deeply about their loved ones, but some participants' relationships suffered under the strain of caregiving and illness. Those who were more social and communicative had stronger relationships with each other (and with their informal support groups) than those who did not.

Establishing good relationships with formal caregivers, such as nurses and health care aides, is important as well (Byrne, Sims-Gould, Frazee, & Martin-Matthew, 2011). If a family caregiver or client did not trust the formal caregiver, it increased their anxiety during visits. Having trustworthy home care personnel gave participants a sense of safety and control. This was especially important for caregivers of clients requiring night-time aid, as they would otherwise be too worried to sleep during evening home care visits (Hearson et al., 2011). Trust was more easily accomplished with caregivers who were familiar to the family, reliable, compassionate, and whose personalities complemented the client's. However, families had little control over the specific nurse or health care aide who came to their home, and most participants had problems with a number of home care agents before finding someone they liked. Participants felt that having a new caregiver was like gambling: they never knew what combination of traits they would get, and just had to hope for the right ones. This problem could be ameliorated somewhat if home care personnel took more time to talk and build compassionate, respectful relations with clients and their families early on in the relationship.

More funding and system support for home care services would help improve the home care situation as well. Ideally, home care personnel should be consistent and not over-booked, as this contributes to being rushed and stressed on the job. It is unsettling that, at times, home care personnel were the roadblocks to helping family caregivers' access equipment or services. This should never be the case. Factors that inhibit access to services and equipment warrant further study in order to determine effective solutions. For example, participants recognized that care providers were often overworked and did not always respond quickly. This suggests that system-level issues, rather than individual caregiver behaviors, might be the root cause of access-related barriers.

Limitations

We used a convenience sample for this study. A purposive sample may have enabled us to consistently identify participants willing to produce artwork. This study sample contains mostly family caregivers rather than clients. Having more client participants would have further strengthened this study. As well, despite our attempts to encourage the production of artwork from study participants, only half ultimately decided to create art. Although we do not believe that this impacted the rigor of this study, more participant artwork may have contributed to the robustness of our findings.

Conclusions

We endeavored to uncover the meaning of home care from the perspective of family caregivers and clients, and used the creation of artwork to facilitate participants' expression of their experiences. Participants all valued home care and were grateful for its services. Although they acknowledged some inherent challenges with home care, participants believed it increased the quality of life of their loved ones as well as themselves. Our findings support the conclusion that home care decreases the burden on family caregivers, provides education and support on how to properly care for clients, and allows clients to remain in their own home longer.

Our findings illustrate that care at home is most often family-oriented and as a result, home care programs should be family-centred rather than specifically client-centred. Family caregivers, when present, are as embedded with the home care experience as the client. It was difficult for participants to discuss the meaning of home care apart from what it meant to care for someone at home; after all, when a paid caregiver leaves the home, caregiving responsibilities continue.

Current policies do not support the notion that home care is a family-centred care practice. Consequently, home care providers may find it difficult to provide care in a family-centred manner when policies reflect a view of the client as an individual and not a family unit. Understanding the meaning of home care from the family's perspective is therefore essential to promoting policy changes which reflect this family-oriented view of home care. Such policy changes will be increasingly necessary as home care is more frequently used as a strategy to meet the overall system demands to care for clients with increasing needs.

References

Archibald, M., Scott, S., & Hartling, L. (2013). Mapping the waters: A scoping review of the use of visual arts in pediatric populations with health conditions. *Arts and Health: An International Journal for Research, Policy and Practice*, *6*(1), 1–19. doi:10.1080/17533015.2012.759980.

Bagnoli, A. (2009). Beyond the standard interview: The use of graphic elicitation and arts-based methods. *Qualitative Research*, *9*(5), 547–570.

Benzin, E., Norberg, A., & Saveman, B. (2001). The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, *15*, 117–126.

Bowden, G., & Bliss, J. (2008). Does using a hospital bed have an impact on the meaning of home? *British Journal of Community Nursing*, *13*(12), 556–562.

Byrne, K., Sims-Gould, J., Frazee, K., & Martin-Matthews, A. (2011). "I'm satisfied, but …": Clients' and families' contingent responses about home care. *Home Health Care Services Quarterly*, *30*(4), 161–177.

Cameron, J. I., Franche, R. L., Cheung, A. M., & Stewart, D. E. (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer*, *94*(2), 521–527.

Cameron, J. I., Naglie, G., Silver, F. L., & Gignac, M. A. (2012). Stroke family caregivers' support needs change across the care continuum: A qualitative study using the timing it right framework. *Disability & Rehabilitation*, Early Online, 1–10.

Canadian Home Care Association. (2013). *Portraits of home care in Canada*. Retrieved 18 April 2013 from http://www.cdnhomecare.ca/content.php?sec=4.

Canadian Institute for Health Information. (2010). *Health care in Canada 2010: A decade in review*. Ottawa: Canadian Institute for Health Information.

Cho, S. (2005). Older people's willingness to use home care nursing services. *Journal of Advanced Nursing*, *51*(2), 166–173.

Cooper, J., & Urquhart, C. (2005). The information needs and information-seeking behaviours of home-care workers and clients receiving home care. *Health Information and Libraries Journal*, *22*, 107–116.

Devlin, M., & McIlfatrick, S. (2010). Providing palliative and end-of-life care in the community: The role of the home-care worker. *International Journal of Palliative Nursing*, *16*(4), 195–203.

Emanuel, E. J., Fairclough, D. L., Slutsman, J., & Emanuel, L. L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine*, *132*, 451–459.

Fitzsimons, D., Mullan, D., Wilson, J. S., Conway, B., Corcoran, B., Dempster, M., et al. (2007). The challenge of patients' unmet palliative care needs in the final stages of chronic illness. *Palliative Medicine*, *21*, 313–322.

Fraser, K. D., & al Sayah, F. (2011). Arts-based methods in health research: A systematic review of literature. *Arts & Health: An International Journal for Research, Policy and Practice*, *3*(2), 110–145. doi:10.1080/17533015.2011.561357.

Fraser, K. D., Estabrooks, C. A., Allen, M., & Strang, V. (2010). Case manager resource allocation decision-making processes: A case illustration. *Care Management Journals*, *11*(3), 151–156.

Fraser, K. D., & Strang, V. (2004). Decision-making and nurse case management: A philosophical perspective. *Advances in Nursing Science*, *27*(1), 32–43.

Furman, R. (2006). Poetic forms and structures in qualitative health research. *Qualitative Health Research*, *16*, 560–566.

Genoud, C., & Weller, J. (2008). Protocol for the evaluation and treatment of chronic wounds in the home care setting. *Schweizerische Rundschau fur Medizin – Praxis*, *97*(6), 317–321.

Gomes, B., & Higginson, I. (2006). Factors influencing death at home in terminally ill patients with cancer: Systematic review. *British Medical Journal*, *332*(7540), 515–521.

Gottlieb, B. H., & Wolfe, J. (2002). Coping with family caregiving to persons with dementia: A critical review. *Aging & Mental Health*, *6*(4), 325–342.

Hearson, B., McClement, S., McMillan, D. E., & Harlos, M. (2011). Sleeping with one eye open: The sleep experience of family members providing palliative care at home. *Journal of Palliative Care*, *27*(2), 69–78.

Jacobs, P., Dumont, S., Turcotte, V., & Anderson, D. (2011). Evaluating the economics loss of caregiving for palliative care patients. *Journal of Palliative Care*, *27*(3), 210–215.

Jepson, C., McCorkle, R., Adler, D., Nuamah, I., & Lusk, E. (1999). Effects of home care on caregivers' psychosocial status. *Journal of Nursing Scholarship*, *31*(2), 115–120.

Kneebone, I. I., & Martin, P. R. (2003). Coping and caregivers of people with dementia. *British Journal of Health Psychology*, *8*, 1–17.

Lau, D. T., Machizawa, S., & Doi, M. (2012). Informal and formal support among community-dwelling Japanese American elders living alone in Chicagoland: An in-depth qualitative study. *Journal of Cross-Cultural Gerontology*, *27*, 149–161.

Liddy, C., Dusseault, J. J., Dahrouge, S., Hogg, W., Lemelin, J., & Humbert, J. (2008). Telehomecare for patients with multiple chronic illnesses: Pilot study. *Canadian Family Physician*, *54*(1), 58–65.

Lin, P. C., & Lu, C. M. (2005). Hip fracture: Family caregivers' burden and related factors for older people in Taiwan. *Journal of Clinical Nursing*, *14*(6), 719–726.

Magnusson, A., Severinsson, E., & Lützén, K. (2002). Nurses' views on situations related to privacy in providing home care for persons with long-term mental illness: An exploratory study. *Issues in Mental Health Nursing*, *23*, 61–75.

Melin-Johansson, C., Ödling, G., Axelsson, B., & Danielson, E. (2008). The meaning of quality of life: Narrations by patients with incurable cancer in palliative home care. *Palliative and Supportive Care*, *6*, 231–238.

Oliffe, J., & Bottorff, J. (2007). Further than the eye can see? Photo elicitation and research with men. *Qualitative Health Research*, *17*(6), 850–858.

Ornstein, K., Smith, K. L., & Boal, J. (2009). Understanding and improving the burden and unmet needs of informal caregivers of homebound patients enrolled in a home-based primary care program. *Journal of Applied Gerontology*, *28*(4), 482–503.

Papastavrou, E., Charalambous, A., Tsangari, H., & Karayiannis, G. (2012). The burdensome and depressive experience of caring. *Cancer Nursing*, *35*(3), 187–194.

Piat, M., Ricard, N., Sabetti, J., & Beauvais, L. (2007). The values and qualities of being a good helper: A qualitative study of adult foster home caregivers for persons with serious mental illness. *International Journal of Nursing Studies*, *44*, 1418–1429.

Plank, A., Mazzoni, V., & Cavada, L. (2012). Becoming a caregiver: New family carers' experience during the transition from hospital to home. *Journal of Clinical Nursing*, *21*, 2072–2082.

Proot, I. M., Abu-Saad, H. H., Crebolder, H. F., Goldsteen, M., Luker, K. A., & Widdershoven, G. A. (2003). Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scandinavian Journal of Caring Sciences*, *17*, 113–121.

Rothera, I., Jones, R., Harwood, R., Avery, A. J., Fisher, K., James, V., et al. (2008). An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods. *International Journal of Geriatric Psychiatry*, *23*, 65–72.

Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in Nursing & Health*, *18*(4), 371–375.

Santos Salas, A. (2006). Nursing practices and the experience of the very ill in the home (Doctoral dissertation, University of Alberta, 2006). *Dissertation Abstracts International*, *64*, 4.

Special Senate Committee on Aging. (2009). *Canada's aging population: Seizing the opportunity*. Retrieved 30 November 2012, from http://www.parl.gc.ca/Content/SEN/Committee/402/agei/rep/AgingFinalReport-e.pdf.

Stajduhar, K. I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, *19*(1), 27–35.

Thorne, S. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.

Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, *20*, 169–177.

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal for Qualitative Methods*, *3*(1), 1–20.

Williams, A. (2004). Shaping the practice of home care: Critical case studies of the significance of the meaning of home. *International Journal of Palliative Nursing*, *10*(7), 333–342.

Williams, A. P., Lum, J. M., Deber, R., Montgomery, R., Kuluski, K., Peckham, A., et al. (2009). Aging at home: Integrating community-based care for older persons. *Healthcare Papers*, *10*(1), 8–21.

World Health Organization. (2002). *The world health report: Reducing risk, promoting healthy life*. Retrieved 15 August 2012, from http://www.who.int/whr/2002/en/whr02_en.pdf.