The influence of culture on home-based family caregiving at end-of-life: A case study of Dutch reformed family caregivers in Ontario, Canada

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A B S T R A C T
Families are facing increased pressure to provide care to their terminally-ill or dying kin in the home. It is known that balancing care with other personal and social roles can adversely affect family caregivers’ (FCGs) health, yet access to supportive services which can mitigate burden is often inadequate. Cultural factors are known to shape the experience of caregiving; however, most research to date tends to neglect the experiences of FCGs from different cultural groups. This understanding is necessary to ensure that supportive services are both meaningful and culturally-appropriate. Using qualitative methods, we undertook longitudinal research with a sample of Dutch Reformed FCGs (n = 5) to understand their experiences of caregiving and bereavement. The results of the study are suggestive of a cultural specificity with respect to caregiving that impacts both responsibilities and reactions to care. Three themes were salient to this group as a cultural entity: cultural attitudes towards care, religious beliefs and coping, and culturally-informed care-seeking behaviours. These three themes were seen to be a function of their religious and ethnic identities and were reinforced by ties to the communities in which they resided. Cultural identity provided a framework through which to understand and make sense of the experience, while group membership provided access to networks of informal support. This research contributes to the geographical literature on care/caregiving by providing insight into the social, cultural and religious context of informal family caregiving with a population who live in close geographic proximity. On a practical level, this case study indicates the importance of considering how these factors may operate in other settings in order to implement timely and appropriate interventions to better support FCGs who are caring for their terminally-ill loved-ones at home.

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In Canada, as elsewhere, the delivery of health care services is dominated by models which favour community-based care over institutional care; this has dramatically increased the likelihood that care will take place in the home. In the home, most care for the elderly or ill is now provided by unpaid family members or friends, most of whom are women (Rajnovich, Keefe, Fast, 2005; Romanow, 2002). In fact, families play a key role in supporting their loved-ones to be cared for and die at home (Grande et al., 2009). This care, referred to as palliative/end-of-life (P/EOL) care, is dedicated to improving the quality of life of patients and their families from problems associated with a life-threatening illness, through the prevention and relief of suffering and the treatment of any physical, psychosocial and spiritual issues (World Health Organisation, 2007). While often rewarding, providing this care often comes at an enormous expense to family caregivers’ (FCGs) physical, emotional, social and financial well-being (Aoun, Kristjanson, Currow & Hudson, 2005). Supportive services, targeted at both patients and FCGs, can help reduce the burden of care, although access to necessary services is fragmented and under-funded (Rajnovich et al., 2005; Romanow, 2002). Increasing support in the home for FCGs has therefore become a major policy and practice issue.

Although a wide literature exists on the effects of caregiving at the end-of-life (Grande et al., 2009), most research has focused on caregiving within the context of different disease categories of the patient or across various care settings, rather than in relation to specific social and cultural identities of FCGs. Culture is a macro-level concept that refers to a “constellation of shared meanings, values, rituals, and modes of interacting with others that determines how people view and make sense of the world” (Kraukauer,
Crenner & Fox, 2002; p. 184). It encompasses several components, including ethnicity, religion, gender, socio-economic status, sexual orientation, health/disability status and geographic region (Blevins & Papadatou, 2006; Guberman & Maheu, 2003–2004). Cultural factors are known to influence the ways in which health and illness are perceived, thereby informing culturally-specific health-promoting and care-seeking behaviours (Srivastava, 2007). Cultural factors are highly relevant to the caregiving experience, given that they shape not only household structures and individual and group identity (Williams, 2002), but norms, beliefs and traditions around illness/health, caregiving, dying, death and bereavement (Dilworth-Anderson, Canty Williams & Gibson, 2002; Kraukauer et al., 2002). An understanding of the ways in which these factors influence the P/EOL caregiving experience can help inform the development of culturally-appropriate supports and services. This is critical given that quality of care may be a function of the cultural meanings around the different dimensions of caregiving and the appropriateness of support that is available in an already ration-alised system. The purpose of this case study was to examine the ways in which cultural factors influence the experience of Dutch Reformed FCGs in southern Ontario who are providing P/EOL care in the home in order to understand how best to support them, the patient and their families. The Dutch Reformed population exhibits distinct patterns of geographic concentration in southern Ontario which is reinforced by strong social, cultural and economic ties to place based on their ethnic and religious identities. As such, they present a unique opportunity in which to begin to address cultural specificity and the potential implications for the caregiving phenomenon.

Background information and review of the literature

While models for community-based care are predicated in part on the assumption that patients want and will be better cared for in the community, they are highly dependent on and expect family support for success (Rajovich et al., 2005; Romanow, 2002). Supporting people to die at home underpins the provision of P/EOL care because of its association with improved quality of life for patients (Stajduhar & Davies, 1998); as a result, it is believed to fit well with the community-based care framework. However, the demanding nature of care in the home has been linked to negative physical and emotional health outcomes and financial strain for FCGs, all of which may increase over time as a function of the patient’s deteriorating health status (Aoun et al., 2005). It is believed that timely and appropriate support interventions can minimise negative outcomes and contribute to a positive bereavement experience for FCGs, thereby supporting the potential of the home as site for care. However, the uncritical application of the home as a site of care is problematic, given that the location of care may not be as important to palliative families as is the quality of care (Stajduhar, Allan, Cohen & Heyland, 2008).

Although there is a clear association between culture and health practices and outcomes, the caregiving research to date—in general, and specific to health geography—has tended to neglect the ways in which social and cultural factors shape FCGs’ experiences (Grande et al., 2009; Milligan, Atkinson, Skinner & Wiles, 2007; Williams, 2002). Much of what is known about diversity in caregiving has emanated from the United States, with comparisons between caregivers of Caucasian, European and African-American descent who are caring for elderly dementia patients (Dilworth-Anderson et al., 2002; Milne & Chryssanthopoulou, 2005; Pinquart & Sorensen, 2005; Sievert, Williams, Dowd, Chappel-Aiken & McCorkle, 2008). While there is likely to be overlap in terms of the experiences, there remains a lack of focus on end-of-life care specifically. Furthermore, comparisons and generalizations across groups and studies are limited, due to ambiguous and inconsistent methodological and theoretical techniques (Dilworth-Anderson et al., 2002). However, several themes appear consistently in the literature and are summarised below.

Various religious, spiritual and cultural beliefs, practices and rituals may shape the ways in which illness, dying and death are structured and provide a framework through which to cope with the fear, stress, and grief associated with dying (Allen, Haley, Roff, Schmid, & Bergman, 2005; Becker et al., 2007; Dilworth-Anderson et al., 2002; Koenig, 2004; Weaver & Flannelly, 2004). For example, increased religiosity or spirituality often provides mechanisms through which to cope with the illness and provides access to various forms of social support. In contrast to western ideals, many non-European—American cultures, including Asian, Latino, African—American and Aboriginal cultures, favour a family-centred approach to care and communication. These may include decisions for care, such as continuing or suspending life-sustaining treatments and filtering the type/amount of information that is communicated to the patient concerning their condition and prognosis (Lai, 2007). This is often a function of trying to protect the patient from bad news and from losing hope, but may conflict with health care providers’ views of full disclosure that are based on western traditions of patient autonomy and decision making at end-of-life. Specific to caregiving, values and beliefs may define perceptions and responsibilities for care, determine how responsibilities are allocated, shape differences in how outcomes are reported, and explain differences in the use of formal services and informal support networks (Dilworth-Anderson et al., 2002; Lai, 2007; Pinquart & Sorensen, 2005; Spitzer, Neufeld, Harrison, Hughes & Stewart, 2003). For example, in Chinese and South Asian cultures, the eldest son typically takes responsibility for care, although the tasks of caregiving are usually performed by women. Daughters generally provide care in Korean cultures, whereas daughters or wives are more likely to do so in Caucasian—American cultures (Lai, 2007; Spitzer et al., 2003). There is some evidence to suggest that higher levels of caregiver burden and depression are more common among Korean and White caregivers than African—American caregivers (Dilworth-Anderson et al., 2002). Levels of depression are not linked to ethnicity per se, but may be related to socio-economic factors and/or the context of caregiving in general (Dilworth-Anderson et al., 2002; Sievert et al., 2008). The context of caregiving, which may be mediated by normative behaviour and/or strong traditions for elder care, may both buffer and engender caregiver burden (Williams, Forbes, Mitchell, Essar & Corbett, 2003). Filial responsibility may buffer distress because caregiving is an expected behaviour, not a burden; however, given the demands of care, the inability to meet expectations and fulfil social roles may be a significant source of stress and guilt (Lai, 2007; Spitzer et al., 2003). The use of formal services may also be culturally-specific, whereby those with stronger traditions towards family care may avoid external help (Lai, 2007). This may be a result of fear of stigmatism or criticism for being unable to cope with familial responsibilities, perception belief that services will not be culturally culturally-appropriate or due to language barriers (Dilworth-Anderson et al., 2002; Lai, 2007; Pinquart & Sorensen, 2005; Spitzer et al., 2003). Cultural factors are clearly implicated in the caregiving experience in myriad ways; however, this is not well-understood within context of the Canadian health care system and P/EOL caregiving.

Research methods

This study was conducted over a 16 month period in 2008–2009. The overall research question guiding this study was: what factors are significant to Dutch Reformed FCGs as a cultural
entity in the provision of P/EOL care? Given that the issue of family caregiving with Dutch Reformed FCGs is not well well-understood, we used an instrumental case study research design (Creswell, 2007; Stake, 2000). This method is appropriate to understand an issue within its context and over time through the collection of data from multiple methods and sources. Qualitative methods, such as longitudinal in-depth face-to-face interviews, observations and photography in the home were used, as they are best suited to understand phenomenon that are not well-known in terms of the meaning that people bring to them (Creswell, 2007). Longitudinal methods were appropriate, given that there is a need to understand the experience of caregiving over time (Grande et al., 2009).

Secondary data sources, including literature reviews, census data and other documents were also used in order to obtain background information specific to caregiving, religion, health care service delivery and the geographic distribution of the group. We also spoke with five key informants (three of whom participated in a formal interview) to gather contextual information and help inform the interpretation of the findings. Researcher field notes were kept to document observations and details of the research process. Ethical approval for this study was obtained from the McMaster University Research Ethics Board prior to data collection. Concerns around recruitment methods, the informed consent process and confidentiality were addressed, as outlined below.

Site and sample

The population in Ontario is diverse; however, distinct patterns of geographical containment exist which may impact the need for culturally-appropriate support. In particular, we note that several areas in southern Ontario are characterised as having large Dutch and Reformed populations. Geo-coded census data specific to the Christian Reformed and Dutch populations across Ontario were accessed to confirm the population distribution of this group. These data were mapped using ArcView GIS (V. 9), the results of which are depicted in Fig. 1.

Based on the 2001 Census, 76,670 people in Canada identified as being Christian Reformed with over half (48,795) of this population residing in the province of Ontario (Statistics Canada, 2001). The Dutch population is the 10th largest ethnic group nationally and provincially; however, it comprises a relatively small proportion of the overall population, with counts of 10,35,965 and 490,995 respectively (Statistics Canada, 2001). As illustrated in Fig. 1, the distribution of the Dutch population is far more pervasive than the Christian Reformed group; however, distinct clusters of both groups are evident in the south-east quadrant of the province, including the study area, with obvious gaps in census subdivisions in northern and central Ontario. Geographical containment based on religion and ethnicity is significant as these factors are likely to shape the context and experience of family caregiving in terms of how needs are defined, as well as potentially addressed through culturally-appropriate social networks of support. The thematic results, together with the discussion section, reveal the significance of this geographical characteristic.

This study was undertaken in collaboration with a local specialist palliative care team. The interdisciplinary team consists of a physician and nurse specialising in palliative care, spiritual and bereavement advisors, as well as representatives from local health care service organisations providing community-level home and hospice care. Specifically, the team played key roles in helping to identify the FCG population and in recruiting participants to the study. Since relatively small proportions of those living in the community receive intensive home care, this was efficient recruitment method, although it may have excluded FCGs not known to the palliative care team. This approach increased the likelihood that the study was meaningful and relevant and that the findings could be applied to programme improvement.

We used purposeful sampling to recruit FCG participants (Patton, 2002). This is a non-random sampling strategy wherein individuals and sites are chosen purposely to inform the phenomenon under study (Creswell, 2007; p. 125). Criterion sampling was first used to delineate the sample to: FCGs of persons on the palliative care team’s caseload; situations where care was taking place in a non-institutional setting, such as the home; and, FCGs who identified as being Dutch Reformed. From there, we applied a maximum variation strategy to ensure that the sample was diverse in terms of age, sex, and disease categories.

Recruitment

Potential participants were approached by the palliative care team over a 16 month period via regularly-scheduled home care visits with patients. Even with the assistance of this specialty palliative care team, only five FCGs were recruited. This reflects the particularly challenging issue of recruitment in palliative care research (Aoun & Kristjanson, 2005). In accordance with ethics approval, potential participants were advised about the study verbally, and in writing by way of a recruitment card. Interested FCGs were given the option of contacting the research team directly or having their contact information forwarded to the research team for follow-up. Arrangements for interviews were scheduled at times and places that were convenient for the FCGs. Five FCGs were recruited to the study. Two to five interviews, which were based on a semi-structured interview guide, were conducted with each FCG, resulting in a total of 15 interviews during the caregiving and bereavement process (see Table 1). Informed consent was obtained from FCGs at the beginning of each interview to ensure their ongoing desire to participate in the research process. Interviews lasted from one to 3 h in duration and were, with participant consent, audio-taped. In appreciation of their time, all FCGs received a $CAD25 stipend after each interview. Several themes were explored in the interviews, including caregiving responsibilities, household adjustments, sources of support and health. Observations from field visits (including the physical characteristics of home and the community and researcher interactions with the participants) were made and recorded in the researcher’s field book.

Analysis and interpretation

Analysis was ongoing with data collection in order to confirm and probe earlier responses, assess any changes to the experience of caregiving over time, and confirm emerging themes with other FCG participants. All interview tapes were transcribed verbatim and potential identifiers removed to ensure confidentiality. Each FCG case was examined over time and contrasted with other FCG cases. Interview data were hand coded; this involved the identification of words or phrases about how FCGs experienced, managed and coped with caring for and grieving the loss of their terminally-ill family members within the context of their cultural frameworks. Initially several codes emerged; however, these were refined into categories and used to code the remaining data (Creswell, 2007). We then reduced these categories into three broad themes which represented culturally-informed features of caregiving that were consistent across cases. Several strategies were used to ensure methodological rigour, including: purposeful sampling, prolonged engagement via a series of longitudinal interviews, member checking, peer debriefing, triangulation, reflective journaling, and thick description (Baxter & Eyles, 1997).
Distribution of the Dutch and Christian Reformed Populations in Ontario by Census Subdivision

Figure 1. (Map: Christian Reformed & Dutch Population in Ontario).
Results

The results of the case study are presented in the following section. We begin with a brief description of the FCG participants, followed by an overview of the locally-situated socio-historical context of the group. This contextual information was provided in part by key informants who were religious leaders in the community. This description, which situates the group in space and time, provides a backdrop which is central to understanding the community. This description, which situates the group in space and time, provides a backdrop which is central to understanding the community. This description, which situates the group in space and time, provides a backdrop which is central to understanding the community. This description, which situates the group in space and time, provides a backdrop which is central to understanding the community. This description, which situates the group in space and time, provides a backdrop which is central to understanding the community.

Sample characteristics

The sample consisted of five FCGs of which three were female and two male, ranging from 46 to 62 years in age. While all FCGs were of Dutch descent, four of the five FCGs identified as Christian Reformed and one as Canadian Reformed. Three FCGs provided care to an aged parent, while two provided care to a spouse. FCGs and spouses lived together in the home, whereas adult-children carers provided care across multiple settings (including homes and institutions). Further FCG characteristics are outlined in Table 1.

Locally-situated social and historical context of the Dutch reformed group

The Reformed Church was introduced into North America by Calvinist Dutch immigrants. Although often perceived as a Dutch religion, reformist teachings are in fact, based on a Calvinist doctrine that arose during the Reformation period in Europe in the 16th century as marked by separation from the Catholic Church due to doctrinal differences [Canadian and American Reformed Churches (CANRC), 2005; Christian Reformed Church (CRCNA), 2009]. The term 'Reformed' refers to a return to the Obedience of God, not a separate brand of Christianity; thus most beliefs are common with other Christian-based religions. Differences lie mainly with interpretations of the Bible, as well as to church organisation and leadership structures. Its spread throughout North America has involved several amalgamations and splits with other reformed denominations, often over minor, but irreconcilable, differences, as mentioned. The Canadian Reformed Church was first established in Canada in 1950 (CANRC, 2005) and is an example of one of the divisions that exist within the Reformed community.

This history of the Dutch Reformed population in Canada is strongly linked to the period of Dutch immigration following the Second World War (CRCNA, 2009). There was a desire to live in close proximity, which served to preserve the culture in the long-term:

"...their Dutch roots is [sic] what shapes their identity because most of them were not born in this country; they were born in the Netherlands, immigrated in the '40s or early '50s — and immigrated into a community that was very sort of sheltered and closed. Not only was there an ethnic component that you needed to find people who spoke Dutch, but you needed to find people who were of the right Conservative Reformed Calvinist religious vent [sic] because you could only associated with like-minded people." (KII, Int 1)

As a result, communities were developed complete with various economic and social structures, including churches and private schools, as well as independently-operated businesses. While many of these structures still exist (i.e. Christian schools and churches), it is clear that cultural norms are loosening and communities have become more ethnically-diverse. We note that this population is dynamic — growing, adapting and changing in space and time; it is within this changing context that caregiving takes place.

Thematic analysis

Our in-depth analysis revealed several factors that are suggestive of a cultural specificity with respect to providing P/EOL care, as described in the following three themes: Cultural Attitudes towards Care, Religious Beliefs and Coping, and Culturally-Informed Care-Seeking Behaviours. While the macro-cultural concept (as previously defined) encompasses several different components, religion dominates these themes; however, cultural nuances that arise from the socio-historical context of the group are also evident. A wide variety of services, referred to as health service geographies (HSGs), were utilised; they include: home and community health care services; formal institutions and alternative community living centres; and, informal supports such as family, friends and the faith communities. In this study, we focused primarily on formal and informal community-level health care services and networks of support.

Cultural attitudes towards care

Having been raised in this multi-generational socially and geographically contained environment, tendencies for care were embedded in the FCGs’ religious and ethnic backgrounds and ties to their communities. Providing care was seen as a normal and essential part of care for the family and community. FCGs found it difficult to distinguish caregiving from other forms of family and group responsibilities:

"It is just something that I do for her, that's all. It's not — I don't feel like I'm going out of my way for her or anything like that. It doesn't really even feel like anything extraordinary. It's just something that needs to be done and that's what I do for her. I do whatever it takes." (FCG01 Int 2, our emphasis)

As part of this caring nature, FCGs spoke about the ways in which their culture values independence and self-reliance; as such, there was a strong desire to support their loved-ones at home throughout the illness and death event. In order to do so, FCGs had to be resourceful in terms of structuring the settings and responsibilities for care depending on the relationship they had with the patient. For example, spouses assumed the role of primary FCG in the home, while adult-children carers used a family approach across different care settings. Where spouses had an inherent leadership role in caregiving, adult-children FCGs tended share responsibilities by capitalising on the strengths that each family member could provide (i.e. skills, strength of character, or time), rather than attempting to manage on their own. This was facilitated by the fact the FCGs were part of large families who were living in close proximity. The propensity and willingness to provide care by the group as a whole reduced their expectations for support through the health care system.

Although the notion of a home death was initially favoured by patients and FCGs, two of three deaths took place in a local hospice and one took place at home. In one case, the patient’s preference was the largest determining factor for the home death:

"So the location really wasn’t that important to me. It was more, that that’s what she wanted, she wanted me with her all the time, at the last days of her life. And she said that many times." (FCG04-01)

However, practical considerations, including the inability of the FCGs to continue managing care, also precipitated a change in settings:

"...I don’t know if you really plan things like that [a home death]. It all depended on how much care she was going to need and how — like our house, we don’t have a big house. And our house is not really adaptable to situations where somebody needs a lot
of care. You know, we did our best and... but there was — like we were really fast coming to a point where I couldn’t do it anymore. Like I was either going to drop her or I was going to hurt myself lifting her — or something like that and that wouldn’t have done anybody any good.” (FCG01 Int 4)

Both settings were highly valued: hospice alleviated the burden of caregiving while providing a comfortable and dignified death, whereas the home provided gratification for facilitating the mother’s final request. FCGs appeared to weigh responsibilities for care against what was practical and possible in light of patients’ deteriorating status. Therefore, having access to either home care or hospice services was meaningful for this group of FCGs at end-of-life.

Religious beliefs and coping strategies

Religion was a critical element of FCGs’ cultural identity; it helped shape their everyday lives and served as a key mechanism through which FCGs coped with the experience. The relationship with God was very important as it enabled FCGs to deal with the suffering so bad and we were tired. And he says no, that’s not being selfish at all. [I was] just starting to feel guilty because of all that, eh? And then he said too, you know, some people say the loss of a child is worse, but he goes, it’s your parent, it’s your mom. How can you say one is worse than the other? It’s still dealing with a loss. So I really appreciated him saying that, and that. Because you are going through this guilt thing. I can’t take it anymore, I just... oh...you know.” (FCG05 Int 2)

Facing such challenges served to strengthen their faith and provided immeasurable comfort to what would otherwise be an unbearable situation.

Additionally, as members of this Dutch and Christian community, FCGs were part of well-established networks that provided support to all families in times of need. Within the church there exists a hierarchy of support that is intended to address both spiritual and concrete needs. An awareness of personal challenges is created vis a vis sermons, church bulletins/newsletters or other avenues, such as personal communication. This serves as a trigger to the wider church community for both emotional and tangible support, such as prayers, cards, visits and phone calls, and help with meals and transportation, as required:

“You know, in our church, if someone is sick, the Minister will pray. Like he will say at the beginning of the sermon, “We want to pray for...” like a prayer request. ...Well, then you get the cards, and people will come up to you at church — the people know you, they know... his parents. “Is there anything we can do?” That’s just how we are, right? ... and if I needed a meal, I never did because I was okay, but they would have gladly brought meals or just helped in the house - clean your house if you needed... We’ve always been — we have a ‘care and share committee’ in the church. So, if I thought I couldn’t handle it, I’d call there, and they’ll come gladly. And they’ll call different people, “can you bring a meal to [names herself] on Tuesday, and you Wednesday.” I’ve done it for a lot of people too, if they have a baby, and they have other children or whatever [who are] not well for awhile.” (FCG03 Int 1)

Being a part of this family reaffirmed faith and engendered a sense of belonging and knowledge that support — in most any form — was available if needed:

“It is... part of what being a Christian Reformed is. The whole Reformed belief is that religion does not happen on Sundays. Religion is everything, it affects everything you do and I strongly feel that that’s true. Everything from our relationships with our neighbours here, how I do my job, how I take care of my family, that was how I was brought up and that is kind of how we feel. It is because of that, when we first found out about this, one of the first calls that I made was to my Pastor. I think we found out on a Thursday and on Sunday morning there was an announcement on the pulpit and 600 people knew. And they were all very supportive. I know that if I need anything I can call and there will be someone here. That’s comforting. That kind of thing, that means a lot.” (FCG01 Int 1, our emphasis)

The use of these Dutch and Christian community-based informal supports differed between the FCGs in this study although, in general, it was limited. They felt that being prayed for and just knowing that community support was available if needed was sufficient and suggested that they would accept help if it was necessary. In addition to relying on support from family members and friends, limited use also appeared to be related to issues of privacy and independence and not wanting to become too dependent on others to manage.

Culturally-informed care-seeking behaviours

Each of the caregiving situations arose through the patients’ diagnosis of terminal cancer and therefore required interaction with the health care system. Confronting culturally-specific beliefs and care-seeking behaviours, for both themselves and their ill family members, constituted an important aspect of caregiving, given that these factors informed the use of services.

The use of health care services was highly valued and an important aspect in dealing with the disease; therefore, patients were likely to engage in medicalised treatments. However, prognosis were often framed by religious belief systems as well, sometimes creating dilemmas regarding the most appropriate course of treatment. For example, the belief in the afterlife is fundamental to the Christian and Canadian Reformed faiths. Death may occur to the human body, but the spirit is understood to live on. One caregiver explains how this affects treatment:

“I think you’re not as concerned about preservation of life as we are sort of about quality of life. Because you don’t have the sense this is the only life you have. I would think that people who believe that this is the only life they have, your goal is to stay as long as you can, whereas that’s not true.” (FCG02 Int 1)

As a result, the propensity to engage in treatments that were considered futile was reduced while those that were understood to improve the quality of life were increased. Therefore, an understanding of medical conditions and possible outcomes were integral to patient care because it informed treatment decisions, service use, and ultimately, arrangements for care.

It was also evident that care-seeking behaviours were shaped by various social norms and standards around issues of self-reliance and independence. While medical care was highly-valued, there was also reluctance in accepting outside help from strangers, especially for the elderly patients. This was strongly linked to their early roots in Canada and the rather close-knit communities they formed:

“I can understand because, you know, if you understand the Dutch immigrants, they came — their family was their friends.
And basically through all their church time, too, their family is their friends. They don’t branch out to anyone else. And then we’re in our own little community — but as us — as kids, we have branched out more. But for them immigrating, ya, and their family came over and so that’s the only people they knew. And that’s how that works.” (FCG05 Int 1)

Additionally, feelings of pride and the need to ‘keep up appearances’ also limited elderly patients’ willingness to accept outside help. For example, FCGs indicated that their elderly parents would often downplay the severity of symptoms when health care providers or visitors were present.

Although FCGs did not use any services personally, they became intricately connected to the formal health care system through their caregiving responsibilities. For example, they were active in providing transportation and attending appointments, and being present in the home when service providers made home visits. Doing so was not only out of necessity (i.e. due to the functional limitations of the patient), but because both FCGs and patients valued receiving this information together. FCGs pointed out, however, that communication issues could arise between elderly Dutch patients and health care professionals. Although the elderly typically learned to speak English upon immigration to Canada, there was a tendency for them to revert back to their mother tongue near the end-of-life. Concerned about the quality of communication between patients and health care professionals who could not converse in Dutch, FCGs felt compelled to be present during health care interactions whenever possible. This was easier when care took place in the home. In general, while religion provided a framework which influenced care-seeking behaviours, subtle cultural nuances also affected the ways in which this population engaged with formal health care services.

**Discussion and concluding remarks**

The purpose of this research was to understand cultural influences on P/EOL caregiving with a Dutch Reformed population living in southern Ontario. To date, there is a dearth of research on cultural diversity in family caregiving, and the research that is available tends to focus mainly on Asian, African American, and Hispanic populations, all of which tend to be pervasive in numerous urban locales. In contrast, the Dutch Reformed population in Canada is, for the most part, geographically-held, residing in only a few parts of the country, with a high concentration in southern Ontario. It may therefore be possible to better meet the needs of this group because they are clearly geographically-defined and closely networked. This study has contributed to our understanding around geographical containment where service delivery can accommodate and meet culturally-specific needs for care, particularly at end-of-life. The results of this research provide a greater understanding of this population, which can potentially inform how health care providers work with this group in the future. However, it is a small sample and locally contingent and caution should be exercised when applying these findings to other contexts. Furthermore, this sample may exclude the voices of those who found caregiving overwhelming and were unable to participate in the research process.

This sample of FCGs appeared to be high-functioning in terms of managing care responsibilities with competing life demands. Personal coping strategies based on a strong faith and perceived adequacies in terms of formal and informal support contributed to their success, possibly serving as a buffer against the high degree of caregiver burden that is often reported in caregiving literature, as discussed below.

This research indicates that Dutch Reformed families play a central role in caring for their loved-ones over the course of an illness and through the dying process. Furthermore, there are likely to be multiple family members involved in caregiving, especially for an aged parent. This approach appears to be more common among ethnic minority groups, such as African American, Asian and Latino populations, rather than in Caucasian populations, because these ethnic minorities typically believe that care for the elderly is a family responsibility (Dilworth-Anderson et al., 2002; Guberman & Maheu, 2003–2004). However, this is not well-understood in Caucasian populations since researchers do not typically disaggregate these caregivers by their ethnic and cultural backgrounds (Dilworth-Anderson et al., 2002). Furthermore, while the expectations for families to provide care may be the norm, the reality is that tasks may not be shared equally among family members. The involvement of multiple family members in the provision of care is reflective of how the Dutch Reformed are socialised to value care for the family and the community; however, it also demonstrates how this group is resourceful in terms of managing caregiving. For example, while research suggests that most caregivers tend to put their own needs on hold to provide care (Grande et al., 2009), FCGs in this sample recognised their personal limitations and tried to find solutions (such as dividing the labor among family members) to manage much of their family member’s life demands and the cultural expectations for care. The fact that multiple family members were all close by, given their geographical containment of this group, allowed this to occur. Attention to the diverse ways in which families approach caregiving can alert practitioners to potential issues that FCGs may face over the caregiving process, including the need for the division of labour within the family dynamic.

Religion was a powerful resource for the FCGs in this study, in terms of dealing with issues around the meaning of life and death and for coping with caregiving in general. The experience both tested and strengthened their faith and contributed strongly to positive emotional health outcomes over the caregiving and bereavement process. For example, research suggests that religion (i.e. religious participation) helps to reduce anxiety and depressive symptoms and improves grief adjustment in bereavement (Allen et al., 2005; Becker et al., 2007). However, negative outcomes, such as feelings of anger, anxiety, depression, guilt and low self-worth, are also possible with religious coping if FCGs are unable to accept God’s plan or lose faith, (Allen et al., 2005). In terms of health, it is therefore important to ensure that FCGs’ religious and/or spiritual needs are met in order to contribute to a positive experience of caregiving and bereavement. It appears that individual-based, faith-specific spiritual support is required for this group of caregivers. Although providing spiritual support is an integral component of palliative care (WHO, 2007), doing so within strong religious communities may fall outside of the capabilities of the palliative care system. As a result, it may be necessary for providers to establish stronger linkages with the religious communities to share in the support of FCGs.

Additionally, access to services and supports played an important role in the caregiving experiences of these FCG participants. Formal services, such as those provided through palliative home care, were instrumental to care in the home and where used, were highly valued because they supported patient independence. However, communication issues, such as understanding patient preferences for care and language barriers that materialise at end-of-life, presented challenges for FCGs. Informal networks, though available, were used differently across caregiving situations. The family unit was the preferred source for assistance with hands-on care and other household tasks. Support from the community, such
as the provision of meals and assistance with transporting patients to doctors’ appointments, was also used, albeit in a limited capacity. The knowledge that support was available, if needed, as well as the prayers and words of encouragement from the church community helped sustain caregivers. However, cultural expectations for privacy and independence by the immigrant parent/patient also limited the extent to which adult-children carers could utilise outside support. It is recognised that positive outcomes in caregiving are linked to perceptions about the adequacy of support, rather than the actual use of this support (Dilworth-Anderson et al., 2002); however, the lack of use may be linked to feelings of respect for their parents and not necessarily what is needed (Lai, 2007; Spitzer et al., 2003). Although frustrating for FCGs, they did feel a duty to some extent to help their elderly parents keep up appearances and remain independent. Health care providers have a duty to some extent to help their elderly parents keep up with their daily tasks, but they may feel frustrated with the lack of support from their parents. Although not the case with spousal caregivers, the data have shown that siblings were more equitable in providing care, tending to divide tasks according to their individual strengths, rather than imposing responsibilities on one another. This was likely due to the fact that they are living in close proximity to one another. Familial units are very strong and very much available, unlike in many other parts of Canada, particularly in the rural context, due to out-migration (Donovan & Williams, in press). Therefore, intergenerational support is enhanced because of the continuity of the extended family unit. Additionally, an important finding has been the amenability of a religious community to support palliative FCGs through culturally-specific practices and structures. The cohesiveness of the family and community is enhanced because of the containment of the group; as a result, networks of support are perpetuated and, in fact, strengthened over time. Future research should address this issue with other religious/cultural groups and in other geographic locales. Furthermore, this research has revealed an important link between caregiving and emotional geographies which requires further research (i.e. Bondi, Davidson & Smith, 2005). For example, the extent to which religion shapes the experience of caregivers — as a framework to understand illness and death and as a means to cope with the burden — has important implications for who provides care and where care takes place. Future research could interrogate this further, with an emphasis on how this may change over time. On a practical level, this research can help inform the palliative care team so that they can implement timely and appropriate interventions to better support FCGs who are caring for their terminally-ill loved-ones at home. For example, there is a need to recognise the importance of family in the provision of care as well as the need for having a Dutch-speaking person on the team, particularly at end-of-life. Once again, the geographical containment of the group facilitates the existence of informal networks while also allowing the palliative care team to meet their needs within this geographic population. Additionally, this case study indicates the importance of considering how these factors may operate in other settings and alerts practitioners to the importance of being informed about and responsive to locally-specific cultures.

Acknowledgements

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Appendices

Table 1 (Family Caregiver Characteristics)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>FCG 01</th>
<th>FCG 02*</th>
<th>FCG 03</th>
<th>FCG 04*</th>
<th>FCG 05</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Interviews</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Sex</td>
<td>M</td>
<td>F</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Age</td>
<td>46</td>
<td>50</td>
<td>47</td>
<td>62</td>
<td>51</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>Married</td>
<td>Married</td>
<td>Married</td>
<td>Married</td>
</tr>
<tr>
<td># Dependents</td>
<td>2</td>
<td>1 (+adult adult-children at home)</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Occupational status</td>
<td>Employed Fulltime</td>
<td>Employed Fulltime</td>
<td>Unemployed</td>
<td>Self-Employed Fulltime</td>
<td>Self-Employed Fulltime</td>
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<tr>
<td>Household income</td>
<td>~$75000</td>
<td>~$200000</td>
<td>~$36000</td>
<td>~$250000</td>
<td>~$75000</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td>Spouse</td>
<td>Daughter</td>
<td>Spouse</td>
<td>Son</td>
<td>Daughter</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Cancer</td>
<td>Cancer</td>
<td>Cancer</td>
<td>Cancer</td>
<td>Cancer</td>
</tr>
<tr>
<td>Culture/Ethnicity</td>
<td>Dutch Canadian</td>
<td>Dutch Canadian</td>
<td>Dutch Canadian</td>
<td>Dutch Canadian</td>
<td>Dutch Canadian</td>
</tr>
<tr>
<td>Length of time caregiving</td>
<td>22 months</td>
<td>~4 months</td>
<td>10 yrs on/off</td>
<td>~1 month</td>
<td>~7 months</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>Live with Patient</td>
<td>Multiple settings</td>
<td>Live with Patient</td>
<td>Multiple settings</td>
<td>Multiple settings</td>
</tr>
<tr>
<td>Outcome of caregiving situation</td>
<td>Death in Hospice (duration: 5 days)</td>
<td>Home death</td>
<td>On-going</td>
<td>Home death</td>
<td>Death in hospice (duration: 22 days)</td>
</tr>
</tbody>
</table>

*Denotes FCGs who were caring for the same patient. The siblings were treated as individual cases; they were interviewed separately and no references or assumptions about each other’s circumstances were made in the interviews.