Caregiving for Elders in First Nations Communities: Social System Perspective on Barriers and Challenges*

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RÉSUMÉ

Cette recherche a examiné les perspectives et les expériences des membres de la communauté des Premières Nations concernant le soutien sanitaire et social pour les personnes âgées demeurant dans 13 nations du nord-ouest de l'Ontario. Des enquêtes (n = 216) et des groupes de discussion (n = 70) ont été menées en 2005 et 2006 avec les peuples autochtones aînés et leurs aidants formels et informels. Les résultats ont indiqué une forte préférence (69%) pour aider les gens à vieillir et mourir à domicile ; pourtant les obstacles et les défis existaient aux niveaux de la famille, de la communauté, du système de santé, et de la politique sociale. Il s'agissait notamment d'un manque d'aidants proches, des ressources locales humaines et de la santé, les valeurs changeants à travers de la communauté, et d'un accès limité aux services de santé provinciaux et des soins adaptés à la culture et à la sécurité des personnes âgées, tous ce qui a entravé la politique sociale et l'autonomisation des communautés. Un meilleur soutien qui permet aux personnes âgées de vieillir au sein des communautés des Premières Nations exigera des changements du système à plusieurs niveaux et à plusieurs secteurs.

ABSTRACT

This research examined the perspectives and experiences of First Nations community members regarding health and social support for elderly people living in 13 First Nations communities in northwestern Ontario. Surveys (*n* = 216) and focus groups (*n* = 70) were conducted in 2005 and 2006 with elderly Aboriginal people and their formal and informal caregivers. Results indicated a strong preference (69%) for helping people to age and die at home; however, barriers and challenges existed at the family, community, health system, and social policy levels. Barriers included a lack of family caregivers and shortage of health care providers and programs; changing community values; and limited access to provincial health services and culturally relevant and safe care, all of which hindered social policy and community empowerment. Enabling elderly people to age within First Nations communities will require multi-level and multi-sectoral system changes.

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INTRODUCTION

Canada's aging population has long been studied, yet the challenges of aging people living in First Nations communities are not nearly as well-known. Similarly, although government policy has begun to address issues faced by older people and their families concerning policy shifts in health care, the economy, and social support, research is limited on First Nations people and aging, particularly research conducted by First Nations researchers. This article begins to address this gap in the literature by reporting findings generated from data collected from participants living in First Nations communities, and analyzed by First Nations researchers.

Demographic Reality

According to the 2006 Census of Canada, the Aboriginal population[1] represents 3.8 per cent of the total population, or 1,172,790 people. The fastest-growing segment of the Canadian population, Aboriginal people show a 20.1 per cent increase from the 2001 Census, as compared to a 4.9 per cent increase for the non-Aboriginal population (Statistics Canada, 2008a). Although Aboriginal people are a relatively young group (with a median age of 26.5), the number of older adults within this population segment is rapidly increasing. From 2001 to 2006, the number of individuals aged 55–64 increased by 53.8 per cent, and individuals aged 65 and over by 43.0 per cent (Statistics Canada, 2008a). This represents the largest increase among all age groups within the Canadian Aboriginal population. Moreover, Statistics Canada has projected (2005) that the Aboriginal population aged 55 and older will more than double by 2017.

Almost one-half of all Aboriginal people (46.8%) live on reserves or in rural and remote areas (Statistics Canada, 2008a),[2] and about 16 per cent of the on-reserve population is 55 years of age or older (National Aboriginal Health Organization [NAHO], 2006). In general, Aboriginal elderly people have a lower level of education than the younger population, with 65 per cent not having graduated high school. The older population is more likely to observe traditional values, with over 70 per cent understanding, and 67 per cent speaking, one or more First Nations' languages (NAHO, 2006).

With aging, rates of chronic illnesses among the Aboriginal population are also on the rise. Chronic illnesses such as arthritis, hypertension, cardiovascular disease, and cancer are much more prevalent among Aboriginal people, and the incidence of end-stage renal disease is twice as common as it is among the non-Aboriginal population (Adelson, 2005; Frohlich, Ross, & Richmond, 2006; Gao et al., 2008; Indian and Northern Affairs Canada, 2006). Diabetes rates are increasing:

19.7 per cent of Aboriginal adults have been diagnosed with diabetes, with the highest rates found among adults living in isolated communities and those speaking or understanding an Aboriginal language. Prevalence increases with age, with about one in three of those aged 55 and older being diagnosed with diabetes (First Nations Information Governance Committee, 2007).

The average life expectancy of Aboriginal people has been improving in recent years but is still well below that of the Canadian population as a whole. On average, Aboriginal people live five to ten years less than Canadians in general (Canadian Institute for Health Information, 2004). Research findings documenting medical problems, physical limitations, and a shorter life expectancy have led some to consider Aboriginals to be "elderly" when they reach the age of 50–55, much younger than the comparable age of 65 generally used to designate the elderly population among non-Aboriginal adults (Buchignani & Armstrong-Esther, 1999; Dumont-Smith, 2002; NAHO, 2006; Statistics Canada, 2006a).

Discourse about how to care for older Aboriginal people has been taking place for some time in Canada (Buchignani & Armstrong-Esther, 1999). Despite these discussions, little research exists on the needs and challenges of caring for Aboriginal elderly individuals living on-reserve. This gap is especially notable when we consider the Aboriginal understanding of health and wellness.

Aboriginal Understanding of Health and Wellness

Aboriginal health is perceived holistically and includes physical, mental, emotional, spiritual, and cultural aspects of life. It incorporates the life cycle and continuum of health. These concepts are interrelated: health is addressed throughout the life cycle of an individual, in a holistic way, within the continuum of care. In the Aboriginal view, health is also understood to extend beyond individual experience and to encompass physical, mental, emotional, spiritual, and cultural aspects of the community and broader world (Government of Ontario, 1994).

The Aboriginal concept of health is well-represented within the Medicine Wheel (see Figure 1).[3] The wheel, which represents Aboriginal peoples' way of life, beliefs and teachings, focuses on understanding, centering, and balance. It is physically configured as a circle with four quadrants (with the directions east, south, west, and north as guides) embedded within it. Each direction represents part of the person, including the physical, emotional, spiritual, and mental domains (MacDonald, 2008; Smylie et al., 2001). Health and wellness are seen as outcomes of the balance and integration of these domains within a person (Chansonneuve,

Figure 1: The Medicine Wheel

2007; McCabe, 2008; McCormick, 1995). If any aspect of the self is out of balance or harmony, so is one's health and thus overall well-being (Cargo, Peterson, Lévesque, & Macaulay, 2007; Montour, 2000; Twigg & Hengen, 2009; Wilson, 2003). The purpose of the Medicine Wheel is not to compartmentalize, but to show what is needed to be whole and how to journey through life (Dumbrill & Green, 2008).

Because individual wellness in each domain is also connected to and influenced by the physical, mental, emotional, spiritual, and cultural milieu of the community and world beyond, an individual's health experience cannot be separated from their experiences of living within these contexts, including their experiences in accessing care and support (MacDonald, 2008).

The Medicine Wheel has wide applicability across cultural traditions and is the broadly recognized and accepted symbol for balance, harmony, and wholeness within Aboriginal health and wellness. The Medicine Wheel, which exists in multiple variations and has been applied in a number of different ways across Aboriginal cultures, always represents a symbol of balance (Dapice, 2006). It applies to all phases of life, including old age (Stewart et al., 2005). The Medicine Wheel framework can contribute to a broader societal understanding of Aboriginal peoples' perception of barriers when interacting with the mainstream system.

Health Profile of Aboriginal Communities

Research evidence indicates the precarious health status of people living on-reserve. Health Canada (2009) has referred to the importance of non-medical determinants of health among Aboriginal people such as education, labour force characteristics, annual income, personal health practices, and the physical environment. The combined influence of these determinants influences the population's overall health status and affects both life expectancy and quality of life.

Aboriginal people living on-reserve have lower levels of education, much higher unemployment rates, and a lower median annual income than the general Canadian population. The overall smoking rate among Aboriginal adults is higher than the rate for Canadians in general, and the proportion of Aboriginal people who report heavy drinking on a weekly basis is double that of the general population. In addition, Aboriginal adults generally have higher body mass index and use fewer preventive health services than the rest of the Canadian population. A large number of on-reserve households are below acceptable housing standards, and nearly a quarter of housing units have a water supply that is inadequate in terms of volume and health requirements (Health Canada, 2009). The comparative analysis of older adults' health and well-being indicates that, relative to the Canada's overall older population, Aboriginal elderly are losing ground. Notably, their health status is worsening compared to the previous generation (Cooke, Guimond, & McWhirter, 2008; Wilson, Rosenberg, Abonyi, & Lovelace, 2010).

Health Care and Support Services

A review of the literature reveals an array of barriers for elderly Aboriginal people in accessing health care and obtaining needed support services, especially for those living in rural and remote communities. These barriers can be grouped into four categories: (a) barriers related to geography and availability of services; (b) economic barriers; (c) systemic barriers; and (d) barriers related to the specific needs of the Aboriginal population.

Numerous resources identify geographic barriers and a lack of available services and support. The NAHO (2003) health survey underscored the pronounced difficulty that the Aboriginal population residing in remote communities has in accessing health care compared to Aboriginals living in non-isolated communities. Many Aboriginal communities have limited access to medical treatment, are unable to offer home-based support in the absence of a committed primary caregiver, and lack access to in-patient care when needed (Hotson, Macdonald, & Martin, 2004). The geographic isolation and remoteness of many Aboriginal communities lead to health care that is under-supplied in terms of both organizational and human resources (Minore & Boone, 2002). Consequently, limitations on services, programs, and support available to geographically isolated communities represent barriers to the population's health and well-being (Crosato, Ward-Griffin, & Leipert, 2007; North West Local Health Integration Network [NW LHIN], 2009).

Literature also identifies economic barriers to accessing health care and support services. In general, Aboriginal

people have low incomes, which can exacerbate the provision of needed resources for their elderly family members (Parrack & Joseph, 2007). The lack of accessible and supportive housing within the community, the high cost of transportation to access services, combined with the costs associated with attending social, recreational, and support programs, all lead to economic hardship for Aboriginal communities (NW LHIN, 2009). Because of the lack of needed health care services available in local communities, elderly people must travel to larger urban centres, which in addition to increased expenses also lead to family separation and loss of control over health care decisions (Salvalaggio, Kelly, & Minore, 2003).

The health of Aboriginal elderly people is affected by broader health system challenges in rural and remote Canada as well as by challenges from social structural issues. The high turnover of the professional staff working within Aboriginal communities often means that paraprofessionals must assume roles beyond their capacity (Minore & Boone, 2002). Moreover, the lack of available education and training for local resource people represents an obstacle to providing optimal care (NW LHIN, 2009). In addition, the changing role of Aboriginal women affects their availability as informal caregivers. Aboriginal women are expected to play an essential role in caring for the elderly; however, these women, including middle-aged women who are more likely to be providing care, have high migration rates. This means that a significant number of Aboriginal women are providing care to elderly family members from a distance. Over half of Aboriginal women live off-reserve, in contrast to the higher proportion of Aboriginal elderly who live on-reserve (Statistics Canada, 2006a). This migration of Aboriginal women to larger population centres is expected to continue while the offloading of responsibilities for elder care from government to family members is becoming a norm, raising concerns as to who will be able to provide care to the elderly, particularly in rural and remote communities (Parrack & Joseph, 2007).

The last set of identified barriers to accessing health care and obtaining needed support relates to specific needs of the Aboriginal population. Traditional cultural values, beliefs, and practices are often not incorporated into their health care (Crosato et al., 2007). This can lead Aboriginal elderly to feel a lack of control over health care decisions (Salvalaggio et al., 2003). In addition, language barriers – and health care professionals who often practice non-culturally appropriate care – can prevent elderly Aboriginal people from seeking needed care (Crosato et al., 2007; NAHO, 2003).

Altogether, three concerns demonstrate the need to identify the health care and social support resources required within Aboriginal communities: (a) demographic projections of rapid aging within Aboriginal communities, (b) the increasing prevalence of chronic health problems, and (c) identified barriers to accessing health and support services for elderly people living on reserves and in rural or remote areas.

PURPOSE OF THE RESEARCH

The purpose of this study was to understand the perspectives and experiences of First Nations community members related to obtaining health services and social support for elderly people living in 13 rural and remote First Nations communities in northwestern Ontario. Although the current literature identifies many issues of health and social care in Aboriginal communities, we specifically endeavoured to understand the experiences pertaining to elderly people. In an effort to provide a community perspective, we collected data from the Elders themselves and from those who informally and formally cared for them in these First Nations communities.

RESEARCH METHODS

Research Setting

Ontario has the highest Aboriginal population of any province or territory in Canada (Statistics Canada, 2008a). The highest concentration is found in northwestern Ontario with 20 per cent of its population being of Aboriginal identity, as compared to 2 per cent of Ontario's overall population (Statistics Canada, 2006b). Northwestern Ontario is home to one-third of the on-reserve Aboriginal population of Ontario, one-quarter of the off-reserve population, and just over one-half of all Indian Reserves and Indian Settlements (NW LHIN, 2010).

Northwestern Ontario has a land area of approximately 525,000 square kilometers and comprises 60 per cent of the province of Ontario but contains just 2.3 per cent of its total population. The region has many small and remote towns and First Nations communities and settlements. The distance between its eastern and western boundaries is slightly more than 1,000 kilometers, with a population density of 0.5 persons per square kilometer. The only major urban community in the region, Thunder Bay, has a population of 109,000 and is considered remote in relation to Ontario's major population areas in the southern part of Ontario (Northwestern Ontario District Health Council, 2001).

The research was conducted in the Treaty #3 area in northwestern Ontario, in partnership with two First Nations organizations which provide health services in Treaty #3 communities: the Kenora Chiefs Advisory in Kenora, and the Gizhewaadiziwin Health Access

Centre in Fort Frances. A key to the project's success was that members of these organizations were actively involved throughout the study, including the design, implementation, and dissemination of the findings back into the communities. Treaty #3 consists of 28 First Nations communities; 26 are located in Ontario and two in Manitoba (see Figure 2 for a map of the Treaty #3 area).

We selected 13 First Nations communities in the Treaty #3 area as study sites through a collaborative decision-making process that included community leaders and local service providers. These communities were diverse, varying in size, population, and proximity to the nearest major health centre. On-reserve populations of the study communities ranged from 97 to 849 people (Indian and Northern Affairs Canada, 2009), and distances from a hospital ranged from 10 to 112 kilometres. Populations in all study communities had increased in size (from 5% to 100%) between 2001 and 2006 (Statistics Canada, 2008b).

The level of and access to health care services available in each study community also varied. Each community's health centre had many services and health care providers, including health directors, community health representatives and/or educators, as well as visiting physicians and nurses whose service provision ranged from one day a month to several days a week, depending on the community's size and population. The communities also had a Home and Community Care Program staffed by a visiting home care nurse and a coordinator, and which might include personal support workers and/or homemakers. This program was delivered either by the community or by a regional First Nation health authority. A long-term care program was available in some communities and was staffed by a coordinator and home support and/or maintenance workers. In some communities, funding for the Home and Community Care Program and the long-term care program was amalgamated to provide

Figure 2: Treaty #3 area

one home-based service. These programs were available only Monday to Friday during regular business hours, with no service available on weekends or after hours due to funding limitations and program design. Medical van transportation for clients was also available in some communities; however, access to transportation was limited as a result of geographical isolation, financial constraints, inadequate vehicles, and lack of medical van drivers.

Research Design

As part of a larger study on palliative care needs in First Nations communities, data collection involved a two-stage process that began in 2005 and concluded in 2006. In the first stage, we collected quantitative and qualitative data through surveys. In the second stage of data collection which included focus group interviews, we used the survey findings to develop the focus group questions. The study received approval for conducting it from Lakehead University's research ethics board.[4] We used cover letters and consent forms to obtain consent, initially from the Chief (on behalf of the community) and then from individual participants.

Sampling

Sampling in each community was purposive. We invited each community to select people with experience in caregiving. With the assistance of local health care providers, we identified 20 key informants from each community who had knowledge of the health care and social support needs of older residents with health problems. All participants were volunteers. In addition, we identified a total of 260 participants to complete the survey, representing the perspectives of the following four groups: (a) Chief and Council; (b) health care providers; (c) Elders[5]; and (d) community members who were 18 years of age or older and had experience in providing care to elderly individuals. Each community was asked to recruit approximately five participants from each of the four groups. The questionnaire did not require respondents to identify which group they belonged to. Health care providers who participated in the survey included community health representatives, home and community care coordinators, long-term care coordinators, home support workers, community wellness workers, nurses, homemakers, health directors, and diabetes educators.

In the second stage of data collection, the First Nations researcher conducted focus groups in ten of the 13 study communities. A total of 70 individuals participated in the focus groups, including people who had previously completed surveys and also those who had responded to a general invitation which was posted in each community. Individual interviews were conducted with

eight key informants in the remaining three communities because it was not feasible to organize a focus group. We recorded focus groups and interviews with the participants' permission and later transcribed them verbatim for analysis.

Data Collection and Measures

As per the ethical principles established for Aboriginal research (Brant Castellano, 2004), we developed survey questions in collaboration with two First Nations project advisors from the partner organizations to ensure that the questions were relevant and asked in a culturally appropriate way, and to verify content clarity and level of readability. The questionnaire consisted of 21 open-ended and closed-ended questions, including categorical, Likert scale, and multiple-choice questions. The questionnaire addressed three overarching themes: (a) awareness, understanding, and perceived access to palliative care resources within First Nations communities; (b) community values and beliefs related to death, dying, and the preferred place for end-of-life care; and (c) service and educational needs of community caregivers in First Nations communities. This article focuses on data that explore peoples' social, economic, health, and caregiving experiences in their communities; it does not include the two themes that specifically focused on palliative care.

Survey data were collected on site in each community by two trained First Nations community project assistants living in the area, one of whom was fluent in the Ojibwe language, and they requested individual consent from participants when the surveys were distributed. Most surveys were completed independently; however, when language, literacy, or frailty issues were a barrier to completion, the project assistant interviewed the key informant and completed the survey on their behalf. Altogether, of the 260 community members who were asked to participate, 216 respondents completed the surveys, for a response rate of 83 per cent. Respondents included 132 females and 111 males, ranging in age from 18 to 61 and older. The largest group of respondents (33%) were between the ages of 31 and 40, followed by those aged 41 to 50 (19%), 30 years old and under (19%), and 51 to 60 years old (11%). Eighteen per cent of respondents (23 people) were over the age of 61.

We analyzed the survey data and used the findings to develop a set of open-ended questions that we later asked in focus group interviews in each community. These questions were designed to further explore and clarify issues emerging from the survey results. We discussed the anonymized findings and focus group questions with the First Nations partner organizations to ensure the questions' relevance and appropriateness.

Analysis

The analyses were completed by a First Nations researcher[6] who was familiar with the communities and their culture and who also conducted the focus groups and interviews for this study. These analyses included descriptive statistics on the numerical data obtained from the survey, and content analysis of the data obtained from the open-ended survey questions. Qualitative data from the focus groups and interviews were transcribed verbatim from audio recordings and analyzed thematically line by line, using accepted principles of analytic induction (Miles & Huberman, 1994). We first analyzed data for each community because research participants consistently described their own experiences within the context of their home communities. Themes from all 13 communities were then grouped to form the conceptual categories for the analysis.

Every community received two copies of the final report: one was directed to the Chief and one was directed to the local health care providers. In addition, we presented the results back to communities through their preferred method which included community meetings, health fairs, and formal conversations.

FINDINGS

The survey data indicated that 69 per cent of respondents from First Nations communities would prefer to remain living in their community right up to their death if services and supports were available and adequate. Thus, there was a strong preference by community members and formal caregivers for helping elderly people to age and die at home.

We have organized the barriers and challenges to First Nations' communities achieving the goal of aging and dying at home by means of a social systems perspective. This perspective focuses on the interrelationships between people and the multiple levels of their environment – family, community, organization, and the broader society. Further, it considers health and well-being to be influenced by multiple physical and social dimensions within these environments as well as by the personal attributes of individuals involved (Best et al., 2003). A systems perspective lets us tackle complex issues, such as the provision of health and social care to elderly First Nations people, by our stepping back and viewing multiple levels and dimensions of the issue and, just as importantly, the interrelationship of these parts. The relationship of parts cannot be treated out of context of the whole; the focus is on relationships or processes at various levels within the system (Ritzer & Goodman, 2004). Multiple points of intervention can thus be identified that target different factors that

impact on health, in efforts to create social change in complex problems (Best et al., 2003).

The systems perspective is a particularly useful approach to understanding the health and well-being of the Aboriginal older adult population. It allows for the examination of findings in a way that can relate to the Medicine Wheel and therefore is most likely to provide researchers with insight on issues from the Aboriginal perspective. Using the systems perspective as a conceptual framework, we organized the research findings into three themes: (a) *Aging in First Nations communities:* lack of family caregivers, strained health human resources, changing community values; (b) *Relationship of the community to the health care system:* limited access to professional health services, lack of culturally relevant and safe care; and (c) *Relationship of the community to the government:* education policy, housing policy, sense of disempowerment.

Aging in First Nations Communities

The findings suggest that the traditional First Nations family system is changing, with an increased reliance on formal care. Some communities are also experiencing a breakdown of family and community networks, with traditional values becoming less important. The dynamics within the communities are changing.

Lack of Family Caregivers

A number of participants commented on the changes in the traditional extended family system within their communities. Lack of sustained economic opportunities in the community is forcing many young people to look for work outside the community. Consequently, as one Elder said:*"Elders are left to care for themselves; there are no longer family members in the community to provide care"*. With the out-migration of youth and middle-aged women to larger, non-Aboriginal communities, the traditional intergenerational family caregiving system is breaking down, and providing informal care to elderly people is becoming a problem. A community member commented:

> Our Elders sometimes don't have family and have to live on their own. They get lonely. You have to start thinking about putting them in a long-term care facility because you are not going to be able to be taking care of them in the home. So they don't really have a lot of choice, which is sad.

Many family members experience ambivalent feelings when the elderly need their help and support; they are torn between their personal obligations, for example work, and the wishes of the loved one. A community and family member observed:

> My mom is in the hospital right now and she would [be] telling me "I want to die at home", and I started to agree with her but the problem now is who is going to stay with her when she gets out of the hospital? The four of us are working, my brothers and sister. We don't have – like, I don't like to say it, but we don't have the time to be with her because we are all working. But the problem is I can't find anybody to live with her.

The communities, out of necessity, are starting to rely more on the formal health care system to take care of their older members. Many respondents felt that the formal programs are needed but they also saw the importance of the family to become more involved. As one health care provider said, *"These services aren't there to take over the role of the families."* A community member opined that *"The family has to provide a safe environment for the Elder."*

Strained Health Human Resources

Due to unavailability of family members, we found a growing dependence on paid community caregivers. However, limited health human resources create a heavy reliance on a very few people. A health care provider said: *"When I was in the hospital, they asked me 'do you have a CHR [Community Health Representative] on your reserve?' I went, 'I am the CHR.' That didn't work out too well for me."*

Given the lack of health professionals, we found many community members and personal support workers taking on medical roles for which they are not qualified and for which they have no training or experience. One health care provider related the following:

> I was in the hospital with appendicitis. And they didn't want to let me go home unless I had someone to come and change my dressing for me 'cause I had a surgery right across my stomach. And I wanted to come home so bad because I've been in there for awhile and so I asked my doctor "Is it possible that you guys could teach my husband how to do the dressing so that I could go home?" [The doctor said] "Yeah, it's possible, that's if your husband is willing to come in and make a promise that he doesn't pass out when he sees it".

A different perspective was offered by a personal support worker:

> I have a couple of clients where I have to sort out their medications. And we have to put them into those huts [pill containers]… I was told "You can't do that because we could be liable." But there is no one else to do it … and I was thinking, I was almost intimidated for awhile because I had no idea how to even pronounce some of these pills they're taking. Much less what they're for. And you got to know which pills to put where.

Several participants illustrated the hardship that community members experience when trying to access local services.

> *We need 24 hour care at times…we only have one PSW [personal support worker]. We have a homecare nurse who comes Wednesdays. That's it.* (Health care provider)

> *I think that we need an emergency response team in our community because when there is an emergency, the first one they look for is this one CHR [community health representative]. And she can't deal with the whole community. She needs other people to help her. And sometimes she's not always here. She can't be on call 24 hours a day; she's got to have her own life too."* (Health care provider)

We found the availability of support services within the local communities to be minimal and often poorly coordinated. The concern about the shortage of local personal support workers was expressed in every community. A health care provider noted that *"People need more care than that; sometimes family members can't always help do everything."* Our study identified many causes, including the shortage of trained personnel, lack of formal education of people in the community, and lack of available training.

> *We do have [a] home care program but we need training. We had one person who was discharged from the hospital that needed bandages changed and we couldn't provide that service … we are not properly trained, and our nurse only comes once a month.* (Health care provider)

> *There were three people taking [a] PSW course and only one graduated but she left the community. I have homemakers that I work with and they need that training.* (Health care provider)

Changing Community Values
Participants spoke about the importance of family and community networks, the value placed on the relationships they have with one another, and the connections they feel. They discussed their *"respect for one another"* and how they value their relationships since, as a Chief and Council representative commented, the *"Creator made man and that's the relationships that we have with one another … that is just the circle of life."* However, some study participants expressed a concern about family and community networks breaking down. They saw changes in how elderly are viewed within the community.

> *What I think it is, [is that] the young people and the Elders are not mixing together … we don't go enough to our Elders on the reserve … there are a lot of Elders that you could learn from but nobody does that. Then the Elders, they ain't coming out,*

> *either, so you know it's kind of a stand-off.* (Community member)

Some participants talked about disrespect towards the elderly they observed in their community. One Elder said: *"Young people, they walk by, they won't even look at you. They won't even help you. I walk to town; nobody wants to spare a ride."* Others felt that elderly people are ignored or even neglected. A community member said that *"Our Elders are being neglected at times. This is not right. When older Aboriginals turn a certain age, they should be looked after 24/7. They need more services for them in their homes."*

Increased dependence on the formal system has resulted in large measure, it would appear, from the out-migration of middle-aged women who have traditionally provided Elders with the majority of support. Out of necessity, community members are taking on new health and support care roles, often with minimal or no training. Members of the community show a strong reliance on the relationships they have with each other, even as they experience the breakdown of family and community networks. Traditional practices of respect for elderly members and intergenerational mutual aid are eroding, accompanied by a disconnect between elderly members and youth.

Relationship of the Community and the Health Care System

Limited Access to Professional Health Services
Many study participants commented that the geographic isolation and remoteness of their communities from larger urban centres has contributed to restricted access to health care and support services, and to the lack of services available in their communities. The respondents pointed out that transportation to a larger town can present a problem, especially at night, due to road conditions and/or long distances from the home community. Some First Nations communities do not have health centres; moreover, transportation costs to the larger urban communities can be a financial strain on the family. The nearest larger community can be at least one hour away by car; a larger urban centre with specialized medical care is even farther away. Many elderly people do not have cars and may not have someone to drive them – instead, they may have to take a taxi to urban centres. Thus, transportation from the home community to health centres or a regional hospital can present the family with a financial and emotional hardship. As one community member commented, "I was taking the bus from [name of First Nations community] all the way to Manitoba to be with my dad in the hospital … I must have [made] at least fifteen trips with no help at all from anyone."

The community, as a whole, experiences financial strain if a family is unable to afford the costs. Often, the First Nations Band Administration Office must provide financial assistance to the family for travels, meals, and accommodation, which can further burden the band's financial status.

A number of study respondents commented on the community's needs for increased, reliable professional health services. In particular, they noted a deficiency in home nursing services, with nursing care available only during regular working hours and not on the weekends. In some communities, the community health nurse might come once or twice a week, but only if she is not detained in some other community. Preventive health services are considered almost nonexistent, which is a concern in communities with a high prevalence of diabetes, hypertension, and arthritis.

> We should have someone to come and check on all seniors but nobody comes. We should have our blood pressure and our sugar taken and somebody should go in and make sure some people take their medication but nobody does. (Elder)

Lack of access to health services in the study communities presents a challenge to the elderly population and also to those who try to assist them. Some communities are not located on regular public transportation routes; therefore, isolation poses an additional challenge. The cost of transportation and lodging to access the needed medical services can be a financial burden, to individuals and their family as well as to the community.

Lack of Culturally Relevant and Safe Care

Cultural sensitivity and language barriers were identified as issues by many elderly study participants. The literature indicates that existing health care services are undergoing cross-cultural challenges and that potential inequalities might exist between Aboriginal and non-Aboriginal patients receiving care (Gao et al., 2008). Most health care providers lack the information to understand how culture influences the clinical encounter and the skills to effectively bridge potential differences. Clinicians, their patients, and the families may have different concepts regarding the nature of the disease, expectations about treatment, and modes of appropriate communication beyond language (Kagawa-Singer & Kassim-Lakha, 2003).Participants spoke openly about their experiences concerning the lack of culturally relevant and safe care in health care environments outside the First Nations community, such as hospitals and long-term care homes. Said one Elder:

> A lot of the long-term care facilities around here aren't culturally sensitive and neither is the hospital. They are not sensitive to First Nations at all … one

> of the actual suggestions from a community member is having a long-term care facility for First Nations in this area so that maybe we can, you know, kind of bridge that gap for First Nations elderly and family.

Some participants expressed their frustration when accessing the health care facilities in larger urban areas. The lack of culturally relevant and safe care can make their experiences with the formal health care system difficult to navigate. Specifically, as one Elder said, *"They should have an Aboriginal person in there working on our behalf. There should be somebody right in there."*

Another barrier to quality health care is the lack of access to health care personnel who speak the native languages of First Nations communities. The First Nations Regional Longitudinal Health Survey (First Nations Information Governance Centre, 2007) noted that 22.3 per cent of surveyed people reported their First Nations language was the one they used most often in daily life. About one in 50 (2.2%) were categorized as First Nations unilingual, speaking a First Nations language but neither English nor French "relatively well" or "fluently" (First Nations Information Governance Centre, 2007). One Elder said *"I think they have a couple of [Aboriginal] girls [who work at the hospital] but they don't know how to speak [the language]."* Another Elder offered this example of what can occur as a result of language difficulties:

> *"This lady was there [in the hospital] … she was hollering [in her own language] that she needed to have a bowel movement. You know she is in a wheelchair, and if she had to go, she had to go in her pants. And that's what happens."*

The lack of culturally relevant and safe care, coupled with health care personnel's inability to converse in native language, can present a difficult situation for those elderly members who must use the formal health care system. Younger community members lack understanding of culturally appropriate health care interventions. Said one health care provider: *"Our Elders had this expertise at one time, but we no longer have that"*. Frustration and disappointment with service provision may lead to Elders' unwillingness to utilize these services.

Relationship of the Community and the Government

Within the broader social system, study participants noted that lack of education, suitable housing, and insufficient government support negatively impacted the health of elderly people in their communities. Specifically, the federal government controls much of the funding and decision making about community resources allocation to First Nations communities.

Education Policy

Participants spoke often about the lack of education of community members as a barrier to better services. A health care provider observed that *"Education is another thing. We [health care providers] can't take some of these training courses because we don't have a certain level of education. That's another [area] where we fell short."*

The survey data revealed a number of education and training needs. These included medical training (CPR and First Aid training), First Response training, diabetes education, foot care training, and medication awareness. Participants also reported a need for information sessions to help them understand a person's illness (symptoms, needed care, what to expect), training in the use of special procedures (dressings, tube feedings), and equipment. What's more, said a community member, *"No one is able to [qualified to] distribute medication".*

The need for psychological support training was another theme that emerged from participants' comments. This included grief support and counselling, identification of depression's signs and symptoms, and crisis management. Proper self-care, including stress management and relaxation therapy, was also reportedly needed. Another need that surfaced was for palliative care training which included workshops on palliative care education, advance care planning, recognizing the signs and symptoms of imminent death, and being knowledgeable about required care interventions.

Our study participants also identified a need for home support training for health care providers and the family, including the need for personal support worker and homemaking training. In addition, participants identified a need for education on personal care such as changing bedding, proper lifting techniques, and assisting with daily living tasks.

Additional educational themes that emerged from our study included spiritual and cultural training for health care practitioners and support personnel, including cultural sensitivity training and an understanding of First Nations traditional teachings and language.

Housing Policy

A major concern for study participants was the need for appropriate housing. Without healthy and safe shelter for many older members, the community's Elders are vulnerable. Participants believe that the government is not providing this needed resource. A health care provider zeroed in on the issue:

> We have a housing shortage in this community and we are overcrowding in some of the homes, and we also have mold issues. It got to the point where some of the houses had to be demolished; that raises health concerns for Elders, too.

In addition to new homes that the community requires, the adequacy of existing homes is questionable. Some of these homes need adaptation to better support the elderly population. As one community member remarked:

> I think it is very important that we have the infrastructure … they are not building houses [that are] handicapped accessible … so if you should move into one of the homes and that Elder is in a wheelchair, you almost have to do the whole house all over again.

Sense of Disempowerment

First Nations communities also expressed frustration in feeling they are not listened to by the governing bodies, and that their input is not taken seriously. Respondents identified several areas of breakdown in communication between the external sources and their community needs.

> The helicopter, when it comes – I've heard complaints about people that don't even need that kind of service. They could have just gone [to a care facility] on the medical van to save the costs. If we could make those diagnoses here instead of having to call the helicopter all the time …. (Health care provider)

> Why don't, instead of going to ten First Nations around here, have one building or one facility to take care of the really sick, and if they want to go back home, at least they would have it on a First Nations. You know, I think that's the important thing." (Elder)

The participants noted that the government is letting them down by not providing the appropriate support to serve the elderly population's needs. Furthermore, the participants believe their needs are not understood, and that their input regarding the communities' needs to provide care and support to the elderly is not considered. For example, said a community member:

> [We had] an Elders' home – yeah, it was a fairly big home, big building – and I was only there for a couple of years, and when the new government came in, they didn't follow through with the plans. They just disregarded the plans and turned [the home] into something else, more of a hotel kind of thing.

The participants raised numerous issues concerning the federal government. Essentially, they perceive the government as an entity which does not understand their needs and concerns, leaving communities to fend for themselves to find solutions. One of the concerns repeatedly expressed was a notion that government bases program budgets on the number of people within a First Nations community and not on the identified level of need. One health care provider responded

that *"The federal programs … go by population. They do not meet the needs of the communities, and the needs of the communities are higher than the population".* A community member likewise remarked: *"So what if there is only 50 people, something like that, eh? But if the need is there, it should be looked at and dealt with".*

DISCUSSION

The need to provide the required health care and social support resources to First Nations communities is amply demonstrated by the combined concerns generated by demographic projections of rapid aging within those communities, the overall status (and increasing prevalence) of chronic health problems, and identified barriers to accessing health and support services for elderly persons living on-reserve and in rural or remote areas.

The World Health Organization in 1978 identified access to health care as a principle of primary health care, stating:

> Accessibility implies the continuing and organized supply of care that is geographically, financially, culturally, and functionally within easy reach of the whole community. The care has to be appropriate and adequate in content and in amount to satisfy the needs of people and it has to be provided by methods acceptable to them. (World Health Organization, p. 28).

To properly assist rural and remote First Nations communities in caring for their elderly, all these aspects need to be considered.

The literature and the findings of this study clearly identify the need to address the lack of support given to the aging population in the First Nations communities. The findings illustrate the barriers and lack of resources which influence the current and future state of caring for First Nations elderly: (a) lack of family caregivers, (b) strained health human resources, (c) changing community values, (d) limited access to professional health services, (e) lack of culturally relevant and safe care, (f) education and housing policies, and (g) a sense of disempowerment.

The research findings demonstrate that participants understand and accept the geographic reality their communities face; however, their main concern relates to the lack of support to overcome the obstacles associated with this geographic reality. Some communities, both on an individual and a community level, struggle with the high monetary costs of obtaining needed services and with the limited financial support received when members must travel outside the community. Increased financial support by the federal government to the community as a whole, based on the identified

need by the residents and not on the number of population, would enable an increase in the number of personal support workers to aid the community's elderly population.

Although family and community networks within First Nations are still strong, the dynamics are changing. Many younger First Nations people are departing for larger urban centres, leaving few behind to take care of elderly members. Increased reliance on formal care, however, cannot fill the gap created by the out-migration of younger population. Many Elders are forced to care for themselves or to seek placement in long-term care facilities outside of their communities.

In addition, traditional values are less observed, resulting in reduced respect towards the Elders and in a disconnect between them and youth. The importance of family and community networks for the well-being of the community and its Elders is observed, and our research shows a need to reinforce these networks, and for the communities to reconnect with their traditional value system, which will enhance the connectedness between the Elders and the younger generation.

Another need identified from our study is enhanced training of local health care and support providers such that the community can utilize them without seeking outside resources. In recognizing the reality of community members' low levels of formal education, government should adopt intensive education and training programs as the main intervention to improve access to better services.

Sporadic or limited professional health services are also a reality for most First Nations communities. Paraprofessionals and laypersons are assuming professional roles, often beyond their capacity or comfort level, to provide urgently needed services. For the elderly population to receive appropriate care, professional services such as nursing or emergency response should be available in the community on a regular basis and, certainly, when exceptional needs arise.

The research indicates that the lack of culturally relevant and safe health care services and support outside the community is another area of concern. Cultural values, beliefs, and practices among First Nations communities are diverse, and for the most part not incorporated into the health care of the First Nations population. The literature has shown that the Aboriginal elderly population is more likely than not to observe traditional values and to use their native language as a primary means of communication (NAHO, 2006). Some Elders prefer to stay in the home community, without needed health care, rather than access services that lack cultural sensitivity or whose practitioners lack the ability to converse in native language.

The broader social system, specifically governing bodies, also contribute to the lack of appropriate support for the First Nations elderly population. The government is perceived as an entity that does not understand the community's needs and does not provide the services perceived as necessary to take proper care of the Elders. Our research further demonstrates alienation from and mistrust by the First Nations communities towards the governing bodies, as well as pervasive feelings of misunderstanding and disempowerment.

CONCLUSION

First Nations teachings emphasize interrelationships among all things, whether animate or inanimate, as well as the need for harmony and balance as integral to a sense of wellness. There is recognition that, to achieve wholeness, individuals must attend not just to their physical selves but also to their emotional, spiritual, and mental selves (Peacock & Wisuri, 2002). The well-being of the individual, the community, and the broader society are interdependent and are influenced by the physical, social, and interpersonal environments.

The health and well-being of the aging population within First Nations communities needs to be understood from a social systems perspective. The underlying concept in a systems approach is that to change a situation perceived as undesirable, the whole system must be considered. With this approach, instead of fixing one component of the system, a system innovation is created. Changes reached in this way are more sustainable, and we can thereby prevent short-term solutions by avoiding a focus on symptoms only (Naaldenberg et al., 2009). Likewise, the Medicine Wheel emphasizes connectedness: that all parts must interact harmoniously (Chansonneuve, 2007; McCormick, 1995). If we fragment the experiences of First Nations communities and focus on solving only one issue, without any attempt to understand the whole system, we will not produce a meaningful change in the care of the elderly who live in rural and remote communities.

End Notes:

1   The term "Aboriginal" refers to the descendants of the original inhabitants of Canada, as defined by the Constitution Act, 1982 (Indians, Inuit, and Métis). The data provided by Statistics Canada and many academic papers do not distinguish between these three groups; therefore, the term "Aboriginal" is used. However, the term "First Nations" is preferred over Indian and used by many people when referring to themselves as a collective group, including the residents of communities where the research took place. Therefore, for the purpose of this article, we use the term "First Nations" only when specifically discussing the population studied.

2   The meaning of rural used in this article is based on the definition of "rural and small town" developed by Statistics Canada: rural Canada includes those towns and municipalities that have a population of fewer than 10,000 people, and are located outside the commuting zone of urban centres larger than 10,000 population (du Plessis, Beshiri, Bollman, & Clemenson, 2002). Remote refers to proximity to urban centres. The term isolated is also used. In this article, we use the following definition: a remote or isolated community has limited services and resources, and is a distance of 80 km or four hours travel time, or more, from a major urban centre of 50,000 population (Rourke, 1997).

3   The Medicine Wheel is an ancient symbol of the universe used to help people understand things or ideas, which often cannot be seen physically. It reflects the cosmic order and the unity of all things in the universe (Hart, 2002).

4   Approval for conducting this study was received by Lakehead University's research ethics board. As none of the First Nations communities we worked with had formal research ethics committees (when such committees do exist, researchers are required to obtain their prior approval for projects), we worked directly with community Chiefs and council members to explain the project and obtain consent to enter the communities. We also used cover letters and consent forms to obtain consent from -individual participants. This study followed an integrative framework for conducting health care research, which consists of five components: (a) community capacity development, (b) cultural competence and safety, (c) participatory action research, (d) ethics, and (e) partnerships (Prince & Kelley, 2010).

5   Consistent with cultural protocol, the term "Elder" was defined by individual communities; researchers did not impose a standard definition on them. *Elder* was therefore defined in relation to community values and beliefs, and included individuals who were from a particular age group (i.e., 55 years and over) or advancing in age (unspecified), as well as individuals who held a particular status in the community as a result of their knowledge and teachings.

6   Holly Prince, co-author of this article.

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