

# The Role of Social Work in Palliative Care: A Comparison across Canada's Three Northern Territories

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## Abstract

A qualitative research study was conducted in northern Canada in 2007 which examined the realities and issues surrounding palliative care with seniors in remote northern settings. As a profession with a recognized role in supporting those who are dying and those who are bereaved, social work has been integral to the development of palliative care support services in northern Canada. However, in regions of the North where the social work profession is less developed and less recognized, the role for social work remains understated.

**Keywords:** Canada, northern, remote, social work practice, dying, palliative care, end-of-life care, seniors, old age

## Introduction

This article will report on a qualitative study conducted in Canada's northern territories to gather information about the realities and issues surrounding palliative care with seniors in remote northern settings. Through this original research, the role of social work practitioners in the provision of palliative care services with seniors was explored.

In 2007, focus groups and individual interviews were conducted with social service practitioners, health care practitioners and volunteers who work with seniors receiving palliative care in the Yukon, the Northwest Territories and Nunavut, Canada. Due to geographic restrictions, interviews were conducted in each of the Territories' three capital cities only – Whitehorse, Yellowknife, and Iqaluit. Participants were identified primarily through Health and Social Service agencies, as well as through word of mouth. In total, 53 individuals were interviewed for this research study.

## Northern Canada

Although Canada's three northern territories cover a large geographic area, they support a relatively low population base. While the 2006 Census reports a total Canadian population of 31,612,897, the population of the Yukon is reported to be 30,392, the population of Nunavut is 29,474, and the population of the Northwest Territories (NWT) is reported to be 41,464 (Government of the Northwest Territories, 2008). Aboriginal identity is defined as those individuals who identify with at least one Aboriginal group – North American Indian, Metis or Inuit (Government of the Northwest Territories, 2008). The population of northern Canada is made up largely of individuals of Aboriginal descent. Approximately 19.1 per cent of the population in the Yukon identify as Aboriginal, while 62.5 per cent in the NWT and 88.7 per cent of the population in Nunavut identify themselves as Aboriginal (Statistics Canada, 2006). Due to the distinct nature of each of Canada's three northern territories, it is necessary to briefly discuss facts relevant to each territory.

The Territory of Nunavut was created on April 1, 1999 (Government of Nunavut, 2008). When the Nunavut Land Claims Agreement was signed by federal, territorial and Tungavik Federation of Nunavut (TFN) representatives in 1993, the decision was finalized to divide the NWT according to the unofficial borders that had divided the single territory into what was originally known as the *Western Arctic* and the *Eastern Arctic* (Indian and Northern Affairs Canada, 1994). Prior to the division of the territory, residents of the Eastern Arctic – now Nunavut – had followed a more traditional lifestyle. Through the establishment of a distinct territory, The Nunavut Land Claims Agreement has sought to ensure that this traditional lifestyle, language, and culture will be protected (Indian and Northern Affairs Canada, 1994). In addition to English and French, Inuktitut is one of the three official languages in the Territory, and is considered to be the *working* language.

There are 26 communities in Nunavut, with the largest being Iqaluit with a population of 6184. There is only one 21-kilometre government-maintained road in the entire Territory (Government of Nunavut, 2008). The majority of communities in Nunavut are accessible by air year round or by ship and barge during the short summer months. The population of Nunavut is considered to be relatively young, with 60 per cent of the current population under the age of 25 years (Government of Nunavut, 2008). The economic activities of the Territory include mining, tourism, fishing, hunting and trapping, and arts and crafts production (Government of Nunavut, 2008). Immigrants account for only 1.6 per cent of the total population of Nunavut (Government of the Yukon, 2008).

In the Northwest Territories, the most frequently reported ethnic origin is *Aboriginal* (Government of the Northwest Territories, 2008). There are eight distinct Aboriginal groups that are recognized throughout the Territory including the Dogrib, Yellowknives, Chipewyan, South Slavey, North Slavey, Gwichin', Inuvialuit, and the Metis (Government of the Northwest Territories, 2008). Overall, immigrants account for only 6.9 per cent of the population of the NWT (Government of the Yukon, 2008). There are 33 communities in the Northwest Territories, the majority of which are accessible by road year round. The more remote communities, like Tuktoyaktuk, are accessible by air and water or by ice road during the winter months. Yellowknife is the capital city with a population of 18, 510 (Government of the Northwest Territories, 2008). This Territory primarily has a resource-based economy and recent development has focused upon mining and natural gas exploration (Government of the Northwest Territories, 2008).

The Yukon Territory was created in 1898, two years after gold was first discovered. Mining still accounts for 30 per cent of industry in the Yukon with tourism having emerged as a close second. In recent years, there has also been development in the forestry industry and commercial fishing (Government of the Yukon, 2008). There are 17 communities in the Yukon, the majority of which are accessible by all weather roads. Whitehorse is the capital city with a population of 24,473. There are six distinct Aboriginal groups recognized in the Yukon Territory including the Kutchin, Han, Tutchone, Tlingit, Kaska, and Tagish. Immigrants make up 10 per cent of the total population (Government of the Yukon, 2008).

## Social Work in Northern Canada

In many ways, social work continues to be seen as a *developing* profession in northern Canada. Challenges for social work practitioners in northern and remote locations are numerous, and the unique nature of such practice is well documented in the literature (Bodor, 2009; Graham, Brownlee, Shier, & Doucette, 2008; Schmidt, 2008). Social workers practicing in northern and remote locations must be equipped to deal with a variety of challenges including "high visibility, high accessibility, dual or multiple relationships, access to too much information, *heightened scrutiny by community members, increased responsibility, and limited access to professional development*" (Schmidt, 2008: 2). The Governments of the Yukon, the Northwest Territories, and Nunavut continue to experience challenges associated with both recruitment and retention of all health related professionals, including social workers (CIHI, 2006).

The majority of practicing social workers and social service workers in northern Canada are employed by regional health and social service boards. Although there are only a small number of social workers in private practice, an increasing number of practitioners are employed by non-profit agencies. However, there are very few social workers who would identify as specialists, and most social workers in northern Canada are required to provide a wide spectrum of services, including palliative care support (Novik, 1998).

All three of Canada's northern territories offer some form of social work education. In the Yukon, Yukon College offers a Bachelor of Social Work degree which is brokered through the University of Regina in Saskatchewan. Through this program, social work students can complete an entire four year BSW on-site at the College in Whitehorse. In the Northwest Territories, Aurora College offers a two year diploma in social work. As part of a brokerage agreement signed with the University of Regina in 2002, students who complete the diploma can request to have the credits applied towards the completion of a BSW at the University of Regina. In Nunavut, Nunavut Arctic College offers a two year Social Services Worker Diploma Program on-site in Iqaluit.

Despite opportunities to pursue professional social work education in northern Canada, the numbers of practicing social workers in these regions remains quite low. Unfortunately, none of the three territories compiles data to identify exact numbers of practicing social workers. In the Northwest Territories, it is estimated that there are approximately 150 social workers (Government of the Northwest Territories, 2007), but similar estimates are not available for the other two territories. In other Canadian jurisdictions, provincial social work associations and regulatory bodies are able to identify numbers of practicing social workers. However, in the north, these agencies are not as developed and it is difficult to determine a precise number of professionally trained social workers.

In 1998, the Association of Social Workers in Northern Canada (ASWNC) was formed. Representing social workers in the Yukon, the Northwest Territories, and Nunavut, ASWNC became a member of the Canadian Association of Social Workers (CASW), which is the recognized national body representing the profession. However, ASWNC remains a membership organization only, and does not carry the responsibility to regulate the profession. In fact, the Governments of the Yukon and Nunavut do not have legislation in place to govern professional social workers. In 2010, the Government of the Northwest Territories officially brought in the *Social Work Profession Act* which will allow for the licensing of social workers beginning in 2012 (Government of the Northwest Territories, 2011). Prior to the establishment of ASWNC in 1998, there had been a number of other attempts to form a professional association in the Northwest Territories in the 1970s.

Due to the lack of opportunity for professional regulation of social workers in northern Canada, many northern social workers have chosen to register with provincial regulatory bodies outside of their own jurisdictions. For example, many professional social workers in the Yukon register with the British Columbia College of Social Workers and many social workers in the NWT have previously registered through the Alberta College of Social Workers. Only those northern social workers who register with other provincial bodies have been counted in the national statistics. In a recent Canadian Institute for Health Information document, it is reported that there were only 125 registered social workers across all three of the northern territories in 2005 (Bodor, 2009; CIHI, 2006).

Low numbers of social workers practicing in the Yukon, the Northwest Territories and Nunavut would suggest that there are few social workers involved in the delivery of palliative care support to seniors. Be that as it may, the role of the profession of social work in palliative care is well defined.

## **Palliative Care and Social Work in Northern Canada**

As a profession, social work has a long history of working with both people who are dying and with those who are bereaved (Holloway, 2009). According to the Canadian Hospice Palliative Care Association, palliative care is a special service that provides health care to both individuals and families who are living with a life-threatening illness that is usually at

an advanced stage (CHPCA, 1997). The goal is to provide comfort and dignity for the person living with the illness as well as to ensure the best quality of life for both the individual and his or her family. Relief of pain and other symptoms is an important objective, along with meeting not only physical needs but also the psychological, social, cultural, emotional and spiritual needs of each person and their family (CHPCA, 1997). According to a UK study, individuals who had previously held widely negative views towards social workers overwhelmingly reported valuing the experience of working with a specialist palliative care social worker when given the opportunity (Beresford, Adshead, & Croft, 2006). The National Association of Social Workers (2010) provides a clear profile of the role of social workers within a palliative care environment. In Canada, specific social work competencies for practice in hospice palliative care have been developed (Bosma, Johnston, Cadell, Wainwright, Abernethy, Feron, Kelly, & Nelson, 2008).

There has been notable research which has demonstrated differences in accessibility to health care and social services in rural settings as opposed to urban settings (MacLean & Kelley, 2001). Palliative care is an aspect of health services that is seen to be particularly important in rural and remote areas due to the fact that most people would prefer to die in their home community (Hotson, et al., 2004; MacLean & Kelley, 2005).

Individuals from rural and remote communities are often referred to long-term care and urban hospitals when they are in the later stages of terminal illness and are nearing the end of life (Hotson, et al., 2004). Currently, the availability of palliative care services in the Northwest Territories and Nunavut is quite limited (Dunbrack, 2003; Fast, Niehaus, Eales, & Keating, 2002; Government of the Northwest Territories, n.d.; Government of Nunavut, n.d.). However, recent developments in the Yukon have increased palliative care supports within that particular Territory (Yukon Health and Social Services, 2010).

Palliative care support services and the role of social work are unique to each territory in northern Canada. Specifically, palliative care services for seniors in these regions appear to be driven by the specific needs of respective populations, the intricacies of unique cultures, and the impacts and pressures of economic realities and development.

## Research Method

This study took the form of a multi-site focused ethnography designed to seek an understanding of perceptions of palliative care services available to seniors in Northern Canada. A focused ethnography collects data intensively over a period of time that is much shorter in comparison to the extensive time spent in the field conducting more traditional ethnographic research (Hornberger & Kuckelman, 1998; Knoblauch, 2005). Within this approach, data is typically collected through technology recording along with incorporation of reflective process notes (Knoblauch, 2005). As such, the primary researcher for this study spent a period of one month travelling across Northern Canada conducting face-to-face focus groups and interviews with 53 individuals representing social service practitioners, health care practitioners and volunteers working with seniors receiving palliative care in the Yukon, the Northwest Territories and Nunavut. The individuals who were interviewed included, nurses, physicians, home care staff, social workers, First Nations Liaison staff, pharmacists, recreational therapists, hospice staff, language interpreters, and family members of seniors who were former palliative patients. Philosophically, ethnography falls within the emic, meaning that it involves an analysis of cultural phenomenon from the perspective of one who participates in the culture under study (Knoblauch, 2005). To build further upon these ideas, this study embraced critical theory as an approach to seek an understanding of the cognition and behaviour of research participants within their particular cultural and social frameworks.

Prior to the commencement of the data collection process, extensive ethics reviews were

conducted specific to each territory. This process, governed by official research bodies in each territory, included in-depth written application and research explanation as well as participation in various stakeholder meetings. The primary researcher participated in each of these meetings via conference call. Following this process of discussion and rigorous review, a research licence was granted by each territory. The regional hospital in the Northwest Territories also required an independent research ethics review in addition to the territorial review. This specific process also required written application and participation in community stakeholder meetings. Finally, this research was also approved by the University of Regina Ethics Board. From beginning to end, the ethics review process spanned a period of five months. As a result of this review process, and partially due to the various research guidelines in place within each territory, the decision was made to exclude current palliative care patients in the study. Instead, the research would include family members of *former* palliative care patients. This extensive preparatory process in advance of beginning the field work is indicative of a research study utilizing focused ethnography.

A purposive approach of snowball sampling was utilized in order to identify study participants. These individuals were asked questions that focused upon the types of services and supports available to seniors who are palliative in each respective community and the manner in which their pain is assessed by care providers. Interviewing is seen to be one of the most frequently used qualitative methods of data collection (Lincoln & Guba, 1985). Both the focus groups and individual interviews followed the same general format. All of the interviews were tape recorded with the permission of the participants. Detailed process notes were completed following each interview and focus group. The incorporation of critical theory typically incorporates reflexive inquiry into its methodology. As a researcher, it is therefore important to attempt to recognize and articulate one's own perspective as a means of acknowledging the biases that one's own limitations, experiences, and institutional standpoints may bear on the collection and analysis of data.

Once the interviews and focus groups were all completed, they were transcribed by an independent contractor. These detailed transcripts were then analyzed using a thematic analysis based upon the main areas explored during the interviews. The process notes further informed data analysis since they recorded impressions of body language, facial expression, and dynamics evident during the focus groups. The data analysis was completed using a regular word-processing program that allowed for the sorting of data into emergent categories. As meaning units were identified during first-level coding, categories were established, and codes were subsequently assigned to each category. This intensive approach to data analysis allows one to become completely involved in the data and presents an opportunity to view the information holistically (Grinnell & Unrau 2005).

## **Findings – The Role of Social Work in Palliative Care**

The significant differences between each of the three Territories were evident in the results of this research study. The unique physical, social, cultural, and historical factors of each Territory have resulted in unique circumstances and services for seniors receiving palliative care support. The findings from each individual territory will be explored in more detail.

### **Nunavut**

As discussed earlier, Nunavut has a relatively young population. As such, the number of seniors requiring palliative care support appears to be very low. Whenever possible, most seniors prefer to remain in their own communities to die. However, those who live in Iqaluit most often prefer to die in the hospital. It has been speculated that these seniors view this option as potentially creating less of a burden for their families. As well, a stay in the

hospital can actually increase the amount of company and community support that they receive and this support is perceived to have a positive impact on the death experience.

There were no social workers familiar with palliative care available in Nunavut to be interviewed for this study. Those individuals who were interviewed included nurses employed in the hospital setting, community nurses employed through home care, home health aides, a language interpreter, a physician, and a family member of a former palliative senior. Although these participants all described a team approach to palliative care, none of the people interviewed explicitly identified social workers as being a part of that care provision team. However, an Inuit and Cancer Fact Sheet released in 2009 does identify social work as part of the palliative team stating, “[P]alliative care involves a partnership between the person who has cancer, his or her family and friends, and the members of the health care team. This team may include the services of a doctor, nurse, social worker, counsellor and spiritual advisor” (Inuit Tapiriit Kanatami, 2009).

Although the traditional lifestyles of the Inuit are beginning to change, some changes are slower than others. At the time of this study, there was only one small care facility for seniors in Nunavut and that facility, located in Iqaluit, was not staffed by registered nurses, social workers, or professionals with medical backgrounds. Some of the staff members had received minimal training similar to that of a home health aide. Currently, there is no specifically defined palliative care team available in the territory, and there are no hospice services. In many Inuit communities palliative care services are virtually unknown and non-existent. Care of the dying is most often provided by family members who often lack appropriate support and skills (Inuit Tapiriit Kanatami, 2009).

## Yukon

The Yukon Territory of northern Canada has a well developed palliative care support system for seniors and other members of the population. There were a total five social workers interviewed for this study from the Yukon, as well as nurses (hospital and community based), a physician, hospice volunteers, a First Nations liaison, a pharmacist, and a family member of a former palliative senior. Social workers were consistently identified as being an integral part of the palliative care team by everyone interviewed. It was evident through the interviews that social workers are working in palliative care in the Territory and that they are being recognized by the allied professions as possessing a valuable and desirable skill set. One of the social workers interviewed for this study talked specifically about what social workers bring to a palliative care team, “...[A]nd I think we’re [social workers] the continuity...”. Another social worker also talked about the specific role of social work in palliative care but she expanded further by suggesting that social workers need to do a better job of making their particular skill set and value base known,

[I] think that’s the benefit that we can bring to it – is that ability to see the big picture, get it? I think we need to do more work around how we, as social workers operate when we have a palliative care client, how we can support, you know. Because I think it’s important for continuity. Again, who is going to be the consistent person?

At the time of this research study, there were a wide range of palliative care services and supports available to seniors, and the Yukon offered hospice services as well as palliative care coordination. Many of the registered nurses, physicians, and social workers in the Territory had received palliative care training through the Victoria Hospice Program. In 2008, the Government of the Yukon launched a Collaborative Integrative Hospice Palliative Care

Program. Social workers are identified as being an integral part of this multidisciplinary hospice palliative care resource team (Yukon Health and Social Services, 2010).

## Northwest Territories

Although the Northwest Territories does not offer hospice services, the Territory does have an identified palliative care working group. However, at the time of this study, the working group was not functional, and had not met in over a year. Individuals interviewed in the NWT included nurses (hospital and community employed), representatives from Home Care, two physicians with specific palliative care training and interest, staff from a long term care facility, two social workers, a First Nations Liaison, an interpreter, one member of the clergy, and a family member of a former palliative senior. All of the participants described a “team approach” to the provision of palliative care for seniors, and social work was consistently identified as a part of that team. One of the nurses described that team as follows,

[T]he other things that we do at the hospitals here is we bring together the nursing staff and social work and a physician. If somebody is from the community and they are dying and the patient and the family have come to that understanding, then we'll work with them in that way.

One of the social workers also described the function of the team, and her role within that,

My involvement comes in; somebody will be admitted; there'll be a general assessment by me, by the physician, the internist, the resident and it's clearly pain management. We'll have big conferences; we'll discuss it.

Another social worker also more specifically described her role in palliative care as follows:

[A]nd my role is to go in and figure out what is the important pieces in this family's life, this person's life, and the person is rarely alone, rarely alone. The person comes with, you know, family members and a person comes with history and experiences and all of those things. So I figure out what's the most important things to them, and how they manage. And oftentimes it's like how, when you've had a difficult problem or a big, big challenge and, you know, sometimes it's like what are the challenges that you've had in life? [T]hen you can begin to figure out what is of value. Like if you can figure out what is of value in that person's life or in that family's life, then you'll understand that. Because every value, every person has different values.

The social workers from the NWT identified a number of tasks specific to their roles with the palliative care team including: the provision of support to the dying individual and his/her family; ongoing assessment; case management; and assistance with travel and funeral arrangements. They also talked about their role in providing support to the rest of the palliative care team,

[S]ometimes it's something very simple, and you go, “oh”. And then sometimes it's more complex. So yeah, you know, and the sad thing is, too, that I find a great sadness in; unfortunately, some people dying when they're alone. You often get and this is the where I have to work with the staff. They get so mad. We've got, you know, someone who's dying and it's so sad and she's all alone and she wants her kids to be here and they're not coming here and then we find out that she was horrible to them for all their life and is mean and miserable and so you go, so you think “okay”. There's so many heartaches here, so many heartaches. And these ... and it impacts the staff....

## Concluding Remarks

The main focus of this study was to gather information about the realities and issues surrounding the provision of palliative care to seniors in northern Canada. There is no question that social workers have a recognized role in palliative care service delivery. However, the extent of this role for social workers in palliative care as delivered in northern Canada directly reflects the state of the social work profession within each respective territory. In the Yukon, where social work is more recognized and there are a variety of opportunities for social work education, social workers appear to have more of a pivotal role in the delivery of a well established palliative care program. In the Northwest Territories, social work also has a clearly defined role in palliative care delivery as part of a larger team. Again, there are more options for social work education in this Territory and social work, as a profession, appears to be seen as having more relevance within the health care system. In Nunavut, social work continues to develop as a profession, and there are not high numbers of social workers employed within the health care system. Perhaps indicative of that reality, social workers were not identified as having a role in palliative care provision by those who were interviewed.

The idea of professional care for the dying is not new to social work. However, as this study demonstrates, this area of practice has special challenges for social workers in northern and remote communities. These challenges include a lack of training and educational support from employers and the lack of professional skill recognition by service-users. Once it is entrenched in the practice area of palliative care, the profession of social work can play an important role in supporting individuals, families, and communities in northern Canada. However, this will only occur when the profession is fully developed and recognized; and when social work practice is professionally regulated across all three northern territories.

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