Palliating inside the lines: The effects of borders and boundaries on palliative care in rural Canada

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**Abstract**

We draw lines to divide our world into specific places, territories, and categories. Although borders and boundaries are dynamic and socially constructed, their existence creates many broad impacts on our lives by geographically distinguishing between groups (e.g., us/them; here/there; inside/outside) at various scales from the national down to the personal spaces of the individual. Particularly, borders and boundaries can be used to define a variety of differing spaces such as the familial, social, economic, political, as well as issues of access — including access to health services. Despite the implicit connection between borders, boundaries, and health, little research has investigated this connection from a health geography perspective. As such, this secondary thematic analysis contributes to addressing this notable gap by examining how borders and boundaries are experienced and perceived to impact access to palliative care in rural Canada from the perspectives of the formal and informal providers of such care. Drawing upon data from qualitative interviews (n = 40) with formal and informal palliative caregivers residing in four different rural Canadian communities, five forms of borders and boundaries were found to directly impact care delivery/receipt: political; jurisdictional; geographical; professional; and cultural. Implicitly and explicitly, participants discussed these borders and boundaries while sharing their experiences of providing palliative care in rural Canada. We conclude by discussing the implications of our findings for palliative care in rural Canada, while also emphasizing the need for more health geography, and related social science, researchers to recognize the significance of borders and boundaries in relation to health and healthcare delivery. Lastly, we emphasize the transferability of these findings to other health sectors, geographical settings, and disciplines.

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Regardless of the scale, we draw lines to divide our world into specific places, territories, and categories (Newman, 2006; Kolossov and Scott, 2013). These lines result in what we commonly refer to as borders and boundaries, signifying limits or discontinuities in space (Popescu, 2010). As a distinct field of academic inquiry, border studies emerged in the early 19th century as an interdisciplinary field that covers a range of concerns such as state sovereignty, globalization, and resource management (Kolossov and Scott, 2013). Although the study of these geographic constructs has been, and continues to be, prevalent within the discipline of geography (Hagen, 2015), their importance in shaping experiences of health and healthcare is presently under-researched (Wastl-Walter, 2011). Here we contribute to addressing this notable gap with an analysis that aims to empirically investigate how borders and boundaries are perceived to impact access to palliative care in rural Canada. To do this, we draw on the findings of a mixed-methods study that investigates ways to improve access to palliative care in rural and remote Canada (see Crooks et al., 2011b). When discussing experiences of palliative care with formal and informal providers (n = 40), references to various forms of political, natural, and socio-cultural borders and boundaries were commonly raised. In examining this theme in depth, we not only address the call for more researchers to examine the experiential perspectives...
of borders and boundaries (Newman, 2006; Kolossov and Scott, 2013), but also provide new insight with respect to how large scale systems, such as the Canadian healthcare system, are experienced in relation to smaller scale and ‘localized’ borders and boundaries. This allows for the identification of gaps in service provision and provides information for decision makers on ways to enhance the provision of palliative care in rural Canada.

Although the context of this paper is situated in Canadian rural palliative care, we believe that our borders and boundaries ‘lens’ is analytically useful not only for health and healthcare geographers, but also for those from other health-related disciplines who intend to examine the effects of borders and boundaries across diverse geographical settings. In the following section, we introduce and define our use of borders and boundaries and then provide a brief background on palliative care in Canada.

1. Borders and boundaries

Traditionally, borders and boundaries have been defined as the physical outcomes of political processes that result in one-dimensional distinct lines that compartmentalize our world into political and/or legal territories (Hagen, 2015; Kolossov and Scott, 2013). However, understandings of borders and boundaries have progressed remarkably. Rather than being seen as tangible, fixed, and static, borders and boundaries are increasingly characterized as processes that are constantly changing, fluid, and socially constructed (Kolossov and Scott, 2013; Hagen, 2015; Newman, 2006). Typically, there is no distinction between the terms ‘boundary’ and ‘border’ in everyday language; however, many use border to designate the formal political division line between territorial units, such as states, and boundary to signify the cultural and social group difference that may or may not be marked on the ground by lines of division (Popescu, 2010).

Regardless of whether we are aware, the social constructions and dynamic processes behind borders and boundaries create broad impacts on our daily lives by geographically distinguishing binaries not only between places, but also between groups (e.g., us/them; here/there; included/excluded) at various scales from the national down to the personal spaces of the individual (Newman, 2006). The process of ‘boundary making’ is highly complex as these lines have no fixed or natural meaning, ultimately resulting in different meanings and experiences for different actors (Hagen, 2015). Generally, borders and boundaries can be understood to define spatial units ranging from the familial, cultural, ethnic, religious, social, geographical, political, to the economic (Newman, 2006; Kolossov and Scott, 2013; Popescu, 2010; Wastl-Walter, 2011), which undoubtedly are connected to various issues of health and its effect on environmental health issues, such as pollution (Bashford, 2007; Di Chiro 2004), or on the global mobility of patients as they increasingly pursue medical care across transnational borders (Greenhough et al., 2015; Johnston et al., 2015).

Some researchers have investigated the health of those residing in borderland regions, for example the area that straddles the United States and Mexico border (Mier et al., 2008; Olson and Tapia, 2009). Another dominant theme looks to examine the health of those who have recently crossed trans-national borders as immigrants (Wang, 2014; Setia et al., 2011), migrant workers (Latif Alnasir, 2015; Chu-Hong et al., 2014), and refugees (Fellmeth et al., 2015; Isok and Wooksoo, 2014). Such research is directly associated with borders and health, yet, the existence, role, and power of borders tend to dissipate into the contextual background. Despite recognition that various forms of borders and boundaries exist and shape our everyday lives, no research to our knowledge has explicitly, and simultaneously, examined them in relation to health or access to healthcare. Considering this, there is a need for more health geographers and other social scientists to consider the ways that various borders and boundaries shape experiences of health and access to healthcare across the life course, including palliative care.

2. Palliative care in Canada

Palliative care is an approach that aims to improve the quality of living/dying for patients facing death and their families (World Health Organization, 2013). Such care can be provided in medical care settings where care takes place, whether a patient’s home, care facility, hospice, or hospital (World Health Organization and Worldwide Palliative Care Alliance, 2014). In Canada, palliative care typically involves services such as pain management, symptom management, psychosocial, emotional, and spiritual support, as well as caregiver support (Canadian Hospice Palliative Care Association, 2013), with providers being drawn from an interdisciplinary group of formal, informal, and allied health care professionals. Formal palliative care can be provided by an intersectoral team of physicians, nurses, social workers, chaplains, counsellors, nutritionists, pharmacists, and rehabilitation specialists (NCPQPC, 2009). There may also be disease-specific specialists involved in providing palliative care, for example cardiologists, neurologists, and endocrinologists (NCPQPC, 2009). Informal or family caregivers are those family members and friends who are generally untrained and unpaid, but provide a range of care across the continuum.

Eligibility for, access to, and availability of healthcare services, including palliative care, in Canada is largely dependent upon where one lives (Williams and Kulig, 2012). This is because of the decentralized nature of Canadian healthcare decision-making and the associated roles, responsibilities, and funding envelopes of various levels of government in providing such care (Carstairs, 2011). Provincial and territorial governments have primary responsibility for the delivery of healthcare services, including palliative care, as legislated by the Canada Health Act (1984), while smaller regional authorities hold responsibility for administering these services (Health Canada, 2015). The federal government is responsible for direct healthcare, and thus palliative care, service delivery for certain populations: First Nations peoples living on-reserve and Inuit, the military and veterans, refugee protection claimants, and inmates of federal penitentiaries (Carstairs and MacDonald, 2011; Health Canada, 2015). First Nations peoples are one of three peoples recognized as Aboriginal in Canada’s Constitution, alongside Inuit and Métis, who are the original peoples of Canada and their descendants (Aboriginal Affairs and Northern Development Canada, 2012). Inuit are a circumpolar people, inhabiting regions in Russia, Alaska, Canada and Greenland, united by a common culture and language (Aboriginal Affairs and Northern Development Canada, 2012). Reserves are tangible representations of Canada’s colonial history and are tracts of bounded land set aside for the use of an Indian band; however, legal title is held by the Crown (i.e., Canadian federal government) and
governed by the federal Indian Act (1876). (Aboriginal Affairs and Northern Development Canada, 2012).

As noted above, palliative care in Canada is simultaneously financed and/or administered across national, provincial/territorial, and regional/local scales (Health Canada, 2015). Despite access to palliative care being argued as a human right (Henteleff et al., 2012; Cunningham et al., 2011; Exley and Allen, 2007), great inequities exist in accessing this care in Canada within and across these administrative borders and boundaries. As such, there is a dire need for more research to examine the experiences of giving and receiving palliative care, particularly in geographically vulnerable regions such as the vast rural landscape of Canada, in order to bring forth evidence about the scope and scale of this inequity and ultimately, to inform policy and practice.

3. Study overview

This analysis is based upon data collected during the final qualitative research stage of a mixed-methods study that aims to determine ways to identify rural Canadian communities that are in need of, and are highly suitable for, expanding their palliative care service provision through creating a siting model specific to this issue. Although varying definitions exist, our study defines rural communities as those with populations of less than 10,000 that are removed from urban services and resources (Statistics Canada, 2001). In 2011, approximately 6.3 million Canadians, about 19% of Canada’s total population, resided in rural communities, as defined above (Statistics Canada, 2013). Rural and remote Canada can be characterized as rapidly aging (Public Health Agency of Canada, 2009), sparsely populated, and as such, various barriers in accessing health services, which include both geographic and temporal connotations, result (Romanow, 2002).

Qualitative interview data were collected in four purposefully selected communities located across Canada following the initial spatial analysis, which identified and ranked rural communities in terms of need for and the capacity to enhance palliative care services (for more information, see Crooks et al., 2011b). The spatial analysis involved: (1) identifying all rural Canadian communities situated outside a one-hour drive time catchment area of existing specialized palliative services; (2) running a siting model that factors in population, isolation, vulnerability, and community readiness (for more information on the palliative vulnerability index, see Cinnamon et al., 2009); and (3) gathering contextual information about the 20 most highly ranked communities identified across Canada by the model in order to select communities for qualitative data collection. It was from this contextual information that the four case-study sites reported on here were purposely selected to capture and represent some of Canada’s rural socio-economic and geographic diversity: (1) Lloydminster, Alberta/Saskatchewan; (2) Thompson, Manitoba; (3) Fort Frances, Ontario, and; (4) Happy Valley-Goose Bay, Newfoundland & Labrador (see Fig. 1: Map of Study Sites and Table 1: Community Demographics). In keeping with the goal of the study, the overall intent of the interviews was to identify factors that would indicate that these communities are indeed in need of and suitable for enhancing their local palliative care service provision.

3.1. Data collection

Semi-structured phone interviews were conducted with formal (n = 34) and informal (n = 6) palliative care providers and administrators in each of the four communities (10 per community). On average, the interviews lasted 74 min and ranged in length from 36 to 118 min. The formal provider participants came from diverse occupations (see Table 2: Participant Occupations). Recruitment involved simultaneously: sending out letters of invitation through existing contacts and to people with publicly available contact information, publishing invitations to participate in local newspapers, and posting information in online bulletins and newsletters. We also used snowball sampling, wherein we asked participants to forward information about the study to others in their networks they thought would be interested in participating. The response to our recruitment strategy varied for each site; however recruitment of formal care providers was easier than family caregivers in all. Although recruitment began in different sites at different times, all interviews were conducted between February 14th and September 18th, 2014. Interviews inquired into participants’ experiences with palliative care provision; community health and healthcare priorities and challenges; community need for palliative care and existing availability; and their perspective on our siting model approach. All interviews were digitally recorded, transcribed verbatim, and entered into NVivo™ software for analysis.

3.2. Analysis

Many participants expressed their perspectives regarding the various ways that borders and boundaries shaped their palliative care experiences, despite not being probed on this topic during the interviews. As such, for the purposes of this paper, we set out to perform a secondary analysis on this emergent theme that diverts from the goal of the larger study (Heaton, 2008). However, the original investigative study team was involved throughout this secondary analysis in order to enhance qualitative rigour. The secondary analytic process began by each team member independently reviewing five random transcripts, and once all authors agreed that various forms of borders and boundaries were evident in the data and shaped participants’ experiences of palliative care, border and boundary literature was reviewed, and then a thematic analysis ensued.

Thematic analysis involves both inductively and deductively reviewing and coding data in order to explore existing research goals as well as any issues which are emergent — and sometimes unanticipated — from a dataset via the identification of patterns that become categories for analysis (Fereday and Muir-Cochrane, 2006). The development of coding schemes involved a four-step process: (1) detailed review of five randomly selected transcripts to identify initial themes that reflected the multiple forms of borders and boundaries raised by participants; (2) drafting of a coding scheme; (3) coding of seven transcripts to confirm scheme; (4) review of the coded transcripts in order to refine scheme; (5) systematic coding of entire dataset. Consistent with thematic analysis, we then compared and contrasted our coded data against the existing borders and boundaries literature in order to determine the scope of our themes and the novelty of our findings. To enhance consistency, the first author led all steps of the coding and analysis process. Multiple investigators were involved in each step to provide feedback and enhance interpretations, thus contributing to the reliability of the findings.

4. Findings

Participants discussed five forms of borders and boundaries evident at all four study sites: (1) political; (2) jurisdictional; (3) geographical; (4) professional; and (5) cultural. Participants discussed these forms of borders and boundaries in both implicit and explicit ways while sharing their experiences of providing palliative care in rural Canada. Although political borders are commonly explored within existing health/border literature, jurisdictional, geographical, professional and cultural borders and boundaries generally are not and, to our knowledge, have yet to be examined.
Table 1
Economic and demographic information on the four research sites - based on 2011 Canada Census Data.

<table>
<thead>
<tr>
<th>Community</th>
<th>Main economic activity</th>
<th>Total population</th>
<th>% Age &gt;85</th>
<th>% New immigrants</th>
<th>% Aboriginal population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lloydminster, AB/SK</td>
<td>Petroleum; agriculture</td>
<td>27,023</td>
<td>1.5</td>
<td>0.3</td>
<td>8.2</td>
</tr>
<tr>
<td>Thompson, MB</td>
<td>Mining; milling</td>
<td>13,446</td>
<td>0.1</td>
<td>0.9</td>
<td>36.6</td>
</tr>
<tr>
<td>Fort Frances, ON</td>
<td>Tourism (fishing); milling</td>
<td>8103</td>
<td>3.2</td>
<td>0.2</td>
<td>16.4</td>
</tr>
<tr>
<td>Happy Valley Goose Bay, NL</td>
<td>Military air base</td>
<td>7575</td>
<td>0.5</td>
<td>0.5</td>
<td>35.9</td>
</tr>
</tbody>
</table>

Table 2
Participants’ occupational grouping.

<table>
<thead>
<tr>
<th>Occupational grouping</th>
<th># Of participants</th>
<th>Fort Frances</th>
<th>Happy Valley Goose Bay</th>
<th>Lloydminster</th>
<th>Thompson</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Caregiver</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Volunteer</td>
<td>5</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Manager/Consultant</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Coordinator</td>
<td>4</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nurse</td>
<td>4</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Chaplain</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Station Nurse</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Home Care Nurse</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Regional service planner</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Social Worker</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Care Aide</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Chief Medical officer</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Counsellor</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Physician</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Totals</td>
<td>40</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>
simultaneously. Recognizing the social construction of borders and boundaries, we acknowledge that those we discuss in this section not only shape, but are also shaped by larger political, economic, social, and geographic processes (Newman, 2006), and as such, strong interconnections between the findings exist.

4.1. Political borders

The most explicit reference to borders and boundaries that emerged was in regard to political borders. Here we define political borders as being formal national/federal and provincial political borders of Canada. The political borders most commonly discussed by participants were in reference to provincial borders (which outline ten provinces and three territories), particularly from those residing in the community of Lloydminster. Lloydminster has the unusual geographic location of straddling two provinces (Alberta and Saskatchewan), but is actually incorporated as a single city with a single municipal administration.

Participants from Lloydminster commonly stated that the provincial border created one of the greatest challenges with regard to providing and accessing palliative care. As this participant describes: “I still think our biggest challenge is the border. Every profession almost needs to be dual-registered and you need to keep up with the two you know [provincial bodies], like continuing competence and all that stuff” (L-01). This participant goes on to explain that physicians in Lloydminster tend to get their licensing in Saskatchewan due to an “easier” program there, however the majority of the population and nursing homes are in Alberta, and therefore “they can’t visit there unless they apply and then get the other license, which usually takes another year or so and sometimes they don’t do it because of cost and stuff. So I really think our border is one of our biggest issues.”

Issues of continuity of care and information sharing were also viewed as being challenged due to provincial borders and the differing healthcare systems, as this participant from Lloydminster stated:

“We have a Saskatchewan computerized program and when people go to any specialists in Alberta they can’t access their medical records or their CT scans or anything cause they’re on the Saskatchewan based profile (L-01).

It was not only those from Lloydminster who described provincial borders as creating such challenges. Because rural Canadians must often travel great distances in order to access necessary care, in some instances, the nearest required service is located in another province. For those in Fort Frances (Ontario), it is relatively equal distance and travel time (four hours by car) to reach the larger metropolis of Winnipeg, in the province of Manitoba, as it is to reach the smaller urban centre of Thunder Bay in Ontario. As this participant explains, this scenario is quite common for many rural residents who must travel for more specialized care:

“One of the big issues we have, and I know this is true across the country; people go to a larger centre ... they’ll be sent to a specialist in Winnipeg, diagnosed with cancer, and their oncologist is in Winnipeg. Then they come back home to the community [Fort Frances] and no information comes back with them, and so you’re trying to provide services and trying to coordinate care and it’s a real challenge getting ... information as to what happened when they went into that larger centre into the hospital and that is particularly challenging when it’s not even the same province (F-03).

Political borders create major barriers in regard to accessing and sharing medical records, which in turn compromises the quality and speed of palliative care being delivered to recipients in these areas.

4.2. Jurisdictional boundaries

During interviews, jurisdictional boundaries were raised by many participants as a geographic distinction that shapes experiences of palliative care. Jurisdictional borders are defined here as being those formal borders within provinces that distinguishes between differing regional health authorities and also between First Nation reserve (federal) and non-reserve (provincial) land. It is important to state that issues regarding Aboriginal populations in Canada are incredibly complex and thus warrant analysis specific to these unique issues. As such, Aboriginal-focussed analyses are currently underway by our team (See also Castleden et al., 2010a).

However, we feel it is also valuable to be inclusive of Aboriginal issues, perspectives, and voices in the current analysis, so long as clear definitions and acknowledgement of the unique socio-historical context is given.

Nearly half of First Nation peoples with registered Indian Status live on reserves in Canada (Statistics Canada, 2014) and residence is governed by both the local First Nation band council as well as the federal Minister of Aboriginal Affairs and Northern Development (Mccue, 2015). Status Indians are people who self-identify to have their names included on the Indian Register, an official list maintained by the federal government. Certain criteria determine who can be registered as a Status Indian and only Status Indians are recognized as Indians under the Indian Act (1867) and are entitled to certain rights and benefits under the law (Aboriginal Affairs and Northern Development Canada, 2012). In regard to healthcare, the federal government is largely responsible for providing treatment and public health services to status First Nation peoples on-reserve through the First Nations and Inuit Health Branch of Health Canada (Aboriginal Affairs and Northern Development Canada, 2015). However, some provincial mandates allow for provincial public health professionals to provide particular services on-reserve in some regions. Although, the federal government supports the transfer of control of health programs to local First Nations governments and organizations, such care varies dramatically depending upon the community and resources available.

First Nation reserves are, in essence, federal and band governed ‘islands’ scattered across a sea of provincially governed land. Some reserves neighbour our case-study sites and these jurisdictional boundaries were viewed as barriers to the delivery of services to First Nation communities. Some participants mentioned these borders in regard to differences in the allocation of funds between the provincial and on-reserve federal governments and the resulting quality of services provided, as this participant from Fort Frances states: “The other challenge is getting, bringing services into the community [First Nation]... the political issues around provincial funding, federal funding, it’s just a quagmire of programs” (F-04). It was also found that the coordination of services between those offered by the province and those offered on reserves were particularly challenging:

“We’re working in a community [First Nation] again right now where the provincial government has the mandate to provide some homecare, so CCAC [Community Care Access Centre] is sending in nursing to clients, but there’s also a home and community care program which is community-based and you know the staff is in the community, going in, and there’s absolutely no communication between the two programs in any way. So that creates a lot of difficulty trying to coordinate properly and provide services (F-04).

Participants also spoke to challenges with regard to continuity of
care between the two health systems. This participant from Happy Valley-Goose Bay, which is located near Inuit communities, describes:

The way it works in some of the communities on the north coast, they’re under the Nunatsiavut [regional Inuit] government, so their homecare nurses are under that government — they’re followed up by community health nurses who are hired under the Nunatsiavut government, but the actual health clinics are still owned and operated by Labrador-Grenfell Health [provincial health system]. Sometimes it’s very frustrating ‘cause these people from those communities from the north coast will come into Goose Bay, and then they go home, and you send a referral to the community health nurse, but it’s two different departments (H-01).

Other jurisdictional-based issues were raised with regard to regional health authorities. Some participants spoke again to the differences in services and what is covered, like this one from Happy Valley Goose Bay:

I would like for the province to take more of an initiative, I guess, to connect us all, like the four different health authorities. Even with the end of life program there’s different things covered in the different authorities. I’d like for everybody to be able to receive the same types of services (H-01).

Participants also emphasized how they would like a system to facilitate information sharing between the different health authorities, particularly for those residing and working in close proximity to jurisdictional boundaries.

4.3. Geographical boundaries

Here geographical boundaries are defined relationally and were raised by participants to informally demarcate between notions of ‘here’ and ‘there’, or ‘near’ and ‘far’, both physically and socially. As data collection took place in rural communities, many explicitly spatial and geographical distinctions were made by participants, particularly with regard to feelings of distance and isolation. In these instances, participants distinguished themselves and their communities from other more densely populated areas, associating this distinction to political influence, and drawing an invisible line that seemed to separate them from others. As this participant from Fort Frances described:

One of our biggest challenges is that we are so far removed from the center of power in the province, like we have zero political influence here … and so much of the … provincial structure is built around that southern Ontario very urban, very well-popolated, you know short distances to anywhere, type of demographic and geography. And we are miles and miles away with a very sparse population. So we have a very difficult time being heard politically … I think that’s always been our biggest challenge here is just our, our remoteness from the rest of the province (F-04).

This sentiment is echoed by a participant from Thompson, who emphasized that it was their geographic remoteness that created unique challenges for them: “It’s just the isolation I guess, being … very far away from a larger centre, for us to get to Winnipeg which would be the place where most people would go for anything major … it’s a nearly eight hour drive” (T-09).

Many participants made comparisons between the services available in more urban areas and those in their rural communities, again spatially differentiating themselves from the more populated centres. As this participant from Happy Valley-Goose Bay states:

I know in the bigger centres they have their palliative care units, they have their palliative care physicians, they have their palliative care nurse practitioners and you know they have a lot of the things that we don’t even have a little pinch of yet (H-08).

From these geographical distinctions, it becomes apparent that participants were experiencing/creating/reaffirming boundaries that differentiated their rural communities from more highly populated and resource rich urban areas.

4.4. Professional boundaries

Professional boundaries are defined as being those informal lines of organization and categorization that demarcate formal care provider occupations (e.g., specialists, physicians, nurses, therapists, social workers) and responsibilities. In communities where there exists more than one formal palliative care provider, but no coherent palliative care ‘team’, it was mentioned that information sharing and communication between formal care providers was a major challenge, particularly with regard to coordination of care, continuity of care, and efficiency in providing quality care. Some participants expressed frustration with this, like this participant from Fort Frances who states that one of the greatest challenges is “probably lack of communication between the professionals, like whether it be the doctor, and the nurses, and the family, and having everyone kind of being on the same page” (F-03). Another participant explains how this lack of information sharing results in creating an extra burden for those families receiving palliative care: “people have to tell their stories several times and at all their different points of access” (F-01). This participant continues to explain how this lack of communication can also result in extra work for professionals who have to take time from their already busy schedules to seek out missing information. Many participants, particularly from Fort Frances, expressed the critical need for better coordination of palliative care and a system, for example the creation of a team that would allow for better information sharing.

It is important to note that not all participants were stymied by professional boundaries. In fact, some participants mentioned that in their communities, professional networks seemed to be relatively close and socially connected due to their local “small-town” culture where “everybody knows everybody”. In these cases, families and various professionals were often in contact and able to discuss care needs and priorities on a regular basis. In other words, the connections between residents in these rural settings aided in overcoming the barriers often imposed by professional boundaries operating in the healthcare system.

4.5. Cultural boundaries

Cultural boundaries are defined here as being those differences in cultural practices, norms, behaviours, and communication that resulted in demarcating between notions of ‘us’ and ‘them’. For example, many participants compared cultural differences between rural and urban ways of life and the quality of palliative care provided, as this participant from Thompson expresses: “Well, I’m not always impressed with palliative care in Winnipeg [nearby urban centre] ‘cause unfortunately … people in Winnipeg don’t understand the challenges of people in the north” (T-02). Distinctions between ‘us’ and ‘them’ were also made with regard to how rural communities have differing strengths and face differing challenges than those from more urban areas.

Cultural lines distinguishing between non-Aboriginal [white European settlers] and First Nation and/or Inuit communities were raised by many participants in all four case-study sites. Non-
Aboriginal providers’ general lack of local First Nation and/or Inuit cultural knowledge was found to create major barriers with regard to the provision of culturally relevant and safe palliative care for these populations. As this participant from Fort Frances states:

... the other thing that’s an issue is the difference and, just on an individual client level again, there’s a cultural difference. First Nations people, they do not reach out and ask for service or ask questions or insist on things ... that as a Western culture we kind of take for granted (F-04).

This participant went on to explain how these cultural distinctions and differences are imbued within relations of power:

If a person that they [a First Nation person] deem to be in authority, like a doctor, says well, for instance, ‘you can’t go home’; they truly hear that statement to be ‘well, I’m not allowed to go home’ ... the balance of power there, for lack of another word, is a real challenge. They don’t see themselves as being empowered to ask questions, to make their own decisions, and so either what happens is they wind up, like I said, staying, you know, being somewhere they don’t want to be or they just try to, you know, they just don’t even want to go to a doctor period because it’s just going to be a bad experience (F-04).

Participants, such as F-04 above, emphasized an acknowledgement of the diversity of Aboriginal culture that exists and the need to provide care at an individual client level. However, other participants were less socially aware and shared statements that were, in essence, clear stereotypes. These findings point to issues reaching far beyond the scope of this paper, but do illustrate some of the challenges that exist in not only providing culturally safe palliative care, but in addressing the perpetuation of broader racial stereotypes.

Another cultural boundary articulated by participants between the local ‘Canadian’ culture (‘us’) and healthcare professionals who were new immigrants to Canada (‘them’). These boundaries point to participants’ experienced cultural differences of communication and language. Many professional newcomers to Canada take their medical practicums/internships/employment placements in rural communities because of the long wait times to do so in major urban centres, which can result in cultural boundaries having an impact on practice:

We have our family doctor, he’s from Nigeria, and I can understand him cause I work with immigrants. I’m around them more. But, for example, my husband, he has a very difficult time understanding him. And, you know, like you keep repeating yourself saying I’m sorry I didn’t get what you said (chuckle) (H-04).

Another participant echoed this notion, stating: “The population, again a lot of the doctors don’t speak first language English so a lot of times people don’t understand, especially if they’re [the care recipient] Aboriginal” (T-05). One Aboriginal-language-speaking participant from Thompson echoed this sentiment:

Yeah, sometimes my husband gets mad, ‘you guys, your accent is so high’ (chuckle). So they’re immigrant doctors mostly ... Yeah, and sometimes people say ... ‘what’s he doing, he can’t even talk English, he can’t talk proper English’ (T-04).

For other participants, great frustration was expressed over the lack of quality care, which was only exacerbated by challenges in communicating with professionals who were not knowledgeable of the local culture and/or did not have English as a first language. For example, this participant from Thompson faced multiple challenges in regard to accessing quality palliative care for her neighbour, as well as care for her own health issues:

The healthcare services in this town are ridiculous ... you can’t communicate with them [doctors], they don’t speak English, you can barely understand a word they’re saying, the continuum of care is zero” (T-01).

Participants’ perceived and experienced boundaries that shaped their access to culturally relevant palliative care. But, as demonstrated in these findings, there seems to also lay embedded racial/cultural tensions. Many participants conflated English language abilities with quality palliative care delivery; however, it is important to acknowledge that these two things are not one and the same. Taken together, these findings illuminate some of the underlying discrimination that is occurring, not only against palliative care patients, but also against healthcare providers in Canada.

5. Implications for palliative care in rural Canada

It is important to acknowledge here that although rural communities do face particular challenges in providing and receiving healthcare services compared to their more urban counterparts, there are rural communities in Canada that provide optimal healthcare for their local populations (Williams and Kulig, 2012). At the same time, many rural residents feel very connected to, and positively identify with, their local rural community and landscape and take pride in the quality of healthcare they provide and receive (Castleden et al., 2010b). However, being focussed on ‘lines that divide’, the current analysis has identified particular challenges in relation to palliative care in rural Canada. Overall, our findings demonstrate the powers of borders and boundaries and how participants perceived and used them to distinguish between the included/excluded; here/there; and us/them (Newman, 2006). Particularly, the findings reveal how multiple borders and boundaries are simultaneously experienced and created by individuals, shaping and influencing experiences of palliative care. Without being prompted to do so, participants in all four case-study sites shared their perspectives on how these five forms of borders and boundaries (i.e., political, jurisdictional, geographic, professional and cultural) resulted in barriers to delivering and accessing palliative care. From here, implications for the provision of palliative care in rural Canada become illuminated.

5.1. Political/jurisdictional

Participants’ experiences highlight what has already been recognized in Canada: it is a country marked by major inconsistencies in the provision of palliative care (Canadian Hospice Palliative Care Association, 2012; Canadian Medical Association, 2015; Collier, 2011). Many participants shared their challenges in navigating between the differing healthcare systems, which here are distinguished by the political provincial borders and jurisdictional boundaries. This challenge was found to be significant not only for the providers, but also recipients of care. The different healthcare systems that exist on each side of these borders/boundaries hold differing health and healthcare priorities, responsibilities, and budgets, which dramatically shape how and where palliative care is defined and provided (Canadian Medical Association, 2015). As such, our findings suggest that those residing in borderland areas and are required to travel across provincial or jurisdictional borders may not be receiving optimal palliative care because of the barriers faced in sharing medical records and coordinating services. Such discrepancies negatively impact patient continuity of care and point to the need to improve and/or reform the way palliative care is provided in Canada.
Due to the complexity of death and dying, we contend the various governmental sectors need to become increasingly intersectoral and involved in palliative care at multiple levels, from the local to the regional, and from the provincial to the national levels, in order to adequately address the complex needs of families experiencing death and dying. This multi-sectoral approach will require coordination, a shared vision, and political commitment from local to national leaders in order to be successful.

5.2. Geographical

Building on the findings from Castleden et al. (2010b), participants commonly discussed issues of distance and isolation, which emphasize the rural context of this study and the unique challenges these citizens face in accessing and providing palliative care. Participants experienced geographic boundaries that distinguished between ‘us/them’ and/or ‘here/there’ that were associated with notions of identity and belonging and situated within relations of power; for example, perceptions of being ‘far removed’ from political centres. As such, these boundaries not only mark geographic distances, but encompass other complex socio-political and economic processes that shape the ‘how’ and ‘where’ healthcare services are provided in Canada (Collier, 2011). Participants’ comments emphasize the challenges inherent in current healthcare trends experienced across Canada, whereby recent decreases in public spending has forced regional health authorities to make cuts, directly and indirectly affecting communities and social services that enable palliative care provision. Consequently, vast spatial inequities exist, especially when comparing rural health authorities to more urban ones (Milligan and Power, 2010; Crooks et al., 2011a). In order to ensure all Canadians have equitable access to quality palliative care, more power and resources must be provided at the community-level, where unique local challenges can be voiced and addressed.

5.3. Professional

Having diversity in care providers can be seen as a strength of palliative care, as it enables provision to be responsive to a range of patient needs (Crooks et al., 2011a). However, this diversity can also pose challenges in fitting together the markedly different training and professional backgrounds (Bliss et al., 2000). In rural areas, providers are not only professionally diverse, but also often geographically dispersed across multiple communities. This lack of professional cohesion was seen as a major challenge by participants who discussed how professional boundaries were perceived to compromise the quality of palliative care provided. Rather than continuity of care, professional boundaries were perceived to result in ‘compartmentalized’ care for families. Lack of professional communication creates extra burdens for families and frustration among formal provider participants. Many tensions were also said to emerge from the lack of a common professional palliative care philosophy, approach, or educational training. Furthermore, the lack of unified teams results in challenges to coordinating services and also creates barriers to providing culturally competent care, particularly for local Aboriginal communities. Together, these findings emphasize the need for more providers to see the value in working together as a team towards shared goals. One suggested path towards achieving this may be via the creation of hubs of expertise in specific rural communities with high need and user demand (Crooks et al., 2009). These hubs would be connected to a specialist palliative care hub located in larger cities. This connectedness would facilitate communication and educational opportunities between providers across regions and allow the development of palliative teams (either locally or via long-distance telemedicine) aimed at providing the best continuous and ‘holistic’ palliative care to their recipients.

5.4. Cultural

Although little research exists on this issue, a few studies have acknowledged the racial and ethnic disparities that exist in palliative care (Johnson, 2013; Castleden et al., 2010a). In general, research demonstrates an under-utilization of health services by cultural minorities, which is often due to cultural and conceptual differences in how health (or death) is understood, as well as systematic and systemic barriers which are embedded in the service systems (Brown et al., 2013; Koehn et al., 2013). Undoubtedly, cultural belief systems and practices will have an influence on how one approaches the process of death and dying, as well as the willingness and capability to access (and provide) local palliative care services and supports (Hotson et al., 2004; Donovan et al., 2011). Specific to the Canadian rural context, many participants in our study made distinctions between the cultural/racial communities of First Nation and/or Inuit and non-Aboriginal (white European settler) populations. Here, participants acknowledged the cultural boundaries that were used to distinguish between ‘us/them’ that were seen as important in shaping access to culturally meaningful palliative care by minority populations. Although great diversity exists among Canada’s Aboriginal populations, they do share a common history of colonization involving marginalization, exploitation, and disgraceful maltreatment (Castleden et al., 2010a; Native Women’s Association of Canada, 2007; Greenwood and de Leeuw, 2012). It is thus likely that these factors affect Aboriginal peoples’ use of formal palliative care (Castleden et al., 2010a). Considering this, cultural boundaries must be overcome and differences addressed in useful ways in order to facilitate the provision of equitable and culturally-safe palliative care. Increasing minority representation among health professionals, providing linguistically accessible palliative care education materials, offering language interpretation and cultural competence training for palliative care providers, and ensuring culturally safe spaces exist for minority groups to practice ceremonies are some of the many recommended interventions that can be made to address cultural issues (Australian Government Department of Health, 2015; Kelley and Prince, 2006). In addition, there is little known about the needs of cultural/racial minority healthcare providers and the possible discrimination that they may be experiencing. Thus, more research is needed that explores this issue, particularly in the rural Canadian context.

6. Conclusion

Although it has been recognized that the geographic constructs of borders and boundaries are implicitly connected to health, few border studies researchers have empirically explored their interconnections. This analysis has contributed to addressing this gap by examining how the everyday lived experiences of those providing and receiving palliative care in rural Canada are impacted by various forms of lines that are continually drawn at various scales. Throughout this analysis, the value of a health geography perspective that applies an ‘experiential’ approach has been emphasized. Newman (2006) suggests that borders should be studied not only from a top-down perspective, but also from the bottom up, with a focus on individual border narratives and the diverse experiences and meanings in which they hold for different people. It is in these everyday experiences that borders and boundaries come to life (Wastl-Walter, 2011; Newman, 2006). We agree, and argue that a need exists for more border studies scholars...
to take an experiential approach in their research in order to gain a better understanding on how borders and boundaries can shape health and access to meaningful and inclusive healthcare.

Borders and boundaries are consistently being lived and created, influencing our experiences of health and health outcomes. Our study thus contributes to the field of health geography by acknowledging the significance of these in/visible lines that are used to define access to healthcare. More specifically, borders and boundaries have an impact on healthcare experiences as they are used to organize populations into particular groups. Whether explicit or implicit, the use of these lines can be interpreted as a principle of organizing social life, whereby boundaries and borders are used to regulate movement in space as a means of ordering explicit or implicit, the use of these lines can be interpreted as a boundary making is about marking difference in space, which is closely associated with notions of identity and power (Popescu, 2010). Thus, in a geographical sense, border and are used to regulate movement in space as a means of ordering explicit or implicit, the use of these lines can be interpreted as a boundary making is about marking difference in space, which is closely associated with notions of identity and power (Popescu, 2010).

The findings of this secondary analysis offer insight into the ways that large scale systems, such as the Canadian healthcare system, are experienced in relation to smaller scale and “localized” borders and boundaries. This perspective has allowed for the identification of various inconsistencies, disparities, and gaps in palliative care service provision and provides information for decision makers on ways to enhance the equity and quality of palliative care service hubs in rural communities: a qualitative case study from British Columbia’s interior. Rev. BMC Palliat Care 8, 15. http://dx.doi.org/10.1186/1472-6840-8-15.


References


