



## 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

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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 access – including access to healthcare and/or social supports.

Examining the impacts of borders and boundaries on health has surprisingly received little attention from border studies researchers (Wastl-Walter, 2011) or health geographers. Much of the limited existing research has been conducted by medical, nursing, and population health researchers who have focused largely at the global scale to examine the effects of trans-national political borders on health. For example, researchers have investigated the role of border control in mitigating the global spread of particular diseases, such as malaria or tuberculosis (Horner et al., 2013; Silal et al., 2015). Border control has also been examined with regard to international agri-food trade and the desire to protect citizens from associated health-related threats (Ackleson and Kastner, 2011; Hsin-Chih et al., 2015). Other researchers have examined the role of 'globalization' 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 trans-national 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, 2011). Such care can be provided wherever 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, along with 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

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