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The development of a spatial palliative care index instrument for assessing population-level need for palliative care services

Nadine Schuurman[a,*], Michael Martin[a], Valorie A. Crooks[a], Ellen Randall[b]

[a] *Department of Geography,Simon Fraser University, 8888 University Drive, Burnaby, Canada V5A 1S6*
[b] *School of Population and Public Health, University of British Columbia, Vancouver, Canada*

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ABSTRACT

We developed an index to measure potential need for palliative care services (PCIX). This is an instrument that enables spatial identification of *potential* population-level need for palliative care services and can be developed using census data. Four indicators of potential need for palliative care services —age, sex, living arrangement, socio-economic status (SES)—were used to produce composite potential need scores for DAs. Scores were graphically mapped, producing a spatial delineation of relative need for end-of-life services. To assess the benefit of combining multiple variables to define potential need, PCIX resolution was compared to general SES-based delineations of need. PCIX scores and maps were generated for all DAs, revealing spatial variability in potential need for palliative care services (PCS). Comparison of PCIX maps to those based on purely on SES indicated that use of variables specifically linked to palliative need resulted in more precise delineations of potential populations in need of PCS. Using composite scores – based on freely available census data - to spatially assess potential need for palliative care services can provide critical data for decision makers charged with rationalizing service locations and service capacity.

1. Introduction

It is estimated that roughly 18.5% of Canadians will be over the age of 65 in 2021, an increase of almost 6% from 2011 (Statistics Canada, 2014, 2015). By mid-century it is projected that close to a quarter of Canadians will fall in that senior category (Statistics Canada, 2014, 2015). As this group grows in numbers, the burden of chronic disease in Canada—including complex conditions like cancers, heart disease, and chronic obstructive pulmonary disease—is also on the rise; the prevalence of chronic conditions in senior Canadians is roughly 75% (Health Council of Canada, 2007). These conditions are often associated with complex care needs, and Canadians have encountered barriers having those care needs met (Schoen et al., 2009). As the population ages, there is mounting pressure to ensure that the health care system can address all the care needs of seniors, including those for end-of-life care (British Columbia Ministry of Health, 2013). Yet it is estimated that less than 20% of Canadians access formal palliative care services (Canadian Institute for Health Information, 2007; Parliamentary Committee on Palliative and Compassionate Care, 2011), and despite an overwhelming preference to die at home, the majority of Canadians still die in long- and short-term care facilities and hospitals (Statistics Canada, 2013).

Over the last two decades, there has been a growing recognition that the development of palliative care service capacity needs to be prioritized in Canada (Canada's Economic Action Plan, 2013; Canadian Hospice Palliative Care Association, 2015; Carstairs, 2010; Gauvin et al., 2013; Parliamentary Committee on Palliative and Compassionate Care, 2011). In order to develop and sustain an appropriate service base in a fiscally viable manner, health policy makers and administrators need to rationalize available dollars, infrastructure, and health human resources—and strategically deploy services where they will best meet the needs of the population. This is no less true for palliative care services. Given the growing demand for, and uptake of, palliative care services across a variety of care contexts (e.g., home, hospice, hospital, long-term care home, respite care facility), matching supply to demand rests in part on understanding where need is greatest.

The purpose of this paper is to describe the development and implementation of a Palliative Care Index (PCIX), an instrument designed to enable the spatial determination of population-level potential need for use of palliative care services, based on demographic and social attributes commonly found to be associated with palliative

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List of abbreviations: BC, British Columbia; CHASS, Computing in the Humanities and Social Sciences; DA, Dissemination area; GIS, Geographic Information Systems; PCIX, Palliative Care Index (of potential need); SES, Socio-economic status; VANDIX, Vancouver Area Deprivation Index

[*] Corresponding author.

E-mail addresses: nadine@sfu.ca (N. Schuurman), memartin@sfu.ca (M. Martin), crooks@sfu.ca (V.A. Crooks), erandall@shaw.ca (E. Randall).

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care service users. Building on the existing Vancouver Area Deprivation Index (VANDIX) methodology (Bell and Hayes, 2012), PCIX was designed to provide a high resolution spatial delineation of levels of potential need for palliative care services. Being able to spatially assess vulnerability for palliative care services, and visually capture areas with heightened need, can provide critical data for decision makers charged with rationalizing service allocation in terms of both service location and overall capacity. A key attribute of PCIX is its base in Census data – that is easily available to researchers and policy makers.

2. Background

In Canada, as in many other countries, palliative care constitutes many different forms of care, but in general refers to support provided in order to maintain the quality of life for people facing life-limiting illnesses, as well as facilitating good quality of death for those at the very end stages (Canadian Hospice Palliative Care Association, 2013; World Health Organization, 2011). Such care can be delivered across the tiers of health care—in other words, it is provided by family physicians and home care nurses (primary care), by palliative medicine specialists and oncologists (secondary care), and by many hospital-based health workers (tertiary care) (Canadian Hospice Palliative Care Association, 2013; National Consensus Project for Quality Palliative Care, 2009). As palliative care pertains to facilitating good quality living and dying, it also involves groups such as social workers, allied health professionals, spiritual counsel, and friends and family (Canadian Hospice Palliative Care Association, 2013; National Consensus Project for Quality Palliative Care, 2009).

From a health services perspective, what constitutes a "palliative care service" is similarly diverse. For example, the Canadian Hospice Palliative Care Association offers a directory of palliative care services that spans acute care hospitals, chronic or long-term care facilities, dedicated hospice palliative care units, homes, hospice societies, non-for-profit organizations, nursing homes, out-patient clinics, private clinics, and residential hospices (http://www.chpca.net/family-caregivers/directory-of-services.aspx). A significant amount of palliative care is provided by non-specialists, and this is particularly true in rural and remote regions of Canada where hospitals are limited and specialists are rare (Pesut et al., 2012; Rainsford et al., 2016; Robinson et al., 2009). Palliative care is also commonly offered using a team-based approach where formal and informal health and social care providers work together in order to facilitate the best quality of life and dying for the person at end-of-life, sometimes in the care recipient's private home (Canadian Hospice Palliative Care Association, 2009; National Consensus Project for Quality Palliative Care, 2009).

Improving and enhancing palliative care across Canada has received significant policy attention in recent years given Canada's aging population (Human Resources and Skills Development Canada, 2013). In the province of British Columbia (BC), it is projected that the percentage of people over the age of 65 will increase from 17.5% in 2015 to 24.9% in 2041, while the percentage of those over the age of 80 will move from 4.6% (2015) to 9.4% (2041) (BC Stats, 2015). These figures indicate that demand for palliative care services will continue to increase. In parallel, an analysis of end-of-life health services usage in BC found that only about 15% of patients used coordinated end-of-life services (Canadian Institute for Health Information, 2007). This figure points to a service gap—a gap that is concerning given the range of benefits associated with having access to palliative care, such as support for informal caregivers, enhanced care coordination, treatment in a variety of care settings, and pain management protocols that address the needs particular to people at end-of-life (Canadian Hospice Palliative Care Association, 2014; Freeman et al., 2013).

In response to these realities, BC's *Provincial End-of-Life Care Action Care Plan* stresses a "population needs-based approach to palliative care" (British Columbia Ministry of Health, 2013, p. 2), one that identifies those who can benefit from having access to palliative care services develops and distributes the delivery of end-of-life services to enable more patients to access needed care in their home communities. Individuals—and populations—can differ in their vulnerability with regard to service access. Traditionally vulnerable populations have included those who are economically disadvantaged, minorities, the elderly, single-parent families, the homeless and, in the US, those who are uninsured. For example, populations that are low-income, suffer some level of social and material deprivation, or are spatially remote, have been shown to be at greater risk for not being able to access needed services, or do so within their home communities (Blendon et al., 2002; Dunlop et al., 2000; Starfield, 2011; van Doorslaer et al., 2006). Within the domain of palliative care, experiences accessing and receiving care have been found to follow this trend (Ahmed et al., 2004; British Columbia Ministry of Health, 2002; Kaasalainen et al., 2012; McNeil et al., 2012; Schuurman et al., 2015). Certain characteristics are associated with a heightened need for care, both formal and informal—e.g., being female or being single (Allan et al., 2009; Han et al., 2008; Karlsson et al., 2006; Mahony et al., 2008; National Hospice and Palliative Care Organization, 2008; Santa-Emma et al., 2002).

The development of a model like PCIX enables spatial identification of populations that could potentially benefit from palliative care based on measures of population-level vulnerability for palliative care services. Its inception arose out of a program of research that employs Geographic Information Systems (GIS) methods to assess spatial dimensions of palliative care service delivery in BC (Cinnamon et al., 2008, 2009; Crooks et al., 2011). In recognition that regionalization and geography influence access to and demand for these services, the initial location analysis model allowed identification of communities with a high need for palliative care, yet with relatively low service access (Cinnamon et al., 2008). This model measured community vulnerability, i.e., heightened need for palliative care that was assessed by determining the proportion of the local population over the age of 65 (Cinnamon et al., 2008). This vulnerability measure was then incorporated into the larger *community suitability model*, developed to support the identification of rural and remote Canadian communities that were suitable as sites for secondary (i.e., non-specialist) palliative care hubs by assessing both availability of existing health infrastructure and potential local demand for services (Cinnamon et al., 2009). It became apparent during the development and testing of this model, including the vulnerability component, that the spatial vulnerability measure being used was not sufficiently sensitive: calculating an age-based population proportion for a given catchment area did not account for other variables that might heighten need for services, and barriers to accessing those services.

The need to capture the interaction of multiple variables to spatially assess population vulnerability through the use of area-based deprivation indices is well established (Bell and Hayes, 2012; Pampalon and Raymond, 2000; Schuurman et al., 2007). This type of composite measure has been used to assess area-level socio-economic status (SES), health outcomes, and use of health services (Curtis et al., 2006; Morris and Carstairs, 1991; Schuurman et al., 2007). One such composite index, the Vancouver Area Deprivation Index (VANDIX), used census data to generate an area-based measure of SES (Bell and Hayes, 2012; Bell et al., 2007a, 2007b). The VANDIX was assembled using seven *constructs* or meta-categories; each construct was populated by two to six actual Census variables – illustrated in Table 1. The constructs include the domains of education, material wealth, employment status, and housing. By combining Census variables into thematic categories, VANDIX produces a nuanced, calibrated area-level score that, when tested, confirmed associations between area-level SES and health status. The VANDIX deprivation index has been applied in a variety of ways including the analysis of the spatial distribution of injury (Bell et al., 2008) and in spatial explorations of disparities in access to medical and social services (Crabbe, 2011; Schuurman et al., 2008). VANDIX also has two advantages for the PCIX index in that it