Which Way from Here?

Navigation Competencies for the Care of Older Rural Adults at the End of Life

Final Report
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Executive Summary

Which Way from Here? Navigation Competencies for the Care of Older Rural Adults at the End of Life is the final report resulting from a Canadian Institutes of Health Research Planning Grant. This final report describes the development of health care provider navigation competencies when caring for older persons with advanced disease and their families living in rural communities. Aligned with the palliative approach put forth by the Canadian Hospice Palliative Care Association (CHPCA), the competencies are cross-disciplinary and for generalist health care providers. They are necessary to help rural seniors and their family caregivers find the services and resources they need while remaining in their own communities. The development of these navigation competencies thus seeks to contribute to the peace and comfort of palliative patients at the end of life.

This report includes a discussion paper which consists of a scientific literature review, an overview of the Delphi study employed in the development of navigation competencies, and a final competencies and skills profile for health care navigators for older adults at the end of life in rural communities. These three sections build upon one another.

Discussion Paper: The discussion paper presents the findings of a literature review focused on three areas: rural aging, rural palliative care, and patient navigation. In highlighting the significant challenges and issues in each area, questions relevant to the development of the navigation competences were raised. The themes of quality of life, independence, and social connections were prevalent throughout the literature on rural aging and rural palliative care. In recognition of the diversity of older adults and their communities, the theme of negotiating the “best fit” for older adults and their communities was also found to be important. However, the research on patient navigation clearly demonstrates that a definition reflecting these themes is lacking. Based on the literature review herein described, a proposed definition of navigation for older rural persons and their families at the end of life was developed; it entails working in collaboration with patients, families, and communities to: a) negotiate the “best fit” between the needs of older rural persons, their families and communities and resources; b) improve access to needed services and resources at the end of life (including death) and bereavement; and, c) to promote quality of life, foster independence, and facilitate community connections utilizing a culturally safe, palliative approach.

Delphi Process: Based on the results of the literature review, a four-phased Delphi approach, developed by the Canadian Partnership Against Cancer Capacity Enhancement Program[1], was utilized to develop draft navigator competencies for health care providers. An expert panel, made up of knowledge users, policy makers, clinicians, and researchers, used this discussion paper as a guide in their identification of navigator competencies. Phases 1-3 were conducted electronically via email. General area competencies were identified with specific competencies under each general area. The competencies that received a consensus of 75 percent agreement for inclusion by the expert panel were included for discussion in Phase 4.

The fourth round of the Delphi Study was in the form of an in person meeting of the Delphi expert panel, which took place in Edmonton, Alberta, on the 23rd and 24th of September, 2013. The purpose of this meeting was to review and to endorse the competencies, and to develop a skills profile.
The resulting skills profile outlines the purpose of the navigation competencies and the population for which it is intended. It includes five General Area Competencies (provide patient/family screening; advocate for the patient/family; facilitate community connections; coordinate access to services and resources; promote active engagement), each with corresponding skills which must be utilized when providing navigation. This skills profile is intended to provide the foundation for the development of future curriculum and future research.

Introduction

Research on rural aging in Canada has identified unique health challenges and issues facing older adults living in rural locations [2]. For older adults who have terminal diseases, palliative care services are underdeveloped in rural areas [3], thus increasing their levels of distress and isolation [4]. A report by the Parliamentary Committee on Palliative and Compassionate Care [5] demonstrated that the Canadian health care system is ill-prepared for the growing senior population; it also highlighted the fact that rural palliative care systems require development. A major recommendation of this report was the need for health care system navigators to guide individuals and families through the intricacies of the health care system. The report describes health care provider navigators as helping to identify solutions, to make decisions in crisis situations, to build consensus between the family and care providers, and to broker, implement, and review care plans. Health care provider navigation competencies (knowledge and skills) specific to rural older persons with advanced disease and their families, however, have not been developed or evaluated. These competencies are needed to help rural seniors and their family caregivers find the services and resources they require to have peace and comfort at the end of life while remaining in their communities. Thus, the development of navigation competencies specific to the care of older persons living in rural areas at the end of life is an important step in implementing the recommendation, made by the Parliamentary Committee, to use health care system navigators. This final report of a funded CIHR Planning/Dissemination grant outlines the process of the development of these specific competencies and the resulting competencies and skills profile.

Discussion Paper

This paper includes a review of the significant literature in three main areas: aging in rural Canada, rural palliative care, and patient navigation. It was undertaken to guide the discussion and development of navigation competencies for rural Canadians during end of life. The challenges, issues, and questions that emerged from this review have also been included to provide insight as to the emergence and the development of the resulting competencies.

Aging in Rural Canada

Keating, Swindle & Fletcher [2] recently completed a systematic scoping review of the research published between 2000 and 2010 on aging in rural Canada. To augment this work, an additional search was conducted on rural aging in Canada using Academic Search Complete. All searches included “Canada” and were limited to peer-reviewed journals published between January 2011 and January 2013. Keywords reflected some of those used by Keating and colleagues, including
rural, rural population, seniors, older adults, aging, and aged. The following summary of the research highlights the Keating et al. article [2] and additional findings from the updated review.

**Issues/challenges in the literature**

In their review of literature on aging in rural Canada, Keating et al. [2] identified many issues and challenges categorized under the following broad categories of rural literature: definitions of rural; work, leisure, and social participation; independent aging; family and social networks; and, health. Using these categories, a summary of Keating et al.’s findings are presented, and where appropriate, are supplemented by recent research.

**Definitions of Rural**

Where definitions of rural were provided in the articles, they could generally be categorized according to geographic and/or socio-cultural criteria. The most common definitions were those in which rural was related to geographic indicators, such as population size, density, and/or distance to urban areas. Statistics Canada’s “rural and small town” definition was commonly cited, wherein rural refers to individuals living in towns or municipalities outside of the commuting zone (250 kms) of larger centres (with populations of 10,000 or more) (i.e., Krahn, Lengyel, & Hawranik, [6]). The second category is socio-cultural in which rural was understood as a set of attitudes, behaviours, and beliefs. The socio-cultural definitions focused on rural ideologies, such as the stoic nature of rural people, or on rural areas as places to work, retire, or play. A study on rural and remote nursing practice concluded that it is more appropriate to focus on the meaning of rurality shared by rural residents rather than a single specific definition [7]. Keating et al. [2] suggest, “further work is needed to link socio-cultural to geographic definitions in order to provide a basis for better understanding the interface between older people’s rural beliefs and the physicality of the places in which they live” (p. 333). Critical gerontologists suggest that although people are continuously interacting with the physical and social contexts in which they live, they are not passive recipients [8]. Instead older adults, through their responses to their contexts, and at times through purposeful interactions, change the contexts in which they live. Thus, older adults are connected to rural places in ways that in part create and recreate their identities in relation to the landscapes that are critical to their lives [8]. A community that can be considered “age-friendly” is one in which the best fit between the various needs of older adults and the resources available in the community occurs [9]. Thus, the interface between personal and environmental resources is important to consider when discussing rural living and aging in Canada.

**Question Raised: How will geographic and socio-cultural definitions of rural aging be reflected in the competencies?**

With respect to rural aging, whether to focus specifically on rural areas or to make comparisons between rural and urban populations should be considered. The benefit of the latter is the possibility of learning more about what is unique or different about service provision in rural areas. However, rural communities are extremely diverse, making comparisons between rural and urban populations, difficult, as is the case with comparisons between rural communities. For example, some rural communities are service rich while others are service poor. They also vary in proximity to urban centres. Keating et al. [9] in a recent article based on data from a mixed methods study of rural communities in Canada categorized rural communities in order to reflect their diversity. The categories are Bucolic, Bypassed, and Farming. A Bucolic community is one that is comprised predominately of retirees that have moved to rural areas. In turn these
communities have a rising cost of living and enjoy increased amenities. This is in comparison to Bypassed communities where there is a longstanding erosion of resources, a lower than average mean income, and a decreasing community infrastructure. Farming communities are distant from services centres and migration from farm to town occurs at retirement. This type of community has an active voluntary sector and community infrastructure for older adults. The diversity of rural communities is often overlooked when comparisons are made across the rural/urban divide.

**Question Raised:** How will the diversity of rural environments be reflected in the navigation competencies?

**Work, Leisure, and Social Participation**

Keating et al. [2] note that concepts of work, retirement, and leisure have been replaced in rural communities by notions of participation and productive activity that cut across employment/retirement and leisure/work divides. This may result in part from rural cultures that value stoic and resilient residents. Participation and productive activity can include unpaid activities such as volunteering, helping others, being a member of organizations, and being involved in active leisure. Less is known about employment and older adults, as most relevant literature focuses on younger residents and how workforce mobility may influence the social formation of communities (see Newhook et al. [10]).

The literature indicates that older rural residents belong to more organizations, spend more hours volunteering, and provide more personal help to others than urban residents [2]. While this participation is often by choice, some authors note that older adults are at risk of becoming ‘compulsory volunteers’ in communities with few local services. Rural community characteristics can foster or constrain volunteering and caring for family members. For example, more help is provided by family and friends in communities that are more remote and less economically diversified [2]. These findings suggest that the characteristics and resources of rural communities are important to consider when determining the extent of help that is provided by family, friends, and neighbours.

**Independent Aging**

In short, research on independent aging has tended to focus on two aspects: 1) aging well and 2) the frailty of older adults and their subsequent need for assistance. Early rural literature on independence focused on how to keep older adults living at home. More recently, the focus has switched from remaining at home to quality of life. In terms of frailty, this new focus has helped move away from images of frailty and dependence to a focus on older adults’ assets and abilities. Frailty and the need for assistance is still prominent in the rural literature, and will be discussed below in the section entitled Health.

**Family and Social Networks**

Research on rural families, on the social and support networks of older adults, and on rural caregivers, comprises a relatively small body of work. Within this limited research field, a number of articles document the out-migration of young people and the geographic distance of network members. This out-migration ultimately limits the availability of family/friend support for older adults (e.g., Newhook et al. [10]). As a consequence of out-migration, Keating et al. [2] observe a growing research interest in the social isolation of older adults in rural communities. This may be the result of geographic distance between relatives or the stoic nature and self-
reliance of some rural seniors. Current gaps in our knowledge include ways to identify which older adults are likely to be embedded in social and support networks, and which may be isolated. Some studies suggest that demographic characteristics, such as gender, be considered when assessing the potential for supportive informal connections [1].

Caregiving has received continued attention in the literature. Most interest though, has focused on family caregivers with little research devoted to non-kin caregivers such as friends and neighbours. Literature on family caregivers reveals the unique challenges of providing care in rural settings. Challenges include: limited access to formal supports; increased reliance on family and friends, fewer opportunities to meet with other caregivers for emotional support; and, for those living in more isolated communities, costly travel to access services.

**Health**

Health is by far the most researched area in Canadian rural aging, and this trend has continued since the publication by Keating and colleagues [2]. Research areas include health status (including physical and mental health of rural older adults), and rural services (including availability, utilization, and restructuring of services). At the aggregate level, research suggests that rural residents experience poorer health than their urban counterparts [11]. Segments of the rural population are more at risk for certain conditions (such as hypertension), but the evidence identifies a wide range of rural health disadvantages. Despite this, rural seniors tend to be more satisfied with their health regardless of these disadvantages. This may be related to rural cultural values, which include stoic approaches to health problems, and the belief that family and friends can be drawn upon if needed. The relationship between the rural environment and the normal changes of aging are important considerations in understanding the health of rural older adults. For example, normal changes that accompany aging (physical, psychosocial, and spiritual) influence the presentation of symptoms, the responses to treatments, and the care needs of older adults [12]. Specifically, the rural setting can influence the ways in which health services are sought, and the ways in which patients are responded to by health care professionals.

Compares to urban seniors, older adults in rural communities have fewer visits to family physicians, to specialists, and to dentists. They are more likely to use emergency rooms, to be admitted to hospital, and to live in residential continuing care centres [2]. In regard to community services such as home care, respite care, and other services such as senior’s centers, there is a paucity of research in this area. This might be due to the absence of these services in rural areas and/or a lack of knowledge about what services are available. To address rural service deficits, strategies such as increasing the availability of health care professionals, enhancing community health resources, using telehealth and other technologies, and relying upon the voluntary sector have been suggested [2].

In their review, Keating and colleagues [2] conclude that two lenses are present in the literature on rural aging and health. The first of these “is focused on older adults who are at risk because they lack personal or community resources to meet their needs” (p. 333). This literature focuses on rural seniors whose health problems might be exacerbated by rural settings. The second rural lens “is focused on quality of life, independence, and social connections” (p. 334). It concentrates on aging well, as well as on the contributions older adults make to their family, their friends, and their community. This lens is important as most other research understands older adults as those who receive care, while not considering the care provided by or exchanged with older adults. Both research lenses highlight the fact that it is important to consider the “best fit”
between the needs of the older adults in a given community, and the community resources available to them [9].

Navigation in rural communities could help older adults and their caregivers to better access existing resources and support the development of new local resources. The goal of navigation would be to facilitate and/or achieve the “best fit” for older adults and community resources.

**Question Raised:** *With respect to rural aging, how will we utilize the lens of quality of life, independence, and social connections to guide the development of navigation competencies specific to rural palliative care?*

*How will the competencies reflect normal changes with aging and the concept of “best fit”?*

Although most rural aging literature to date falls under the topic of health, relatively little is known about palliative care in rural Canada. Keating et al. [2] note that “palliative care is underdeveloped in rural areas…and there has been a call for tailored approaches to address local concerns and priorities as urban-based policies that are scaled down do not always work in rural and remote areas” (p. 332). In a broader context, palliative care traditionally exceeds and transcends conventional definitions of healthcare and thus includes social, psychological, and spiritual care. In the next section of this discussion paper, we consider what is known and what gaps exist in our knowledge about rural palliative care in Canada.

**Rural Palliative Care**

Based on the literature pertaining to rural palliative care, those living in rural locations are clearly influenced by their geographical location, their population density, and their community ties. As well, they have differing values regarding end-of-life care than do those residing in urban environments [3, 13-19]. Given the aging Canadian population and the trend for older adults to desire aging in place, there is a sense of urgency to properly provide equitable access for palliative patients in rural locations; a seminal component of this initiative is to design appropriate policies and services that are responsive to the uniqueness of rurality [3, 4, 14, 18-26]. However, a definition of palliative care specific to rural contexts does not currently exist. In order for approaches to be relevant to rural locations, researchers and policy makers must employ a critical gerontological approach, wherein the perspectives of rural patients and caregivers inform the development of definitions and solutions designed for this population.

**Challenges and Issues**

*The Concept of ‘Rurality’ and the Dying Process*

According to Castleden et al. [13], rurality is not simply a geographical location, but an identity shaped by the intersection of social, political, economic, and cultural factors. In general, an ethical approach to rural health must take these factors into account [18]. The dominant imagining of rural life is characterized by “tight-knit families, a strong sense of community, and a pace of life that is well-distanced, both socially and physically, from urban affairs” [13] (p. 288). This image is rendered questionable by the realities of dying and death in rural areas—such as, isolation, lack of services, commuting for care, high levels of caregiver burden, and urban-centric palliative policies—that are in sharp contrast to the imagined ideal [3, 4, 13-16, 18, 20, 27, 28]. Delivering palliative care equitable to that experienced by urban residents is challenging in rural settings. This is largely due to the dominance of palliative care models designed for
urban locations of large population density, in which care is delivered by specialist teams and where services and institutions are accessible by patients and their families [23, 29].

The dying process is also influenced by the interpersonal relationships characteristic of rural contexts, “where dying is not a private medical event, but rather a whole-person-in-community event, and where care is offered as a natural expression of independence and reciprocity that characterizes rural community life” (p. 103) [16]. Rural palliative care patients and their families value independence and connection to their communities [4]. While there is no agreed upon definition of a ‘good’ death in a rural context, one perspective is that moving palliative patients to urban centres is often counter to their wishes and to their conceptions of how they wish to die [14, 19].

In their ethnographic study in rural Alberta, Wilson et al. [19] found that “the good rural death is an outcome of rural community values” (p. 28). As such, the consideration of context and the specificities of the community are necessary when delivering palliative care in which a ‘good’ death is a goal. The authors also found that residents were committed to having access to high quality end-of-life care, but were aware that they faced socio-political barriers. What was not found in this study, but is evident in the palliative care literature, is that one outcome of a ‘good death’ is decreased stress for families during bereavement [19]. The consequences of providing care to a family member at the end of life include intense grief, acute distress, and decreased physical and mental health during bereavement [30]. Support during bereavement is a hallmark of comprehensive, high quality palliative care services [31, 32].

**Question Raised: How can the competencies reflect the rural identity of valuing independence and connections to their communities?**

**Should the competencies reflect quality end-of-life care (including a good death) and support during bereavement?**

**Palliative Care in Rural Settings**

Palliative care is influenced and shaped by geographical realities, social, political, and economic factors, and cultural influences. Issues concerning the provision of rural palliative care are related to access, coordination of care, maintenance of multidisciplinary palliative care teams, bed allocation, and place of death [18]. Rural patients can experience end of life as both an isolating and a community event, with limited access to resources [4]. Palliative care in rural settings differs from care received in urban centres with respect to: a) providers’ collaborative and generalist approach, b) necessity to perform multiple roles; and c) overlap of personal and professional relationships [23]. The delivery of appropriate palliative care is also constrained by the limited number of health care professionals (HCPs) employed in rural areas, and the limited attention given to issues of palliative care during their formal education and training. Consequently, HCPs perform dual roles and feel under-qualified to do so. Dual relationships/roles can also pose ethical dilemmas for HCPs when confidentiality is difficult to maintain or when breaches are perceived as necessary to mobilize resources [14, 17, 18, 20, 21, 26, 27, 33-35]. Pesut, Robinson, and Bottorff [36] suggest that rural palliative care involves a complex web of responsibilities among families, HCPs, and administrators. These responsibilities are usually negotiated and long-standing. As such, a careful analysis of changes to these negotiated responsibilities should be completed before any changes to policy and practice are made. Moreover, palliative care initiatives in rural areas are often championed by an individual and held together through informal networks, in which the program suffers immensely
in their absence [18]. The strong interpersonal relationships present in rural contexts, as well as a collective sense of responsibility, are strengths in the delivery of palliative care [3, 15, 17, 18].

The extension of urban frameworks to rural communities does not appear to result in equitable care for rural community members. Successful community palliative programs are those that a) emerge from the community; b) are specific to the needs and resources of communities in question; c) do not employ specialist teams; and, d) respect the resourcefulness of rural HCPs and citizens [22, 23, 26]. Spice et al.’s [26] research in the Calgary Zone of Alberta demonstrates the effectiveness of relevant palliative care in allowing patients to remain in their communities. During the first four years of this program, almost 75% of residents died in their communities.

Health Services Access and Utilization
Goodridge et al.’s [37] comparison of healthcare utilization during the last 12 months of life in urban/small urban versus rural/remote residents in Saskatchewan reveals that those residing in rural and remote locations visit with a primary care physician less often and are less likely to receive home care services provided by professionals, such as palliative care and physiotherapy. The authors question whether these inequities account for the higher rates of admission to long-term care facilities amongst rural and remote residents.

Rurality and socio-economic disadvantage also affect one’s referral and/or access to palliative radiotherapy (PRT), a treatment shown to improve the quality of life for dying patients. Lavergne et al.’s [38] research in rural Nova Scotia reveals that older adults, women, and those residing in nursing homes are less likely to undergo PRT. Increased commuting time and community deprivation also decrease the likelihood of PRT. As well, Olson et al. [35] report that family physicians are more likely to refer patients to PRT if physicians have undergone post-MD training in either palliative care or radiotherapy.

Wilson et al.’s [28] examination of Statistics Canada mortality information from 1994 to 2000 reveals a universal decrease in hospital deaths; this included a 12.4% decrease in rural locations, thus reflecting an increased number of deaths occurring in nursing home and home locations. The authors predict that, when baby boomers reach end of life, the death rate will be twice that of the period of time they studied; this will be coupled with a vast shortfall of hospital beds able to accommodate this trend. Yet, it is not clear whether these statistics still reflect current hospitalization and end-of-life care in rural areas following changes made to the health care system since 2000.

Barriers to patients remaining at home and/or in their communities during end of life include limited human and financial resources to provide palliative care, and limited palliative education for those working in rural communities, either during formal training and/or during professional development opportunities [4, 21, 23, 27]. Because most patients prefer in-home care and a home death, they only seek the services of a hospital when symptoms became unmanageable [18, 20, 39]. The Canadian Hospice Palliative Care Association (CHPCA) suggests that a palliative care approach should integrate primary-secondary (and tertiary if available) hospice palliative care services within a region or geographic area [40].

Indigenous Populations
Indigenous populations experience decreased and/or blocked access to palliative care for many reasons. Allan et al. [39] report that Indigenous peoples rarely access palliative care beds in the hospital even though hospital administrations claim to have structured their palliative care unit to
be able to meet their needs. This is likely because access to services for Indigenous populations is far more complex than the physical designation of a certain space. Physical settings that are ‘institutional like’ may trigger memories of residential schooling [33], group homes, and prisons. Moreover, medical professionals may deliver stratified levels of care based on a patient’s ethnicity and individuals may hesitate to reveal themselves as Indigenous due a history of discrimination [33]. Castleden et al. [33] list “having an appropriate physical location and care space, being in close proximity to natural surroundings, being able to practice ceremonial activities while receiving care, having access to traditional foods and the use of traditional medicines” as necessary components for providing culturally-relevant palliative care to Indigenous populations. This requires the formal support of government bodies, the availability of training programs, and the commitment of healthcare services to provide safe and appropriate care that result in equitable outcomes for patients. Furthermore, “recruiting formal and informal Aboriginal palliative care providers is a logical extension to facilitate culturally safe spaces and culturally competent care” [33] (p. 489).

**Ethnic Minorities**

There is very little written in the rural palliative care literature herein discussed that addresses ethnic minorities, other than to problematize this absence. Castleden et al. [13] hypothesize that that ethnic minorities in rural communities more often receive palliative care from family members in their homes because their institutional settings are not designed to meet their socio-cultural needs. Robinson et al. [3] mention the ethnic composition of rural communities to show the diversity amongst rural areas. In later work Robinson and colleagues [41] state the need for research that is socio-culturally sensitive. As such, this remains an undeveloped area of in the scientific literature to date.

**Question Raised:** *How will the competencies reflect a cultural safety approach?*

**Persons with Advanced Disease and Families**

For persons with advanced disease and their families, rural palliative care often entails caregiver isolation and burden, the financial and emotional strain of commuting to urban centres (coupled with the fear of becoming the responsibility of neither urban nor rural healthcare systems), and limited access to services [15, 24, 27]. While the perspectives of patients and caregivers are limited in the rural palliative care literature [3], this absence is especially pronounced for Indigenous populations.

**Persons with Advanced Disease**

Those dying in rural locations have varying and complex needs that reflect their geographical, physical, and social location [4]. For example, patients feel both connected to their communities and isolated in their experiences. They feel compelled to exert independence while concurrently realizing their increasing dependence upon others. Inasmuch as rural communities and residents often value independence; this can lead residents to avoid seeking support and/or accessing resources.

Rural palliative patients are disadvantaged in terms of availability and proximity of care. As a result, they perceive that they have fewer choices regarding where they will die [4, 18]. Hospital deaths are perceived positively if admission occurs within the patient’s community during last 48 hours of life. This is specific to the rural context, wherein those working in the hospital had a prior-established relationship with the patient and their family. Thus, the effects of closing small
hospitals are more widely felt than simply increasing the travel time for family and loved ones [18].

Goodridge et al. [37] argue that, although the home death rate for urban and rural residents is similar (16.3% vs. 15.4%), rural residents experience hospital deaths outside of their home communities differently than do urban residents. She suggests that hospital deaths outside home communities are “particular hardships for rural families who may need to travel extensively or temporarily relocate to be closer to the hospital where their loved one is dying” (p. 2). Being removed from one’s community is considered antithetical to a ‘good death’ by some patients [14, 18, 37]. The ‘first available bed’ policy in British Columbia and Ontario is an example of how policies are unable to meet the needs of rural palliative patients. In practice, such policies can result in patients being housed outside of and far from their community of residence [13, 18].

**Question Raised:** How will the navigation competencies support rural residents remaining in their communities as much as possible?

**Family Caregivers**

Findings from one study comparing urban and rural caregivers of persons receiving palliative care demonstrated no significant differences in the participants’ perceived health status and caregiver burden based on geographic location [42]. However, findings from another study of Canadian rural women caregivers indicate their mental and physical health to be below the 25th percentile of US population norms [43]. As such, the quality of life of rural caregivers of persons receiving palliative care is of concern. A CHPCA [44] report on family caregiving strongly suggests that well-resourced, integrated hospice palliative services should provide relief, support, and comfort for family caregivers. Support for families is also highlighted in a synthesis of recommendations from national reports on hospice and palliative care [45].

The value of independence, often attributed to rurality, means that caregivers only seek respite at the point when their health declined as they are reluctant to rely on homecare and volunteer services [18]. The reasons for this are varied, but prominent factors are the unease of having those they considered strangers in their homes, the discomfort resulting from having those they knew from the community having intimate knowledge of their personal lives, and the impetus to manage and avoid the patient’s removal from the community if proper home care was untenable [18]. Patients are also unlikely to ask HCPs for additional support when experiencing ongoing problems [17].

Based on research with rural family caregivers, Robinson et al. [25] conclude that strategies aimed at supporting rural family caregivers should bolster caregiving abilities and self-care as a component of caregiving. Participants rarely desire more help from healthcare professionals; instead, they wanted increased knowledge of how to care for their family member, increased information, and the ability to manage multiple demands. Similar findings were also reported in a study of the transition experience of rural palliative care patients and their caregivers [15]. Based on this study, a self-administered transition intervention was developed and evaluated [46]. The resulting “Changes Toolkit” was described as feasible, acceptable, and easy to use. It also showed the potential to help families in rural areas deal with transitions. Aligned with the importance of caregiver self-care and independence, the living with hope program showed potential in bettering the quality of life for rural women caregivers of persons with advanced cancer. Specific to this population, an evaluation of the living with hope program for these caregivers showed that this program decreased feelings of loss and grief, while increasing
feelings of self-efficacy. In turn, these caregivers reported increased hope and an improved quality of life [47].

**Question Raised: How do the competencies value independence and community connections of rural family caregivers?**

**Volunteers**
The resourcefulness of palliative care ‘champions’/volunteers in communities is integral to the mobilization of services that allow patients to remain in their communities and/or homes [18]. According to McKee et al. [16], palliative care volunteers are often an important factor allowing home deaths to occur in rural communities that are under-resourced. Their findings show that volunteers have multiple roles in the rural setting, “one that fuses elements of formal caring (training, confidentiality) with the informal, friendly visiting of neighbours and friends” (p. 109). McKee et al. [16] highlight the element of the informal “just sitting and listening” as important and often invaluable to the dying patient (p. 109). Thus, volunteers may be important resources for rural palliative care patients and their families.

In contrast, volunteer drivers to assist with commuting to services may not always be viewed positively by family caregivers [27]. Although commuting is a strain, family caregivers positively describe the time spent with their loved ones. As a result, they may be resistant to volunteer drivers. The utilization of volunteers should be a choice for families, and research should target the ways in which volunteers would be most effective in supporting rural older persons at the end of life and their families.

**Question Raised: How can the competencies empower volunteers in rural communities in meaningful ways?**

**Health Care Professionals**
Many HCPs working in rural settings are devoted to delivering the best possible care to their patients. They approach palliative care “as a way of life rather than simply a job” [18] (p. 81). They demonstrate resourcefulness and often go beyond their job description [17, 18, 20]. However, many HCPs may feel obligated to do so because of the tight-knit environment of rural settings and a feeling of community accountability. As such, the risk for burn out for these HCPs is potentially increased.

HCPs describe several barriers to providing rural palliative care [48]. These include spatial-temporal barriers, professional practice barriers (i.e., lack of specialization in palliative care, attitudes and beliefs of health care providers, working with families, conflict among health care providers), and existing policies. Robinson et al. [18] report that rural nurses feel frustrated by contracts that do not allow for overtime, wherein nurses who work more than their allotted hours are considered volunteers and are not entitled to their health and safety benefits should an incident occur during this time. Such policies are not responsive to the rural setting where no other help for families may be available, and where pre-existing interpersonal relationships may naturally influence the desire of HCPs to devote more time to their patients.

Pesut et al. [17] demonstrate a link between how nurses are facilitated or constrained in achieving palliative principles in rural contexts and the influence on outcomes experienced by patients and their families. This research points to the necessity of palliative-specific education. For example, palliative care principles are more easily realized in the rural context when nurses
take “a patient well-being approach” (p. 299). This requires consideration of how patients and families experience time in different ways than patients with reversible diseases as well as balancing the simultaneous need for privacy and attention to both patients and caregivers. Family caregivers also benefit from nurses directing them to resources, helping them understand policies, and regularly providing them with information. Nurses also act as a liaison between physicians and families [17].

Questions surrounding pain and symptom management are often cited as the primary concerns of rural HCPs [20, 21, 23, 49]. As a result, this content area has been the focus of HCP educational programs. Education and training programs have been developed and evaluated for rural HCPs in long-term care facilities [21] and for community based palliative care teams [50]. Examples of programs include Learning Essential Approaches to Palliative and End-of-Life Care (LEAP) [51] and Comprehensive Advanced Hospice Palliative Care Education (CAPCE) [52]. Bringing educational initiatives to the community, either physically or virtually, was key to the success of these models; this is because challenges for rural HCPs include being unable to leave their work setting (because finding a replacement is difficult), and being unable to travel long distances [21, 50].

Hall et al. [50] report that community based palliative care teams are most successful when the group works together toward achieving their goals. The successful functioning of the team is facilitated by academic-community partnerships wherein academic teams develop education and training specific to the needs of their community partners. This educational component was cited as essential to the delivery of appropriate rural palliative care. HCP education has been enhanced by the use of telephone and virtual technologies. Findings from Ridley and Gallagher’s [49] study regarding the utilization of a palliative telephone hotline show the majority of users were rural health care providers who sought consultation for pain management and gastrointestinal issues. Watanabe et al. [53] report that utilizing technology (telehealth) is a feasible approach to provide palliative patient consultation in rural Alberta. However, in a review of the literature on rural palliative care, Robinson, Pesut & Bottorff [3] suggest that technology is useful for provider education and consultation but not for patient consultation. The limitations noted were the cost, use and application of technology, literacy, and internet resources, especially in a rural setting.

Secondary palliative care service hubs (SPCHs) may serve as facilitators of education and information dissemination. Crooks et al. [14] tested the implementation of a SPCH in a rural location in the British Columbia interior and found that SPCHs need not be a physical office location, but can be virtual. What was important is that these hubs provide the opportunity for two-way communication between palliative specialists, generalists, and communities. However, the implementation of health information technologies is complicated in the rural setting by physical infrastructure concerns and the importance of interpersonal connections [34].

**Question Raised:** What competencies are addressed in the existing educational programs for rural health care professionals, how can navigation competencies be integrated in these programs, and is there a role of technology in supporting HCPs?

There is a debate in the literature, particularly among rural physicians, about whether palliative care should be delivered through a specialist or a generalist model in rural settings [18]. Some believe the primary responsibility for palliative care should rest on formal specialists, while others believe it should be a fundamental part of all primary care. The debate and resultant
tension is thought to result in the reluctance of rural physicians to consult with local palliative care programs. The CHPCA suggests that using a palliative approach is causing an overall shift in approach, from specialist led models to a generalist multidisciplinary integrated approach [40]. This debate raises the issue of whether navigation competencies should be developed for generalists, for specialist palliative care HCPs, or for both.

**Question Raised:** *Will the competencies focus on generalist or specialist palliative care HCP or both?*

**Will the competencies be cross-disciplinary?**

**Summary of Issues and Challenges Rural Palliative Care**

The implementation of urban-centric palliative policies in rural contexts has resulted in inequities in access to end-of-life care and outcomes for rural-living persons who are palliative [3, 4, 13, 16, 17, 20, 22, 29]. Caregivers experience high levels of burden and often try to manage independently, and thus strategies for supporting caregivers must take this into account [18, 25]. HCPs are constrained by limited financial and human resources as well as educational opportunities in their ability to deliver appropriate care [21, 23].

The exclusion of palliative patients and caregivers and the application of urban-centric palliative care approaches are connected. Based on the literature review, strategies to facilitate patients remaining in their communities and/or dying in their homes is fundamental to achieving a ‘good’ rural death [19, 20, 25]. There is a need to understand what palliative care should entail as defined by those receiving and providing care in rural settings. This is especially pertinent for Indigenous populations [3, 33]. As such, research programs and navigation competencies could focus on discovering how to dismantle systemic barriers to equitable palliative care as well as how to develop culturally safe care. The perspective of rural participants is essential to developing relevant policies, interventions, and models of care. *Similar to research on rural aging, an examination of the research that focuses on the perspective of patients and families receiving rural palliative care reveals that the values of quality of life, independence, and social connection to their communities are important.*

**Question Raised:** *How can navigation disable system barriers to palliative care and reflect family-centered culturally safe care?*

*How can navigation reflect the values of quality of life, independence, and connection to their communities?*

**Patient Navigation**

Patient navigation is becoming an emerging phenomenon of interest in the health care delivery system as an approach to effective care coordination and increased patient satisfaction. However, its focus has been on cancer care. In cancer care, patient navigation is an intervention aimed at addressing cancer health disparities by eliminating barriers to diagnosis, treatment, and services most prevalent amongst marginalized populations who have limited or difficult access to health care resources [54]. The term ‘navigator’ has been applied to any type of service that assists individuals in overcoming obstacles from screening to treatment, and in coping with challenges during survivorship [55].
**Challenges and Issues in the Literature**

The literature suggests that patient navigation programs result in a reduction in cancer care disparities, especially among marginalized populations. This is achieved by facilitating earlier cancer screening, reducing diagnostic delays, and overcoming other barriers experienced during the care of oncology patients [55]. Patient navigation has been proposed as an innovative intervention to address known barriers to obtaining cancer care. Most of the literature, however, has focused on the role of a patient navigator (a position) without consensus of a definition of navigation. One of the major challenges in the review of the literature is the lack of a generally accepted definition for patient navigation and very little consensus on the actual roles and responsibilities of navigators [56]. The literature also uses the terms ‘patient navigation program’ and ‘patient navigator’ interchangeably. In Canadian Health Care, system navigators have been also called case managers, clinical coordinators, cancer support nurses, follow-up nurses, breast specialists, breast cancer coordinators, and patient navigators [57].

An integrated literature review by Case [58] examined eighteen research studies in which an oncology nurse was involved as a navigator. The patient navigator’s role in these studies was to assess individual needs; plan for education, coordination, communication, and support; implement effective transitions through the illness trajectory; and evaluate the effect on patient, family, and organizational outcomes [58]. Although these studies did suggest that navigators reduced the time waiting for diagnosis and appropriate treatment and increased patient satisfaction, the evidence is conflicting in regards to its effect on decreasing cancer patients’ distress and health care costs [58]. Overall, the review supports the value of the nurse as navigator in oncology care. A separate study reports successful outcomes of non-professional navigators who functioned as integrators and coordinators of community resources for cancer patients [59].

Subsequent to the Case review [58], Pedersen & and Hack [60] identified the need for patient navigators to include a psychosocial perspective. They proposed the British Columbia Patient Navigation Model (BCPNM) as a practical alternative. The BCPNM elucidates the role of the navigator within the context of cancer care, postulating six integral components: (a) provision of information, (b) emotional support, (c) facilitating decision making, (d) creating linkages to resources, (e) provision of practical assistance, and (f) identifying and developing community supports. However, this model has not been evaluated and does not appear to address the comprehensive palliative care needs of the patients within a rural context.

A navigation model developed by Fillion et al. [57] was validated in the Canadian context utilizing a qualitative methodology. This model has two dimensions of navigation: (a) facilitating continuity of care and (b) promoting patient and family empowerment. Facilitating continuity of care, within the health system, results in the patient’s experience of care as coherent and connected. Promoting patient and family empowerment is the patient-centered dimension in which care providers are supportive partners in care. This dimension includes cancer self-management. It is unclear, however, if the model was also validated in a rural context with older persons who are palliative and their family members.

Fillion et al. [61] compared two Canadian models of navigation: Quebec’s Pivot Nursing in Oncology (PN) and Nova Scotia’s Cancer Patient Navigator (CPN). This study used qualitative interviews with navigators, front-line staff, physicians, and health administrators using a previously developed model of navigation. Professional navigators in both programs performed
similar functions and faced similar challenges. Unfortunately, outcomes of the programs were not evaluated even though the framework includes descriptions of effective outcomes.

Challenges common to the Quebec Pivot Nursing [62] and the Fillion et al. [57] models are that both dimensions of navigation (continuity of care and patient empowerment) are limited in their approach. Palliative care is an approach to care that emphasizes quality of life as a goal [63]. Continuity of care is only one aspect of care and may not be the goal in rural palliative care. Although the dimension of empowering the patient includes self-management of their cancer, it does not include self-navigation. Models of navigation have been criticized for not recognizing the need for self-navigation [54]. Independence is highly valued by rural populations, as reported in research on rural palliative care [4]. Thus, supporting family/friend caregivers and older rural persons to also participate in navigation is an important consideration. Rural Canada has very few health system services [3], so navigation specific to this population will need to include accessing other community resources (in addition to health), and informal services.

**Question Raised:** What is the definition of navigation in rural palliative care for persons with advanced disease and their families?

What are the goals of navigation in the care of older rural palliative persons and their families?

How can the competencies reflect self-navigation and the importance of accessing community resources as well as health system resources?

**Definitions of Navigation and Competencies**

Based on their own definitions, two Canadian organizations—the Canadian Partnership Against Cancer (CPAC) and the National Case Management Network (NCMN)—have developed navigation competencies. CPAC [64] defines navigation as “a system of services and resources that are mobilized based on the immediacy and severity of patients’ needs. It is “a proactive, intentional process of collaborating with a person and his or her family to provide guidance as they negotiate cancer care” (p. 6). This definition, built on the work of Fillion et al. [57], suggests navigation is a process that is accomplished through collaboration with patients and their families to negotiate cancer care. This definition assumes the availability of cancer care services. Unfortunately, formal palliative care services are not always available and/or may not be accessed by persons living in rural areas. Thus, this definition may not be applicable to rural palliative care. CPAC identifies two main dimensions to navigation: facilitating continuity of care and promoting patient and family empowerment (see Appendix 1 for detailed competencies). The competencies developed based on the CPAC definition describe navigation functions as well as outcomes for each of the competencies. As mentioned previously in the critique of Fillion et al.’s [57] model of navigation, these dimensions of the model may also not reflect the palliative approach.

In contrast, the NCMN views navigation as helping clients to navigate the health and social care system by working with their networks to identify and address barriers [65]. The NCMN identifies two case management key competencies: anticipate, identify, and help remove barriers to holistic care; and, facilitate safe and effective connections to services across settings (see Appendix 2 for detailed competencies). This definition recognizes the importance of the social care system and networks in addressing barriers to care. These concepts are more reflective of rural aging. However, the dimensions do not address the values of quality of life, independence,
and community connection that are prevalent in the rural aging and rural palliative care literature.

A Parliamentary Committee on Palliative and Compassionate Care Report [5] suggests that navigation for persons receiving palliative care can help “…with solution identification, decision making in crisis situations, consensus building between the family and care providers, the brokerage, implementation and review of care plans. Navigation is different than case management as “it is driven by the family and patient’s needs, not the health care system. It is knowledge transfer and translation. It is a family/person not a disease model” (p. 37). Navigation in palliative/end-of-life care was described as a family-centric collaboration that facilitated finding solutions, decision making, and consensus building between families and HCP as required to brokerage needed resources. Brokerage as a term implies arranging transactions between the health care system and the patient. The definition also identifies possible functions of navigation in palliative care, such as finding solutions, fostering decision making and consensus building, removing barriers, and improving access to needed resources. Similar to other definitions of navigation, it does not address the values of quality of life, independence, and community connections.

**Summary of Issues and Challenges in Patient Navigation**

A review of research studies to date indicates that various models of patient navigation have been applied in different settings. Yet, the current state of the literature shows that there is a need to understand the efficacy of patient navigation programs within the premises of these different models and frameworks, including whether or not they are cost effective. Furthermore, patient navigation models have not been developed for older rural persons receiving palliative care and their families, nor do they appear to reflect the palliative care approach or incorporate the values of independence and community connection that are part of the rural context. Continued research is thus needed to refine the role of patient navigators in palliative care, which would include a diversity of conditions such as cancer and non-cancer diagnosis. Future research on patient navigation should evaluate what type of navigation model is needed in particular settings and circumstances, and which components of navigation are most effective in a given setting. It should also explore the ways in which navigation benefits the patient and their family, and thus supports a more holistic approach to healthcare.

**Discussion Paper Literature Review Summary**

Our goal in reviewing the literature was to form a framework for health care provider navigation competencies for the care of older persons and their families living in rural communities. These competencies are required to help rural seniors and their family caregivers find the services and resources they need to have peace and comfort at the end of life while remaining in their own communities. The review raises many questions to be considered in the development of competencies for the care of this diverse population. Consistent with the palliative approach outlined by the CHPCA, the competencies should be cross-disciplinary and for generalist health care providers.

The themes of quality of life, independence, and social connections are prevalent throughout the literature on rural aging and rural palliative care. However, research on patient navigation clearly demonstrates that a definition reflecting these themes is lacking. Thus, a proposed definition of navigation is as follows: working in collaboration with patients, families, and communities to: a) negotiate the “best fit” between the needs of older rural persons, their families and communities.
and resources; b) improve access to needed services and resources at the end of life (including death) and bereavement; and, c) to promote quality of life, foster independence, and facilitate community connections utilizing a culturally safe, palliative approach. Proposed dimensions of navigation include: promoting quality of life (physical, emotional, psychological, relational, financial, existential, and spiritual), fostering independence, and facilitating community connections.

**Delphi Approach**

A four phased Delphi process was utilized in the development of the competencies and skills profile. In the first phase of the Delphi process, an international expert panel comprised of 30 researchers, health care professionals, and community stakeholders was asked to identify possible competencies for each of the following dimensions: a) promoting quality of life (physical, emotional, psychological, relational, financial, existential, and spiritual), b) fostering independence, and c) facilitating community connections. These were then collated and categorized into general areas of competencies (GACs).

The resulting GACs were: Provide Patient/Family Screening, Advocate for Patient/Family, Facilitate Community Connections, Coordinate Access to Services and Resources, and Promote Active Engagement. Associated with each GAC were more specific competencies.

In the second round, panel members were asked to rank all the specific competencies in each GAC in order of importance. The top ranked 5 competencies were then retained.

In the third round, using a consensus tool, the competencies were then evaluated for importance of inclusion. Competencies had to receive a 75% consensus from expert panel members to be retained. A competency was removed if it ranked lower than the 75% threshold. Only one competency was removed during this process: “Encourage development of family/friend/community resource based plans with minimal dependence upon professional support.” The rationale from the expert panel was that this was a duplicate competency.

**Phase 4 Delphi**

A planning meeting occurred in person in Edmonton on September 23rd and 24th, 2013. It brought together experts (in rural aging, rural palliative care and navigation), decision makers, knowledge users, researchers, and rural community members. The first day served as the 4th phase of the Delphi Process. The goals of which were to achieve consensus around a preliminary set of navigation competencies for the care of older rural adults at the end of life. The outcome of the meeting was the profile of navigation skills. Two experts in a process of developing competencies and skills were engaged to facilitate the process. They utilized a process entitled “Designing a Curriculum (DACUM)” whereby expert practitioners are assembled to consider a job, vocation, role or course(s) of studies in their field; in this case the DACUM process was used to develop navigation competencies for older rural adults and their families at the end of life.

Using “object + verb” language, the team described the activities performed by at least two expert practitioners. Each of those activities contained at least two steps each and were assembled under a collection of Generally Accepted Competencies (GACs). The focus was on the competencies and skills that must be utilized to provide navigation.
Navigation Competencies and Skills Profile

Context:
As a result of the Parliamentary Committee on Palliative and Compassionate Cares’ report and the subsequent successful CIHR grant application, “Which way from here? Navigation competencies for the care of older rural adults at the end of life”, an analysis of navigation competencies will inform several national, provincial and regional initiatives that are currently being undertaken in the area of health care navigation.

Object:
Generalist Health Care providers in rural Canada who are required to navigate resources for older rural adults at the end of life. Generalist health care providers are professionals who have health care training and provide care to patients and families, but are not specialists in palliative care.

Scope:
Navigation, for the purpose of this analysis, is “working in collaboration with patients, families, and communities to: a) negotiate the “best fit” for the needs of older rural persons, their families and communities and resources; b) improve access to needed services and resources at the end of life (including death) and bereavement; and, c) to promote quality of life, foster independence, and facilitate community connections utilizing a culturally safe, palliative approach.” The competencies reflect a family centric approach, in that they are focused on the patient and their family. For the purpose of this competency chart, provision of navigation services commences when an older adult is deemed palliative and will include bereavement. Please note that the use of patient here refers to older adult persons with advanced disease whether they are at home, long term care or in an acute care facility.

Resource providers providing care in rural settings may include:
- Rural seniors
- Rural family care givers
- Rural communities
- Formal and informal care services
- Generalist Health Care Providers

The following definitions apply to the competencies and skills:
1) QOL Domains include: physical, emotional, psychological, relational, financial, existential, and spiritual.
2) Local knowledge keepers and resources should be known as: patients, family, religious/spiritual leaders, other health care professionals, etc.
3) Services for older adults may include: psychosocial, emotional, spiritual and physical to support desired level of independence.
4) Generalist health care providers are professionals who have training and provide care, but are not considered specialists in palliative care.
5) Family is defined broadly as relatives, friends and neighbors.
6) Palliative is defined as a no response to the “surprise question” ‘Would you be surprised if this patient were to die in the next 6-12 months?’

The following General Area Competencies (A-E) are not listed in order of importance or sequence. All competencies and skills must be utilized when providing navigation either by an individual or health care team.
## Skills Profile

Care practitioners and care providers in rural Canada who are required to navigate resources for older rural adults at the end of life must be able to:

| C. Facilitate Community Connections | C1. Perform environmental scan for community services, care providers and events | C2. Identify community assets for patient/family | C3. Identify best-fit for patient/family with community resources | C4. Create linkages to local leaders, professionals and resources | C5. Broker linkages amongst local knowledge keepers and resource providers | C6. Assist patient/family to build and connect with networks/connections |
| D. Coordinate Access to Services and Resources | D1. Identify patient/family concerns/needs | D2. Develop care plans reflective of patient/family needs and concerns | D3. Assess patient/family need for supports for values-based end of life care | D4. Provide family with caregiving and support resources | D5. Coordinate access to needed services | D6. Assess patient/family service usage | D7. Facilitate discussion with patient/family regarding advance care planning and goals of care |
| E. Promote Active Engagement | E1. Determine effective and appropriate ways to meet client needs | E2. Identify level of desired patient/family involvement | E3. Build capacity with patient/family towards their desired level of independence and engagement | E4. Promote engagement in decision-making and end of life issues by patient/family | E5. Evaluate continuously the level of patient/family engagement in decision-making and end of life issues |

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*Which Way from Here? Final Report*
Summary

The undertaking of the discussion paper was essential in ensuring an evidenced based approach to develop the navigation competencies. The information outlined in the discussion paper provided the basis, framework, and definition for the development of navigation competencies for rural older adults at the end of life. The Delphi process was successful in bringing experts in rural aging, rural palliative care and navigation along with health care providers and community partners to inform the development of the competencies.

As a DACUM process was utilized, and a skills profile also developed, curriculum designers can now develop the content for educational programs for health care providers. A validation process of the general area competencies and skills is the proposed next step, followed by research studies evaluating the competencies. However without this initial ground breaking work, the competencies would not have reflected the current knowledge of rural aging, rural communities, rural palliative care and navigation. This marks the first articulation of navigation competencies specifically designed for rural older palliative patients, in ways that honour and respect rural communities and values. As such, these navigation competencies represent a commitment toward achieving equity of care for rural older adults at the end of life, and for their families.
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