

Canadian Oncology Nursing Journal

Revue canadienne de soins infirmiers en oncologie

Volume 25, Issue 2 • Spring 2015
ISSN: 1181-912X (print), 2368-8076 (online)



Canadian Association of Nurses in Oncology
Association canadienne des infirmières en oncologie

Supportive care needs of rural individuals living with cancer: A literature review

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ABSTRACT

Regardless of geographic location, the cancer journey is an extremely difficult experience for both patients and their families. The aim of this literature review is to explore the impact of rural or remote residence on the supportive care needs of individuals living with cancer. This review included ten qualitative, seven quantitative, and six mixed design studies. Data collection, analysis, and evaluation were guided using a multi-domain supportive care framework based on seven domains: physical, emotional, informational, psychological, spiritual, social, and practical (Fitch, 2009). This review will suggest that there are distinct experiences that present both challenges and benefits to individuals living with cancer in rural areas. These findings will be detailed with recommendations, and grounding for future research outlined.

Key words: cancer, supportive care, rural, qualitative, quantitative, research, adult, travel

KEY POINTS

- Rural living is often associated with delays in diagnosis, challenges of travelling long distances to urban centres, limited access to oncology services, economic disparities, and treatment decisions that are made based on geographic location.
- People choose rural life for reasons that directly affect their quality of life and sense of well-being. As a result, the benefits of rural living need to be considered when caring for patients from rural communities.

Cancer is a serious, life-threatening illness that affects all aspects of a person's life, regardless of geographic location. An illness can be defined as "a human experience of symptoms and suffering, and refers to how the disease is perceived, lived with, and responded to by individuals and their families" (Larsen, 2006, p. 4). People living with cancer are faced with many demanding, illness-related experiences, including changes to everyday life, effects on quality of life

and well-being, uncertainty about treatment options, treatment-related toxicity, and concerns about long-term outcomes. Uncertainty, hopelessness, dependence, role changes, and an ongoing search for meaning throughout the illness are also common experiences among individuals with cancer (Fitch, 2009; Shaha, Cox, Talman, & Kelly, 2008).

Cancer is a unique chronic illness associated with specific challenges, including long-term treatments, unpredictable phases of illness, and transitions across the disease trajectory from diagnosis to palliative care (Canadian Association of Nurses in Oncology [CANO], 2001). A 'chronic illness' continues indefinitely and often becomes the person's identity. Chronic illness can take on many forms, including exacerbations and remissions, and can become a juggling act of managing the demanding treatments while also maintaining wellness or improving quality of life (Larsen, 2006). Each individual will have a unique cancer journey and nurses play an integral role in the continuum of cancer treatment, service, and care throughout the disease trajectory.

BACKGROUND

In 2013, it was estimated there would be 187,600 new cases of cancer and 75,500 cancer deaths (Canadian Cancer Society [CCS], 2013a). Since cancer prevalence and survival are both on the rise, more Canadians will require ongoing cancer treatment, surveillance, and supportive care (CCS, 2013a). As a result, individuals living in rural areas will continue to experience health disparities while coping with the burdensome travel associated with a cancer diagnosis, treatment, and follow-up care (CCS, 2013a). Although most individuals make a conscious choice to reside in a rural community, rural health care is nonetheless an important public health concern. The literature suggests that individuals enjoy rural life for many reasons, including a close-knit community of support, positive cultural experiences, a sense of peace or harmony, and enhanced autonomy in daily life (Duggleby et al., 2010; Kuliq & Williams, 2012; Rogers-Clark, 2002; Wilkes & White, 2005). However, individuals living with cancer may choose to leave rural areas so they are closer to specialized medical care. Even though individuals may prefer to remain in their place of residence, rural geography can become a major obstacle to receiving necessary care.

Canadians who live in rural or remote communities have ongoing challenges in the delivery of health care and access to services. Since delivery of rural oncology care varies across provinces and territories, the scope of available services will differ across the country (Kuliq & Williams, 2012). Rural areas tend to have limited access to primary health care services, difficulties with recruitment and/or retention of health care providers, and scarce access to specialized treatments and

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DOI: 10.5737/23688076252157166

diagnostics services (Kuliq & Williams, 2012; Romanow, 2002). Additionally, the ongoing reality that urban centres will remain the centre of excellence for oncology care in many provinces across Canada further necessitates the need to explore oncology experiences in rural health care. The findings from this literature review suggest that individuals living with cancer in rural areas experience high levels of unmet needs that are dissimilar to their urban counterparts.

Margaret Fitch and colleagues (Fitch, Porter & Page, 2009) formulated a domain-specific, supportive care framework to assist cancer care professionals in conceptualizing the type of assistance required by their patients and engage in efficient planning for service delivery. According to this framework, all cancer patients require ongoing supportive care from a multi-domain perspective. Key constructs associated with the supportive care framework include “human needs, cognitive appraisal, coping and adaptation as a basis for conceptualizing how human beings experience and deal with cancer” (Fitch, 2009, p. 12). Patients’ supportive care needs can be further categorized based on the nature of the individual’s illness, from basic service provision to highly specialized or intensive and complex intervention.

Humans have various needs related to physical, emotional, psychological, practical, social, and spiritual entities and develop a collection of skills throughout the lifespan to meet their own needs. A cancer diagnosis can create new demands and sources of anxiety, as well as feelings of vulnerability and uncertainty when basic human needs are not met. Unmet human needs can lead to significant distress. Cognitive appraisal is a concept inherent to the supportive care framework and represents the series of stages that individuals go through in order to categorize an event. If the event evokes a threat that is beyond the individual’s capacity to manage, then emotional distress will escalate. Coping with stressful situations, unmet needs, and emotional distress can be difficult in any circumstance. In the event of a cancer diagnosis, adaptation and the development of coping strategies is a complex process. Individuals will respond to a cancer diagnosis or its treatment in their own distinctive way. As a result, interventions tailored to each individual and based on the multi-domain framework can assist with meeting basic human needs and, thus, reduce emotional distress and improve adaptation to the illness experience. The supportive care conceptual framework can be used as an instrument for service or program development, a foundation to organize educational approaches in cancer care, and a model for designing research projects (Fitch, 2009).

PURPOSE

The aim of this literature review is to explore the impact of rural or remote residence on the supportive care needs of individuals living with cancer. The supportive care framework (Fitch, 2009) was used in compiling the data, evaluating the research articles, guiding the analysis and discussion, and considering the relationships between the supportive care needs being reviewed.

METHOD

Computer databases (CINAHL, MEDLINE, and Cochrane) were searched for research studies, dated from 1990 to present, that examined adult cancer patients’ experiences in a rural setting. Grey literature, including web-based resources and reference lists, were also explored for studies that could be included in the review. Key words used for the search included cancer, supportive care, rural, qualitative, quantitative, research, adult, and travel. Other similar MESH terms were included in the search strategy.

Criteria for inclusion of articles in the review included the following: 1) written in English only; 2) published in a peer-reviewed journal between 1990 and present; 3) primary sources cited a specific qualitative, quantitative, or mixed research design; 4) adult patients with a diagnosis of cancer as the sole research participants, or participants within the context of the family; and, 5) patients from rural or remote areas as the sole research participants. Comparisons to urban populations were accepted in the literature review to provide insight into the differences in the urban/rural challenge variations.

The search strategy revealed more than 200 articles that were selected for possible inclusion. Abstracts were scanned to determine if they were suitable for the purpose of the review, and 60 articles were selected for further evaluation. Twenty-three articles met the outlined criteria and were included in the review. Articles were excluded based on the following: secondary sources, service provision, non-cancer diagnosis, survival outcomes, and descriptive reviews. Table 1 outlines the following information about each study included in this review: authors’ names, study design, location of the research, sample, cancer indication and research question.

The authors individually reviewed each of the articles, summarizing the data according to author, study design, location, sample, research question, data collection/analysis, and findings. The data were categorized according to the domains in the supportive care framework and a collaborative thematic analysis was completed to identify any variations or similarities in the materials. Once consensus was achieved, the authors of this review concluded that data saturation had occurred.

LITERATURE REVIEW FINDINGS

The findings in this review have been categorized according to the supportive care framework (Fitch, 2009), under the following domains: physical, informational, social, practical, spiritual, psychological, and emotional. The data extracted from the articles are specifically related to the challenges or benefits of living in rural or remote communities during the cancer experience. Although the results of this review suggest that individuals in both rural and urban settings often have similar unmet needs, the aim of this review was to focus on specific details related to individuals living with cancer in rural areas.

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Table 1: Articles reviewed

Authors	Study Design	Location of Study	Sample Size	Cancer Indication	Research Question
Bain, Campbell, Ritchie, & Cassidy, (2002).	Qualitative. Focus Groups. In-depth interviews.	North and Northeast of Scotland, U.K.	Purposive sample. Focus Groups, n=22 patients and n=10 family members. In-depth interviews, n=32 patients and n=24 family members.	Colorectal	To explore how colorectal cancer patients perceive their care.
Baldwin, Yong, Larson, Dobie, Wright, Goodman, Matthews, & Hart, (2008).	Quantitative. Descriptive, cross-sectional study.	5 States and 7 county-based areas, USA.	Purposive sample. n=27,143 rural and urban.	Colorectal	To examine travel patterns and distances of rural and urban colorectal cancer patients to 3 types of cancer services-surgery, medical and radiation medical consultation services.
Burris & Andrykowski, (2010).	Quantitative. Population based comparative study.	Kentucky, USA	Purposive sample. n=54 rural and n=62 nonrural.	Breast Colorectal Hematologic	To identify disparities in mental health outcomes between rural and nonrural cancer survivors.
Celaya, Rees, Gibson, Riddle, & Greenberg (2006).	Quantitative. Retrospective Study.	New Hampshire, U.S.	Purposive sample. Total n= 2,861.	Breast Breast conserving surgery +/- radiation therapy.	To ascertain if proximity to a radiation treatment facility and season of diagnosis affected treatment choice for women with early-stage breast cancer.
Clavarino, Lowe, Carmont, & Balanda, (2002).	Mixed Method. Interviews and Survey.	Queensland, Australia	Convenience sample. n=28 patients, n=19 family caregivers.	Cancer diagnosis not specified. Receiving radiation therapy.	To examine the impact of travelling for treatment on cancer patients and their families.
Duggleby, Penz, Goodridge, Wilson, Leipert, Berry, Keall, & Justice, (2010).	Qualitative. Grounded theory. Interviews and focus groups.	Saskatchewan, Canada.	Purposive sample. n=6 patients, n=10 bereaved family caregivers, n=12 palliative care health care professionals.	Lung Stomach Pancreatic	To explore the transitional experience of older rural persons with advanced cancer from a patient, family caregiver and health care professional perspective.
Engleman, Perpich, Peterson, Hall, & Ellerbeck, (2005).	Quantitative. Exploratory, Cross-Sectional Survey Study.	Kansas City, Kansas.	Random sample. n=801 patients, n=36 rural family practitioners.	Cancer diagnosis not specified.	To assess cancer information needs and awareness of cancer related resources in a population of rural Kansas communities.
Fitch, Gray, McGowan, Bunskill, Steggle, Sellick, Bezjak, & McLeese (2003).	Qualitative. In-depth interviews.	Ontario, Canada	Purposive sampling. n=118 participants divided into travel and non travel groups.	Breast Prostate	To evaluate patients' perspectives about travelling for radiation treatment.
Girgis, Boyes, Sanson-Fisher, & Burrows, (2000).	Quantitative. Cross-sectional, Exploratory survey study.	New South Wales, Australia	Random Sample. Rural: n=129. Urban: n=100.	Breast	To assess the prevalence and predictors of perceived unmet needs among women diagnosed with breast cancer, with a particular focus on the impact of location.

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Authors	Study Design	Location of Study	Sample Size	Cancer Indication	Research Question
Gray, James, Manthorne, Gould, & Fitch, (2004).	Mixed Method. Demographic Data and focus groups.	Ontario, Canada	Convenience sample: n= 276 rural women, divided into 17 focus groups.	Breast	To evaluate the health and supportive care needs of rural women with breast cancer.
Hegney, Pearce, Rogers-Clark, Martin-McDonald & Buikstra, (2005).	Qualitative. In-depth interviews.	Toowoomba, Australia	Convenience sampling. n= 14 women and n=3 men.	Variety of cancer diagnosis.	To evaluate experiences of rural people with cancer travelling to a major city for radiotherapy treatment.
Martin-McDonald, Rogers-Clark, Hegney, McCarthy, & Pearce, (2003).	Qualitative. In-depth interviews.	Queensland, Australia	Purposive sample. n= 39 female and n=7 male	Variety of cancer diagnosis.	To explore the issues related to rural people with cancer whose choice of radiotherapy treatment necessitated travel and accommodation in a metropolitan centre.
Matthews, West, & Buehler, (2009).	Quantitative. Descriptive, Exploratory Survey study	Newfoundland and Labrador, Canada.	Convenience sample. Total n=484, urban n=258, rural n=226.	Breast Lung Colorectal Prostate	To look at how out-of pocket costs and other factors affect cancer related treatment decisions for rural versus urban residents.
McConigley, Holloway, Smith, Halkett, Keyser, Aoun, & Monterosso, (2011).	Qualitative. In depth, semistructured interviews.	Western Australia.	Purposive sampling: n=18 participants, n=12 male, n=6 female.	Variety of cancer diagnosis.	To explore the reasons why people living in rural areas may delay diagnosis and what issues affected the decisions they made regarding their cancer treatment.
McGrath, (2001).	Mixed Method. Longitudinal, Exploratory Survey Study. Open ended comments.	Queensland, Australia	Purposive sampling. n=115	Hematological Malignancy.	To explore the experience of patients and their families after returning home to a rural or remote area after receiving treatment for hematological malignancies.
McGrath, Patterson, Yates, Treloar, Oldenburg, & Loos, (1999).	Qualitative. In-depth interviews.	Queensland, Australia.	Purposive sampling. Women with breast cancer n=24 and service providers n=3.	Breast	To provide a preliminary indication of the support needs of post diagnosis women with breast cancer in remote and isolated areas.
Payne, Jarrett, Jeffs, & Brown, (2001).	Mixed Method. Interviews and survey.	Guernsey and Southampton, U.K.	Convenience sample. Total n=84, n=42 from Guernsey and n=42 from Southampton.	Variety of cancer diagnosis.	To identify differences in perceived social support and perceptions of health care between patients who remained at home or travelled daily during treatment and patients who are required to move to the urban centre for treatment.
Pesut, Robinson, Bottorff, Fyles, & Broughton, (2010).	Mixed Method. Interviews and survey.	British Columbia, Canada.	Convenience sample. n=15 individuals, n=8 women and n=7 men	Advanced cancer.	To gain an understanding of the experiences of rural cancer patients who commute to an urban cancer centre for palliative care.
Punglia, Weeks, Neville, & Earle, (2006).	Quantitative. Retrospective, cross-sectional Study.	U.S.	Purposive sampling. n=17,712 mastectomy only, n=2,075 post mastectomy radiation therapy.	Breast	To study the effect of distance to the nearest radiation treatment facility on the use of post mastectomy radiation therapy in elderly women.

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Authors	Study Design	Location of Study	Sample Size	Cancer Indication	Research Question
Rogers-Clark, C. (2002)	Qualitative. Feminist postmodern narrative.	Queensland, Australia.	Purposive sampling. n=9 completed breast cancer therapy.	Breast	To explore rural living as a dimension of women's experiences of living through breast cancer.
Wilkes & White (2005).	Qualitative. Semistructured interviews.	New South Wales, Australia	Purposive sampling. n=19 family members, n=10 rural palliative care nurses.	Cancer diagnosis of family member unknown.	To explore day to day demands placed on family members caring for rural cancer patients and how specialist palliative care nurses support these family members.
Wilkes, White, & Riordan, (2000).	Qualitative. Semistructured interviews.	New South Wales, Australia.	Purposive sampling. n=19 family members, n= 10 rural palliative care nurses.	Cancer diagnosis of family member unknown.	To examine the importance of information for empowerment of families during their cancer journey with a sick relative.
Wilkes, White, Mohan & Beale, (2006)	Mixed Method. Questionnaire and focus group interviews.	New South Wales, Australia	Convenience sample: n=111 patients and n=67 family members.	Cancer diagnosis not specified.	To explore the practical needs of patients and families travelling from rural areas in Australia to cities for cancer treatment.

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Physical domain. Symptom management of cancer-related problems and treatment-related toxicity is an integral role of the nurse (Langhorne, Fulton, & Otto, 2007). Management of symptoms, such as pain, nausea, fatigue, diarrhea, myelosuppression, dyspnea, sleep disturbances, and mucositis can pose significant challenges for nurses and directly impact the quality of life of the individuals living with cancer (Langhorne et al., 2007). Many of the studies included in this review found that individuals who had to travel lengthy distances to receive care experienced exacerbations of treatment side effects and disease symptoms (Fitch et al., 2003; Hegney, Pearce, Rogers-Clark, Martin-McDonald, & Buikstra, 2005; Martin-McDonald, Rogers-Clark, Hegney, McCarthy, & Pearce, 2003; Pesut, Robinson, Bottorff, Fyles, & Broughton, 2010). Three of the studies exclusively examined individuals who travelled to urban centres for radiation therapy. It was found that side effects of the radiation treatment, such as burning, fatigue, pain, and nausea, made travel very problematic (Fitch et al., 2003; Hegney et al., 2005; Martin-McDonald et al., 2003).

In addition, unmet needs were noted in the physical domain as a result of the lack of medical or nursing support services or palliative care expertise in the rural/remote settings (Girgis, Boyes, Sanson-Fisher, & Burrows, 2000; McGrath, 2001; Wilkes, White, & Riordan, 2000). In rural communities, management of the physical symptoms of illness places a great demand on family members. Family caregivers living in rural areas are often required to take on a momentous role in assisting their ill family member with physical care and management of distressing symptoms. Family members reported this role was stressful and emotionally draining. Moreover, they felt unprepared to deal with medical problems, care for certain devices such as central lines, and

administer certain medications such as morphine (Clavarino, Lowe, Carmont, & Balanda, 2002; Wilkes & White, 2005).

Informational domain. The operational description of this domain is related to the information required during the cancer trajectory. This includes information regarding side effects of treatment, drugs, treatment regimens, care processes, and other services. Therefore, this domain is directly related to service provision and access to professional assistance (Fitch, 2009). The most noteworthy finding in the reviewed studies was that participants face challenges related to service provision in their rural communities. Of the 23 studies reviewed, 10 articles revealed service provision challenges such as lack of access to cancer information, limited access to professional or hospital assistance, and isolation from professional support or other supportive services were enduring challenges (Clavarino et al., 2002; Duggleby et al., 2010; Engleman, Perpich, Peterson, Hall, & Ellerbeck, 2005; Fitch et al., 2003; Gray, James, Manthorne, Gould, & Fitch, 2004; McConigley et al., 2011; McGrath, 2001; Rogers-Clark, 2002; Wilkes, White, & Riordan, 2000; Wilkes, White, Mohan, & Beale, 2006).

As well, the participants expressed feeling unprepared to deal with medical problems or crises and reported that delays in diagnosis, inadequate support for symptom management, and limited access to additional home care supports were also significant challenges (Bain, Campbell, Ritchie, & Cassidy, 2002; Clavarino et al., 2002; Girgis et al., 2000; McGrath, 2001). In the rural setting, there is limited access to information, support groups, home care, trained specialists, treatments, and tests. Limitations in service provision can often lead to delays in diagnosis or elicit treatment-related decisions that may not be in the patient's best interests (Gray et al., 2004; Hegney et al., 2005; Martin-McDonald

et al., 2003). It was reported that rural family doctors may not possess appropriate or current information, recognize symptoms of illness, or have the expertise to make a cancer diagnosis, all of which may lead to delayed diagnosis and/or compromised quality of care (Bain et al., 2002; McConigley et al., 2011; Rogers-Clark, 2002; Wilkes et al., 2000; Wilkes et al., 2006). Alternatively, Baldwin and colleagues (2008) revealed that individuals living with colorectal cancer preferred to travel to urban centres because they were more confident with the care provided by highly specialized teams in these settings.

In two studies by Wilkes and colleagues (2000; 2006), it was reported that nursing played an integral role in providing support and information services to clients and families living in rural settings. The nurses acted as coordinators of care and sources of strength for the patients and their families. Many had some expertise in cancer or palliative care situations and were able to facilitate access to necessary equipment and provide education regarding service availability. Other sources of informational support included books, pamphlets, internet, and networking with other family members or friends in similar circumstances (Wilkes et al., 2000; Wilkes et al., 2006).

Social domain. In many instances, a cancer diagnosis affects the entire family. The social aspect of cancer involves the immediate or extended family, close-knit neighborhood groups, and the wider community.

The studies in this review revealed that nurturing supportive networks and close-knit communities often exist within rural areas (Duggleby et al., 2010; Rogers-Clark, 2002). Alternatively, challenges related to lack of privacy, feelings of isolation, and difficulties finding the appropriate support or support groups at home were also identified (Gray et al., 2004; Rogers-Clark, 2002). Studies noted that patients found it difficult to cope with the burden of care placed on their family or friends. Additionally, patients found it equally difficult to be isolated from their loved ones. Families reported that the cancer experience was associated with disruptions in family life, changes in living arrangements and roles, caregiver burden, and relationship problems associated with spending extended periods of time apart. In addition, various studies revealed that patients were often worried about their partners or children while they received treatment and were concerned about the burden placed on the family to maintain the home or organize child care (Clavarino et al., 2002; Fitch et al., 2003; Hegney et al., 2005; Martin-McDonald et al., 2003; McGrath et al., 1999; Payne, Jarrett, Jeffs, & Brown, 2001). Furthermore, patients had frequently reported feeling less connected with and supported by their families during extended periods of absence, noted they had no one to accompany them to the city for treatments, and indicated that aspects of social life often had to be put on hold, leading to feelings of isolation (Duggleby et al., 2010; Fitch et al., 2003; Gray et al., 2004; Hegney et al., 2005; Martin-McDonald et al., 2003; McGrath et al., 1999).

Alternatively, some positive aspects of support were also revealed in the studies. For example, living away from one's home in a hostel setting played a vital role in the overall cancer

treatment experience. In these settings, patients were able to establish supportive networks with others in similar situations and share the cancer experience. These supports helped counteract the loneliness associated with being away from home for extended periods and served as an immense source of emotional support. When patients returned home to their rural communities, they often reported that those close bonds were sorely missed (Fitch et al., 2003; Gray et al., 2004; Hegney et al., 2005; Payne et al., 2001; Pesut et al., 2010; Wilkes et al., 2006). The role of social support in health is widely documented in the literature. Positive supportive networks play a role in improving health outcomes, decreasing physical and mental illness, and reducing mortality rates (Callaghan & Morrissey, 1993; Uchino, Uno, & Holt-Lunstad, 1999).

Practical domain. Practical needs associated with the cancer experience encompass a broad range of tasks, such as house-keeping, finances, child care, transportation, housing, shopping, or legal needs (Fitch, 2009). The financial hardships of cancer are related to two factors: 1) the dramatic decline in family income due to disability; and 2) the rising out-of-pocket expenses associated with a cancer diagnosis. This can lead to severe financial destitution from which some families never recover (CCS, 2013b). Rural and northern residents who need to travel for medical treatments are at the greatest risk of financial devastation. For many rural individuals, travel expenses can exceed the cost of medications (CCS, 2013b). Financial disparities associated with living in a rural setting include the costs associated with wear and tear on the family vehicle, fuel, accommodations, maintenance of two households, meals in restaurants, parking in the city, time away from work, telephone usage, and additional child care (Clavarino et al., 2002; Fitch et al., 2003; Gray et al., 2004; Hegney et al., 2005; Matthews, West, & Buehler, 2009; Martin-McDonald et al., 2003; McGrath et al., 1999; McGrath, 2001; Pesut et al., 2010; Wilkes et al., 2006).

Housing and accommodation are a basic human need. Affordable and supportive housing is a service that is vital to the well-being of rural cancer patients who must relocate to urban centres for care. When these services were available in the urban treatment centre, patients reported high degrees of satisfaction (Hegney et al., 2005; Fitch et al., 2003; Martin-McDonald et al., 2003; Payne et al., 2001; Pesut et al., 2010; Wilkes et al., 2006).

Maintaining daily responsibilities at home and work while undergoing cancer treatment can be challenging for patients. Individuals living in rural settings must cope with the additional stress related to long travel days and frequent commutes to the city for treatment (Martin-McDonald et al., 2003; McGrath, 2001). Studies by Martin-McDonald and colleagues (2003) and McGrath (2001) both reported that patients struggled with maintaining their work responsibilities, feeling uncertain regarding job status, losing their work-related roles, and coping with work-related challenges while undergoing treatment. Patients reported these were significant stressors that affected their overall quality of life (Martin-McDonald et al., 2003; McGrath, 2001). A large Canadian

study (n=276) of rural women with breast cancer identified that coping with changing work-life was a major theme during the cancer experience. Employment in rural and northern settings is often self-determined, part-time, or temporary and, therefore, associated with a lack of job security and benefits. The women in the study were frequently left without employment options during their illness because of the need to relocate to an urban centre for care (Gray et al., 2004).

Other practical needs that markedly affect rural patients and their families include the time required to prepare for travel, arrange accommodations, and organize test schedules and medical appointments. Extensive travel, heavy city traffic, and poor weather conditions can intensify these challenges. Patients also expressed concerns related to feeling unsafe while walking in an unfamiliar city environment and having difficulty navigating the city or large hospital setting (Clavarino et al., 2002; Fitch et al., 2003; Girgis et al., 2000; Gray et al., 2004; Hegney et al., 2005; Pesut et al., 2010; Wilkes et al., 2000; Wilkes et al., 2006).

The burdens associated with travelling to urban centres for cancer treatment are a significant finding in this review. In two of the studies reviewed, it was disturbing to note treatment decisions were made based on the burdens of travel. The first quantitative study by Punglia, Weeks, Neville, and Earle (2006) described the effect of distance to the nearest radiation treatment facility on the use of post-mastectomy radiation in a large cohort of elderly breast cancer patients (n=19,787). The authors concluded that patients who resided the furthest distance from the treatment centre were least likely to use adjuvant radiotherapy based on the burden of travel (Punglia et al., 2006). This decline in treatment access became statistically significant for individuals who lived greater than 75 miles from the nearest cancer treatment centre. Similarly, a concurrent study found that women with early stage breast cancer were less likely to proceed with post-operative radiotherapy after breast conserving surgery when they had to travel great distances to a treatment centre or when diagnosis occurred in the winter months when long-distance travel was more challenging (Celaya, Rees, Gibson, Riddle, & Greenberg, 2006). Radiation therapy is a standard of care for women with limited stage, invasive, or advanced breast cancers. It remains an important treatment modality alone or in combination with other therapies. Radiotherapy is often used to achieve local control of disease or prevent locoregional recurrence (Langhorne et al., 2007; National Comprehensive Cancer Network, 2014). It is alarming that treatment decisions may sometimes be made based on geography rather than on the best interests of the patient or an understanding of the treatments that are most likely to succeed. As a result, the burden associated with travelling for cancer care may carry serious implications.

Spiritual domain. Spiritual wellness is a central dimension of this domain. Personal or religious beliefs and finding the meaning of life are inherent human needs. A cancer diagnosis can often trigger spiritual distress, existential despair, pain, and suffering (Fitch, 2009). The spiritual domain was addressed in two of the studies included in this literature review. A

qualitative study by Rogers-Clark (2002) explored the features of resiliency and suffering among rural women who were long-term survivors of breast cancer. The results revealed both positive and negative features in the context of spirituality. Rural life was described as a peaceful sense of balance and personal connection to the land. In addition, the authors also identified that patients experienced a sense of resiliency, strength and inner peace, community connectedness, independence, strength, and stoicism. The women in the study most notably articulated their connection to and appreciation for rural life and their “dislike” of urban life. Although the women also reported feelings of loneliness, threats to personal privacy, and a sense of isolation, the positive features of rural life far outweighed the difficulties associated with relocation to an urban centre. The authors concluded that rural living in the context of the illness experience should be considered an important health topic, yet tends to be ignored in the literature. Rural individuals may be able to draw upon a number of these strengths in response to stress. Therefore, interventions targeted at individuals living with cancer in rural settings should be geared toward programs based on supportive care that can enhance adaptation to the cancer experience (Rogers-Clark, 2002).

Pesut and colleagues (2010) conducted a mixed method study to gain an understanding of the experiences of rural cancer patients who had to travel to a regional centre for palliative treatment. The participants in this study described the features of rural life that were most important to them, including physical beauty, peaceful living, privacy, community support, and proximity to religious affiliations. The authors concluded that rural lifestyle is an important component of overall well-being for these individuals and that disruption, such as re-location to an urban setting, can lead to emotional and spiritual distress (Pesut et al., 2010).

These studies by Pesut and colleagues (2010) and Rogers-Clark (2002) add to the body of literature that emphasizes the value of rural living in the context of overall well-being, particularly spiritual and emotional wellness. Many of the rural attributes and features revealed in these studies are consistent with other research and scholarly works (Kuliq & Williams, 2012; Long & Weinert, 1999). This further demonstrates the value of community-based supportive care programs and access to oncology care resources in rural areas both of which can contribute to positive patient outcomes and enhanced well-being.

Psychological and emotional domains. The primary feature of the psychological domain is the ability to cope with the illness experience and its associated disparities. The emotional domain is characterized by a sense of belonging, comfort, and understanding that exists during times of vulnerability. Challenges within these domains may include grief, uncertainty, fear, anxiety, loss, and depression. Within these domains, patients may experience fears of recurrence or changes in body image or self-worth. All cancer patients experience some degree of psychological and emotional stress during the course of the illness experience. Patients’ ability to cope with these stressors or receive the required emotional support facilitates adaptation (Fitch, 2009).

It was frequently reported throughout studies in this review that, in the rural context, the cancer experience creates significant psychological and emotional disruptions for patients and their families. Cancer care of rural patients presents a multifaceted and complex problem. Many disparities that have been highlighted, including the burden of travel and its associated challenges, the financial, practical, and social disruptions in everyday life, the lack of services and supportive care in rural settings, and feelings of isolation, will have an impact on the psychological and emotional well-being of individuals and their families.

The following are some specific examples from the literature review in which living with cancer in a rural setting directly impacted individuals' emotional and psychological well-being: lack of services in the rural setting led to feelings of anxiety among family members and caregivers (Clavarino et al., 2002); difficulties with managing practical needs created undue stress (Wilkes et al., 2006); the need to travel into an urban centre led to feelings of fear and uncertainty (Wilkes et al., 2006); the lack of privacy in the rural setting led to embarrassment and isolation (Rogers-Clark, 2002); disturbances to family life were associated with a sense of loneliness (Martin-McDonald et al., 2003); long waits and delays in treatment created uncertainty and anxiety (Fitch et al., 2003); the isolation associated with treatment in urban settings led to "homesickness" and the need to discuss emotional concerns with people in similar circumstances (McGrath, 2001); and the challenges of coping with medical crises in a rural community caused significant distress to patients and families (McGrath, 2001). These are examples of challenges that disproportionately affect rural cancer patients and have the potential to lead to severe emotional and psychological distress. In one study, Burris and Andrykowski (2010) compared the mental health outcomes of rural and non-rural cancer survivors. The rural participants reported higher rates of anxiety, depressive symptoms, overall distress, and poorer mental health functioning and life satisfaction when compared to urban participants. These results are consistent with the many disparities noted in this review in the context of rural living and the cancer experience (Burris & Andrykowski, 2010).

Alternatively, results of this review suggest that there are many positive features of rural life that contribute to the psychological and emotional well-being of individuals living with cancer. Examples of positive features of rural life include: the positive culture and supportive community networks (Pesut et al., 2010; Wilkes et al., 2000); a sense of peace and the benefits of being part of a close-knit community (Rogers-Clark, 2002); survivorship and stoicism developed through past experiences of living in a rural setting (Rogers-Clark, 2002); individuality and connectedness to the community (Duggleby et al., 2010); and support from the wider community (McGrath et al., 1999). Moreover, emotional and psychosocial well-being was often maintained even when relocation was required. Factors that contributed to a greater sense of well-being while away from home included staying in affordable and comfortable accommodations, developing

close ties with individuals in similar circumstances, fostering a sense of comfort by being close to expert oncology services, alleviating the demands of driving every day, or spending additional quality time with significant other (Fitch et al., 2003; Martin-McDonald et al., 2003; McConigley et al., 2011; Pesut et al., 2010).

DISCUSSION

This review of the literature suggests that there are distinct and unique experiences that present additional stressors and challenges for individuals living with cancer in rural areas. As such, rural cancer patients face distinctive social disruptions and service provision challenges when compared to their urban counterparts. Rural living is often associated with delays in diagnosis, challenges of travelling long distances to urban centres, limited access to oncology services, economic disparities, and treatment decisions that are made based on geographic location.

The cancer experience can be long and difficult. In addition, the unpredictable nature of the disease creates uncertainty, anxiety, and ongoing emotional, spiritual, or psychological distress. As a result, it is imperative to isolate the additional burdens and unmet needs of rural Canadians living with cancer. This is invariably a complex process and is beyond the scope of this review, as only four of the studies under review were completed in Canada.

The supportive care framework (Fitch, 2009) is a valuable tool to understand the global needs of cancer patients from a person-centred care approach. As well, aspects of the framework are essential components of care for all health care practitioners and associated agencies (Fitch, 2009). Cancer patients receive care in many settings, from primary care clinics to outreach programs and urban cancer centres. It is clear from this review that the rural challenges in cancer care service delivery are multifaceted, comprehensive, and occur across many dimensions of health care. In order to improve the quality of care provided to rural individuals, we must recognize service gaps, develop tailored, multi-domain intervention strategies, and engage multiple disciplines within the global health care community. Considering the rising incidence and prevalence of cancer in Canada, as well as the number of individuals living with cancer in rural and remote areas of the country, health care practitioners, administrators, researchers and policy makers must pay particular attention to this important health care topic.

Clinical standards can guide the establishment of interventions and strategies. The supportive care framework outlines that ongoing assessment of supportive care needs, access to resources, capabilities for self-referral, and ongoing informational support, while also considering unique individual variations, should become a standard of care (Fitch, 2009). Interventions that should be at the forefront of health care activities include incorporating supportive care into the organizational structure, improving the ability to recognize and respond to patient and family distress, and enhancing access to specific services and informational support (Aranda, 2009). The supportive care framework provides useful information

at an organizational level to assist in developing tailored interventions for this vulnerable population of cancer patients. It can also provide nurses with a framework for assessing the unique challenges encountered by this population.

This review highlights that people choose rural life for reasons that directly affect their quality of life and sense of well-being. As a result, the benefits of rural living need to be considered when caring for patients from rural communities. Front-line nurses, both in the urban and rural settings, remain integral to the management of oncology populations, as they are well positioned to implement positive changes in the provision of care. Tailored or individualized interventions represent a customized approach to intervention management, while considering the unique characteristics of a specific client group (Sidani & Braden, 2011). Delineation of this process requires assessment of the client characteristics, development of interventions that address a targeted problem based on those characteristics, and detail an algorithm that customizes the application approach. This thoughtful process to intervention development contributes to personally relevant information or services meaningful to the specific client group. In addition, it has the capacity to motivate and empower individuals and, ultimately, impact health, well-being and quality of life (Sidani & Braden, 2011). It is essential that we develop a deeper understanding of this important health care topic to tailor interventions to the needs of this client group.

There are several methodological limitations that affect the generalizability of the findings in this review. Studies that utilized multiple sampling methods, examined diverse populations of individuals with varied diagnoses and ages, included English language only, investigated multiple treatment methods and used different research designs were incorporated in this review, thus making it difficult to generalize to a specific population of cancer patients. Relatively few studies were found from the Canadian population. The majority of research retrieved was from Australia, the United States, and international populations. Canadian living is associated with distinctive challenges, such as long winters, poor driving conditions, and great distances between towns and cities. Since many of the studies reviewed were international-based,

it is also difficult to ascertain the variations that exist between service provision and supportive care services in the different settings. Based on these limitations, further research is warranted for Canadians living with cancer in rural areas. Future research should focus on studies that examine supportive care services in rural Canadian communities, based on location, economic disparities, and supportive, psychosocial, medical, and nursing services required to improve the health and well-being of rural Canadians living with cancer. Based on this literature review, the authors will explore a qualitative research proposal. The aim of the proposed study will be to examine the supportive care needs and health service challenges of individuals with cancer who live in rural and remote communities in Manitoba.

CONCLUSION

Cancer diagnosis and treatment represents a life-altering and extremely difficult experience for both patients and their families. Geographic location of the patient and family creates additional obstacles that must be considered. This literature review outlines some key findings that could significantly impact quality of life, health, and wellness of individuals living with cancer in rural settings. The review contributes to a body of evidence-based knowledge and may help inform future practice and research endeavours.

The supportive care framework utilized in this review is a well-designed model that can guide work in this area of practice and research. It is beneficial to advance the understanding of the additional burdens experienced by rural Canadian populations and the unique characteristics of rural individuals, as well as specific services required, so that tailored cancer care interventions can be incorporated. In addition, the benefits of rural living cannot be overlooked and must be considered in this process. In order to develop meaningful health and social services, and help mitigate the impact of cancer and improve the quality of life for rural individuals living with cancer, research studies must situate the experiences and needs of rural Canadians living with cancer at the centre of inquiry.

REFERENCES

- Aranda, S. (2009). *The supportive care model in action: An Australian case example*. In M.I. Fitch, H.B. Porter, & B.D. Page (Eds.) *Supportive care framework: A foundation for person-centred care* (1st ed., pp. 56–63). Pembroke, ON: Pappin Communications.
- Bain, N.S.C., Campbell, N.C., Ritchie, L.D., & Cassidy, J. (2002). Striking the right balance in colorectal cancer care: A qualitative study of rural and urban patients. *Family Practice*, 19(4), 369–374.
- Baldwin, L., Yong, C., Larson, E.H., Dobie, S.A., Wright, G.E., Goodman, D.C., ... Hart, L.G. (2008). Access to cancer services for rural colorectal cancer patients. *National Rural Health Association*, 24(4), 390–399.
- Burris, J.L., & Andrykowski, M. (2010). Disparities in mental health between rural and nonrural cancer survivors: A preliminary study. *Psycho-Oncology*, 19, 637–645. doi:10.1002/pon.1600
- Callaghan, P., & Morrissey, J. (1993). Social support and health: A review. *Journal of Advanced Nursing*, 18, 203–210.
- Canadian Association of Nurses in Oncology (CANO) (2001). *Standards of care, roles in oncology nursing, and role competencies*. Retrieved from <http://www.cano-acio.ca/~ASSETS/DOCUMENT/Practice/standards%20of%20care.pdf>
- Canadian Cancer Society. (2013a). *Canadian cancer statistics, 2013: Special topic liver cancer*. Retrieved from <http://www.cancer.ca/~media/cancer.ca/CW/publications/Canadian%20Cancer%20Statistics/canadian-cancer-statistics-2013-EN.pdf>
- Canadian Cancer Society. (2013b). *Financial hardship of cancer in Canada: A call for action*. Retrieved from <http://www.cancer.ca/~media/cancer.ca/MB/get%20involved/take%20action/financial%20hardship%20of%20cancer%20in%20canada/financialhardshipofcancer-MB-EN.pdf>
- Celaya, M.O., Rees, J.R., Gibson, J.J., Riddle, B.L., & Greenberg, E.R. (2006). Travel distance and season of diagnosis affect treatment choices for women with early-stage breast cancer in a

- predominantly rural population (United States). *Cancer Causes Control*, 17, 851–856. doi:10.1007/s10552-006-0025-7
- Clavarino, A.M., Lowe, J.B., Carmont, S., & Balandia, K. (2002). The needs of cancer patients and their families from rural and remote areas of Queensland. *Australian Journal of Rural Health*, 10, 188–195.
- Duggleby, W.D., Penz, K.L., Goodridge, D.M., Wilson, D.M., Leipert, B.D., Berry, P.H., Justice, C.J. (2010). The transition experience of rural older persons with advanced cancer and their families: A grounded theory study. *BMC Palliative Care*, 9(5), 1–9.
- Engleman, K.K., Perpich, D.L., Peterson, S.L., Hall, M.A., & Ellerbeck, E.F. (2005). Cancer information needs in rural areas. *Journal of Health Communication*, 10, 199–208. doi:10.1080/10810730590934217
- Fitch, M.I., Porter, H.B., & Page, B.D. (2009). *Supportive care framework: A foundation for person-centred care*. Pembroke, ON: Pappin Communications.
- Fitch, M.I. (2009). *Supportive care framework: Theoretical underpinnings* (1st ed.). In M.I. Fitch, H.B. Porter, & B.D. Page (Eds.), *Supportive care framework: A foundation for person-centred care* (pp. 11–29). Pembroke, ON: Pappin Communications.
- Fitch, M.I., Gray, R.E., McGowan, T., Bunskill, I., Steggle, S., Sellick, S., ... McLeese, D. (2003). Traveling for radiation cancer treatment: Patient perspectives. *Psycho-Oncology*, 12, 664–674. doi:10.1002/pon.682
- Girgis, A., Boyes, A., Sanson-Fisher, R.W., & Burrows, S. (2000). Perceived needs of women diagnosed with breast cancer: Rural versus urban location. *Australian and New Zealand Journal of Public Health*, 24(2), 166–173.
- Gray, R.E., James, P., Manthorne, J., Gould, J., & Fitch, M.I. (2004). A consultation with Canadian rural women with breast cancer. *Health Expectations*, 7, 44–50.
- Hegney, D., Pearce, S., Rogers-Clark, C., Martin-McDonald, K., & Buikstra, E. (2005). Close, but still too far. The experience of Australian people with cancer commuting from a regional to a capital city for radiotherapy treatment. *European Journal of Cancer Care*, 14, 75–82.
- Kulig, J.C., & Williams, A.M. (2012). *Health in rural Canada*. Vancouver, BC: UBC Press.
- Langhorne, M.E., Fulton, J.S., & Otto, S.E. (2007). *Oncology nursing* (5th ed.). St. Louis, MO: Mosby Elsevier.
- Larsen, P.D. (2006). *Chronicity* (6th ed.). In I.M. Lubkin & P.D. Larsen (Eds.), *Chronic illness: Impact and interventions* (pp. 3–22). Sudbury, MA: Jones and Bartlett Publishers, Inc.
- Long, K.A., & Weinert, C. (1999). Rural nursing: Developing a theory base. *Scholarly Inquiry for Nursing Practice: An International Journal*, 13(3), 257–269.
- Martin-McDonald, K., Rogers-Clark, C., Hegney, D., McCarthy, A., & Pearce, S. (2003). Experiences of regional and rural people with cancer being treated with radiotherapy in a metropolitan centre. *International Journal of Nursing Practice*, 9, 176–182.
- Matthews, M., West, R., & Buehler, S. (2009). How important are out-of-pocket costs to rural patients' cancer care decisions? *Canadian Journal of Rural Medicine*, 14(2), 54–60.
- McConigley, R., Holloway, K., Smith, J., Halkett, G., Keyster, J., Aoun, S., ... Monterosso, L. (2011). The diagnosis and treatment decisions of cancer patients in rural Western Australia. *Cancer Nursing*, 34(4), 1–9. doi:10.1097/NCC.0b013e3181f795e7
- McGrath, P. (2001). Returning home after specialist treatment for hematological malignancies: An Australian study. *Family Community Health*, 24, 36–48.
- McGrath, P., Patterson, C., Yates, P., Treloar, S., Oldenburg, B., & Loos, C. (1999). A study of postdiagnosis breast cancer concerns for women living in rural and remote Queensland. Part I: Personal concerns. *Australian Journal of Rural Health*, 7, 34–42.
- National Comprehensive Cancer Network (2014). *Breast cancer*. Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/breast.pdf
- Payne, S., Jarrett, N., Jeffs, D., & Brown, L. (2001). Implications of social isolation during cancer treatment. The implications of residence away from home during cancer treatment on patients' experiences: A comparative study. *Health & Place*, 7, 273–282.
- Pesut, B., Robinson, C.A., Bottorff, J.L., Fyles, G., & Broughton, S. (2010). On the road again: Patients perspectives on commuting for palliative care. *Palliative and Supportive Care*, 8, 187–195. doi:10.1017/S1478951509990940.x
- Punglia, R.S., Weeks, J.C., Neville, B.A., & Earle, C.C. (2006). Effect of distance to radiation treatment facility on use of radiation therapy after mastectomy in elderly women. *Radiation Oncology Biology Physiology*, 66(1), 56–63. doi:10.1006/ijrobp.2006.03.059
- Rogers-Clark, C. (2002). Living with breast cancer: The influence of rurality on women's suffering and resilience. A postmodern feminist inquiry. *Australian Journal of Advanced Nursing*, 20(2), 34–39.
- Romanow, R.J. (2002). *Building on values: The future of health care in Canada*. Retrieved from <http://dsp-psd.pwgsc.gc.ca/Collection/CP32-85-2002E.pdf>
- Shaha, M., Cox, C.L., Talman, K., & Kelly, D. (2008). Uncertainty in breast, prostate, and colorectal cancer: Implications for supportive care. *Journal of Nursing Scholarship*, 40(1), 60–67.
- Sidani, S., & Braden, C.J. (2011). Design, evaluation and translation of nursing intervention. United Kingdom: John Wiley & Son, Inc.
- Uchino, B.N., Uno, D., & Holt-Lunstad, J. (1999). Social support, physiological processes, and health. *American Psychological Society*, 8(5), 145–148.
- Wilkes, L.M., & White, K. (2005). The family and nurse in partnership: Providing day-to-day care for rural cancer patients. *Australian Journal of Rural Health*, 13, 121–126.
- Wilkes, L.M., White, K., Mohan, S., & Beale, B. (2006). Accessing metropolitan cancer care services: Practical needs of rural families. *Journal of Psychosocial Oncology*, 24(2), 85–101. doi: 10.1300/J077v24n02-06
- Wilkes, L., White, K., & Riordan, L.O. (2000). Empowerment through information: Supporting rural families of oncology patients in palliative care. *Australian Journal of Rural Health*, 8, 41–46.