



Breast Cancer in Rural Communities

Julia M. Fuchs

Lakehead University

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**Abstract**

This paper provides a review of the existing research on women's experience of breast cancer in rural communities. It includes a total of 46 studies that used quantitative and qualitative research methods. In the review of the literature, the challenges identified for rural women with breast cancer include: travel issues; financial hardships; work-related issues; impacts on family members and caregivers; psychosocial adjustment; and information needs. The findings indicate that rural and urban women often receive different treatments for breast cancer; that access to health care services is more limited in rural communities; and that rural women and their families have a considerable need for support and information. Nonetheless, rural women with breast cancer are able to rely on friends and family, peer supports, doctors, and informal networks in their close-knit communities. Further, utilization of health care delivery approaches such as mobile breast screening, telemedicine and teleoncology have the potential to increase rural women's access to health services. The review discusses the practice and policy implications of these findings as well as suggestions for future research.

**Keywords:** breast cancer, rural community, cancer treatment, rural caregiving, peer support, telehealth, telemedicine, teleoncology.

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## Introduction

Breast cancer is an important public health issue as it represents the most common cancer diagnosis in Canadian women (Canadian Cancer Society [CCS], 2009). A breast cancer diagnosis is always difficult to deal with, but women in rural communities face additional challenges. Compared to urban residents, rural women with breast cancer contend with limited access to health care services, long travel distances for treatment, greater financial hardships, and fewer opportunities for support from breast cancer survivors and peer support groups (Bettencourt, Schlegel, Talley, & Molix, 2007; Canadian Breast Cancer Network [CBCN], 2001; Gray, James, Manthorne, Gould & Fitch, 2004; Lightfoot et al., 2005; McGrath, Patterson, Yates, Treloar, Oldenburg, & Loos, 1999a). The economic realities of rural life mean that these women are more likely to be unemployed or work part-time, have lower incomes, and are less likely to have employee-based or private health insurance for prescription drugs (Canadian Institute for Health Information [CIHI], 2006; Lightfoot et al., 2005; Mathews, West & Buehler 2009). Attempts have been made by governments and organizations to help level health care disparities, yet the quality of life and survival rates for rural women with breast cancer are still lower than urban counterparts (CBCN, 2003; CIHI, 2006; Gorey et al., 2008).

This paper will begin by describing the methods used and will provide an overview of the study limitations. The relevant terms will then be defined, followed by a statistical overview of women with breast cancer in the general Canadian population as well as those residing specifically in rural communities. Information on rural women's access to health care services will be examined in terms of primary care, breast cancer screening, diagnosis, and surgical and adjuvant treatments (e.g. radiation therapy, chemotherapy). The literature on the impacts of breast cancer on rural women will then be reviewed, which primarily focuses on the following

areas: travel issues; financial strains; work-related issues; impacts on family members and caregivers; psychosocial adjustment and information needs (Bettencourt et al., 2007; CBCN, 2001; Gray et al., 2004; Lightfoot et al., 2005; McGrath et al., 1999a, Mathews et al, 2009). The findings indicate that rural women with breast cancer and their families have profound needs for support and information about the care and management of their disease (CBCN, 2001; Gray et al., 2004; McGrath et al., 1999b). For emotional and practical support, rural women with breast cancer may rely on various personal and professional resources, including health care providers, peer support groups and informal networks within the community (Bettencourt et al., 2007; Gray et al., 2004).

This discussion will be supplemented by a review of promising health care delivery approaches being used with women living in rural communities, including mobile breast cancer screening and telehealth initiatives (Brigden, Minty, Pilatzke, Vedova, Sherrington, & McPhail, 2008; Doolittle & Spaulding, 2006). Implications for policy and practice include: expanding drug and insurance coverage; making changes to travel subsidies; increasing awareness among health care providers; promoting the use of national guidelines for information and support; and improving access to health care services in rural communities. This paper concludes with recommended areas of future research for meeting the needs of rural women with breast cancer.

## **Methods and Critical Analysis**

### ***Methods***

An extensive literature search was performed using the PubMed, PsychInfo, ProQuest Nursing & Allied Health Source, and Sage Journals Online databases. The search was restricted to the last 10 years and used a combination of the following keywords: breast, cancer, rural,



remote, community, treatment, radiation, chemotherapy, caregiving, support peer-support, programs, reviews, teleoncology, telehealth, and telemedicine. Journals with at least three selected articles (Psycho-Oncology, Patient Education and Counseling, The Breast Journal, European Journal of Cancer Care, Current Oncology, Australian Journal of Rural Health) were searched for further relevant publications. Reference lists were also reviewed for additional eligible publications, and resulted in 7 additional articles, 2 of which were from the year 1999 and were included due to their particular relevance to the paper topic. Screening of the articles identified for this paper was based on their abstracts.

The inclusion criteria were as follows: English language, rural population included in the sample, qualitative and/or quantitative findings, relationship to breast cancer including diagnosis, treatment and programs. This review did not include First Nations and Inuit women's literature because there are few studies that have been carried out among these populations and also because the socio-cultural and political context of Aboriginal health add unique dimensions that are beyond what can be adequately addressed in this paper. There were four literature reviews on the effectiveness of peer support programs and one review on the effectiveness of breast nurses that were included in this paper despite not having focused on a rural population. These studies were included only because no systematic reviews have been carried out on these topics specifically for rural women with breast cancer. All of the systematic reviews cited in this paper were thorough and used diverse strategies to gather their research articles including databases, reference lists, and/or consulting with experts in the field.

The 46 studies chosen for this report used various methods to carry-out research, including: case series using cancer registries and census data (6); secondary analyses of existing large-scale survey datasets (2); surveys/questionnaires, three of which were random population-

based studies (telephone, mail or interviews) (15); unstructured/semi-structured interviews and focus groups (10); 5-year prospective, randomized experimental design study (1); randomized psychoeducational intervention study (1); cohort studies (2); and systematic literature reviews (9). The studies used were predominantly quantitative or employed both quantitative and qualitative research methods. There were (9) studies that used solely a qualitative approach. In this paper, there was an additional (19) resources consulted, including publications and websites from reputable organizations or government sources, review papers from journals, and two books. A critical appraisal is provided below noting the limitations and the generalizability of the research findings.

### ***Research Limitations***

There are a few research limitations that are noteworthy. Most important is the definition of “rural”. In the studies reviewed, there were a wide range of characterizations used for rural communities and some of the studies used non-specific definitions of rurality. This is important to note since the criteria used to define rural can often determine the results of a study (Bettencourt et al., 2007). In the studies reviewed, there may also have been differences between samples in terms of demographics, stage in the cancer journey, health status, and context in which respondents had utilized health care services, which may have affected some of the findings.

Next, several quantitative studies had small sample sizes in their projects. As a result, these studies may have had limited capacity to detect a statistically significant difference and may cast some doubt about the generalizability of the findings (Crombie, 1996). These survey studies were included because they pointed to possible distinct experiences for rural women with breast cancer. There were only a limited number of random surveys, largely because of the

narrow study parameters being investigated (Crombie, 1996). Many of the participants in the survey and questionnaire studies were self-selected. It is therefore unknown if the findings are reflective of all rural women since non-responders may have had insights to share that were not identified. Many of the surveys were also author-developed, lacked tested reliability and validity, and it is possible that not all variables that could potentially affect rural women with breast cancer were included (Collie et al., 2007). In addition, the use of self-reporting measures in many of the studies raise questions about the accuracy of the responses, which could have been subject to lapses in recall, misunderstandings and response bias (Collie et al., 2007; Crombie, 1996).

The case series studies that used cancer registries or other medical-related data sources may also have research limitations. These data sources are dependent upon the vigilance of medical personnel during data entry, abstraction and verification. Further, there may have been limitations related to the procedures used by cancer registries to collect data and it has been reported that pertinent information (e.g. patient insurance status, radiation therapy information) may be missing, incomplete, inaccurate, and/or underreported in central registries (Celaya et al., 2006; Crombie, 1996; Schroen et al., 2005). Many studies also focused primarily on breast cancer patients who presented for treatment and follow-up appointments at cancer clinics or hospitals. As observed by Mathews et al. (2009), this study approach may not capture individuals who decided to forgo medical treatment altogether. Given the large number of variables that can be associated with rural health outcomes such as breast cancer, it is possible that some studies did not adequately account for confounding variables that affected the observed relationships (Crombie, 1996).

### ***Generalizability of Research Findings***

This paper includes research literature carried out in the United States, Australia and

European countries as well as Canadian literature. The statistics on breast cancer within the general population from these countries are comparable. The United States, northern Europe and Australia have incidence rates for breast cancer that are similar to Canada and are amongst the highest in the world (CCS, 2009). As in Canada, breast cancer death rates have been declining in the United States, the United Kingdom and Australia (CCS, 2009). The risk factors associated with breast cancer are also comparable in these countries (CCS, 2009). Researchers have also stated that the challenge of providing specialized cancer care to residents of geographically distant areas is not confined to Canada, and that Australia has populations that are as physically dispersed (Brigden et al., 2008). Given these similarities, it is reasonable to state that the findings cited in this paper can be generalized to Canada. The studies related to breast cancer treatment carried out in the United States may be the only research findings that would not be generalizable to Canada, due to differences in costs of treatment under a universal health care system compared to the U.S. structure. It is also important to note that a few of the studies used provincial or regional cancer registry data, which may reduce the generalizability of the findings.

The majority of studies did not include urban comparison groups making it difficult to ascertain the uniqueness of the experiences among rural breast cancer patients (Bettencourt et al., 2007). Even without an urban comparison group, the findings nonetheless indicate that these women were coping with many challenges brought about by a diagnosis and treatment of breast cancer, in addition to other issues related to their geographic location (McGrath et al., 1999a). The qualitative research used in this review provided an in-depth understanding of these challenges for rural women with breast cancer.

## Definitions

### *Breast Cancer*

Breast cancer involves cancer cells that form in the tissues of the breast, usually in the ducts (ductal carcinoma) and lobules (lobular carcinoma) (National Cancer Institute, n.d.). Factors that can increase the risk of breast cancer include: “age, country of birth, hormonal factors (affected by age at menarche, age at menopause, age at the first full-term pregnancy and nulliparity), long-term use of hormone replacement therapy, obesity, radiation, family and genetic risks, diet and alcohol, physical activity and smoking” (CIHI, 2006, p. 80). This paper focuses solely on the breast cancer experience of women. Although breast cancer does occur in men it is rare and represents only one percent of all estimated breast cancer cases (CCS, 2009).

### *Rural Communities*

Statistics Canada defines rural as the “fringes of census metropolitan areas (CMAs) and census agglomerations (CAs), as well as populations living in rural areas outside CMAs and CAs. A CMA or CA is an area consisting of one or more adjacent communities situated around a major urban core. To form a CMA, the urban core must have a population of at least 100,000. To form a CA, the urban core must have a population of at least 10,000” (Statistics Canada, as cited in Romanow, 2002, p. 160). Health Canada defines rural and remote communities as “those with populations of less than 10,000 and removed from many urban services and resources” (Sutherns, McPhedran, & Haworth-Brockman, 2003, p. B3). In the research literature there are inconsistent definitions of “rural” applied, such as the size of the community, population density or geographic location. Despite the range of definitions used, rural communities do share common problems in health status and more restricted access to health care, among others. (Romanow, 2002). Due to the multitude of parameters used to define rural communities, this

paper will employ a broad definition that encompasses all characterizations of rural, including remote and northern communities.

It is important to note that rural communities are not single homogenous populations, but rather they differ considerably across geographic regions of Canada (Gray et al., 2004; Romanow, 2002). “Diversity is a characteristic of Canada and it applies to smaller communities just as it does to the largest cities” (Sutherns et al., 2003, p. B4). Both the health needs of residents and the way in which they should be addressed vary for different rural communities (Romanow, 2002). The research literature needs to be viewed with this diversity in mind recognizing that there is not a standard “one size fits all” solution for issues of rural health (Romanow, 2002).

Explanations of the effects of geography on health have traditionally been based on a simple view of rural life (Thurston & Meadows, 2003). In reality, rural living is heterogeneous and “to ignore this may perpetrate generalizations about rurality that are too simple to be useful and that have the potential to obscure important features of place” (Thurston & Meadows, 2003). There is significant heterogeneity within rural communities and among rural people (Sutherns et al., 2003). It is important to understand that the culture, economic and demographic changes, and history of rural communities themselves can be very important in shaping the experiences of rural women (Thurston & Meadows, 2003).

## **Statistics**

### ***Incidence***

Breast cancer is the most common female cancer in Canada with over 22,000 new cases each year (CCS, 2009). One in nine women will have a diagnosis of breast cancer in their

lifetime (CCS, 2009). The incidence of breast cancer increases drastically with age as is the case with most cancers, but what is unique is that there are already significant incidences of breast cancer in women as young as 25 years old (CCS, 2009). From 1969 to 1999, breast cancer incidence rose approximately one percent annually (or 30 percent over 30 years) for all age groups (CCS, 2009). This long-term increase is partly due to increased participation in and improved quality of mammography screening (CCS, 2009). Other potential explanations include increasing tendency to delay childbearing, having lower numbers of children, and changing patterns of hormone use (i.e. oral contraceptives and hormone replacement therapy) (CCS, 2009). Since 2000, the incidence of breast cancer for women of all ages has remained stable (CCS, 2009).

### ***Mortality Rates***

The mortality rate from breast cancer is higher than any other cancer except lung cancer, with a rate of 5,000 women a year, or one in every 24 women (CCS, 2009). The age-standardized mortality rate for breast cancer in Canadian women has decreased 25 percent since 1986 (CCS, 2009). These rates have declined markedly, due largely to the development of organized screening programs, increases in screening participation and quality, and advances in adjuvant therapy following breast cancer surgery (CCS, 2009).

### ***Survival Rates***

With declining mortality rates, increasing numbers of women are surviving breast cancer (CCS, 2009). The climbing survival rate has implications for health care resource utilization and survivorship issues, such as reoccurrences, long term effects of treatment, and impact on family members (CCS, 2009). An estimated 162,600 Canadian females, approximately one out of every

100 women, has had a diagnosis of breast cancer at some point in their lives (CCS, 2009). The five-year survival rate for all women diagnosed with breast cancer is 86 percent and the 20-year survival rate is approximately 70 percent (CCS, 2009).

### ***Rural-Urban Patterns of Breast Cancer***

The Canadian Institute for Health Information's (2006) study on the health of rural Canadians interestingly discovered that breast cancer incidence rates were significantly lower in rural compared to urban communities. The same study reported that rural women also had lower mortality rates from breast cancer (CIHI, 2006). However, women with breast cancer living in rural communities have an inferior five-year survival rate compared to urban counterparts (CBCN, 2003). Similar survival rate findings were discovered in a provincial study based on data from the Ontario Cancer Registry. In very small cities, the breast cancer survival rate was significantly lower than mid-large cities (Gorey et al., 2008). The study reported that "there was also a persistent effect of living in smaller places such as towns and villages, and rural and remote areas that were less than 100km from urban centres" affecting survival rates (Gorey et al., 2008, p. 13). While rural residents experience less overall cancer incidence and mortality, the long-term prognosis may in fact be poorer (CBCN, 2003; CIHI, 2006).

Researchers have cited several potential explanations for the fact that rural women are less likely to get breast cancer, but more likely to have poorer long-term prognosis. The lower incidence rates may be the result of a protective effect of lower age for childbirth and higher rates of teen pregnancy (CIHI, 2006). Rural women are also less likely to receive breast screening and mammography, which could mean that there are women in rural communities who remain undiagnosed (CIHI, 2006). Lack of access to screening and mammography has been linked to presenting to physicians with a more advanced stage of breast cancer, and resultantly,



poorer prognoses and survival rates (CIHI, 2006; Elliott, Elliott, Renier, & Haller, 2004; Gumpertz et al., 2006). Rural women also have less access to radiation therapy, which can reduce the risk of breast cancer reoccurrence by approximately 70 percent (CCS, 2009).

### **Rural Women's Access to Cancer Care Services**

#### ***Health Care Provision in Rural Communities***

A recent National Commission that examined health care in Canada reported that individuals living in rural communities do not have as good a health status as the general Canadian population (Romanow, 2002). The health of individuals in a community is also inversely related to the remoteness of its location (Romanow, 2002). Characteristics distinct to rural living that most likely contribute to differences in health outcomes may include socio-economic disparities and limited access to health care services and providers (Romanow, 2002). Rural communities have ongoing problems attracting and retaining health care professionals (Romanow, 2002). Specialized cancer care, including specialists, diagnostic services, and advanced treatments, are not available in rural communities and pose a barrier to cancer prevention and treatment for residents (CIHI, 2006; Romanow, 2002).

A qualitative national Canadian study found that women with breast cancer living in rural communities spoke about issues of access to necessary services, including family doctors, cancer specialists, screening centres and treatment centres (Gray et al., 2004). As such, rural women with breast cancer often travelled to obtain medical services (CBCN, 2001; CBCN, 2003; Davis, Williams, Redman, White & King, 2003). Rural women's experience with hospital stays and post-treatment follow-up indicated that many felt they were sent home too early especially given the distance they needed to travel and the relative lack of medical and nursing supports available

once they arrived home (CBCN, 2001).

The issue of limited access to local physicians in rural communities is particularly salient given that women with breast cancer rely on their physicians for support and information (CBCN, 2001; Davis et al., 2003; McGrath et al, 1999b). Barriers also exist for mental health care for rural women with breast cancer, including lack of access to and availability of mental health specialists, an inability to pay for mental health care, and geographic remoteness (National Agricultural Centre as cited in Bettencourt et al., 2007, p. 884). Relative to urban counterparts, many rural communities have fewer cancer prevention activities, less information and cancer resources, and limited access to support groups (Elliott et al., 2004; Gray et al., 2004; McGrath et al., 1999a; Romanow, 2002).

### ***Breast Cancer Screening***

Both the Canadian Task Force on Periodic Health Examination and the Canadian Cancer Society recommend breast screening for women ages 50 to 69 every two years by clinical examination and mammography (CCS, 2009). Additionally, the Canadian Cancer Society also recommends breast self-examination (CCS, 2009). Mammography is considered the most effective method for detecting early stage breast cancer malignancies at an average of one to three years before a lump is discovered with breast self-examination (Lane & Martin, 2005; Lane, Martin, Uhler, & Workman, 2003). Mammography also isolates tumours too small to be found by clinical examination (Lane & Martin, 2005).

Every province and territory in Canada except Nunavut currently utilizes organized breast screening programs (CCS, 2009). Although breast cancer screening is increasing in most provinces and territories, none of the programs have reached the Canadian participation target of 70 percent (CCS, 2009). Further, studies indicate that participation in screening and

mammography is significantly lower in rural communities (CBCN, 2003; CIHI, 2006; Maxwell, Bancej, & Snider, 2001; McDonald & Sherman, 2008). Breast screening resources are primarily located in urban centres and as a result, rural women have less access to information on breast screening and mammography services (CBCN, 2003; McDonald & Sherman, 2008). Further, rural physicians may be less likely to comply with recommended screening practices and rural women's attitudes and beliefs about preventative health care may affect their usage (CIHI, 2006; Maxwell et al., 2001; McDonald & Sherman, 2008; Steven, Fitch, Dhaliwal, Kirk-Gardner, Sevean, Jamieson, & Woodbeck, 2004). The Centre for Disease Control and Prevention has identified fear, cost, and distance as the three highest-ranking barriers to early breast screening activities by rural women (Centre for Disease Control, as cited in Lane et al., 2003, p. 293).

### ***Later Diagnosis***

Upon diagnosis, breast cancer is staged based on tumour size and extension to other areas (CCS, 2007). Staging of breast cancer provides an indication of survival rates (CCS, 2007; CCS, 2009). Although national statistics are unavailable, data from Ontario demonstrated that the survival rate is 96 percent for stage I (tumour is 2cm or smaller and has not spread) and 86 percent for stage II (tumour is 2 to 5 cm or has spread to lymph nodes) (CCS, 2007; CCS, 2009). Survival rates for women diagnosed at stage III (cancer has spread to lymph nodes and other nearby tissues) and stage IV (cancer has spread to distant parts of the body) were inferior at 56 and 29 percent, respectively (CCS, 2007; CCS, 2009). Staging has particular significance to rural women, who are more likely to present themselves to a physician with an advanced stage of cancer compared to their urban counterparts (Elliot, Elliott, Renier & Haller, 2004; Gumpertz, Picker, Miller, & Bell, 2006). Researchers have reported a connection between less access to

screening and mammography in rural communities and more advanced stage of breast cancer at diagnosis (CIHI, 2006; Elliott et al., 2004; Gumpertz et al., 2006).

### ***Treatment for Breast Cancer***

Surgery is the most common medical treatment for breast cancer (CCS, 2007). Numerous studies have found that rural women are less likely to undergo breast-conserving surgery with radiation therapy and are more likely to have a mastectomy, which is a more aggressive approach (CBCN, 2003; Celaya et al., 2006; CIHI, 2006; Gray et al., 2004; Schroen et al., 2005).

Radiation therapy can reduce the risk of breast cancer reoccurrence by approximately 70 percent (CCS, 2009). Radiation therapy for breast cancer is typically only available in larger urban centres and requires patients to receive frequent administrations and attend the treatment facility on a daily basis for weeks (CCS, 2007; Mathews et al., 2009). Among rural women treated at specialist centres in Ontario, more distant patients were found to be less likely to receive chemotherapy and radiation therapy (Iscoe, Goel, Wu, Fehringer, Holowaty, & Naylor, as cited in Gray et al., 2004). Breast-conserving surgery is also more readily available at larger hospitals in urban centres, rather than smaller hospitals in towns and small cities where rural women are more likely to go for treatment (Iscoe et al., as cited in Gray et al., 2004).

## **The Impacts of Breast Cancer on Rural Women and their Families**

### ***Travel Issues***

Women with breast cancer from rural communities are typically required to travel significant distances for treatment - either driving daily or being away from home during care (Davis et al., 2003; Gray et al., 2004). A significant percentage of women with breast cancer in rural Australia traveled more than 100km for treatment - 32 percent travelled more than 100km

for surgery, 68 percent for radiation therapy, and 36 percent for chemotherapy (Davis et al., 2003). Canadian research reports similar findings with respect to long travel distances required for cancer treatment (Lightfoot et al., 2005; Gray et al., 2004). Gray et al.'s (2004) qualitative study of rural women with breast cancer found that 50 percent of the women traveled over one hour for surgery and 25 percent traveled over three hours. Long travel times for chemotherapy and radiation therapy were also reported (Gray et al., 2004). In order for many of these women to access treatment at cancer centres, they had to travel long distances by car, plane, train or bus (Gray et al., 2004). A study carried out in Northern Ontario cited that the average one-way distance travelled by cancer patients, including women with breast cancer, was close to 400km (Lightfoot et al., 2005).

Travelling long distances for treatment has physical impacts on rural women with breast cancer. Researchers studying mostly breast cancer patients in Northern Ontario reported that more than half experienced physical symptoms and 28 percent reported discomfort ranging from "a fair amount" to "very much" (Lightfoot et al., 2005). The side effects of travelling for breast cancer treatment include burns and blistering from radiation therapy, which make it difficult for women with breast cancer to wear a seatbelt (Hegney, Pearce, Rogers-Clark, Martin-McDonald, & Buikstra, 2005). Studies have also stated that that travelling for radiation therapy along with the treatment itself causes fatigue among patients (Fitch et al 2003; Hegney et al., 2005).

Decision-making around treatment options is also impacted by the need to travel to access health care services outside of rural communities. As mentioned previously, rural women with breast cancer are statistically more likely to undergo mastectomy rather breast-conserving surgery and radiation therapy (CBCN, 2003; Celaya et al., 2006; CIHI, 2006; Schroen et al., 2005; Gray et al., 2004). Studies have shown that there are a number travel-related reasons why

rural women with breast cancer chose to forgo radiation therapy, including: distance, inclement weather, financial/economic factors, time, and the need for prolonged periods away from home and work (CBCN, 2001; Celaya et al., 2006; Gray et al., 2004; Schroen et al., 2005).

Rural women with breast cancer have also reported that travelling for treatment interfered with family life and many experienced isolation in urban treatment centres (Gray et al., 2004). Rural cancer patients, including those with breast cancer, reported that traveling for radiation therapy resulted in a lack of closeness to family and friends (Hegney et al., 2005). Lightfoot et al.'s (2005) study of breast and other cancer patients found that most participants (80 percent) reported emotional difficulty associated with travelling to a cancer centre. Participants in other studies reported both benefits and drawbacks of being away from home (Fitch et al., 2003). Although "many report being lonely and wished they had not had to make the journey, they found comfort in their peers that surrounded them" (Fitch et al., 2003, p. 12). Cancer patients that travelled for treatment on a daily basis, instead of staying in urban settings, did not have the same access to peer supports or the benefits of sharing experiences with other cancer patients (Gray et al., 2004; Fitch et al., 2003). Women who developed relationships with other breast cancer patients while being away for radiation treatment felt a loss of social support upon returning to their rural communities and families (Gray et al., 2004).

### ***Financial and Work-Related Issues***

In Canada, rural populations are less highly educated, have higher unemployment rates, and have lower annual incomes (\$49,449 compared with \$56,817 for urban counterparts) (CIHI, 2006). Many rural residents do not have employee-based group health plans to cover drug costs and cannot afford private health insurance that usually have higher premiums (Lightfoot et al. 2005). Mathews et al. (2009) examined out-of-pocket costs incurred by rural cancer patients in

Newfoundland and Labrador, including women with breast cancer. Rural cancer patients were more likely to report not having private health insurance, lower incomes and less education and were more likely to make treatment decisions based on financial costs (Mathews et al., 2009). McGrath et al.'s (1999a) qualitative study of rural Australian women with breast cancer found that the majority of participants had suffered financially as a result of their illness. When the women worked on farms or were self-employed, their financial hardships were even greater (McGrath et al., 1999a). Focus group sessions held with rural women with breast cancer from communities across Canada expressed concerns related to the rural context:

The women emphasized the uniqueness of employment practices in rural communities where work options rarely include a full-time salary with a single organization. Many women were working multiple part-time jobs, all without benefits and/or job security. Others were self-employed. These women were left without options when they needed time off work for sickness or to travel for treatments. (CBCN, 2001, p. 19)

Rural women with breast cancer are often unable to work during treatment (Lauzier et al., 2008; Lightfoot et al., 2005). A study including mostly breast cancer patients in Northern Ontario found that over 60 percent of participants indicated that travelling for cancer treatments affected their ability to work or attend school and almost 25 percent indicated that it completely prevented them from doing their job (Lightfoot et al., 2005). Other Canadian research on both rural and urban breast cancer patients found that the women had taken one full-time absence from work that lasted on average 7 months and resulted in a average wage loss of 27 percent of annual salary, after taking into account any financial compensation received (Lauzier et al., 2008). Further, the study found that the greater the loss of annual wages, the more women reported worrying about their financial situation and the adequacy of family income to meet regular expenses (Lauzier et al., 2008). The cancer patients that were more likely to lose higher proportions of their annual wages had characteristics that are typical of rural populations,

including: self-employment and part-time work; lower levels of education; lower levels of social support; and further distances to travel to the hospital (CIHI, 2006; Lauzier et al, 2008). The researchers concluded that the study findings point to wage losses as an adverse consequence of having breast cancer in Canada (Lauzier et al., 2008). In the same vein, other researchers have reported that travelling for cancer can adversely affect family incomes because caregivers often have to take time off work to travel with patients (Clavarino et al., 2002).

Rural women with breast cancer often incur travel-related expenses while receiving treatment (Gray et al., 2004; Mathews et al., 2009). Numerous researchers have cited that financial strains brought about by the cost of relocation and travel for treatment is a stressor among rural women with breast cancer (CBCN, 2001; Gray et al., 2004; Hegney et al., 2005; McGrath et al., 1999a). All of the breast cancer patients in Fitch et al.'s (2003) study reported that they incurred financial costs as a result of traveling for radiation treatment. Over 40 percent of the participants in Lightfoot et al. (2005) study reported difficulty in meeting the financial demands of travelling for treatment and half reported that government-sponsored travel subsidies needed improvements. Rural cancer patients were also more likely than urban counterparts to have out-of-pocket costs (re: travel, drug and child care costs) and two times more likely than urban counterparts to report that these financial costs were important considerations in their treatment and health care decision-making (Mathews et al., 2009).

### ***Impacts on Family Members and Caregivers***

Treatment for breast cancer for women living in rural communities may require being physically separated from family for extended periods of time (Gray et al., 2004). Hegney et al.'s (2005) qualitative study of rural cancer patients, including women with breast cancer, reported that there are significant burdens placed on families when patients are required to travel for



radiation therapy. Study participants reported feeling a lack of closeness to family and were sad over leaving their children at home while they received treatment (Hegney et al., 2005). McGrath et al.'s (1999a) study also found that rural women with breast cancer expressed concerns related to children, namely: the effects resulting from the absence of the mother during treatment; the future impact of having had cancer on their children; and the potential long-term emotional effects from the loss of positive childhood experiences. In a study of rural and urban Australian women with breast cancer, over 40 percent reported concern with the meaning and impacts of their breast cancer for daughters or sisters (Girgis, Boyes, Sanson-Fisher, & Burrows, 2000).

Studies have reported that there are impacts on the partners and/or family caregivers of rural women with breast cancer (Clavarino et al., 2002; Hegney et al., 2005; McGrath et al., 1999a). A qualitative study with rural women found that they expressed concern about how partners and family members would cope during their absences for treatment or illness (McGrath et al., 1999a). Rural women with breast cancer have also reported that they felt they were an emotional and financial burden on their families (Hegney et al., 2005; McGrath et al., 1999a). In a study of mainly breast cancer patients, rural family caregivers expressed similar concerns about coping in the absence of women receiving treatment. These family caregivers most frequently cited demands related to assuming more responsibility of household tasks, re-organizing daily family living arrangements, and disruption to their schedule and normal routines (Clavarino et al., 2002). Male caregivers reported that they experienced role changes caused by having to provide for children left behind or relocated for the duration of treatment (Clavarino et al., 2002). These caregivers also reported poorer family functioning than did the cancer patients themselves, suggesting that there are potentially high levels of distress associated with a dual caring role (Clavarino et al., 2002). In fact, research has found that rural family caregivers had higher levels

of anxiety and depression than patients, and that both were higher than the general population (Clavarino et al., 2002). Family caregivers also worried about the future financial impact of cancer (Clavarino et al., 2002). The authors concluded that there are significant disruptions experienced by cancer patients and family caregivers in relation to the demands of family life in rural communities (Clavarino et al., 2002).

### ***Psychosocial Impacts on Rural Women***

Rural women with breast cancer face psychosocial distress, anxiety and significant emotional concerns as a result of their disease (McGrath et al., 1999a, Koopman et al., 2001). In McGrath et al.'s (1999a) qualitative study of rural women with breast cancer, the impact of breast cancer was described among patients as an "emotional rollercoaster with anxiety heightening close to check-up time and during symptoms" (McGrath et al., 1999a, p. 37). Many of these women reported distress over changes in body image, due to hair loss and mastectomy (McGrath et al., 1999a). Additionally, a review of the literature indicated that there is some evidence that rural women with breast cancer diagnoses may feel stigmatized as a result of their disease (Bettencourt et al., 2007). In Koopman et al.'s (2001) study many of the rural women experienced traumatic stress regarding their breast cancer. The average woman in this study considered her diagnosis of breast cancer to be among the four most stressful life events ever experienced (Koopman et al., 2001).

Researchers have reported that living in rural communities may place women with breast cancer at high risk for depleted psychological resources compared to urban women (Palesh et al., 2006). Rural cancer patients, including those with breast cancer, have reported considerable anxiety and depression (Clavarino, Lowe, Carmont & Balanda, 2002). These findings are similar to studies carried out using both rural and urban samples, which found that depression and mood

disturbances frequently co-occurred with breast cancer (Koopman et al., 2001; Palesh et al., 2006). Girgis et al.'s (2000) study found that both urban and rural women with breast cancer reported that they had psychological needs in the following three areas: (1) fear about the cancer spreading; (2) anxiety or stress; and (3) feeling down and depressed (Girgis et al., 2000). Feelings of loneliness or isolation were also often reported among women with breast cancer in rural communities (Gray et al., 2004; McGrath et al., 1999a).

The psychological effects of breast cancer for rural women continue even after treatment is concluded. Rural breast cancer survivors have reported higher levels of helplessness and hopelessness compared to studies with non-rural samples (Koopman et al., 2001). Qualitative studies have found that rural women with breast cancer express fear of cancer reoccurrence and reduced life span (CBCN, 2001; McGrath et al., 1999a). Albert, Koller, Wagner and Schultz (2004) examined three psychological quality of life (QoL) dimensions among rural women with breast cancer - emotional functioning, futures perspective, and global quality of life. The researchers found that QoL levels remained below the population average even 12 months after discharge (Albert et al., 2004). Similarly, other researchers have found that experiencing greater burdens, such as less than average upper-body function, high amounts of stress and poor handling of stress, a lack of social support, and feeling less confident in relation to managing one's health, were all associated with lower health-related QoL among rural survivors of breast cancer, 12 months after diagnosis (DiSipio, Hayes, Newman, & Janda, 2009). The researchers stressed the importance of supporting rural breast cancer survivors by improving physical functioning, lowering stress and providing psychosocial support (DiSipio et al., 2009).

There is significant evidence that suggests that a significant proportion of women do not feel that their psychosocial support needs have been adequately met with existing resources in

rural communities (Bettencourt et al., 2007; Gray et al., 2004; McGrath et al., 1999a). Rural women with breast cancer had difficulty accessing support groups even when they existed and often lacked opportunities to meet with other breast cancer survivors (Gray et al., 2004; McGrath et al., 1999a). Many rural women also reported that family members needed support and that there were challenges in locating help within rural communities (CBCN, 2001; Clavarino et al., 2002; Gray et al., 2004). The findings point to a need for greater availability of psychosocial supports for rural women with breast cancer.

### ***Information Needs***

Receiving more health and oncology-specific information is a commonly expressed need among rural women with breast cancer (Bettencourt et al., 2007; Girgis et al., 2000; McGrath et al., 1999b). Research with rural and urban Australian women found they described a high need for information related to the diagnosis, treatment and management of breast cancer as well as information on support groups (Girgis et al., 2000). Approximately half of the rural participants in McGrath et al.'s (1999b) study experienced "some or great difficulty" in attaining adequate information on issues such as hormone replacement therapy, alternative therapies, latest research on the disease, implants, specific chemotherapeutic drugs, psychological impact of cancer and support services. Davis et al.'s (2003) study found that only half of the participants received adequate information about radiation therapy and breast reconstruction. Bettencourt et al.'s (2007) review of the literature also commented on the lack of health information and stated that breast cancer survivors wanted greater patient education and more information on what to expect during and post-surgery and treatment. Women with breast cancer may also have difficulty obtaining information about travel subsidies and accommodations for treatment located away from home (CBCN, 2001; Davis et al., 2003; Lightfoot et al., 2005).

The families of rural cancer patients may also felt they did not receive enough support, services and information during diagnosis and treatment from health care providers (Clavarino et al., 2002; Davis et al., 2003). Davis et al.'s (2003) study found that 35 percent of families felt they had not received enough support during women's diagnosis and treatment from health care providers. Similarly, Clavarino et al. (2002) found that family caregivers reported a high need for greater information, resources and services from the health care system and felt they were considered peripheral in the cancer diagnostic and treatment process. "This could mean that carers are marginalized in terms of medical discussions of treatment and indicates inadequacies in the provision of information" (Clavarino et al., 2002, p. 193). They also felt unequipped to handle problems that could arise from the cancer and reported feeling isolated from professional assistance (Clavarino et al., 2002). In this study, family caregivers reported a greater need for information than did the cancer patients themselves (Clavarino et al., 2002). The research highlights the importance of providing information to both rural women and their families.

Research indicates that rural Canadian women from across the country have difficulty accessing information locally or regionally about the diagnosis and treatment of their disease (CBCN, 2001; Gray et al., 2004). These women reported difficulties in accessing general practitioners (GPs) and even when women had GPs, poor communication from specialists at treatment centres to family physicians often meant that they were not able to get the information they needed (CBCN, 2001). A lack of local health information was also reported by Australian researchers who revealed that 30 percent of rural breast cancer survivors reported that living outside a major city had limited their access to information (Davis et al., 2003). Further, over 90 percent of women with breast cancer stated that there were not given resources that were targeted specifically for rural women (Davis et al., 2003). There is clearly a need for information on

breast cancer that is tailored to the rural context.

### **Sources of Information and Support for Rural Women**

#### ***Health Care Providers***

The importance of health care providers, namely general practitioners and surgeons, for breast cancer care is widely recognized. These individuals play a prominent role for breast cancer patients, from initial diagnosis to coordination and management of care (CBCN, 2003). Focus groups with rural women with breast cancer found that their primary source of information and support was medical professionals (Gray et al., 2004). Similarly, research with rural Australian women found that most of their support came from health care providers, general practitioners, surgeons, or volunteers with a history of breast cancer (Davis et al., 2003; McGrath et al., 1999b).

Researchers have indicated that relationships between rural women with breast cancer and their health care providers were optimized when: (1) they could visit the provider immediately with their concerns; (2) they could trust their provider; (3) their provider listened to them; and (4) they perceived mutual respect (Wilson, Anderson, and Meischke, 2000). In contrast, the factors that may result in negative interactions between rural breast cancer patients and primary care practitioners include: (1) poor communication with physicians; (2) feeling ignored; (3) waiting long periods for test results; and (4) feeling rushed in decision-making (Gray et al., 2004; Wilson et al., 2000). These findings suggest that rural women with breast cancer have a need for strong, trusting and open communication with health care providers (Wilson et al., 2000).

***Breast Care Nurses***

Programs involving clinical nurse specialists or breast care nurses have had success as a support intervention for women with breast cancer (Eicher, Marquard, & Aebi, 2006; Eley, Rogers-Clark, & Murray, 2008; Lane et al., 2003). “A specialist breast nurse’s role is to provide continuity of care through counselling, information and support related to all aspects of breast care for women with breast cancer” (National Breast Cancer Centre, as cited in Eley et al., 2008, p. E16). A systematic review of the literature from the United Kingdom found that specialist breast nurses improved physical and psychosocial well-being among urban cancer patients (Eicher et al., 2006). Among rural Australian women with breast cancer, Eley et al. (2008) found that breast nurse specialists were more approachable than physicians, had more time to attend to patients’ needs, and helped them understand information given to them by other health professionals. Women in the study also reported that communication with the breast care nurse helped reduce the normal isolation that would be experienced by rural residents (Eley et al., 2008). Focus groups with rural women in Canada recommended having nurses specializing in oncology available within rural communities (CBCN, 2001). Researchers have supported this recommendation of having breast nurses available to provide rural women with ongoing information and support (Eley et al., 2008; Rogers-Clark, 2002). These nurses could meet with rural women to address health issues, thereby lowering the costs associated with accessing specialists and lightening the workload of oncologists (CBCN, 2001). There are also recognized benefits of breast care nurses for coordination and liaison of the health care team in rural communities (Eley et al., 2008; Lane et al., 2003; Rogers-Clark, 2002).

***Mental Health Professionals***

Research has documented a lack of mental-health services for rural women with breast

cancer and their families (Davis et al., 2003, Gray et al., 2004; Rogers-Clark, 2002). Rogers-Clark (2002) found that none of the study's rural breast cancer participants were referred to counselling, support groups or other mental-health services. Similar findings were reported by Davis et al. (2003) with only 10 percent of rural women with breast cancer or their families receiving support from social workers or other mental health professionals. This study noted that the provision of healthcare in rural and remote areas has changed significantly in the past two decades, including decreased availability of both health professionals and mental health services (Davis et al., 2003). Statistics from the United States have also indicated that in rural areas, barriers to mental health care include a lack of access to and availability of mental health specialists (National Agricultural Centre as cited in Bettencourt et al., 2007, p. 884). In rural communities, women may have difficulty talking about their breast cancer because of concerns over privacy (McGrath et al., 1999a). Moreover, rural women may be less likely to seek mental health care because of the negative attitude and stigma associated with psychological support services (Bettencourt et al., 2007; McGrath et al., 1999a).

Research supports complementary care being provided by mental health professionals, social workers and other helping professionals to support women with breast cancer (Davis, 2004; Ganz, 2000). Cumulative evidence has demonstrated that psychological therapies can reduce distress in cancer patients and can improve emotional adjustment and social functioning (Devine and Westlake; Meyer and Mark; Sheard and Maguire, as cited in National Breast Cancer Centre [NBCC] and National Health and Medical Research Council [NHMRC], 2000). Including mental health professionals, as part of the care team has also proven very effective in addressing the psychosocial needs and concerns of patients at diagnosis and across the continuum of breast cancer care (Davis, 2004; Ganz, 2000). Davis et al (2003) stated that having rural social workers



as well as medical social workers in treating hospitals could be a valuable resource for rural women and their families.

### ***Informal Networks***

Informal networks can be an important source of support for rural women with breast cancer (Gray et al., 2004; McGrath et al., 1999b). Informal networks can include partners, family, friends, neighbours, church, community, colleagues, and local community and charity organizations (Bettencourt et al., 2000; Davis et al., 2003; Gray et al., 2004; Koopman et al., 2001; McGrath et al., 1999b). Several studies have found that the rural community itself can be supportive for breast cancer patients (Bettencourt et al., 2007; Gray et al., 2004; Rogers-Clark, 2002). Based on qualitative research with rural women, Rogers-Clark (2002) recommended that resources to support cancer survivors need to build on the existing strengths in rural communities (Rogers-Clark, 2002). Rural women with breast cancer have expressed the following viewpoint:

... they [rural women] would not have traded the benefits of their supportive rural communities for the convenience of living in an urban environment. In tightly knit rural communities, friends and neighbors often show support by calling, visiting and providing food. (Bettencourt et al., 2007, p. 884)

Family and friends provide ongoing practical and emotional support for rural women with breast cancer (Hegney et al., 2005; McGrath et al., 1999b). Over 70 percent of breast cancer patients in Hegney et al.'s (2005) study acknowledged the crucial role of family members or friends in providing support during radiation treatment. The research also indicated that the majority of rural and urban women who chose not to use peer support programs already had adequate support from family or friends (Rankin, Williams, Davis & Girgis, 2004). Partners were seen as having a major role in supporting women through the experience of breast cancer (McGrath et al., 1999b). However, even though social support provided by partners has been

cited as beneficial, in at least some cases, rural women were reluctant to disclose fears, worried about burdening their partners, and reported a lack of support from their partners (McGrath et al., 1999b). In addition, women with breast cancer who are relatively new to a rural community may not experience the support and benefits of informal networks (McGrath et al., 1999b).

### ***Peer Support Programs***

Peer support refers to support provided to cancer patients by others who have also experienced the disease (Gray, Fitch, Davis and Phillips, as cited in Hoey, Ieropoli, White & Jefford, 2008, p. 315). Peer support programs are seldom uniform in delivery and can be professional or volunteer-led, group or one-on-one format, and can be provided face-to-face, via the Internet, by videoconference or by telephone/teleconference (Dunn, Steginga, Rosoman, & Millichap, 2003; Hoey et al., 2008). Peer support has been identified as a useful source of support for rural women with breast cancer (Gray et al., 2004; CBCN, 2001). Rural breast cancer patients have stated that having the opportunity to meet with other breast cancer survivors was helpful in reducing fears, normalizing experiences and providing a survivorship standpoint (Gray et al., 2004). Gray et al. (2004) reported that the most frequent recommendation from rural breast cancer patients was to facilitate interaction with other breast cancer survivors. The benefits of peer support include emotional and informational support, along with improved coping skills, reduced isolation, mutual identification, shared experiences and a sense of belonging, which may all contribute to positive psychological outcomes (Campbell, Phaneuf, & Deane, 2004; Dennis, as cited in Gray et al., 2004, p. 316).

Focus groups across Canada have indicated that face-to-face peer support groups can be a useful source of support for rural women with breast cancer (Gray et al., 2004; CBCN, 2001).

However, there are indications that access to in-person peer support groups is a challenge in rural

communities. Identified barriers to attendance include holding meetings and activities either at night or too far away from the homes of rural women (McGrath et al., 1999a). Rural breast cancer survivors have also reported problems establishing breast cancer support groups because they are difficult to organize, and it is hard to locate a suitable facility and maintain the service (Gray et al., 2004). Women in this study commented that facilitators did not have the required training and it was recommended that there be access to better-run support groups by health professionals or trained peers (Gray et al., 2004).

Literature reviews have been carried out to assess the effectiveness of peer support programs for breast and other cancer patients (Campbell et al., 2004; Dunn et al., 2003; Hoey et al., 2008; Macvean, White & Sanson-Fisher, 2008). The majority of the studies examined in these reviews generally found that participants benefited from peer support programs. However, there were only a limited number of well-designed studies among them, as most did not have theoretical frameworks, adequate program descriptions, data on non-participants, validated instruments, or rigorous research methodologies (Campbell et al., 2004; Dunn et al., 2003; Macvean et al., 2008). A few of the evaluations found that participation in peer support programs resulted in greater confidence in talking with physicians, which is particularly significant given their importance in the breast cancer experience (Campbell et al., 2004). Hoey et al.'s (2008) review of the literature focused on various delivery formats and concluded that one-on-one face-to-face and group Internet peer support programs should be given priority when considering ways to offer peer support. However, these researchers also stated "regardless of the way peer support is delivered, having contact with other people with cancer assists patients in practical, social and emotional ways" (p. 333). These literature reviews covered peer support programs for both rural and urban cancer patients, but no formal comparisons were made or reported in the

findings. Although the research literature covered all types of cancer, the vast majority of peer support programs were targeted specifically for women with breast cancer.

There are a limited number of studies that specifically focused on evaluating peer support programs for women living in rural communities. The existing studies examined technology-based distance delivery of peer support programs, including Internet, videoconferencing and audioconferencing venues (Collie et al., 2007; Curran & Church, 1999; Solberg, Church & Curran, 2003; Lieberman et al., 2003). Two Canadian studies of audioconferencing peer support programs found that they were beneficial for overcoming isolation through the sharing of experiences with other breast cancer survivors (Curran & Church, 1999; Solberg, Church & Curran, 2003). Other benefits included meeting informational needs, anonymity, and immediacy of audioconferencing, while negative aspects were associated with technological difficulties (Solberg et al., 2003). Solberg et al. (2003) reported that delivering support programs via audioconferencing can transcend geographical distance. A study in the United States of a videoconferencing program found that participants were comfortable using this format and that the program was valuable for sharing information and forming emotional bonds with other rural women with breast cancer (Collie et al., 2007). Pre-test and post-test comparisons showed significant decreases in depression and posttraumatic stress disorder symptoms among participants (Collie et al., 2007). Lieberman et al.'s (2003) study evaluated an Internet-delivered electronic support group for women with breast cancer, half of them from rural communities. The results of the study indicated that breast cancer patients had significantly reduced depression and reactions to pain (Lieberman et al., 2003). The researchers concluded that this type of intervention holds promise as a source of support for women in rural communities who have limited access to face-to-face support groups (Lieberman et al., 2003).

### ***Resilience Among Rural Women***

Resilience among rural women involves “developing new strategies and enhancing existing strategies that are both behavioural and psychological in nature to maintain and advance health in the face of health threats” (Leipert & Reutter, 2005, p. 56). Research with women in Northern, isolated communities found that resilience was a key strategy used to maintain their health (Leipert & Reutter, 2005). Having a positive attitude, hardiness and self-reliance gave women hope and encouragement to persevere despite difficult challenges (Leipert & Reutter, 2005). Providing support to each other was also seen as central to women’s health in the North (Leipert & Reutter, 2005).

The research literature on breast cancer aligns with this concept of resilience. Rogers-Clark (2002) focused on rurality and resilience as dimensions of women’s experiences of living through breast cancer. The study found that rural breast cancer survivors’ resilience was based on the following: a sense of peace through personal connection with the land; the nurturing support they found within rural communities; and self-reliance or coping on their own (Rogers-Clark, 2002). These rural breast cancer survivors felt that “country women are more positive and can get through a lot more things...” (Rogers-Clark, 2002, p. 37). Wilson et al. (2000) also reported that ‘trying to maintain a positive attitude’ was a common strategy used among rural breast cancer survivors. McGrath et al’s (1999b) study found that rural women focused on staying mentally positive, being surrounded by supportive, positive people, and talking openly about their experience of breast cancer. Interventions aimed at supporting rural women with breast cancer should include optimizing their resilience in the face of health challenges.

## **Health Care Delivery Approaches for Rural Communities**

### ***Outreach Clinics and Mobile Screening for Breast Cancer***

One approach that can be used to overcome the lack of specialty health care services in rural communities is outreach clinics, whereby physicians travel to rural areas to provide health care services (Doolittle & Spaulding, 2006). Outreach clinics allow patients to receive care close to home with the initial expertise of the oncologist and day-to-day management with local primary practitioners (Doolittle & Spaulding, 2006). However, outreach clinics have not gained significant popularity for a method to improve access as there are many disadvantages such as travel time for the oncologist, flight costs, and inclement weather that can result in cancelled clinics (Doolittle & Spaulding, 2006).

As mentioned earlier, breast cancer screening through mammography is an effective method for detecting early stage malignancies (Lane et al., 2003). Some provinces have addressed the lack of access in rural areas with success by providing mobile screening services, where mammography and examination are carried out in rural communities (CBCN, 2009). Northwestern Ontario was one of the first rural areas to provide mobile mammography as part of the Ontario Breast Screening Program, which now reaches close to 30 communities (Thunder Bay Regional Health Centre [TBRHC], n.d.). Northwestern Ontario has the second highest screening rate in the province, demonstrating the mobile screening program's success (TBRHC, n.d.). A Manitoba-based study found that the introduction of a province-wide breast screening program that included a mobile mammography screening service significantly increased screening rates among rural women to the point where the traditional gap between urban and rural women virtually disappeared (Gupta, Roos, Walld, Traverse, & Dahl, 2003). Greater employment of mobile mammography clinics along with campaigns to raise awareness and

improve compliance to mammography screening recommendations could be a useful combined strategy for increasing screening for women living in rural communities (CIHI, 2006; McDonald and Sherman, 2008).

### ***Telemedicine and Teleoncology***

Telemedicine and/or teleoncology are innovative approaches that could be used to overcome distance and improve specialty health care services for rural women with breast cancer. Telemedicine uses information technologies to link patients and health care providers to a range of information and services in order to provide accessible health care (Romanow, 2002). The World Health Organization defines telemedicine as “the delivery of healthcare services, where distance is the critical factor, by all healthcare professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment, and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interest of advancing the health of individuals and their communities” (Ricke and Bartelink, 2000).

Teleoncology uses a variety of telecommunication technologies to provide oncology services at a distance (Olver, 2003). Teleoncology includes the following components: the use of electronic devices to aid in cancer diagnosis, treatment and follow-up; video and images of clinicians and patients; and the sharing of data, pathology reports and radiology images (Olver, 2003). Teleoncology mimics traditional face-to-face visits with specialists with the difference being that it is provided via technology from a distance (Doolittle & Spaulding, 2006). The oncology specialist works at a distance and is assisted by a trained clinician, oncology nurse or nurse practitioner at the rural site for the physical examination (Doolittle & Spaulding, 2006). Teleoncology services require collaboration among a team of professionals including the

oncologist at a distance; nurses located at the remote sites, administrative personnel, and technical support staff (Doolittle & Spaulding, 2006). Teleoncology is increasingly being used to provide specialized cancer services to rural communities (Brigden et al., 2008).

Despite the widespread introduction of telemedicine and teleoncology, few studies have robustly evaluated their use. Research that exists has primarily focused on overall efficacy, cost-benefit analyses, and patient and physician satisfaction (Brigden et al., 2008). Systematic reviews of the literature have found that most studies only examined short-term outcomes and found little evidence of efficacy (Roine, Ohinmaa & Hailey, 2001). There is also currently no conclusive evidence on the cost-effectiveness of telemedicine interventions and only teleradiology (CT scans) have been found to be cost-effective (Roine et al., 2001; Whitten, Mair, Haycox, May, Williams, & Hellmich, 2002).

Despite the lack of robust evaluations on the effectiveness of telemedicine, the literature does suggest that there are numerous potential benefits to patients and physicians. Teleoncology practices have been generally well received by patients with the stated benefits being: improved access to physicians; financial savings due to less travel time and time away from employment; and decreased stress (Campbell, Ritchie, Cassidy, and Little, as cited in Brigden et al., 2008, p. 10; Mair, Whitten and May, as cited in Doolittle & Spaulding, 2006, p. 229). Telemedicine also has the potential to increase enrolment of rural patients in clinical trials (Doolittle & Spaulding, 2006). Concerns with teleoncology that were expressed include depersonalization, lack of face-to-face interaction with the specialist physician, and discomfort with having a nurse perform various aspects of the physical examination rather than a doctor (Brigden et al., 2008; Mair et al., as cited in Doolittle & Spaulding, 2006, p. 229). Despite these concerns among patients, the majority simultaneously stated that they appreciated the utility of telemedicine services and



valued the improved access to specialized health care (Mair et al., as cited in Doolittle & Spaulding, 2006).

Physician satisfaction with telemedicine is very high (Brigden et al., 2008). A Canadian study found a satisfaction rate of 86 percent among physicians with no reports of being dissatisfied with the teleoncology service (Brigden et al., 2008). Further, 96 percent reported they would definitely recommend the use of teleoncology to their colleagues (Brigden et al., 2008). Other benefits for the telehealth team included: decreased need for travel; optimized professional time; potential for increased productivity; and greater educational and collaborative opportunities (Fieling, Macnab, Swann, and Kunkler, as cited in Brigden et al., 2008, p. 10). Researchers have concluded that with the benefits for patients and physicians in mind, telemedicine and teleoncology may be one potential solution for increasing access to specialty health care services in rural communities throughout the country (Brigden et al., 2008; Doolittle & Spaulding, 2006).

### **Implications for Policy and Practice**

#### ***Drug Coverage and Insurance Programs***

As mentioned previously, a number of studies have reported that rural women with breast cancer may require financial assistance due to drug costs, travel needs, and lost wages due to time away from work (CBCN, 2001; Gray et al., 2004; Hegney et al., 2005; Mathews et al., 2009; McGrath et al., 1999a). Compared to their urban counterparts, rural residents are more likely to be unemployed, self-employed, or working part-time (CIHI, 2006; Lightfoot et al., 2005). As a result, they are less likely to have employee-based group plans to cover cancer care-related drug costs (Lightfoot et al., 2005; Mathews et al., 2009). Although private insurance is available, it is usually at higher premiums than employee-based group plans and, as a result, rural

residents are less likely to enrol in them (Lightfoot et al., 2005). There are also financial barriers in Canada's publicly funded health care system that disproportionately affect rural residents (Mathews et al., 2009). Canada's public health care insurance covers medically necessary drugs provided in hospitals and prescription medications provided outside hospital settings are not covered (e.g. new oral chemotherapy agents that can be administered at home or drugs given to manage the side effects of cancer treatments) (Phillips, 2009; Mathews et al., 2009). All provinces have public drug insurance plans, but they are typically only available to individuals with very low incomes or those 65 years of age and older, and coverage varies significantly from province to province (Mathews et al., 2009).

The provision of catastrophic drug coverage could help alleviate the financial strains often experienced by rural women with breast cancer. Catastrophic drug coverage is defined as "the provision of a general level of coverage that protects individuals from drug expenses that threaten their financial security or cause undue financial hardship" (Fraser and Shillington, as cited in Phillips, 2009, p. 1). Unlike most countries that are members of the Organization for Economic Cooperation and Development (OECD), Canada does not have a national catastrophic drug coverage system, nor does it have a national universal prescription drug coverage plan (Phillips, 2009). Instead, provincial drug coverage is applied inconsistently across the country and a range of public and private drug insurance plans exist (Mathews et al., 2009; Phillips, 2009; Romanow, 2002). Through recent federal government investments, two provinces (Nova Scotia, and Newfoundland and Labrador) and one territory (Northwest Territories) have introduced catastrophic drug coverage programs, "thereby presumably reducing the percentage of Canadians currently at risk of experiencing financial hardship as a result of high drug costs for residents" (Phillips, 2009, p. 2). However, both researchers and National Commissions have

suggested that more federal investments are needed to expand existing provincial and territorial drug programs and ensure they are consistently available across the country (Kirby, 2002; Mathews et al., 2008; Phillips, 2009; Romanow, 2002).

The majority of rural women with breast cancer are unable to work during the treatment phase of cancer, and therefore, may experience income loss and financial hardship (Lauzier et al., 2008; McGrath et al., 1999a). Modification of Canadian policies for publicly delivered illness insurance programs may help with the financial strain experienced by rural women with breast cancer (Lauzier et al., 2008). Researchers have recommended that the duration of compensation be examined, since “the combination of evidence-based treatments that offer the best chance for cure for many women with breast cancer can result in absence from work that can considerably exceed the 15-week maximum currently allowed in Canada” (Lauzier et al., 2008, p. 330). Researchers have also recommended that special attention be given to women with breast cancer who work on farms, are self-employed, or work part-time because they have the lowest levels of financial compensation to counterbalance lost wages (Lauzier et al., 2008; McGrath et al., 1999a).

### ***Travel Subsidies***

Rural women with breast cancer have reported that financial costs caused by relocation and/or travel for treatment are a significant barrier to care (CBCN, 2001; Gray et al., 2004; Hegney et al., 2005; McGrath et al., 1999a). In Canada, most provinces provide medical travel subsidies for residents who are required to travel outside their region to access health care services (Mathews et al., 2009). Despite the availability of travel subsidies, eligibility criteria and subsidy rates vary considerably by province (Mathews et al., 2009).

One example of a provincially funded subsidy is Ontario’s Northern Health Travel Grants

(NHTG) Program. This subsidy covers some of the travel-related costs for rural residents travelling at least 100 kilometres one-way to visit medical specialists or designated health care facility services that are not locally available (Ontario Ministry of Health and Long Term Care [OMHLTC], 2008). In addition, the NHTG Program provides an accommodation allowance of \$100 per eligible trip to residents whose one-way travel distance is a minimum of 200 kilometres (OMHLTC, 2008). Patients traveling for cancer treatment in Northern Ontario frequently described inadequacies with the NHGT, including needing more information (e.g. how to appeal when denied funding) and suggesting increases to the NHGT to cover all travel expenses (CBCN, 2001; Lightfoot et al., 2005). Women have also recommended that travel-related financial assistance be provided up-front, rather than being reimbursed (Gray et al., 2004). Similar findings were discovered during focus groups with rural women with breast cancer from across the country (in every province in Canada and Yukon) (CBCN, 2001). These rural women expressed frustrations with limited/scarcely assistance, challenges with claiming reimbursements, non-reimbursable items (such as phone calls from urban treatment centres, childcare costs), and financial inequities compared to urban women (Gray et al., 2004). Financial subsidies may be more effective and better received by cancer patients if they are expanded and consistently applied across geographic regions of Canada (Gray et al., 2004; Lightfoot et al., 2005).

### ***Increasing Knowledge and Awareness among Health Care Providers***

As mentioned previously, rural women rely on health care providers (e.g. general practitioners, nurses, surgeons) for information and support on the diagnosis and treatment of breast cancer (Gray et al., 2004). It is therefore critical that health care providers be knowledgeable of the support and information needs of rural women (CBCN, 2001; Bettencourt et al., 2007). The fact that the majority of rural women turn to health care providers also

underscores the importance of ensuring strong doctor-patient communication and the provision of up-to-date knowledge that is relevant to rural living (Bettencourt et al., 2007; CBCN, 2003). Based on extensive consultation with rural women, the Canadian Breast Cancer Network recommends providing workshops to health care professionals to increase their awareness and understanding of available programs and challenges facing women with breast cancer who live in a rural context (CBCN, 2003). With respect to overall cancer management, it would be beneficial to facilitate a multidisciplinary approach with knowledge sharing and cooperation among all health care providers in rural areas (Bettencourt et al., 2007; CBCN, 2003).

General practitioners play a role in secondary prevention, providing clinical breast examinations and optimizing uptake of mammography screening (McDonald & Sherman, 2008). Family doctors in rural communities should be aware of the lower screening rates in rural communities and should follow recommended guidelines to facilitate equitable access to health care (McDonald & Sherman, 2008). Additionally, many rural women report receiving inadequate information from clinicians to guide their treatment decision-making and are often not informed about practical and emotional support, even when such services exist (Gray et al., 2004; NBCC and NHMRC, 2000). Travel time and financial costs are often factored into rural women's treatment decisions, rather than merely choosing the best treatment option (CBCN, 2003; Celaya et al., 2006; CIHI, 2006; Gray et al., 2004; Schroen et al., 2005). It is therefore important that medical professionals provide women with all relevant information to make informed decisions related to their care, including: information on travel subsidies, available supports, the physical impacts of travelling, other side effects, and current knowledge on recommended treatments (Bettencourt et al., 2007; CBCN, 2001; Gray et al., 2004; Davis et al., 2003; Girgis et al., 2000; Lightfoot et al., 2005; McGrath et al., 1999b). Ideally, information needs of cancer patients

should be a central and integrated component of the medical treatment plan. It has been suggested that information kits on breast cancer specifically tailored for rural women be made available for doctors to provide to their patients (Gray et al., 2004). “All members of the treatment team may also play a role in strengthening the woman’s own resources by providing emotional, informational and practical assistance, and appropriately fostering a sense of hope or optimism” (NBCC and NHMRC, 2000, p. 2).

The families of rural cancer patients may also feel that they do not receive enough support, services and information during diagnosis and treatment from health care providers (Clavarino et al., 2002; Davis et al., 2003; Gray et al., 2004). As stated earlier, family members may be considered peripheral in the cancer diagnosis and treatment process and many feel unequipped to handle the problems that can arise from cancer treatment (Clavarino et al., 2002). Family caregivers have reported higher levels of anxiety, depression, and information needs than cancer patients themselves (Clavarino et al., 2002). Studies have reported that women felt there were challenges in locating help for families in rural communities and many family caregivers reported feeling isolated from professional assistance (Clavarino et al., 2002; Gray et al., 2004; CBCN, 2001). It has been recommended that cancer treatment centres make professional services available to family members of rural breast cancer patients (Gray et al., 2004). It appears that it is also important for health care providers to be aware of the support and information needs of family members and caregivers of rural women with breast cancer. When appropriate, health care providers can facilitate access to appropriate counselling and supports.

### ***Recommendations for Psychosocial Support***

There is clear evidence that rural women with breast cancer need more information and psychosocial supports (Bettencourt et al., 2007; Davis et al., 2003; Gray et al., 2004; McGrath et

al., 1999b). Based on consultations with rural women from across Canada, *The National Strategy and Action Plan for Rural, Remote and Northern Women and Men with Breast Cancer*, developed by the Canadian Breast Cancer Network, has made the following recommendations: “(1) increase access to existing information and support programs and services; (2) stimulate the development of new information and support services and programs to fill the gaps; and (3) increase the involvement of partners and other relevant organizations and individuals in the roll-out of the National Strategy and the implementation of actions plans” (CIHI, 2006; CBCN, 2003, p. 2). It has also been recommended that more funding be allocated for nurse oncology practitioners in rural communities and that access to mental health professionals be facilitated when required (CBCN, 2003; Ganz, 2000; Davis, 2004). It may also be a worthwhile endeavour to train rural medical professionals in providing appropriate support and referrals for their breast cancer patients (Davis et al., 2003).

Australia has developed evidence-based guidelines for supportive care entitled *Psychosocial Clinical Practice Guidelines: Providing Information, Counselling and Support to Women with Breast Cancer* (NBCC and NHMRC, 2000). These guidelines were developed through an extensive process, including the participation of patients (NBCC and NHMRC, 2000). Although the guidelines were developed for all women with breast cancer, they still align with the research findings on rural women’s needs for support and information. Specific recommendations in the report include: (1) that women receive adequate emotional and social support from the treatment team; (2) that support provided by family and friends should be considered to ensure it is sufficient; and (3) that women should be provided with information about peer support programs (NBCC and NHMRC, 2000).

As stated earlier, face-to-face peer support groups for rural women with breast cancer can offer significant psychosocial support (Gray et al., 2004; CBCN, 2001). However, there are many barriers to participation that are primarily caused by the nature of rural living (e.g. distance, hours of operation, lack of facilities) (CBCN, 2001; Gray et al., 2004; McGrath et al., 1999a). It is therefore recommended that peer support groups for rural women be flexible and delivered in a manner that aligns with rural needs (Gray et al., 2004). Distance-delivered (e.g. telephone, Internet) peer support groups may be beneficial for some rural women, but need to be provided in a manner that is highly accessible and should take place with appropriate technical supports to limit technological difficulties (Bettencourt et al., 2007; Hoey et al., 2008; Solberg et al., 2003). The Internet could be used to increase access to online support groups and to remove information barriers for rural women with breast cancer. However, it is important to note that rural communities may have limited Internet access as the “National Broadband Task Force estimates that there are approximately 5,000 communities (79% of all Canadian communities) that fall into the “harder to serve” category” (Romanow, 2002, p.168).

### ***Improving Access to Health Care Services***

Qualitative research has indicated that rural women feel more positive about their health care providers when they receive care locally, rather than further away (Dunaway, Hueston, and Clevinger, as cited in Bettencourt et al., 2007, p. 881). Providing access to health care closer to the homes of rural women with breast cancer would help ease both the financial and psychological burdens of travel (CBCN, 2003; Mathews et al., 2009). Distance-delivered telehealth practices such as mobile breast screening and teleoncology have the potential to help address the issue of access to services for rural women (CBCN, 2009; Gupta et al., 2003; Lane et al., 2003; McDonald & Sherman, 2008; Romanow, 2002). Studies have shown that mobile



mammography can increase screening rates among rural women and that teleoncology has generally been well received by patients and physicians (CBCN, 2009; Gupta et al., 2003; Lane et al., 2003; Mair et al., as cited in Doolittle & Spaulding, 2006, p. 229; McDonald & Sherman, 2008). Remote health care through telemedicine is improving and is becoming more widely accepted as one way to overcome barriers to accessing care (Romanow, 2002). However, there still needs to be increased attention paid to the evaluation of telehealth applications in order to ascertain their effects on patient outcomes and cost effectiveness (Doolittle & Spaulding, 2006; Roine et al., 2001).

### **Conclusion**

Breast cancer is potentially life threatening and can have significant effects on the psychosocial and economic aspects of a woman's life (Bettencourt et al., 2007). Although rural women may have supportive families and tight-knit communities in which they live, they still require additional information, and emotional and financial supports to manage the diagnosis and treatment of breast cancer (Bettencourt et al., 2007; Gray et al, 2004; CBCN, 2001; McGrath et al., 1999b). The inferior survival rate for rural women with breast cancer has been associated with more limited access to breast screening and the fact that many rural communities are medically underserved (CIHI, 2006; Romanow, 2002). It is understood that living in a rural community is symbolic with making certain sacrifices that many urban women may take for granted. As a result of where they live, rural women with breast cancer have to travel long distances to access treatments, they must contend with being separated from family members and their homes, and have difficulty accessing support groups locally that meet their needs.

Significant efforts have been made in recent years to address health care access issues for rural women. Provincial and territorial ministries of health and regional health authorities have

used a number of approaches including outreach programs, mobile screening, financial assistance for people who need to travel to access care, and new delivery approaches like telemedicine and teleoncology (Romanow, 2002). These efforts, to greater or lesser degrees, have helped improve access, yet a more aggressive approach is required to truly meet the health, social and economic needs of rural women with breast cancer. In order to reduce health disparities, funding for research investigations could be allocated for: (1) large-scale evaluations of mobile screening programs and telemedicine initiatives to determine their impact on patient outcomes, including rural women with breast cancer; and (2) new investigations into best practices for meeting the health and support needs of rural women. Efforts could also be made to raise awareness among health care providers of rural women's supportive, informational and financial needs. For example, encouraging the use of national strategies and guidelines among professionals and more collaborative practices in rural communities that would result in more patient-sensitive care. Governments could play a more active role by implementing greater use of mammography and teleoncology; by expanding coverage and equal access to travel subsidies; and by examining potential expansions to public drug coverage and illness insurance programs. It is also important to reiterate that diversity is inherent within rural communities and that policy-makers need to understand that both the health needs of residents and the way in which they should be addressed vary for different rural communities (Romanow, 2002). Ideally, these combined efforts could meet the needs of rural women with breast cancer and allow them to be treated close to their homes and families without compromising access to high-quality health care.

### **Directions for Future Research**

Research investigations into the experiences of rural women with breast cancer are generally sparse and future research is warranted in a number of key areas. Travel costs, income losses and other financial impacts on rural women with breast cancer have rarely been addressed in the literature. As observed by Lauzier et al. (2008), the pathways to financial hardship during and after breast cancer are multifactorial and the factors involved may interrelate in complex ways to produce economic strain. More research is warranted on the relationships between long-term work productivity, income losses, employment status, and financial costs for rural women who have experienced breast cancer.

Societal trends for shorter hospital stays, and greater reliance on outpatient care and family caregiving, have important future research implications (Clavarino et al., 2002; Romanow, 2002). The research on the impact of breast cancer on families and caregivers in rural communities has been very limited, and existing research has mainly focused on the perspective of the patient. As Davis et al. (2003) remark, a women's view of her family's supportive care needs may not be accurate. Hence, future research is needed to understand the unique challenges rural families and caregivers must face when confronted with a diagnosis of breast cancer in a family member.

A large number of studies have identified that rural women with breast cancer have significant needs for psychosocial and information support. Existing research on intervention strategies for meeting these needs have predominately focused on peer support groups. These supports appear to be an intervention of choice among breast cancer patients, yet there is no sound evidence available to demonstrate whether these efforts contribute to improving psychosocial outcomes among rural women with breast cancer specifically. Although a few

studies have shown that distance-delivered peer support programs hold promise, limited evaluation studies have been carried out and most can be criticized on methodological grounds. Therefore, future research is warranted to evaluate peer support programs in rural communities and demonstrate their effects on women with breast cancer. After determining which types of interventions work and best practices, research should focus on ways to effectively implement these support programs in rural communities.

Given the importance of health care providers as a source of information and support for women with breast cancer, more research is needed on venues to maximize these relationships and information sharing. Future studies are also needed to develop a broader, more reliable research basis on the utilization of breast care and specialist nurses, including addressing the role and skills required for them to be effective in rural contexts (Eicher et al., 2006). Further studies are also warranted to ascertain the health outcomes of intervention strategies such as outreach clinics and mobile screening, and to identify barriers to breast health screening behaviors among rural women (Lane & Martin, 2005; McDonald & Sherman, 2008). Additional research is needed to evaluate promising distance-delivered applications such as telemedicine and teleoncology as they move into regular use (Roine et al., 2001). The assessment literature has yet to address the longer-term impact of telemedicine approaches on health status and costs for organizations.

More research is needed to examine the breast cancer experiences of rural women from various backgrounds. There is limited research on the breast cancer experiences of ethnic minority women in rural communities. Additionally, few studies have focused on First Nations and Inuit women with breast cancer in remote Canadian communities. This knowledge gap was echoed by researchers who reported that more studies are needed to examine the extent to which the needs of rural women with breast cancer differ by ethnicity, social class, and religious

affiliation (Koopman et al., 2001).

Researchers need to accurately define rural samples and possibly even standardize rural definitions to produce uniform categorizations of residence and in turn, comparable research. There were only a limited number of studies that used both rural and urban samples to make comparisons among women with breast cancer. Bettencourt and colleagues (2002) made similar observations suggesting that research needs to evaluate the differences between the experiences of urban and rural breast cancer patients to further elucidate the unique issues that rural women encounter. Additionally, comparative research will allow for the appropriate allocation of health care resources according to public need.

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