

Review

The breast cancer experience of rural women: a literature review

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Abstract

This report is a review of studies that focus on rural breast cancer survivorship. It includes a total of 14 studies using large databases and 27 other studies using qualitative and quantitative methods. In our review of this literature, we identified four broad themes, including access to treatment and treatment type, medical providers and health information, psychosocial adjustment and coping, and social support and psychological support services. We review the findings of the rural breast cancer survivorship studies within each of these broad themes. A few of the findings of the review include that rural and urban women receive different primary treatments for breast cancer, that rural women may have greater difficulty negotiating their traditional gender roles during and after treatment, that rural women desire greater health-related information about their breast cancer, and that rural women have less access to mental health therapy. The review discusses the implications of these findings as well as the weakness in the literature.

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Cancer is for rural people, a very lonely experience and as prevalent as the disease is, not many people can understand the emotional toll it takes.

Rural cancer patient [1, p. 41]

Thousands of studies have examined the psychosocial and physical adjustment of breast cancer survivors. The overwhelming majority of these focus on urban women. That is, researchers have largely ignored rural women's psychological and physical adjustment to breast cancer. Nevertheless, we were able to identify 27 study reports, most of which were conducted in the US, that focus on the adjustment of rural breast cancer survivors. Additionally, we identified 14 study reports of data derived from breast cancer registries that compare the treatments administered to rural and urban breast cancer patients. The purpose of the present work was to review the available empirical literature on rural breast cancer treatment and survivorship.¹ The aims of the review were to:

- Describe the surgical treatment for breast cancer in rural women.
- Describe the psychosocial adjustment and support needs of rural women.

¹ This review does not include studies about cancer screening, diagnosis, or mortality.

Method

To identify studies, we conducted literature searches on CINAHL (1982–2006), Medline (1950–2006), and PsychInfo (1806–2006), using the following keywords: breast cancer, breast neoplasms, and rural. Also, we searched the reference sections of each identified study report for additional citations. Studies were included if they had an identifiable rural sample, reported either qualitative or quantitative findings regarding breast cancer treatment or survivorship, and were published in the English language.

Tables 1 and 2 include lists of these studies. Table 1 identifies the cancer registry database studies that document the rates of types of treatment that rural breast cancer patients receive. Eight of these registries were located in the United States, five in Australia, and one in Canada. Most have relatively clear definitions of rurality, but a few are somewhat unclear. The majority include data from a relatively large number of rural breast cancer patients and an urban comparison sample. Table 2 lists the articles reporting studies of psychosocial and physical adjustment; 20 used quantitative methods, five used qualitative methods, and two used both. About two-thirds of the studies had relatively small samples [100 or less, range = 6–100], and 78% of these studies did not include an urban comparison group. Table 2 also

Table 1. Database studies, sample characteristics, country, and primary findings

Study	Rural definition	Database	Rural N	Urban N	Sample	Country	Finding
Answini et al. [16]	Rural counties	National Cancer Database and North Carolina Cancer Registry	1057	3349	Breast cancer (BC) patients from 1991 to 1998 in Charlotte-Mecklenburg County North Carolina and BC patients from 1995 to 1997 in six surrounding rural counties	United States	Rates of breast-conserving surgery were higher in the urban county than in the surrounding rural counties for stage I and II breast cancer
Beaulieu et al. [6]	County information; Beale code of rural-urban continuum	Kentucky Cancer Registry	2952	5142	BC patients diagnosed from 1995 to 1999	United States	Rates of breast-conserving surgery were highest in the most urban counties and decreased in a linear fashion with increasing rurality
Craft et al. [15]	Rural regions (comprised of large rural towns, rural and remote areas)	Australian national Medicare records	1170	3483	All BC patients who underwent surgery in 1993	Australia	Rates of breast-conserving surgery were higher in urban regions than rural areas
Goel et al. [20]	Unclear	Provincial cancer registries of Ontario and British Columbia	283	1597	BC patients who were diagnosed with node-negative BC in 1991	Canada	Rural residence was associated with a lower likelihood of breast-conserving surgery and radiation therapy in British Columbia, but not Ontario
Haggstrom et al. [21]	County either distant or adjacent to a metropolitan area with a population of less than 20 000	SEER program of the National Cancer Institute (NCI)	3830	18 871	BC patients diagnosed with early-stage BC between 1992 and 1999, aged 66–79	United States	Rural women were less likely to receive breast-conserving surgery, radiation therapy, adequate documentation of estrogen receptor status and adequate care
Hall and Holman [24]	Remoteness of area	Western Australia Record Linkage Project	Unclear ^a	Unclear ^a	BC patients who underwent breast reconstructive surgery after a mastectomy or breast-conserving surgery from 1982 to 2000	Australia	Rates of breast reconstructive surgery were higher for women from metropolitan areas than women in rural areas

Hersman <i>et al.</i> [23]	Residence not in a metropolitan area	SEER program of the National Cancer Institute (NCI)	541	4466	BC patients diagnosed from 1991 to 1999 aged 65 or older who received chemotherapy	United States	Residence outside a metropolitan area was associated with an increased number of days between surgery and beginning chemotherapy
Howe <i>et al.</i> [27]	Ten contiguous rural counties in Illinois	Illinois State Cancer Registry	547	—	BC patients diagnosed from 1986 to 1989	United States	Among this rural sample, women younger than 55 were most likely to receive separate diagnostic biopsy, limited surgery and chemotherapy, whereas women 55–74 were most likely to receive hormone therapy
Kok <i>et al.</i> [17]	Rural, remote and metropolitan areas (RRMA)	Breast Screen Victoria	945	2610	BC patients diagnosed from 1993 to 2000	Australia	Rural women were less likely to undergo breast-conserving surgery and radiation therapy, and were more likely to have a mastectomy
Meden <i>et al.</i> [25]	Rural region of Michigan	Medical records from three hospitals in northern Michigan	66	—	BC patients treated between 1999 and 2000	United States	Among this rural sample, utilization of breast-conserving therapy was half the national average and was negatively correlated with travel distance to a radiation oncology center
Mitchell <i>et al.</i> [19]	Postcode of woman's usual residence	Western Australia Cancer Registry	206	693	BC patients diagnosed in 1999	Australia	Rural women were less likely to receive breast-conserving surgery, radiation therapy, and hormonal therapy
Samnakay <i>et al.</i> [18]	Australia post definitions of metropolitan and rural areas	Royal Perth Hospital Multidisciplinary Breast Service Database	587	136	BC patients treated at Royal Perth Hospital between 2000 and 2002	Australia	Women from rural areas were more likely to undergo mastectomy, but this difference was not significant
Schootman and Aft [22]	Not living in a Metropolitan Statistical Area (MSA) at the time of diagnosis	SEER program of the National Cancer Institute (NCI)	503	6485	BC patients diagnosed from 1991 to 1996 in nine geographic regions	United States	Rural women were less likely to receive radiation therapy following breast-conserving surgery
Tropman <i>et al.</i> [11]	Rural North Carolina	Reaching Communities for Cancer Care	251	—	BC patients receiving treatment from 1991 to 1996 in five North Carolina counties	United States	Rural patients did not receive adjuvant therapy as often as NCI standards recommend. Mastectomy was performed significantly more often than breast-conserving surgery

—, sample size is zero.

^aData reported for the entire sample, total N = 7303.

Table 2. Non-database studies, rural definitions, method, sample characteristics and country

Study	Rural definition	Method	Rural N	Urban N	Sample	Country
Albert et al. [42]	Defined rural area with 252 000 inhabitants (small-area analysis)	Quantitative survey	269	—	Breast cancer (BC) patients began study at hospital discharge, subsequent surveys at 6, 12, 24, and 36 months	Germany
Collie et al. [34]	Seven rural counties in Sierra Nevada, California	Quantitative survey	100	—	BC patients within 3 months of diagnosis or BC survivors ^a within 3 months of completing treatment	United States
Cuellar et al. [46]	Rural communities in Southern Mississippi	Quantitative survey and interview	30 ^b	—	Time since treatment unclear; patients with breast cancer ^c	United States
Davis et al. [5]	An area of residence outside the metropolitan area in which the treatment center is located	Quantitative phone survey	80	—	Time since treatment unclear; BC survivors	Australia
Davis et al. [4]	Residing outside a capital or metropolitan city	Quantitative survey	204	—	BC survivors, time since diagnosis ranged from 6 to 12 months	United States
Demaree [31]	Rural communities; not metropolitan	Quantitative survey	6 ^b	—	BC patients receiving radiation therapy	United States
Doorenbos et al. [29]	Women from rural hospitals	Quantitative survey	108	242	Women newly diagnosed with breast cancer and undergoing chemotherapy	United States
Dunaway et al. [30]	Five county area of rural Northeastern Kentucky	Qualitative interviews	10	—	BC survivors, time since diagnosis ranged from 12 to 36 months	United States
Girgis et al. [7]	Postal codes in New South Wales were classified as rural	Quantitative survey	129	100	BC patients and survivors, time since diagnosis ranged from 3 months to 6 years	Australia
Gray et al. [3]	Self-report of living on a farm/country home/village, or living in a town, or small city	Quantitative survey and qualitative focus groups	276 focus group only; 157 focus group and survey	—	Time since diagnosis ranged from less than 2 years to more than 6 years	Canada
Heishman [12]	Counties with less than 50 000	Quantitative interview	36	—	BC patients in treatment (N = 30) and BC survivors who had completed treatment (N = 6)	United States
Hokanson et al. [13]	Towns with populations less than 1000, 1000–15 000, 15 000–30 000, and more than 30 000. Sample categorized as predominantly rural	Quantitative survey	161	—	BC survivors who were initially referred to the clinic between 1995 and 1996	United States
Howe et al. [26]	Ten counties with a population density of less than 100 persons per square mile	Review of hospital medical records	147	451	BC patients diagnosed from 1986 to 1987	United States

Koopman <i>et al.</i> [41]	Seven rural counties in Sierra Nevada, CA	Quantitative survey and interview	100	—	BC patients within 3 months of diagnosis, or BC survivors within 6 months of completing treatment for BC	United States
Lengacher <i>et al.</i> [44]	Not living in an urban or suburban area	Quantitative survey	63	40	Time since treatment unclear; women with a diagnosis of BC	United States
Lopez <i>et al.</i> [48]	Three rural counties, each having a population of less than 30 000	Qualitative group discussion sessions	18	—	BC survivors who had completed their initial treatment; time since diagnosis ranged from 1 to 53 years	United States
Lyons and Shelton [43]	Rural areas of the Alabama and Mississippi	Quantitative	Approx 24	Approx 29	Women diagnosed with breast cancer during the previous 6 months	United States
Mastaglia and Kristjanson [14]	Not living in an urban center	Quantitative survey	87	174	BC patients and survivors; time since surgery ranged from 0 to 8 months	Australia
Mathews <i>et al.</i> [33]	Rural North Carolina	Qualitative interviews	26	—	BC patients and survivors who were eventually diagnosed or had been previously diagnosed with advanced BC; time since biopsy varied	United States
McGrath, <i>et al.</i> [8,9]	Rural Queensland (based on Australia's standard classification)	Qualitative and quantitative structured interviews	24	—	BC patients and survivors; time since diagnosis varied	Australia
Palesh <i>et al.</i> [35]	Seven rural counties with populations less than 12 000 in Northern California	Quantitative	82	—	BC patients recruited either within 3 months of diagnosis or within 6 months of completing medical treatment	United States
Rogers-Clark [49]	Participants lived in rural southwest Queensland	Qualitative interviews	9	—	BC survivors who were diagnosed at least 5 years prior	Australia
Saegrove [47]	One rural county—municipality; total population 100 000	Quantitative	28	—	Time since diagnosis unclear; women who had 'cancer of the breast'	Norway
Tulloch and Goldworthy [28]	Rural town with population of 15 000 and surrounding farm population of 2000	Quantitative analysis of medical records	28	—	BC patients diagnosed from September 1992 to August 1995	Australia
van der Weg and Streuli [45]	Rural area of Switzerland	Quantitative interview	53 ^b	—	BC patients and survivors; time since diagnosis varied	Switzerland
White <i>et al.</i> [39]	Patients referred to the Rural Cancer Care Clinic	Quantitative survey of knowledge rates	48 ^b	—	BC patients recruited at various phases of disease and treatment	United States
Wilson <i>et al.</i> [32]	Twenty predominantly rural communities in Washington	Qualitative focus groups	128	—	BC survivors; time since diagnosis was one year or more	United States

—, sample size was zero.

^a The term survivor was used to denote individuals who had completed primary and adjuvant treatment.

^b Study included patients with other kinds of cancer, *N* reported for breast cancer patients only.

shows the period of time after diagnosis varied across the studies, and the definitions of rurality varied considerably across studies; most definitions were not highly specific. Only two studies reported relying on urban–rural county codes and eight studies referred to the population of a town or county. The remaining 17 studies merely stated that the study was conducted in rural counties, regions or communities. As identified in Table 2, about two-thirds of the studies have been conducted in the US (19.2% of total population is rural; [2]); the remaining studies were conducted in Australia (8.4% of total population in Australia/New Zealand is rural), Canada (18.9% rural), Germany (11.5% rural), Japan (34.3% rural), Norway (22.6%), and Switzerland (32.5% rural). With a few exceptions, the results across studies tend to indicate continuity across these rural areas. Nevertheless, we recognize that rural experiences are likely to have within-country as well as within-county/state uniqueness.

To organize our review, first we summarized all of the findings available in each study report. Next, we identified common themes evident in these findings.² Finally, we structured the current review according to these common themes. The themes include: (1) access to treatment and treatment type; (2) medical providers and health information; (3) psychosocial adjustment and coping; and (4) social support and psychological support services.

Results

Access to treatment and treatment type

Travel issues

Studies confirm that rural breast cancer patients must travel long distances to receive oncology-related care and that many must stay in urban areas for the duration of their primary cancer treatment. For example, based on a focus group study, Gray *et al.* ([3]; $N = 433$) revealed that 50% of the rural breast cancer patients in their sample traveled over 1 h for surgery and 25% traveled more than 3 h. Likewise, for this same sample, 21% traveled more than 3 h for chemotherapy, and 61% traveled more than 3 h for radiation therapy. Similarly, Davis *et al.*'s ([4]; $N = 80$) study of rural women with early-stage breast cancer in Australia revealed that 32% traveled more than 60 miles for surgery, 68% for radiotherapy, and 36% for chemotherapy. In an earlier study, Davis and colleagues ([5]; $N = 80$) conducted a telephone survey of rural breast cancer survivors in Australia and found that the majority (83%) reported

staying away from their homes to receive treatment, and the primary reason for this was lack of available treatment facilities in rural areas.

As might be expected, traveling long distances to receive treatment can be stressful. Davis *et al.* ([4]; $N = 204$) showed that the great majority of their participants reported problems obtaining information about travel and accommodations. Some reported difficulties due to disruption of family life and employment. In addition, rural breast cancer patients may experience a sense of isolation and displacement in urban treatment settings. Moreover, those who develop relationships with other cancer patients in urban settings may feel a loss of social support upon returning to their rural communities [3].

Surgical and adjuvant treatments

Not only do rural women experience more difficulties with accessing treatment facilities but also, compared to their urban counterparts, they often receive different primary and adjuvant treatments. Studies ([3,4,6–11]; see also Hershman [12]; Hokanson *et al.* [13]; Mastaglia and Kristjanson [14]) suggest that, compared to urban breast cancer patients, rural breast cancer patients are more likely to undergo mastectomy and receive chemotherapy and are less likely to undergo lumpectomy and receive radiation therapy. For example, in a study ([15]; $N = 4653$) of Australian women receiving medical benefits, frequency of breast-conserving surgery was significantly lower among rural women (also see Answini *et al.* [16] for similar results in North Carolina; $N = 4406$). Kok *et al.* ([17]; $N = 6418$) report that rural patients in Australia were less likely to undergo breast-conserving surgery, despite that there were no differences between rural and urban women in tumor size (see also Samnakay *et al.* [18]; $N = 723$). Similarly, another study in Australia (Mitchell *et al.* [19]; $N = 899$) suggests rural women are not only less likely to undergo breast-conserving surgery but are also less likely to receive radiation therapy and hormone therapy (also see Goel *et al.* [20] for similar results in British Columbia; $N = 1880$).

Several authors have utilized the national Surveillance, Epidemiology, and End Results (SEER)—Medicare database, which includes tumor registries of nine geographic areas in the US and covers 14% of the nation's population. Utilizing SEER, Haggstrom *et al.* ([21]; $N = 22\,701$) reported that rural breast cancer patients, between the ages of 66 and 79, were less likely to receive breast-conserving surgery, radiation therapy, adequate documentation of estrogen receptor status, and adequate care in general (also see Schootman and Aft [22]; $N = 6988$). Additionally using SEER, Hershman *et al.* ([23];

²Directly comparing the separate literature on rural breast cancer survivors to that of urban breast cancer survivors goes beyond the scope of this review.

$N = 5007$) identified all women who received chemotherapy within 12 months of primary breast surgery. The results of their analysis revealed that living outside a metropolitan area was associated with an increased number of days between surgery and beginning chemotherapy. The authors note that this is important because delayed onset of chemotherapy is associated with increased mortality.

Factors affecting treatment

The relative distance between an urban treatment facility and rural breast cancer patients' homes may play a role in determining the type of treatment they receive. For example, compared with those living in highly remote areas, breast cancer patients who lived in less remote, 'highly accessible' rural areas in Western Australia were more likely to have been treated in metropolitan areas and to have received reconstructive surgery ([24]; $N = 7303$). Also, Beaulieu *et al.*'s ([6]; $N = 8094$) analysis of a cancer registry from the state of Kentucky found that those breast cancer survivors who lived in rural counties that were adjacent to a metropolitan area were more likely to receive breast-conserving surgery than their counterparts living in rural counties not adjacent to a metropolitan area. Finally, Meden *et al.* ([25]; $N = 66$) found that in a rural region of Michigan, use of breast-conserving therapy was nearly half of the US average and that, within the same sample, greater travel distance was negatively correlated with the use of breast-conserving therapy.

Several researchers have pointed to possible reasons that distance influences the type of treatment a breast cancer patient receives. Davis *et al.* [4] concluded that rural women may make treatment decisions that are influenced by difficulties with transportation, lack of easily accessible health-care services, and events occurring at home. Other researchers [3,8–10,12] point to the need for prolonged periods away from home and the social and economic costs associated with travel.

Somewhat consistent with the findings related to treatment facility distance, Howe *et al.* ([26]; see also Howe *et al.*'s [27]) database study revealed that rural breast cancer patients treated in rural hospitals in the state of Illinois were less likely to have access to state-of-the-art treatment than those treated in urban hospitals. Importantly, however, one study of treatments provided within a rural hospital in Australia ([28]; $N = 28$) suggests that a rural setting need not be an obstacle for rural women receiving breast-conserving treatment (also see Doorenbos *et al.* [29]; $N = 350$). This study focused on a rural hospital that adopted a 'multidisciplinary approach' to breast cancer treatment that included an oncologist, a specialist

breast surgeon, and telephone conferences with other specialists. Medical records revealed that 68% of the 25 patients treated at this hospital over a three-year period received breast-conserving surgery.

In addition to the influences of distance from treatment facilities and rural location of treatment facilities, it appears that physicians may play a particularly influential role in rural breast cancer patients' treatment decisions. For example, in Gray *et al.*'s [3] study, six of the eight participants who had a mastectomy reported that they deferred this decision to their physician. Related to this finding, Stafford *et al.*'s ([10]; $N = 191$) survey showed that 70% of their mostly rural *early-stage* patient sample reported that their surgeon discussed both mastectomy and lumpectomy surgery options with them. Fifty-five percent of these patients recalled that their surgeon said mastectomy was the better option for them, 34% recalled that they were told that the treatments were equal options, and only 10% recalled that they were told that breast-conserving surgery was a better option. Likewise, more than half of the patients in Stafford *et al.*'s study reported that the most influential person in their decision process was their surgeon. These findings should be considered in light of Dunaway *et al.*'s ([30]; $N = 10$) results that showed that rural breast cancer survivors who felt they had retained control and were allowed to participate in their treatment decisions reported better experiences than did those who felt they did not.

Medical providers and health information

Relationships with medical providers

Clearly, rural women need the support and information that medical care professionals can provide. Demaree's ([31]; $N = 6$) survey findings suggest that rural breast cancer survivors were highly satisfied with the support they received from their medical care staff during their primary treatment. Rural breast cancer patients in Wilson *et al.*'s ([32]; $N = 128$) qualitative study reported that relationships with medical care providers were best when the women (1) could see the provider immediately with their concerns; (2) believed that they could trust their provider; (3) felt that their provider listened to them; and (4) perceived mutual respect. Moreover, rural women in Dunaway *et al.*'s [30] qualitative study who received care locally felt more positive about their providers than did those who had received care further away.

Wilson *et al.* [32] revealed that only 20% of the rural breast cancer survivors in their focus group study reported that they had been treated poorly by the health-care system and that they had

unsatisfactory interactions with medical care providers. Such dysfunctional interactions can include (1) poor communication with physicians; (2) feeling ignored; (3) waiting long periods for test results; and (4) feeling rushed in decision-making [3,30,32,33]. One survey of rural breast cancer patients and survivors studied predictors of difficulties communicating with health-care professionals ([34]; $N = 89$).³ The study showed that those participants who were unmarried, had lower levels of self-efficacy for seeking and understanding medical information, and had more difficulty regulating negative affect, reported greater difficulty communicating with health-care professionals. Somewhat related to this, rural breast cancer patients in Dunaway *et al.*'s [37] study reported wanting more compassion, honesty, and an appreciation of their individuality from their physicians.

Despite that there is some evidence that rural women are largely satisfied with the medical support they receive during primary breast cancer treatment, their satisfaction may decrease following the completion of primary treatment. One reason that rural breast cancer patients may lack medical support after the completion of primary treatment is that local physicians may not be readily available [3]. Another is that, when local physicians are available, they may lack adequate knowledge of oncology-related care. Howe *et al.* ([26]; $N = 547$) suggest that having the expertise required for cancer care is challenging for rural physicians because they have minimal access to continuing education about cancer and its treatment (also see Gray *et al.* [3]). Consistent with this, Hatzell *et al.*'s [38] survey of physicians located in rural areas suggested that they were unaware of some of the recommended treatments in the guidelines of the National Cancer Institute (USA). Further exacerbating the problem, poor communication between local rural physicians and cancer specialists who remotely treat rural breast cancer patients may lead patients to feel that they lack adequate medical care [3].

Other sources of health information

Beyond the problem that general practitioners may lack oncology-related health information, rural breast cancer patients themselves report lacking adequate access to relevant health-related information [3,4]. For example, Davis *et al.* [4] revealed that 30% of the breast cancer survivors in their study stated that living outside a major city had limited their access to health information and that less than 50% received adequate information about radiotherapy and breast reconstruction. Wilson *et al.*'s [32] study suggested that rural breast cancer

survivors desired greater patient education, wanted more information about what to expect during and after surgery and treatment, and felt ill prepared to deal with the consequences of surgery and chemotherapy. Finally, there is little evidence that rural breast cancer patients are provided with information that is targeted toward rural women in particular [4,5,8,9,32].

The implications of lack of health information

The apparent lack of oncology-related and general-health information provided to rural breast cancer patients is especially troubling, because at least some rural breast cancer patients are likely to have misinformation and misconceptions about cancer. Deficits in knowledge about breast cancer and its treatment have been revealed in a survey conducted by White *et al.* ([39]; $N = 48$). Their results showed that 73% of the late-stage rural breast cancer patients and 49% of the early-stage rural breast cancer patients lacked important cancer-related knowledge. For late-stage breast cancer patients, the greatest deficit was in their knowledge about chemotherapy, and for early-stage breast cancer patients, the greatest deficit was in their general knowledge about the disease of cancer. In another study, McGrath *et al.* ([8,9]; $N = 24$) found that rural breast cancer patients were often unaware of the stage of their cancer (also see Howe *et al.* [26]).

With respect to misconceptions, a few of the rural women interviewed by Heishman [12] attributed breast cancer symptoms to hard work, bumping of the breast, weather, or menopause. Also, some of these same rural cancer survivors stated that they had thought they were too young to get breast cancer, suggested that if the cancer is exposed to air during surgery it will spread, and conveyed that lymph nodes aid in moving cancer through the body. The majority of women in Heishman's study who had undergone mastectomy believed that the mastectomy would 'get rid of all the cancer.' Mathews *et al.* ([33]; $N = 26$) points to similar misconceptions, showing that rural women in their sample believed that cancer screening is 'looking for trouble,' that the disease is virtually unstoppable, that attempts to look for cancer tempted fate, and that refusing to name or acknowledge the disease would protect them from suffering its full effects. Making cancer-related health information more available to rural women is important not only for redressing these misconceptions, but also for providing helpful information about coping strategies [40].

Psychosocial adjustment and coping

Distress, body image, and stigma

Studies [7–10,12,32] suggest that rural breast cancer survivors experience psychological distress

³The participants of Collie *et al.* [34] and Palesh *et al.* [35] are the same as those originally reported in Koopman *et al.* [36].

during and after treatment. For example, rural breast cancer survivors report having anxiety and emotional difficulties as well as being worried about the recurrence of cancer [8–10,12,32]. Consistent with this outcome, Koopman *et al.* ([41]; $N = 100$) found that a large majority of rural breast cancer survivors in their sample considered their diagnosis to be one of their most stressful life events, reported relatively high levels of helplessness/hopelessness, and some met the criteria for Post Traumatic Stress Disorder. Similarly, Albert *et al.*'s ([42]; $N = 269$) quantitative-survey findings showed that rural breast cancer survivors had a relatively low level of quality of life when they were discharged from the hospital. Although the levels of quality of life for rural breast cancer survivors tended to improve over a 12-month period, these levels remained below the population average. Finally, Paresh *et al.* ([35]; $N = 82$) showed that lower levels of emotional self-efficacy and greater levels of stressful life events, but not satisfaction with social support, predicted greater mood disturbance among their sample of rural breast cancer patients.

There is some indication that living in a rural area may be particularly problematic, in terms of adjusting to breast cancer. Girgis *et al.* ([7]; $N = 129$) revealed that a higher proportion of rural women than urban women indicated that they needed help with their cancer-related fears (also see Heishman [12]; Wilson *et al.* [32]). Lyons and Shelton ([43]; $N = 53$) found that women in rural areas of Mississippi and Alabama reported lower quality of life, compared with those living in urban areas. Nevertheless, at least one study ([44]; $N = 103$; also see van der Weg and Streuli [45]) revealed no evidence that rural women are more likely to use complementary and alternative therapies for breast cancer and its side effects than were urban women.

A few studies [45–47] have compared rural breast cancer patients to rural patients with other diseases. For example, a study of rural Norwegian breast cancer patients ([47]; $N = 28$), prostate cancer patients ($N = 21$), and patients with other cancer diagnoses ($N = 35$) showed that, whereas the mental health and general health of different types of patients were similar, breast cancer patients reported lower energy levels and lower levels of vitality than other patients. These breast cancer patients (as well as prostate cancer patients) reported that poor physical health influenced their daily activities more than did other patients. Also, Cuellar *et al.*'s ([46]; $N = 30$; also see Demaree [31]) survey of rural breast cancer patients and other rural patient groups showed that levels of depression were similar for patients with breast cancer, myocardial infarction, and stroke. Nevertheless, 12% of the breast cancer patients had scores (using the Center for Epidemiological Studies Depression

Index) that indicated substantial levels of depression.

Other issues related to psychological adjustment include concerns about body image and being stigmatized [8,9,32,48]. In Heishman's [12] study of 36 rural breast cancer patients, 13 women mentioned appearance and self-esteem issues, nine of whom felt self-conscious in public, five of whom said they felt ugly or disgusting after mastectomy. By comparison, of those breast cancer patients in Heishman's study who had received a lumpectomy, many reported that the lumpectomy enabled them to maintain a positive self-image. Additionally, there is some evidence that rural women may feel stigmatized because of their breast cancer diagnosis. McGrath *et al.* [8,9] report that in the rural setting, breast cancer is seen as a difficult topic to talk about, which was described by one participant as 'a backwoods taboo.' Lopez *et al.* ([48]; $N = 18$) suggested that stigmatization of cancer in a rural African American community might have been shaped by beliefs that cancer always leads to death, that it is contagious, and that cancer may lead to rejection by male partners.

Social roles

Treatment for breast cancer can disrupt rural women's social-role performances, especially in gender-specific roles. Rural women may be especially concerned about role disruption because their social roles as caregivers are central to their lives [8,9] and position them as valued members of their communities [48]. Rural breast cancer patients who must reside away from home during treatment report being concerned about the disruption of their family-related social roles [4]. Consistent with this, rural women in Gray *et al.*'s [3] study felt that running a home and taking care of children while coping with breast cancer diagnosis and treatment was more difficult in a rural area, where services were less accessible. Girgis *et al.* [7] revealed that, compared to their urban counterparts, rural breast cancer survivors were 2.5 times more likely to report needing help with physical and daily living needs after treatment. Consistent with this finding, Heishman [12] reports that many of the rural breast cancer survivors in her sample felt significant relief when others helped with traditional gender role demands.

Coping strategies

Rural women seem to use a variety of strategies to cope with their breast cancer diagnosis, treatment, and recovery. Studies [12,31] suggest that rural women may be particularly inclined to use avoidant coping strategies, such as denial. Based on her qualitative study, Heishman [12] summarized that avoidance was the most commonly reported coping

strategy used by rural breast cancer survivors. Heishman used the phrase 'Don't dwell on it' to represent the responses of these rural breast cancer survivors. Heishman identified acceptance as another coping strategy common among her sample of rural breast cancer survivors. Somewhat consistent with this finding, Wilson *et al.* [32] reported that 'trying to maintain a positive attitude' was a commonly used coping method among their sample of rural breast cancer survivors.

Some rural breast cancer survivors report turning to their religious faith as a means of coping, but perhaps not to the extent that might be expected. Wilson *et al.* [32] reported that only 10% of their sample indicated that relying on religious beliefs was helpful to them, and Heishman [12] reported that 8 of the 36 women in her sample reported that their religious beliefs and activities helped them cope with breast cancer. Nevertheless, religion may be especially important to some rural subgroups, such as African American women [33,48]. Both Matthews *et al.* and Lopez *et al.* report that rural African American breast cancer patients frequently state that they 'turn things over to God' as a way of coping.

Social support and psychological support services

Davis *et al.* [4] revealed that the great majority of rural breast cancer patients in their study perceived receiving enough social support during their diagnosis and treatment. These rural patients indicated that their primary sources of support during this period were medical personnel and volunteers with a history of breast cancer. In a similar vein, Demaree [31] found that, during primary treatment for cancer, rural breast cancer patients appeared to be more satisfied with social support from medical staff than from their families. Nevertheless, Demaree's findings revealed that, compared with other rural cancer patients, rural breast cancer patients' levels of satisfaction with emotional support from all sources decreased over time.

Support from family members seems to be of particular concern among rural breast cancer survivors. Although many rural breast cancer patients report fearing that they may put a strain on their families, they concurrently report needing additional support from family members [8,9,31]. Similarly, Heishman [12] revealed that the majority of the rural breast cancer survivors in her sample cited their friends as more supportive than family members.

Rural communities can be supportive for some rural breast cancer patients [3,12,49]. All but one participant in Rogers-Clark's [49] study said that they 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 (also see, Heishman [12]; Gray *et al.* [3]). Nevertheless, the results of these same studies reveal that rural breast cancer survivors report that living in a rural community can be isolating because of concerns about privacy and gossip [3,8,9,49].

Research documents a lack of mental-health services for breast cancer survivors who live in rural areas [4]. For example, Davis *et al.* [4] revealed that very few rural breast cancer patients or their families received support from social workers or other mental health professionals. Similarly, Rogers-Clark ([49]; also see Curran and Church [50]) reported that none of their participants were referred to counseling, support groups, or other mental-health services. In rural areas, barriers to mental health care include lack of access to and availability of mental health specialists, an inability to pay for mental health care, geographic isolation, and stigma associated with mental illness [51]. Gray *et al.* [3] report that rural breast cancer survivors have problems establishing breast cancer support groups because they are difficult to organize and maintain as well as because it can be difficult to find a suitable facility. Nevertheless, Wilson *et al.* [32] reported that some of the rural breast cancer patients in their study stated that they would have liked to attend a support group.

In a related vein, studies [3,32] reveal that rural breast cancer patients often lack opportunities to meet other breast cancer survivors. Yet, Gray *et al.* [3] revealed that the most frequent request from their rural breast cancer patients was to facilitate interaction with other breast cancer survivors. Rural breast cancer patients cite having an opportunity to talk to other breast cancer survivors as helpful for minimizing fears, normalizing experiences, and offering a 'survivorship' perspective [3,30,32].

Discussion

As we noted at the outset, relatively few studies of breast cancer survivors have focused on rural women. Nevertheless, our review of the available literature suggests that rural breast cancer survivors have distinct experiences and challenges. For example, our review of studies using large databases (e.g. breast cancer registry databases) showed, almost uniformly, that rural women were less likely to receive breast-conserving treatments. Almost by definition, rural women are more likely to travel greater distances to receive primary breast cancer treatment as well as to stay away from home during this treatment. As such, rural breast cancer patients face unique social and economic costs, compared to their urban counterparts. Also, the

literature review suggests that the anticipation of these costs may play a role in determining the types of primary treatments that rural breast cancer patients receive. For example, rural women may be less likely to receive breast-conserving surgery because of the travel and time demands associated with adjuvant therapies (e.g. radiation therapy). Moreover, at least one study suggested that women who are treated in rural hospitals appear to be less likely to receive breast-conserving treatments. Importantly, the literature suggests that physicians might play a particularly influential role in determining the breast cancer treatments rural women receive. It is important to recognize that physicians who lack knowledge about state-of-the-art breast cancer treatment limit the treatment choices of rural women.

Nevertheless, the review suggested that medical personnel may be rural breast cancer patients' principle source of support during primary treatment. Once treatment has been completed, however, rural breast cancer patients may need additional support from both medical personnel and family members. One of the ways in which medical personnel can support rural breast cancer patients is to provide them health-related information. Overall, rural women desire greater access to health-related information during treatment and after treatment. Some of this information may need to specifically focus on the unique needs of rural women.

Rural women may have special needs because they indicate feelings of isolation and report a lack of psychosocial support after the completion of primary treatment. Rural women may encounter greater stress with respect to the demands of traditional gender roles. Finally, there is some evidence that rural breast cancer patients may experience greater stigmatization and feel a greater loss of privacy as a function of living in smaller rural communities.

There seems to be little doubt that living in a rural community restricts rural breast cancer survivors' access to psychological support services. Not unlike the findings for primary treatments for breast cancer, the literature review suggests that some of the obstacles for receiving psychological services stem from a lack of access. Moreover, rural women may be less likely to seek mental health care because of negative attitudes about seeking psychological services or the stigma associated with mental health treatment.

Our review of the studies that have focused on rural breast cancer survivors suggests that they may experience unique issues and obstacles compared to their urban counterparts. As such, those seeking to provide services to rural breast cancer patients should attempt to redress these issues and obstacles. For example, although rural women may have close family ties or supportive communities in

general, rural breast cancer survivors may require additional supportive and educational services. These supportive services, however, must be highly accessible, such as through remotely accessible mechanisms such as the telephone (telephone counseling), internet (educational websites), or email (informational or supportive emails sent to survivors). Also, it may be beneficial to facilitate greater information sharing and cooperation among oncologists and general practitioners in rural areas, with the aim of keeping rural general practitioners knowledgeable about current recommended treatments.

Despite that our literature review pointed to possible distinct experiences for rural women, much more research is warranted. The available studies are limited in a number of ways. First, with the exception of the database studies, most of the studies are characterized by relatively small sample sizes and by non-specific definitions of rurality. As such, these limitations cast some doubt about the generalizability of these study findings. Clearly, researchers need to be more precise about their definitions of rural samples. Next, most studies did not include urban comparison groups. Although urban comparison groups may not always be necessary, comparing the experiences of urban to rural breast cancer survivors may help to further elucidate the unique issues that rural breast cancer survivors encounter. Future studies of rural breast cancer patients and survivors should seek to address these limitations, as a means to better understand the experiences of rural women with breast cancer.

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