

# CADTH RAPID RESPONSE REPORT: SUMMARY WITH CRITICAL APPRAISAL

# Rural Breast Cancer Surgery Programs: A Rapid Qualitative Review

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#### **Abbreviations**

BCS Breast-conserving surgery
EBC Early breast cancer
GP General practitioner

CPAC Canadian Partnership Against Cancer

# **Context and Policy Issues**

Breast cancer is one of the most commonly diagnosed cancers in Canada, accounting for 25% of all cancers among females and 1% among males.¹ Approximately 26,300 Canadian women were diagnosed with breast cancer in 2017 in Canada, yet breast cancer mortality rates have declined in the last thirty years,¹ likely due to increased mammography screening and effective breast cancer therapies.¹

Despite these improvements, breast cancer care remains an important yet complex and multi-stage process that typically requires multiple interventions delivered by a variety of health professionals located in separate centres and over prolonged periods of time. Equitable, universal, and high quality care can be difficult to provide in a geographically diverse country as Canada.<sup>2</sup> In particular, rural health care facilities cannot always provide specialized care on site and as a result accessing health care services can be challenging for breast cancer patients living in rural areas.<sup>2-4</sup> Rurality may affect the health of rural patients by increasing the level of risk due to isolation and limited access to health care services. 4,5 Rural individuals may be more vulnerable to advanced breast cancer conditions and complications due to delayed diagnosis. 3,6,7 Travel, time off work, and associated family and financial burdens may influence rural patients' treatment decisions and cancer care experiences. 3,4,6,8,9 For example, recent surgical treatment advancements allow more patients with early-stage cancer (stage I & II) to conserve most of the breast tissue through breast-conserving surgery (BCS). 10-13 Yet, in most cases BCS is followed by radiotherapy often requiring frequent trips to cancer care centres. As a result, patients who live in rural areas and who feel uncomfortable and distressed by travel may choose mastectomy for early stage cancers as this approach is less likely to need radiation and to avoid multiple trips to the clinic. 12,13

In light of these issues, this qualitative rapid review aims to provide a better understanding of patients', caregivers', and health care professionals' perspectives and experiences of breast cancer surgical care in rural areas.

## Research Questions

1. What are the experiences and perspectives of breast cancer patients, their caregivers and their health care providers with respect to breast cancer surgical care in rural areas?

To ensure the relevance of the analysis to the objectives of the primary research question, a secondary set of research questions was explored during data extraction and analysis:

- a) How do people with breast cancer, and their families, experience travelling for breast cancer surgical care?
- b) What is the meaning and impact of receiving breast cancer surgical care close to home, from the perspective of patients and their families?



c) How does the need to travel for breast cancer surgical care shape patients', their families' and their health care providers' experiences and perceptions of breast cancer surgical care?

# **Key Findings**

This review aimed to describe rural patients', caregivers' and health care professionals' experiences of breast cancer surgical care and their resultant perspectives on barriers, facilitators and preferences for the same. Twelve studies were identified in this review. Two analytic themes emerged: geography, which included distance and travel, and rural culture; and availability of health care professionals, which included shortage of health professionals, and coordination of care.

Geographic distance and travel were identified as barriers to access. Long distances, isolation, and transportation issues represented a great challenge and a source of additional stress among breast cancer rural patients and their caregivers. When patients lacked the support of partners, family, or their health professionals, they felt vulnerable and lonely both in rural as well as in urban settings. Travel barriers magnified the physical and emotional trauma of distance. Physical and logistical challenges, such as transportation barriers, travel expenses, and disruption of work and family commitments intensified patients' and caregivers' discomfort and distress. Such conditions often exacerbated patients and caregivers experience of care leading patients to seek the "less stressful [treatment] pathway" or to deny cancer treatment in the case of advanced cancer stage, old age or lack of support. Health care providers expressed similar feelings of frustration due to distance and their patients needing to travel.

In some instances, patients' perceptions of rurality mitigated or exacerbated these barriers. Some patients viewed travel and travel expenses as part of rural life, thus not identifying these issues as barriers to care. Other patients' perspectives of breast cancer surgical care were also influenced by rural values of self-sufficiency and endurance. Rural culture can carry a commitment to self-reliance leading patients to opt for a treatment pathway that limited work and life disruptions and to avoid relying on others. For some patients this meant choosing mastectomy over breast conserving surgery, which allowed patients to avoid radiation therapy and repeated trips to the cancer centre. Rural stoicism was also characterized by a general reticence to seek care. Participants in the included studies suggested that this stoicism might have contributed in part to the common phenomena of delayed diagnosis among rural breast cancer patients. However, rural patients and caregivers generally expressed high levels of satisfaction with their treatment and care, especially when compared to their urban counterparts.

Distance and travel alone were not the only barriers to access care. Shortages of health care professionals and fragmented health care services represented a great disadvantage experienced by patients, caregivers, and care providers in rural settings. Constrained availability of care providers meant that rural patients experienced delayed diagnosis, more trips, shorter consultations, and limited access to medical support. For health care professionals this also meant shifting roles and delegating responsibilities across specialties and patients. Poor communication and care coordination among care providers left patients confused about care professionals' roles and responsibilities as well as lost in the "cracks" of the health care system. Care providers described collaboration and integration of care across sites and specialties as crucial for providing high quality, coordinated care for rural breast cancer patients.



Overall, travel and distance alone do not affect the experience of breast cancer surgery care. Rather patients, caregivers, and health care professionals rationalize distance and travel differently in relation to additional factors, such as rural culture, access to support, age, cancer conditions, availability of health care professionals and coordination of care.

# **Methods**

## Literature Search Methods

A limited literature search was conducted on key resources including Medline CINAHL, The Cochrane Library, University of York Centre for Reviews and Dissemination (CRD) databases, Canadian and major international health technology agencies, as well as a focused Internet search. Methodological filters were applied to limit the retrieval to qualitative studies. Where possible, retrieval was limited to the human population. The search was also limited to English language documents published between January 1, 2009 and March 28, 2019.

#### Selection Criteria and Methods

One reviewer screened citations and selected studies. In the first level of screening, titles and abstracts were reviewed and potentially relevant articles were retrieved and assessed for inclusion. The final selection of full-text articles was based on the inclusion criteria presented in Table 1.

## **Table 1: Inclusion Criteria**

| Population    | <ul> <li>People living in a rural setting who are diagnosed with any stage or type of breast cancer and are eligible for surgery</li> <li>Caregivers caring for people diagnosed with any stage or type of breast cancer who live in a rural setting and are eligible for surgery</li> <li>Health care providers caring for people diagnosed with any stage or type of breast cancer who live in a rural setting and are eligible for surgery</li> </ul>  |
|---------------|---|
| Intervention  | Breast cancer care (with a focus on surgical care)  |
| Country       | Studies conducted in Canada and countries which have comparable health care systems (i.e. United States, Australia, New Zealand, and European Economic Area).   |
| Settings      | Rural or urban settings. Definitions of "rural" vary, and may relate to population density, population size, or distance from an urban area or an essential service. For this review, any definition of a rural setting was eligible.   |
| Outcomes      | Issues emerging from the literature that relate to the research questions, including but not limited to: perspectives on, expectations of and experiences with breast cancer surgical care close to home in a rural setting; perspectives on, and experiences with needing to travel to receive breast cancer surgical care; perspectives on and preferences for care closer to home; perspectives on quality of care in rural settings; perspectives on quality of care in urban settings; acceptability, feasibility and impact of needing to travel for surgical care; barriers to travelling for surgical care; communication and decision-making about location of breast cancer surgical care. As appropriate and if possible, differences were explored by patients' characteristics, including distance needed to travel, age, or stage or type of cancer or surgery. |
| Study Designs | Primary qualitative studies of any design, the qualitative component of mixed methods studies, qualitative meta-syntheses of any design   |



#### **Exclusion Criteria**

Articles were excluded if they did not meet the inclusion criteria outlined in Table 1, they were duplicate publications, or were published prior to 2009. Primary studies that did not employ a qualitative or mixed- or multiple-method research design were excluded. Papers that were not peer-reviewed (e.g., reports, theses), case reports commentaries or editorials, not in English, reported animal or in vitro data, reported non-empirical studies, or were off-topic (that is, not addressing the lived experience of breast cancer surgery care or the lived experience of surgical care in rural areas) were excluded. Studies addressing breast reconstruction were excluded as they are an elective (optional) surgery. Due to the limited information available in abstracts, studies or results presented in abstract form only were excluded.

# Critical Appraisal of Individual Studies

A single reviewer with experience in qualitative research design and synthesis assessed the quality of included papers. Assessments were guided by the Critical Appraisal Skills Programme quality appraisal checklist for qualitative research. Following current conventions in qualitative meta-synthesis, papers were not excluded from the review on the basis of indicators of quality. This approach recognizes that procedural details are typically under-reported and that theoretically sophisticated findings are not necessary to contribute valuable information to a synthesis of multiple studies, or to inform applied health research questions.

# Data Analysis

Included qualitative studies were analyzed using techniques of integrative qualitative meta-synthesis, 16,17,19,20 also defined as qualitative research integration. Qualitative meta-synthesis summarizes and integrates findings across a set of qualitative studies with the aim of combining results across multiple articles. The objective of qualitative meta-synthesis is twofold: first, the aggregated sum of results reflects the range of findings across studies while retaining the original meaning; second, by comparing and contrasting findings across studies, a new integrative interpretation is produced.

The analysis followed a staged coding process similar to grounded theory and passed through three stages: open or line-by-line coding, descriptive coding, and development of analytic themes.<sup>21</sup> The constant comparison method was adapted to include comparing codes across codes and across studies.<sup>21</sup> One reviewer with experience in conducting integrative qualitative meta-synthesis proceeded through the three stages of coding and development of analytic themes.

In analyzing the data, secondary research questions were used as sensitizing concepts to assist the researcher in interpreting findings and concepts in the data. They provided general guidelines for approaching the data, to open up and refine inquiry, without imposing or prescribing a specific analytical lens. <sup>21,22</sup> Secondary questions provided a beginning point for constructing the analysis during the line-by-line and descriptive coding process. During this stage, the reviewer sought empirical accounts of breast cancer patients', their caregivers', and health care providers' perspectives on breast cancer surgical care experiences in rural settings. The perspectives of caregivers and health care providers were used here to corroborate context and to add depth to the issues of breast cancer treatment relative to the experience of breast cancer patients living in areas.



Sensitizing concepts derived from secondary questions further informed the analysis helping to refine the initial descriptive codes into abstract categories and themes.

The reviewer used NVivo 11<sup>23</sup> (QSR International Pty Ltd Version 11, 2017) to extract and manage qualitative data from included reports, that is the qualitative result statements of each included study relevant to the research question. Result statements are typically presented within the "results" section of a report, and are characterized as data-driven and integrated findings based on participant experiences. <sup>16</sup> Before being coded, each result statement was assessed to ensure it was differentiated from raw data, methods, external data, or researchers' conclusions and implications. Only qualitative data were extracted; the quantitative component of mixed methods studies was not included in this analysis. Given that discrepancies have been noted between results presented within abstracts and main reports, only results presented within the main report were extracted. <sup>24</sup>

# Summary of Evidence

## Quantity of Research Available

A total of 443 citations were identified in the literature search. Following screening of titles and abstracts, 394 citations were excluded and 49 potentially relevant reports from the electronic search were retrieved for full-text review. In addition, 13 potentially relevant publications were retrieved from the grey literature search, and in total 62 full-text publications were reviewed for potential inclusion. Fifty publications were excluded for various reasons and, in total, twelve articles were included in this analysis. Appendix 1 presents the PRISMA<sup>25</sup> flowchart of the study selection process.

# Summary of Study Characteristics

Characteristics of the included studies are summarized below, and details are available in Appendix 2, Table 2.

## Study Design (and Data Collection)

Some study authors identified using a particular qualitative study design, while others reported an analytic approach or approach to data collection without naming a specific study design.

Among the twelve included studies, three employed hermeneutical phenomenology, <sup>26-28</sup> three thematic analysis, <sup>14,29,30</sup> four grounded theory, <sup>31-34</sup> one ethnography, <sup>35</sup> and one qualitative content analysis. <sup>36</sup> One was conducted as part of a mixed-methods study. <sup>30</sup> Four used semi-structured interviews as a data collection strategy, <sup>14,32,33,36</sup> two used focus groups, <sup>30,31</sup> one used open-ended interviews, <sup>32</sup> one used both interviews and participant observations, <sup>35</sup> one both structured interviews and focus groups; <sup>29</sup> and two both semi-structured interviews and focus groups. <sup>28,34</sup>

## Country of Origin

Of the twelve studies, four of the studies recruited participants in Canada,  $^{26,32,33,36}$  three studies included participants from the United States,  $^{27,30,31}$  four studies were conducted in Australia,  $^{14,28,29,34}$  and one study included participants from Denmark.  $^{35}$ 



#### Settings

Two studies reported a definition of "rural" adopted in the study.<sup>29,31</sup> The remaining 10 studies reported only sampling rural participants or conducting the study in a rural area, without following a specific definition.<sup>14,26-28,30-36</sup>

# Patient Population

Characteristics of study participants are summarized below and details are available in Appendix 3, Table 3.

The twelve studies included 535 participants including 260 patients, 22 caregivers, and 127 healthcare professionals. Sample sizes in each study ranged from one to 126. Six studies recruited only patients, 14,26,27,30,32,36 another study included only health care professionals, 33 one both patients and caregivers, 31 one both patients and health care professionals, 35 and three studies included patients, caregivers, and health care professionals. 28,29,34 The authors of one study didn't indicate the number of patients versus the number caregivers included in the sample; however, they reported that 30.1% of the included population sample were cancer patients or survivors. 31

The proportion of female patients in the study samples varied from 50%<sup>29</sup> to 100%.<sup>26,27,35,36</sup> Patients' age ranged from 18 <sup>26,27,35,36</sup> to 99 years.<sup>28,34</sup>

Participants were recruited in a variety of settings. Eight studies recruited patients, caregivers, and health care professionals in both urban and rural settings. <sup>26,28,31-36</sup> Three recruited only patients in rural areas. <sup>14,27,30</sup> One recruited patients and caregivers in rural areas and healthcare professionals from both urban and rural settings. <sup>29</sup>

Of the twelve studies, six included only patients with breast cancer, <sup>14,26,27,30,35,36</sup> three of which focused on patients' lived experience of surgical care. <sup>14,26,36</sup> Five included breast cancer patients among other cancer patients (i.e. ovarian, uterine, prostate, colorectal, bowel, lung, melanoma, and leukemia). <sup>28,29,32,34</sup> In these studies, the percentage of patients with breast cancer ranged from 10% <sup>28,34</sup> to 36%. <sup>29</sup> Four included health care providers tending to breast and other types of cancers. <sup>28,29,33,34</sup> One reported including patients with all types of cancer without specifying the type of cancer patients included in the study. <sup>31</sup>

# Summary of Critical Appraisal

A summary of the strengths and limitations of each study can be found in Appendix 4.

Overall, the quality of the included studies was assessed as good. All twelve studies clearly stated the research objectives in the abstract or background sections of the paper. In every case, the qualitative methodology was appropriate to address the aims of the research and to explore the experiences of the research participants. Four identified with a qualitative study design. 26,27,33,35 Eight studies were generically described as "qualitative" without mentioning a formal study design. Rather these studies defined only the approach used to guide data analysis. 14,28-32,34,36 While uncertain, this raises questions about the authors' experience with qualitative methods, which could limit the depth of the reported results.

All studies reported ethics board approval, while one noted that participants had not provided informed consent.<sup>29</sup> Seven papers reported a purposive sampling recruitment strategy, as is appropriate for qualitative research, <sup>14,26,28,29,33,34,36</sup> while the other five were silent on the issue. Eight articles reported that recruitment continued until data saturation was achieved, <sup>14,26,28-30,32-34</sup> while again the remaining four did not mention data



saturation.<sup>27,31,35,36</sup> Failing to reach data saturation can affect the credibility of the studies as findings and themes may reflect the researcher's ideas rather than ideas generated by participants and through analysis.

Most papers omitted any discussion of the relationship between the researcher and the study, except one.<sup>14</sup> The lack of authors' acknowledgment of their own perspective could contribute to limited depth of the analysis in the remaining studies.

All studies included clear statements of findings and linked their findings to existing literature. All but one<sup>33</sup> considered and discussed the implications of the findings. Most provided clear recommendations for practice and suggestions for improvement.<sup>14,26-28,30,31,35,36</sup>

# Summary of Findings

The following sections explore the results of the thematic analysis. In accordance with the analytic plan, the analytic themes represent the meaning of those experiences and perspectives of breast cancer patients, their caregivers, and their health care providers with respect to breast cancer surgery care in rural areas. The studies included in this review primarily focused on breast cancer patients' and health care providers' perspectives, as caregivers' perspectives were represented to a small extent in the included studies. As a result, the themes likewise have a similar focus.

Two analytic themes emerged within the analysis: geography, which includes factors such as distance and travel, and rural culture; and availability of health care providers, which includes shortage of health care professionals, and coordinated and personalized care.

# **Analytic theme: Geography**

The first analytic theme encompasses a set of geographic factors that shape breast cancer patients', their caregivers', and care providers' experiences of breast cancer surgical care in rural areas. These factors include: (1) *distance and travel*, and (2) *rural culture*.

#### Distance and travel

Geographic distance and travel characterized rural patients' and caregivers' experiences of breast cancer care and surgery. Distance and travel challenges represented access barriers to care by adding both physical and emotional stress to the treatment pathway. 14,27,29,34 Care providers shared similar feelings of distress in providing care for patients in distant geographical locations. They saw distance and travel as time-consuming and overwhelming as they tried to provide care across large geographic distances. 28,29,33,34

#### Isolation

Rural patients, caregivers, and providers commonly understood distance as the geographic distance between the patient's place of residence and points of access to the health care system. 

14,27,29,34 Specialist cancer services were generally limited to major urban areas and most rural patients had to travel long distances to access specialized care often away from home. 

28,29,31,34 Some patients and caregivers reported experiencing isolation and lack of support as a result of these distances, which magnified the perception of distance as a major structural barrier to access. 

14,27-29,34 One study reported patients' feelings of loneliness especially once they returned home to their local area upon discharge from urban tertiary centres. 

The lack of follow-up services or family support intensified patients' feelings of isolation in rural areas. 

28,29,31 Two studies noted that rural patients and their



caregivers often lacked access to support services especially when compared to urban patients. <sup>26,29,32,36</sup> Seamless follow-up care in rural areas was acknowledged as potentially difficult to obtain due to distance, travel, and a limited number of available health care professionals. <sup>29,31,34</sup> Care providers reported that distance and travel led to fewer face-to-face consultations and support. <sup>29</sup> Health care staff described the time spent driving for home care in rural locations as "frustrating" and "time-consuming" taking away time spent with patients. <sup>29</sup> Health care providers also expressed feelings of professional and social isolation, remarking the lack of educational opportunities and peer support programs in the rural context. <sup>29</sup>

Generally rural patients were satisfied with the overall quality of care received in rural clinics<sup>26,27,29</sup> feeling "better off" than in urban centres.<sup>29</sup> Patients and caregivers who travelled to the city described the experience of receiving treatment in urban areas as "impersonal," "lonely," and "daunting." The lack of social support and proper accommodation in the city exacerbated their feelings of emotional distress. 14,29 In one case, even when they did have social support and accommodation, patients still reported feeling uncomfortable residing in someone else's home during treatment. Rather, patients reported a preference to receive care in a familiar environment closer to home. Accommodation to receive treatment in an urban centre as a "holiday."

#### Travel barriers

Several papers noted the physical, emotional and financial burden endured by patients and caregivers who travelled to obtain specialized care. 14,27,29-32,34 Breast cancer care is a multistage process that can involve many tests, treatments and consultations with specialists. In some cases, breast cancer services were not located in one single location, forcing patients to travel to different medical centres.<sup>29,31</sup> Many patients described travelling repeatedly to separate clinical centres as "exhausting" and "stressful" expressing the desire to avoid travelling "back and forth" to the clinic 14,27,29,31 Two studies noted that distance and travel influenced patients' treatment decision-making process. 14,29 In these studies, patients with early breast cancer chose to undergo mastectomy rather than breast conserving surgery (BCS) to avoid frequent travel and lengthy stays away from home. 14,29 One of these two studies also highlighted how distance alone was not always a determining factor for choosing mastectomy. Rather, old age, the lack of support, fear of cancer reoccurring and fear of radiation therapy combined with their perception of travel informed patients' decision to decline BCS and choose mastectomy instead. 14 Some patients saw travelling as potentially harmful to their health during a time in which they felt unwell and unfit to travel. 14,27 In some cases, health care professionals also noted that patients with advanced cancer living in rural areas refused cancer treatment to avoid repeated trips and prolonged stays away from home.<sup>29</sup>

Other patients reported physical barriers due to the lack of private or public transportation options, forcing them to rely on their partners' and family support to travel. 27,31 Distance related challenges often meant time off from work for both the patient and their caregiver. 27,31 Patients and caregivers had to strike a balance between multiple priorities, such as family, work, and treatment commitments, which led to additional stress and discomfort. 27,29,34 For example, one woman who relied on her partner to travel to the clinic for her radiation therapy remarked, "he was totally stressed out at that time, but so was I. It's hard to co-ordinate your work to get off to go to the hospital when you know you might be there all day. So he was stressed... He ended up having to take me and still come back



and do his job."<sup>27</sup> In addition to physical, logistical, and emotional challenges, patients and caregivers also reported the burden of travel expenses for gas and accommodation. These expenses added extra financial stress to other out-of-pocket costs for treatment and recovery such as medications, prosthetics and wigs.<sup>27,29,30,32,34</sup> Patients in one American-based study mentioned health insurance and the cost of cancer care as an additional logistical barrier adding to the travel related financial strain, although this topic was not prevalent in countries that cover the costs of cancer care through a universal health care system.<sup>31</sup>

## Positive impacts of rurality

Although distance, isolation, and transportation presented noticeable challenges, three studies noted some positive impacts of living in rural areas on patients' experience of breast cancer care. <sup>26,27,32</sup> Patients in one study described the rural environment as a beneficial part of their healing process defining rural space as "therapeutic." <sup>27</sup> In some cases, personal relationships among rural dwellers mitigated the stressful effects of distance, isolation, and transportation problems. <sup>26,27,32</sup> Partners, family, and community members supported patients by offering physical help by cooking food, <sup>27</sup> logistical assistance by driving them to the clinic, <sup>27</sup> emotional support by providing someone to talk to, <sup>26,27,32</sup> and financial aid by raising money to help cover out-of-pocket cancer related expenses. <sup>32</sup>

#### Rural culture

Some studies in this review emphasized the influence of rural culture on patients' breast cancer treatment experiences, and the importance of understanding how rural culture affects patients' access to care and treatment decision-making in rural areas. Rural cultural traditions of self-reliance and endurance eased some of the challenges of obtaining care and of choosing among different treatment pathways. Rural stoicism and low health literacy, on the other hand, posed additional barriers to care, and treatment decisions.

# Mitigating rural barriers to care

Two studies noted rural patients describing a distinctive tolerance for barriers to care due to their rurality. 14,32 Patients in one of the studies perceived travelling to obtain care as "just part of country life." 14 This perception of rurality allowed patients to justify their decision of undergoing BCS rather than mastectomy and rationalize the inconveniences of travelling for radiation therapy as part of rural life, 14 as remarked by this patient, "well, I mean you've got to travel wherever you go when you live in a small country town." 14 Another study comparing rural with urban patients noted that rural patients did not address travel expenses as a barrier to care as much as their metropolitan counterparts. 32 The authors suggested that rural patients in this study may have perceived out-of-pocket travel expenses as "normal" and thus not a real barrier to care. 32

When compared with urban patients, rural patients generally reported higher levels of satisfaction with the clinical encounters and overall care. <sup>26,29,32</sup> In some instances, rural patients reported having low expectations of rural health care services. <sup>32</sup> For this reason they did not consider their rural area as under-serviced, and appreciated the challenges health professionals typically faced in rural practice. <sup>32</sup>



#### Rural stoicism

Other patients' attitudes exhibited attributes associated with rural-living stoicism. <sup>14,27</sup> Stoic individuals are self-reliant, self-efficient and endure hardship without displaying feelings or voicing complaints. Rural culture can carry a commitment to make do with available resources and solve one's problems autonomously. In this review, "stoic" rural patients adopted a more practical approach to breast cancer treatment, describing mastectomy as the least disruptive pathway to recovery. <sup>14</sup> These patients viewed mastectomy as requiring less trips to the clinic and thus avoiding the disruptive inconvenience of travel. These patients expressed a preference for self-reliance and self-sufficiency over body image and aesthetics. They expressed the desire to be seen as 'strong,' 'tough' and to avoid to 'rely on' or 'burden others.' Rural patients who were concerned about their body image and chose BCS instead, still described worrying about others' judgements as being seen as "vain." <sup>14</sup> In some situations, concerns over one's appearance carried negative moral connotations of weakness and self-indulgence, discouraging BCS and favouring mastectomy instead.

Self-reliance also meant that patients were reticent to seek help. Reticence implies a reluctance to speak and voice one's needs. Care providers noted that some rural patients and caregivers were reluctant to rely on help outside of their family and needed more time to trust the care providers and communicate their needs.<sup>29,35</sup> Some studies also noted that low health literacy contributed to delaying seeking medical treatment, making rural patients more vulnerable to adverse health outcomes and negative care experiences.<sup>29,35</sup> Several care professionals reported that dealing with these patients required extra effort in terms of administrative support and time to help them communicate their needs.<sup>28,29,35</sup>

#### Analytic theme: Availability of health care providers

Availability of health care providers affected access to health care, treatment and rehabilitation for breast cancer in rural settings. This section describes the perspectives of breast cancer patients, caregivers and health care professionals pertaining to access, availability and responsiveness to care in a rural context. Two particular issues influenced patients' and caregivers' experiences: (1) shortage of health care professionals, and (2) coordination of care.

#### Shortage of health care professionals

Several studies noted that health care professional shortages in rural areas posed a crucial barrier to access care. <sup>28-31,33-35</sup> Rural cancer care is characterized by a prevalent lack of physician specialists, <sup>29,34</sup> as well as of other professionals including cancer care nurses, community care nurses, care coordinators, psychologists, dieticians, and alternative therapists among others. <sup>29,31,33,34</sup>

Patients and care providers noted that limited available staff hindered providers' ability to dedicate appropriate time and medical support to respond to their needs. <sup>26,29,34</sup> Patients remarked their dissatisfaction with care providers' short consultation times and lack of follow-up care – especially among patients recently discharged from outpatient surgery. <sup>26,29,34,36</sup>

Patients and health care professionals noted that rural patients often received delayed diagnosis due to the lack of on-site specialists.<sup>31,32,34</sup> However, they noted that also local rural general practitioners (GPs) were not always readily available due to high demands and low retention rates. <sup>29,34</sup> Distance and limited resources also influenced care



professionals' roles and responsibilities. Health care staff in rural medical clinics typically dealt with all cancers as opposed to urban professionals who specialized in specific tumour sites. <sup>29,34</sup> Two studies remarked that rural care providers adopted "generalist roles", <sup>29,34</sup> as this cancer nurse coordinator remarks, "I think that's the hard part for rural people, it's not streamlined, it's not just breast [cancer], it's breast, colorectal or whoever turned up in your centre, you're doing everything." <sup>34</sup> Due to the high volume demands, rural medical staff often distributed their resources across different specializations and patients. <sup>29,34</sup> Visiting oncologists and rural GPs delegated patient care to the local nurses, emergency room staff, and allied health professionals. <sup>29,34</sup> The lack of time and resources added pressures and the overwhelming feeling of working outside of their expertise related "comfort zone." <sup>29,31,34</sup>

#### Coordination of care

Limited availability of health care providers also highlighted the important role of care coordination and multidisciplinary care teams in the provision of rural breast cancer. <sup>28,29,33</sup> Care coordination encompasses several factors including timely referral, delivery of appropriate and timely information, health care professionals' support and team-based individualized treatment plans. The lack of coordinated care can lead to fragmented care and patients "falling through the cracks" of the system. <sup>28,29,33,34</sup>

## Timely referrals

Rural staff faced high care coordination demands when referring patients to specialists due to rural patients' logistical, emotional and financial barriers to access care due to distance and travel. <sup>28,29,33,35</sup> Some surgeons reported attempting to consider patients' logistic barriers when referring patients to oncologists and follow-up care, <sup>33</sup> even though it often proved to be challenging, <sup>33</sup> as remarked by this surgeon "In our rural areas, we have some really good volunteer groups that look after cancer patients. ... You have to deal with the situation that you have and try to give every patient the best opportunity to get the best treatment available, and sometimes that requires jumping through extra hoops". <sup>33</sup> When radiation therapy was provided locally, health care staff noted patients and caregivers to suffer less stress, financial hardships and life disruptions compared to when they accessed care in urban clinics. <sup>29</sup> However they were unsure about the feasibility of providing radiation therapy in a centre serving an area with less than 50,000 residents. <sup>29</sup>

#### Delivery of appropriate and timely information

Patients differed in how they viewed the information they received about the surgery treatment. They highly valued receiving this information and most patients deemed the information received sufficient and satisfactory. <sup>26,36</sup> Most patients remarked on the importance of a pre-surgery needs assessment and preparation by preadmission nurses about the surgery and post-operative care. <sup>26</sup> Timely information about their treatment plan, costs, appointments and availability of transport and accommodation was paramount to cope with their illness and prepare for future adversities. <sup>28</sup>.

Other patients however highlighted how this information was at times lacking or delivered at the inappropriate time and were disappointed with their health care providers for not receiving the information as a result.<sup>26,30,31,36</sup> Some patients remarked that receiving information right before surgery was overwhelming.<sup>26,36</sup> Lack of preparation and information at discharge led to loss of confidence and increased distress, as remarked by this patient



entering surgery without knowing whether or not she was going to stay overnight, "[it was] terrifying... I went into the surgery not knowing if I had to go home or not."<sup>36</sup>

#### Health care professionals' support

Despite the provider shortages endemic to rural health services, some studies also identified some quality advantages to rural health care – particularly, healthcare professionals' support and personalization of rural care. Patients in these studies expressed great satisfaction with rural staff, feeling more cared for and supported than in urban centres. 14,29 Patients receiving treatment in rural areas described these care providers as "friendly" and "caring." 14,27,29,34 Patients reported that rural staff reassured them and enabled them to put "their mind at rest." 14,27,29,34 In one study, rural medical staff's support mitigated patients' isolation and loneliness. 27 In some situations, these features also generated greater trust in the surgeons' recommendations when early breast cancer patients had the option to choose between mastectomy and BCS. 14 Caregivers, however, noted having little access to one-on-one psychosocial support care, both in rural and urban areas. 34

Patients and caregivers also described feeling assured and supported by having a "key contact person" helping them navigate the treatment journey. <sup>28,29</sup> They described care coordinator nurses as providing valuable support in accessing information at all times, coordinating care, and providing support before and after surgery. <sup>26,28,29,36</sup> Some rural patients who also identified as belonging to a minority cultural group remarked that limited access to care coordinators or navigators affected their treatment experience, however, as they were often less able to communicate their needs and preferences and understand the health care provider, adding an additional layer of challenges. <sup>31</sup>

The availability and support of community health nurses was so crucial during home followup care that patients expressed dissatisfaction when they were unable to support them during their recovery at home, especially during weekends.<sup>26,36</sup>

# Health care professional collaboration

Three studies noted the important role of care collaboration among health care providers across disciplines and settings. <sup>28,33,34</sup> Care professionals described professional peer communication and multidisciplinary team care as facilitating care coordination. Multidisciplinary team care is an integrated treatment plan shared within and across settings aimed at achieving coordinated, high quality care. <sup>34</sup> Care providers noted that peer consultations enabled them to provide personalized treatment plans responding to patients' needs and preferences, as remarked by this surgeon, "The benefit of having people you can call is for the people that don't fit the mold, and you can't plug everybody into the same protocol and you can't plug everybody into the same algorithm, and when you have got those people, it is wonderful to call [a colleague] and say, "this is not the run of the mill." <sup>33</sup>

#### Barriers to care coordination

When care coordination and integration was not implemented across settings and health care professionals, participants described patients as "fall(ing) through the cracks."<sup>34</sup> Barriers to care coordination included: lack of clear roles and responsibilities and limited communication among care professionals.<sup>28,33,34</sup> One study noted that the lack of clear roles and responsibilities among care providers confused patients and caregivers leaving them often unsure about where to seek help and advice.<sup>28</sup> Care providers remarked that the lack of communication among specialists and between specialist and primary care



providers hindered the delivery of coordinated care.<sup>28,33,34</sup> Surgeons noted that communication was often lacking especially with oncology colleagues, as illustrated by this surgeon,

[T]he biggest problem is the oncologists in [centre A] do not communicate with those of us outside of [centre A] very well in what their feelings are on management and that sort of thing. When new studies are published and they change their practice, they don't tell the rest of us. ... I ask them "well, what is the group's approach to this?" and they don't communicate.<sup>33</sup>

Similarly, rural GPs reported receiving inconsistent and delayed information about their patients' diagnosis, treatments, and follow-up care from their urban counterparts.<sup>34</sup> This delayed and intermittent communication inhibited GPs' ability to support their patients who contact them in between appointments during their treatment.<sup>34</sup>

#### Limitations

Qualitative research provides theoretical and contextual insights into the experiences of limited numbers of people in specific settings. Qualitative research findings are not intended to generalize directly to populations, although meta-synthesis across a number of qualitative studies builds an increasingly robust understanding that is more likely to be transferable between settings. Qualitative insights often enlighten the understanding of experiences across different settings. The findings of the studies reviewed here – and of this synthesis – are felt to generalize to the Canadian population. However, the findings are limited to the conditions included in the body of literature synthesized (i.e., breast cancer). That said, the body of evidence reviewed in this synthesis has a number of limitations arising from the quality and scope of the included studies.

We identified twelve studies relevant to patients', caregivers' and health care professionals' perspectives and experiences with rural breast cancer care and surgery. All the papers addressed participants' perspectives and experiences of breast cancer surgical care in rural settings. However, only a small number of studies exclusively focused on surgery. Even though this may be seen as a limitation, cancer patients rarely differentiate between diagnosis, acute treatment and cancer follow-up care when discussing their experiences with cancer. For many patients it is all "cancer care." For this reason, a decision was made for broad eligibility criteria and to include studies not only focused on breast cancer surgery but also on cancer care in general. The body of included literature, however, is modest and further investigation is warranted to capture deeper and richer understandings of patients', caregivers', and health care professionals perspectives on breast cancer surgery care in rural areas. The differences in travel preferences and perceptions among patients in particular warrants further investigation to shed light on the relationship between travel and treatment choice.

Other limitations stem from the rapid nature of this work. A single researcher identified eligible studies and extracted, analyzed, and interpreted the data. A team-based approach would have provided opportunities to discuss and challenge the initial analysis with alternative but potentially relevant lines of thinking. Particularly in working with qualitative data, a team of researchers can help enhance the analysis' rigour and dependability and help to ensure the resultant analysis represents a comprehensive range of participants' experiences. Finally, other strategies to enhance the rigour of the analysis, for example, seeking negative or disconfirming cases or pursuing member checking, were not conducted. Taken together, these constraints limited the ability to produce an in-depth



analysis, although the presented results raise important issues to consider within the context of decision-making.

# **Conclusions and Implications for Decision or Policy Making**

This rapid qualitative review outlines a number of factors related to breast cancer surgery care in rural areas that may impact patients', caregivers', and health care professionals' experiences. Twelve studies were included in this thematic synthesis and two analytic themes emerged: (1) geography, which included distance and travel, and rural culture; and (2) availability of health care professionals, which included shortage of health professionals, and coordination of care. By including patients, caregivers, and health care professionals' perspectives, this review allowed us to draw on a more comprehensive evidence base to inform relevant policy questions rather than just focusing on patients. Whereas patients and caregivers reported sharing many common experiences with breast cancer surgical care in rural settings pertaining to travel and distance, health care providers' perspectives shed light on greater systemic barriers to the delivery of care.

The findings of this review resonate with common knowledge on access and availability of cancer care services in rural settings. <sup>3,8,37-40</sup> As in this review, literature on rural dwellers' experiences of cancer care indicated rural patients' and caregivers' susceptibility to external and structural conditions of the environment and of the health care system (such as distance, travel, transportation and accommodation costs, shortage of health care professionals, and care coordination barriers). <sup>3,4,8,37-39</sup>

The findings also seem to shed light on the geographic differences in mastectomy and BCS rates that have been identified in previous studies and add a deeper understanding of the reasons for these differences.<sup>3,6,7</sup> Past studies have shown that rural patients are more likely to present with advanced disease and undergo mastectomy in higher numbers compared to urban patients.<sup>3,6,7</sup> Evidence in this synthesis illustrated how differences in patients' cancer stages and treatment pathways are not only due to distance and access barriers to health services. Rather, participants' perceptions of geography and lack of access to care were affected by other factors such as rural culture, support, old age, cancer conditions, availability of health care professionals, and care coordination. Perhaps less commonly identified in the literature is the role of rural culture in health care access and experiences of breast cancer surgical care. This review highlighted that rural culture can alleviate or magnify access barriers as well as influence patients' treatment choices. This report highlights not only rural groups' access challenges and problems, but sheds light on some positive advantages of rural health care including heightened social, emotional, and logistical support from personal networks and care providers, in addition to the therapeutic benefits of living in a rural area.

Our review is also highly concordant with a recent Pan-Canadian report on breast cancer surgery standards that provides guidance on the resources and requirements that need to be in place to improve surgical cancer care and outcomes.<sup>39</sup> This document identifies a set of key actionable recommendations to ensure the delivery of optimal breast cancer care in Canada. As in our review, the authors of this report place great emphasis on the regionalization of care and the need for collaboration among health care professionals. Both reviews observe the unequal distribution of resources across regions and indicate the importance of an integrated multidisciplinary team-based approach to better respond to the needs and preferences of patients and their families. As identified by the findings of this study, the Pan-Canadian Standards report highlighted the need to address care providers'



workflow and collaboration barriers to facilitate medical staff's work in underserved rural areas. While surgeons play a central role in patients' treatment pathway, only an integrated team approach can optimize patients' care. Better communication and support among specialists, rural GPs, and ancillary health professionals across clinical settings and geographic locations should be established to ensure seamless and timely delivery of care. This will allow providers to provide timely referrals, timely information and timely follow-up care while attending to patients' decision-making and travel needs.

Given the unequal distribution of resources across regions, the importance of care integration and coordination, and the paucity of literature on the issue, further research should focus on investigating what strategies should be implemented to ensure the delivery of seamless and high-quality breast cancer surgical care in rural settings.



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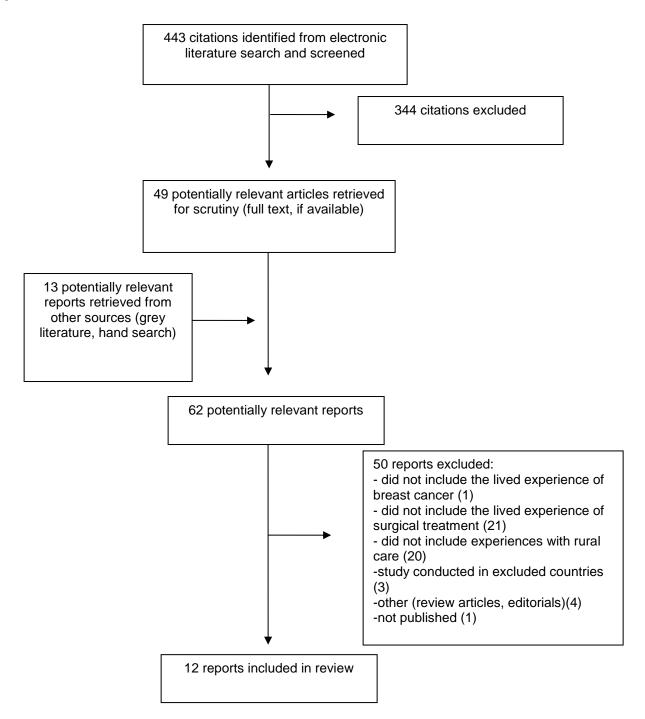
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# **Appendix 1: Selection of Included Studies**





# **Appendix 2: Characteristics of Included Studies**

**Table 2: Characteristics of Included Studies** 

| First Author,<br>Publication Year,<br>Country | Study Design or<br>Analytic<br>Approach | Study<br>Objectives   | Sample Size  | Inclusion<br>Criteria   | Data<br>Collection*  |
|---|---|---|--|---|--|
| Nyholm, 2018,<br>Denmark <sup>35</sup>        | Ethnography                             | To explore health care encounters among breast cancer patients who by healthcare professionals are perceived and categorized to be vulnerable.  | 12 patients<br>8 health<br>professionals   | Post-surgery patients before discharge  Socio-economic or ethnic minority vulnerable patients   | Participant<br>observation and<br>individual<br>interviews |
| Torres, 2016, USA <sup>30</sup>               | Thematic analysis                       | To explore the experiences of African American breast cancer survivors in rural North Carolina to expand the understanding of their experiences throughout the continuum of breast cancer care, specifically to better understand the barriers and facilitators in accessing breast cancer treatment and challenges in adherence to follow-up care. | 31 African American women with breast cancer in three rural counties in Eastern North Carolina | Self-identified as African American women who completed their breast cancer treatment within the last 10 years, who reside in either county where the study was conducted, and who were 18 years of age or older. | Focus groups   |
| Urquhart, 2016,<br>Canada <sup>33</sup>       | Grounded theory                         | To explore how cancer surgeons make decisions related to oncology referral.   | 29 surgeons  | Surgeons in the province of Nova Scotia who were performing non—small-cell lung, breast or colorectal cancersurgery   | Semi-structured individual interviews                      |
| Ristevski, 2015,<br>Australia <sup>14</sup>   | Thematic analysis                       | To identify what factors rural women perceived to influence their surgical choice for end stage breast cancer.  | 70 patients  | Patients with end stage breast cancer and eligible for both surgical options, mastectomyand BCS; no previous diagnosis of breast cancer; consulted a surgeon in the region; and lived in                          | Semi-structured individual interviews                      |



| First Author,<br>Publication Year,<br>Country | Study Design or<br>Analytic<br>Approach | Study<br>Objectives  | Sample Size  | Inclusion<br>Criteria   | Data<br>Collection*  |
|---|---|--|--|---|--|
|   |   |  |  | the Gippsland region at the time of treatment   |  |
| Dawe, 2014,<br>Canada <sup>36</sup>           | Qualitative content analysis            | To report the findings of a study about the informational and emotional needs of women having outpatient surgery for breast cancer.  | 19 patients  | Outpatient breast cancer surgical patients 6 months following outpatient breast cancer surgery  | Semi-structured individual interviews                      |
| Itty, 2014, USA <sup>31</sup>                 | Grounded theory                         | The goal of the project was to identify and categorize illness beliefs and barriers to symptom management faced by American Indian cancer patients and survivors and family members, and to better understand how these constructs impact the cancer experience. | 126 patients or<br>survivors and<br>caregivers or family<br>members (the<br>study does not<br>report how many<br>per group of<br>participants)   | (1) self identify as American Indian, (2) age 18 years or older, (3) experience as a cancer patient or survivor, or experience as a family member or caregiver of patients or survivors   | Focus groups   |
| Grimison, 2013,<br>Australia <sup>29</sup>    | Thematic analysis                       | To identify concerns about cancer care and strategies for improvement by seeking the opinions of health professionals as well as patients and caregivers, and included locations lacking resident oncologists or local radiation oncology services.              | 36 patients, 14 caregivers and 32 health professionals were interviewed in seven focus groups (ranging in size from three to nine participants) and 42 individual interviews (32 health care professional, nine patients, one caregiver) | Patients over 18 years, with any cancer in the last 2 years, able to speak English and living in rural area.  Patients' caregivers.  Patients who declined to invite a caregiver or whose caregiver declined to participate were still eligible to participate in the study.  Health-care professionals treating rural patients from rural and metropolitan | Focus groups<br>and structured<br>individual<br>interviews |



| First Author,<br>Publication Year,<br>Country | Study Design or<br>Analytic<br>Approach            | Study<br>Objectives   | Sample Size  | Inclusion<br>Criteria   | Data<br>Collection*                         |
|---|--|---|--|---|---|
|   |  |   |  | locations   |   |
| Miedema, 2013,<br>Canada <sup>32</sup>        | Grounded theory                                    | To compare the experiences of young adult cancer patients regarding their cancer care in two distinct areas of Canada: New Brunswick, a rural Eastern Canadian province, and Toronto.   | 30 patients<br>(15 from New<br>Brunswick and 15<br>from the Greater<br>Toronto Area) | Patients between<br>18 and 39 years of<br>age recruited 1 to 5<br>years post-<br>diagnosis, with any<br>kind of cancer  | Semi-structured individual interviews       |
| Walsh, 2011,<br>Australia <sup>28</sup>       | Phenomenological approach based on grounded theory | To investigate the views and experiences of key stakeholders of cancer care coordination in order to identify its essential components.   | 20 patients, 4 caregivers and 29 health professionals                                | Patients over 18 years of age within 3–15 months of commencing treatment for any stage and type of cancer.  Patients' caregivers.  Health professionals involved in cancer care (surgeons, medical oncologists, cancer nurse coordinators and general practitioners). | Semi-structured interviews and focus groups |
| Greenslade, 2010,<br>Canada <sup>26</sup>     | Phenomenology                                      | To investigate the lived experiences of women having same-day breast cancer surgery. Because the participants lived in an area (Newfoundland) which is geographically dispersed with small urban centres scattered throughout, understanding how they psychosocially adjusted and coped with same-day | 13 patients  | Same day surgery patients who agreed to post-surgery  Patients who were admitted overnight were excluded.   | Unstructured individual interviews          |



| First Author,<br>Publication Year,<br>Country | Study Design or<br>Analytic<br>Approach | Study<br>Objectives  | Sample Size   | Inclusion<br>Criteria   | Data<br>Collection*  |
|---|---|--|---|---|--|
|   |   | surgery was important.   |   |   |  |
| Sawin, 2010, USA <sup>27</sup>                | Phenomenology                           | To examine the experiences of rural women aged 55 years and older, who dealt with their breast cancer diagnosis with a nonsupportive intimate partner.   | 9 patients  | Women 55 Years of age and older who were in a 'difficult' intimate partner relationship while being diagnosed with or treated for breast cancer   | Semi-structured individual interviews and closed questions |
| Walsh, 2010,<br>Australia <sup>34</sup>       | Grounded theory                         | To explore the views and experiences of patients, their caregivers and health professionals involved in cancer care regarding the key issues and challenges to achieving effective cancer care that is well coordinated. | 20 patients, 4 caregivers and 29 health professionals | Patients over 18 years of age within 3–15 months of commencing treatment for any stage and type of cancer.  Patients' caregivers.  Health professionals involved in cancer care (surgeons, medical oncologists, cancer nurse coordinators and general practitioners). | Semi-structured interviews and focus groups                |



# **Appendix 3: Characteristics of Study Participants**

**Table 3: Characteristics of Study Participants** 

| First Author,<br>Publication Year,<br>Country | Sample Size  | Sex (% female)   | Age range in years  | Breast cancer population   | Type of<br>population<br>(rural, urban)  |
|---|--|--|---|--|--|
| Nyholm, 2018,<br>Denmark <sup>35</sup>        | 12 patients<br>8 nurses                                | 100%   | 35 – 84   | All breast cancer  | Rural and urban  |
| Torres, 2016, United States <sup>30</sup>     | 31 patients or survivors                               | 100%   | 10% under age 40<br>68% 40 - 64<br>23 % 65 and older              | All breast cancer  | All rural participants   |
| Urquhart, 2016,<br>Canada <sup>33</sup>       | 29 surgeons  | 17%  | NR  | Surgeons<br>performing non—<br>small-cell lung,<br>breast or<br>colorectal cancer<br>surgery | Rural and urban<br>(Nova Scotia<br>province)   |
| Ristevski, 2015,<br>Australia <sup>14</sup>   | 70 patients  | 100%   | Average age 60  | All breast cancer<br>(with a focus on<br>surgery)  | All rural participants   |
| Dawe, 2014, Canada <sup>36</sup>              | 19 patients  | 100%   | 38-72   | All breast cancer<br>(with a focus on<br>surgery)  | 16 urban<br>3 rural residents  |
| Itty, 2014, USA <sup>31</sup>                 | 126 patients or<br>survivors and<br>caregivers         | 71%  | 18 and older  | NR   | 81 urban (64.3%) 45 rural (35.7%)  20.6% of the urban sample were cancer patients or survivors  9.5% of the rural sample were cancer patients or survivors |
| Grimison, 2013,<br>Australia <sup>29</sup>    | 36 patients, 14 caregivers and 32 health professionals | 50% Patients<br>93% Caregivers<br>75% Health care<br>professionals | Patients 26-80  Caregivers 53-79  Health care professionals 30-63 | 13 breast cancer patients 2 breast cancer caregivers   | All rural patients<br>and caregivers<br>26 rural health<br>professionals   |
| Miedema, 2013,<br>Canada <sup>32</sup>        | 30 patients  | 53% of New<br>Brunswick<br>patients<br>87% of Toronto<br>patients  | 19 – 39   | 3 New Brunswick<br>breast cancer<br>patients<br>4 Toronto breast<br>cancer patients          | 15 rural (New<br>Brunswick)<br>15 urban (Toronto)  |



| First Author,<br>Publication Year,<br>Country | Sample Size  | Sex (% female)                 | Age range in years                  | Breast cancer population                          | Type of<br>population<br>(rural, urban)        |
|---|--|--------------------------------|-------------------------------------|---|--|
| Walsh, 2011,<br>Australia <sup>28</sup>       | 20 patients, 4<br>caregivers and 29<br>health<br>professionals | 58% of patients and caregivers | Patients or caregivers 35 and older | 10% were breast cancer patients                   | Rural and urban<br>(New South Wales<br>region) |
| Greenslade, 2010,<br>Canada <sup>26</sup>     | 13 patients  | 100%                           | 32–74                               | All breast cancer<br>(with a focus on<br>surgery) | 9 urban<br>4 rural                             |
| Sawin, 2010, USA <sup>27</sup>                | 9 patients   | 100%                           | 53-71                               | All breast cancer                                 | All rural participants                         |
| Walsh, 2010,<br>Australia <sup>34</sup>       | 20 patients, 4<br>caregivers and 29<br>health<br>professionals | 58% of patients and caregivers | 35 and older                        | 10% breast cancer patients                        | Rural and urban<br>(New South Wales<br>region) |



# **Appendix 4: Critical Appraisal of Included Studies**

# **Table 4: Strengths and Limitations of Included Studies**

| Strengths  | Limitations   |
|--|---|
| Dawe,  | 2014 <sup>36</sup>  |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Purposive sampling</li> <li>Four authors independently read and coded all interview transcripts</li> <li>Includes recommendations for practice and future research</li> </ul>   | <ul> <li>No mention of data saturation</li> <li>Poor description of code and theme development procedure</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> </ul>  |
| Greenslad  | de, 2010 <sup>26</sup>  |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Purposive sampling</li> <li>Recruitment continued until data saturation had been reached in the analysis</li> <li>Three authors independently read and coded all interview transcripts</li> <li>Includes member-checking (to ensure credibility)</li> <li>Includes recommendations for practice and future research</li> </ul>  | No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)   |
| Grimisor   | ո, 2013 <sup>29</sup>   |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Study includes patients, caregivers, and health care professionals</li> <li>Purposive sampling</li> <li>Recruitment continued until data saturation had been reached in the analysis</li> <li>Description of the relevance of the study findings in the context of the subsequent policy actions taken by the government to mitigate barriers in the pathways to breast cancer care</li> <li>Includes recommendations for practice and future research</li> </ul> | <ul> <li>No mention of participants' informed consent about participating in the study</li> <li>No mention of interview and focus group duration</li> <li>Only six of 82 transcripts analyzed by two or more authors to develop a coding frame; 76 transcripts coded by one researcher supervised by one other author</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> </ul> |
| ltty, 2  | 014 <sup>31</sup>   |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Study includes both patients and caregivers</li> </ul>  | <ul> <li>Researcher has not clearly justified the selection of research methodology based on her research objective</li> <li>The participant sample is poorly described – not</li> </ul>  |



| Strengths   | Limitations   |
|---|---|
| <ul> <li>Two authors independently read and coded all interview transcripts</li> <li>Includes member-checking (to ensure credibility)</li> <li>Includes recommendations for practice and future research</li> </ul>   | <ul> <li>clear which type of cancer patients are included</li> <li>No mention of data saturation</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> </ul>  |
| Miedema   | , <b>2013</b> <sup>32</sup>   |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Researcher has clearly justified the selection of research methodology based on research objective</li> <li>Recruitment continued until data saturation had been reached in the analysis</li> <li>Includes recommendations future research</li> </ul>  | <ul> <li>Three authors independently read and coded three transcripts; one researcher analyzed and coded 27 and supervised by the other two authors</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> <li>Does not include recommendations for practice</li> </ul>                          |
| Nyholm,   | 2018 <sup>35</sup>  |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Researcher has clearly justified the selection of research methodology based on research objective</li> <li>Study includes patients and health care professionals</li> <li>Five authors independently read and coded all interview transcripts</li> <li>Theoretical framework underlying analysis</li> <li>Includes recommendations for practice and future research (reflexivity)</li> </ul>                            | <ul> <li>No mention of data saturation</li> <li>No mention of interview duration</li> <li>No clear description of all eligibility criteria</li> <li>Participant recruitment process for health care provider sample is not reported</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> </ul> |
| Ristevski   | i, 2015 <sup>14</sup>   |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Purposive sampling</li> <li>Recruitment continued until data saturation had been reached in the analysis</li> <li>In-depth description of the analysis process</li> <li>Three authors independently read and coded all interview transcripts</li> <li>Study included acknowledgment of the investigator's own assumptions about the phenomenon of study</li> <li>Includes discussion of clinical implications</li> </ul> | Researcher has not clearly justified the selection of research methodology based on research objective  |



| Strengths   | Limitations   |
|---|---|
| <ul> <li>Includes recommendations for practice and<br/>future research</li> </ul>   |   |
| Sawin,  | 2010 <sup>27</sup>  |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Researcher has clearly justified the selection of research methodology based on her research objective</li> <li>Includes recommendations for practice and future research</li> </ul>   | <ul> <li>Relatively small sample size (n=9) and no mention of data saturation or justification for a small sample size</li> <li>Appears to be a single author analysis, under supervision of other authors (unspecified number); no description of initial independent coding</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> </ul>     |
| Torres,   | 2016 <sup>30</sup>  |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Researcher has clearly justified the selection of research methodology based on research objective</li> <li>Combination of quantitative and qualitative data sources</li> <li>Recruitment continued until data saturation had been reached in the analysis</li> <li>Two authors independently read and coded all interview transcripts</li> <li>Includes recommendations for practice and future research</li> </ul> | <ul> <li>Details of how the qualitative and quantitative components of the mixed-methods study contribute to knowledge is unclear</li> <li>Data analytical approach not clearly identified but description outlines the processes of a thematic analysis</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> </ul>                          |
| Urquhar   | t, 2016 <sup>33</sup>   |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Researcher has clearly justified the selection of research methodology based on research objective</li> <li>Field testing of interview guide</li> <li>Purposive sampling</li> <li>Recruitment continued until data saturation had been reached in the analysis</li> <li>In-depth description of the analysis process</li> <li>Includes recommendations for future research</li> </ul>                                | <ul> <li>Two authors independently read and coded 14 interview transcripts; one author finished coding the 15 remaining transcripts under the supervision of two researchers</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> <li>No description of the implications for health providers and no recommendations for practice</li> </ul> |
| Walsh,  | 2010 <sup>34</sup>  |
| <ul><li>Ethics approval sought</li><li>Clear statement of research objectives or</li></ul>  | Researcher has not clearly justified the selection of research methodology based on her   |



| Strengths   | Limitations  |
|---|--|
| <ul> <li>question</li> <li>Purposive sampling</li> <li>Study includes patients, caregivers, and health care professionals</li> <li>Recruitment continued until data saturation had been reached in the analysis</li> <li>Three authors independently read and coded all interview transcripts</li> <li>Description of the relevance of the study findings in the context of the subsequent policy actions taken by the government to mitigate barriers in the pathways to breast cancer care</li> </ul> | research objective.  • Poor description of code and theme development procedure  • No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)   |
| Walsh,  | <b>2011</b> <sup>28</sup>  |
| <ul> <li>Ethics approval sought</li> <li>Clear statement of research objectives or question</li> <li>Purposive sampling</li> <li>Study includes patients, caregivers, and health care professionals</li> <li>Recruitment continued until data saturation had been reached in the analysis</li> <li>Two authors independently read and coded all interview transcripts</li> <li>Includes recommendations for practice</li> </ul>   | <ul> <li>Researcher has not clearly justified the selection of research methodology based on her research objective.</li> <li>Poor description of analytical procedure</li> <li>No acknowledgment of the investigators' own experiences and assumptions about the phenomenon of study (reflexivity)</li> </ul> |