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SUMMARY WITH CRITICAL APPRAISAL

Screening and Diagnostic Services for People at Risk of Breast Cancer: A Rapid Qualitative Review

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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 females were diagnosed with breast cancer in 2017 in Canada, yet breast cancer mortality rates have declined in the last thirty years,¹ which could be a result of increased availability of mammography screening (the vast majority of Canadian provinces have implemented breast cancer screening programs since the 1990s) and effective breast cancer therapies.¹

For women between the ages of 50-74 living in Canada, the Canadian Task Force on Preventative Health Care has conditionally recommended screening with mammography every two to three years in Canada. For those who are between the ages of 40-49, screening with mammography is not recommended. These recommendations are “conditional on the relative value a woman places on possible benefits and harms for screening.”(p.E1443)² Diagnostic mammography is used to take more detailed images of the breast from more angles, to inspect things like self-identified lumps or suspicious areas identified through screening mammography or clinical exam.³

In Canada, both screening and diagnostic mammography are read by radiologists accredited by the Canadian Association of Radiologists. The number of mammograms required to remain an accredited radiologist was recently doubled from 500 to 1,000. This change to accreditation guidelines may mean that radiologists located in smaller, more rural centres may not read the required volume, while those in the large urban centres read a volume of exams far exceeding the requirement.

This discrepancy poses a challenge for jurisdictions with large rural populations and breast cancer screening programs that provide multiple rural screening locations for these populations. Adapting programs to fit these new accreditation requirements for radiologists could mean that jurisdictions are faced with challenging options like limiting the number of screening centres available in rural settings where radiologists are less likely to read the required number of mammograms annually or keeping these rural centres in operation and sending images to radiologists located in higher density settings. Were screening centres limited to higher density settings, people eligible for screening or requiring diagnostic mammography would need to travel farther to these centres.

Considering these issues, this qualitative rapid review aims to provide a better understanding of the perspectives and experiences of people eligible for breast cancer screening or diagnostic mammography, and the health care professionals working with these people.

Research Questions

1. How do people at risk of breast cancer understand, communicate, experience, and make decisions to undergo screening and diagnostic services in rural or urban settings?
2. How do families, caregivers, and health care providers who care for people at risk of breast cancer, understand, communicate, experience, and make decisions regarding screening and diagnostic services in rural or urban settings?

Key Findings

When determining whether, or when, to engage with breast cancer screening or diagnostic mammography, women indicated these decisions could be impacted by logistical challenges of attendance. These could include where one lived in relation to screening centres, the

scheduling flexibility of screening centres, other life plans (e.g. upcoming vacation), and the ability to navigate daily responsibilities such as work or childcare.

While screening for breast cancer was often understood as a choice, women described feeling as though it were more of a responsibility to attend than an option. Trust in the health care system broadly, and primary care providers specifically, played a pivotal role in the decision to pursue screening, or not. This included more than direct experiences with breast cancer screening or diagnostic services. It was also possible for women to rely on their own knowledge of their bodies and desire to control what happens to them.

Decisions to engage with available screening services could also be influenced by whether people were aware of the screening services available to them or what breast cancer screening guidelines recommended, as well as how people perceived the potential for screening and diagnostic mammography to impact their lives. Women described learning about the services available to them and the importance (or not) of engaging with them through the experiential knowledge of mothers or friends.

It was important for women to feel comfortable with the individuals conducting the screening and the attention paid to their concerns while undergoing screening.

Methods

Literature Search Methods

A limited literature search was conducted by an information specialist on key resources including PubMed, the Cochrane Library, the University of York Centre for Reviews and Dissemination (CRD) databases, Scopus, the websites of Canadian and major international health technology agencies, as well as a focused Internet search. The search strategy was comprised of both controlled vocabulary, such as the National Library of Medicine's MeSH (Medical Subject Headings), and keywords. The main search concepts were breast cancer screening and diagnosis, and accessibility to health care. Search filters were applied to limit retrieval to qualitative studies and studies relevant to the perspectives and experiences of patients and their caregivers or care providers. Where possible, retrieval was limited to the human population. The search was also limited to English language documents published between Jan 1, 2014 and Sep 25, 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 using SPICE

Setting	<p>Settings of interest include health care systems similar to the Canadian model (i.e., countries that are members in the Organization for Economic Co-operation and Development, having universal or near universal coverage for core medical services), as well as the United States of America.</p> <p>Rural or urban settings. Definitions of “rural” vary, and may be related to population density, population size, or distance from an urban area or an essential service. For this review, any definition of a rural setting is eligible.</p>
Population/ Perspective	<p>Q1: People eligible for screening, or people at risk of, or with suspected, breast cancer.</p> <p>Q2: Families, caregivers, and health care providers caring for people who are eligible for screening, or people who are at risk of, or with suspected, breast cancer</p>
Intervention	Breast cancer screening or diagnostic services in a rural setting
Comparison	Breast cancer screening or diagnostic services in an urban setting
Evaluation	<p>Q1: Issues emerging from the literature that relate to the research question, including but not limited to:</p> <ul style="list-style-type: none"> - Perspectives on, expectations of, and experiences with breast cancer screening or diagnostic services in a rural or urban setting; - Experiences accessing and engaging with services in these settings; - Perspectives on quality of care, or features in screening or diagnostic services that may lead to better outcomes, in rural and urban settings; - Acceptability, feasibility, and impact of travel for breast cancer screening or diagnostic services; - Communication and decision-making about location of breast cancer screening or diagnostic services; <p>As appropriate, differences may be explored by patient characteristics including but not limited to:</p> <ul style="list-style-type: none"> - Travel distance; - Age; - Typically marginalized populations (e.g., immigrant/refugees; Indigenous Peoples; people of colour; people navigating homelessness; lesbian, gay, bisexual, transgender, queer and others) <p>Q2: Issues emerging from the literature that relate to the research question, including but not limited to:</p> <ul style="list-style-type: none"> - Perspectives on, expectations of, and experiences with caring for people seeking breast cancer screening or diagnostic services in a rural or urban setting; - Perspectives on quality of care, or features in screening or diagnostic services that may lead to better outcomes, in rural and urban settings; - Communication and decision-making about location of breast cancer screening or diagnostic services; <p>As appropriate, differences will be explored by family, caregiver, or health care provider characteristics including but not limited to:</p> <ul style="list-style-type: none"> - geography (e.g., urban, rural); - care setting (e.g., primary, secondary, tertiary, quaternary);

Exclusion Criteria

Articles were excluded if they did not meet the inclusion criteria outlined in Table 1, were duplicate publications reporting on the exact same data and same findings or were published prior to 2014.

Critical Appraisal of Individual Studies

One reviewer assessed the quality of the included publications. An assessment of credibility, trustworthiness and transferability of the studies was guided by the ten items from the Critical Appraisal Skills Programme (CASP) Qualitative Checklist.⁴ Results of the critical appraisal were not used to exclude studies from this review; rather they were used to understand the methodological and conceptual limitations of the included publications in specific relation to this review. In particular, the critical appraisal contributed to the analysis by identifying the limits of transferability of the results of included publications to this review.

Data Analysis

A descriptive thematic analysis⁵ intended to identify the diversity of experiences with and perspectives of breast cancer screening was conducted, primarily by a single reviewer, with some conversations with colleagues to probe for analytic clarity. To reflect diversity and breath, rather than develop themes based on the aggregative presence of similar experiences across studies, themes presented in this review could come from experiences reported in as little as one included study. Approaching the analysis in this way allowed for a broader engagement with and description of perceptions of screening.

Preliminary analysis began at the screening stage through the use of memoing (e.g. noting broad themes and populations) and subsequent conversation with colleagues experienced in rapid qualitative evidence synthesis. Given the small number of included studies (n=12), memoing continued to be used in lieu of formal coding.⁶ This second set of memos built on those from the screening stage and helped to describe the findings of included primary studies and note preliminary spaces of confluence between studies. As such, the second round of memoing and diagraming used an initial, tentative set of themes to tease out findings and supporting data in the studies and explore their relationships across studies.

Included studies and memos were re-read and key findings and themes were identified and the linkages between studies were explored. Memoing and re-reading continued until themes were well-described and stable, and all relevant findings and supporting data from the included studies had been accounted for within those themes.

Note on terminology: It is important to note here that we recognize people navigating the worlds of breast cancer may not identify as women nor is breast cancer specific to female bodies. In recognition of this, we use gender neutral pronouns and terms where possible. When reporting results from published literature, gender neutral language is not used, to be consistent with the terms used in the source material. No studies focused on males' experiences with breast cancer screening were found.

Summary of Evidence

Quantity of Research Available

A total of 1049 citations were identified in the literature search. Following screening of titles and abstracts, 1020 citations were excluded and 29 potentially relevant reports from the electronic search were retrieved for full-text review. No potentially relevant publications were retrieved from the grey literature search for full text review. Of these potentially relevant articles, 17 publications were excluded for various reasons, and 12 publications met the inclusion criteria and were included in this report. Appendix 1 presents the PRISMA⁷ flowchart of the study selection.

Additional references of potential interest (e.g., engage with experiences of breast cancer screening, but do not meet inclusion criteria) are provided in Appendix 5.

Summary of Study Characteristics

Details regarding the characteristics of included publications and their participants are provided in Appendix 2 and 3.

Study Design and Data Collection

Authors of four of the included publications did not report the study design used.⁸⁻¹¹ Three described their study design as qualitative description¹²⁻¹⁴ One each was described as exploratory and reflexive,¹⁵ cultural framework for health,¹⁶ information-motivation-behavioural skills model,¹⁷ theory of planned behavior,¹⁸ and participatory model.¹⁹

Five studies used focus groups only to collect data,^{10,12-14,16} four used interviews only,^{8,11,15,17} two used focus groups and interviews,^{18,19} and another used interviews, focus groups and yarning circles.⁹

Country of Origin

Of the thirteen included studies, eight were conducted in the USA,^{10-12,14,16-19} and one each in Canada,¹⁵ the UK,⁸ Sweden,¹³ and Australia.⁹

Study population

The population of the thirteen of the included studies was made up of 408 women eligible for screening.⁸⁻¹⁹ There were no studies that focused on men's experiences with breast cancer identification. Two studies included seven health care navigators.^{9,14} Three studies included 71 other health care providers (e.g., screening technicians, general practitioners, oncologists).^{9,14,19}

Summary of Critical Appraisal

In general, included publications were assessed to be of moderate to high quality. Details of the critical appraisal can be found in Appendix 4.

One of the key issues affecting the quality of the included studies was the limited reflection on the relationship between researchers and study participants.^{8,11,14,16-19} For example, studies interested in exploring factors associated with adherence to regular breast cancer screening intervals among typically marginalized populations (as defined in the inclusion criteria). Framing research as an attempt to understand why people from these populations may not adhere to screening guidelines, and how to correct this, risks othering these women as abnormal and deviant. As such, without carefully considering the power dynamics at play in this encounter, how participants' responses are elicited and subsequently interpreted may be more reflective of the authors' perspectives than the participants. For this reviewer, the limited critical reflection along these lines was perceived as influencing the credibility of the subsequent study findings. Recognizing the potential power dynamics at play between researchers interested in exploring why some women may not adhere to screening guidelines for breast cancer could have helped improve the credibility of study findings.

Another key issue affecting the quality of the included studies was the sample population. Three studies^{11,13,18} focused on breast cancer screening (e.g., not diagnostic mammography) included either exclusively, or primarily only, those who were up-to-date

with screening according to current guidelines. Including only, or primarily, those who are up-to-date with screening recommendations privileges screening adherence and may miss concerns or structural barriers for people who are not up-to-date.

Summary of Findings

People's decision making around screening

The decision to engage with recommended mammography timeframes could be impacted by logistical challenges of attendance

Women described logistical challenges such as where one lived in relation to screening centres, the scheduling flexibility of screening centres, and ability to navigate responsibilities such as work or childcare as impacting their ability to undergo screening.^{9,11-14,16,17,19} While the exact look, meaning or severity of these challenges might differ along geographic, socioeconomic and racial lines, they were present across the broad majority of included studies.

For those who had received either unclear screening results (e.g. poor image quality) or results suggesting the possibility of cancer, decisions to pursue a follow-up diagnostic mammography could be influenced by logistical issues such as not wanting to interrupt upcoming travel plans.¹³

For people living in rural or remote locations, attending screening could be difficult as it required coordinating travel options with screening dates (e.g., asking for a ride from friends or family, catching public transportation), additional fuel expenses, and taking a day off work.^{13,19} Mobile mammography units that could travel to rural locations were generally appreciated by study participants living in these locations.^{9,13,19} For some who had recently lost access to mobile mammography units, there was a desire for them to be returned as they helped to alleviate some of the extra burden associated with screening.¹³ That being said, there was also an expressed concern about the accuracy of these units, and a few women indicated they had received poor imaging results and needed to follow up in a screening centre anyway.¹³

For some American Indian and Alaskan Native (AIAN) women living in remote locations, travel was further complicated by the modes of transportation needed to attend mammography appointments. The lack of functioning road systems meant fly-in (or ferry-in) communities relied on good weather conditions and accessible transportation schedules.¹⁹ As such, something as uncontrollable as high wind gusts could prevent women in these communities from making their scheduled mammography. Similarly, any cuts to transportation coverage or schedules could restrict the timeframes available for these women to travel for screening.

Living in the same city as the screening centre, however, did not necessarily alleviate these challenges as for some people travelling across town could be experienced as similarly arduous.^{16,17} While several women indicated needing to rely on family or friends to take them to appointments,¹⁷ for others, asking family or friends to drive might be out of the question as they were perceived to be too busy.¹⁶ Furthermore, public transportation fares could be expensive for some,¹⁷ and there is still the need to take off full days of work or find childcare.¹⁴

When scheduling screening appointments, some women found it difficult to ensure that they would be available months ahead of time. This could be difficult due to things like the variability in the weather and the impact this could have day of (as described above), new

jobs that they had worked at long enough to take time off, or childcare falling through. Timing of screening and the requirement this places on the attendee could also be difficult.^{11,9}

Several women expressed the desire to see services expanded to larger health care facilities, more clinic sites, more flexible hours.¹¹ They also described the helpfulness of having patient navigation services that could guide women through both pre-screening steps (e.g., scheduling appointments, ensuring appointments are achievable) as well as what happens if there is the need for follow-up due to potential or actual diagnosis.^{11,16,19} To support actually making it to appointments, some women suggested creating a buddy system of sorts: “say that some woman came in and she doesn’t have anybody. If there was maybe a buddy system where [the clinic] can call and say ‘we have this certain lady. If you’re not busy would you be able to bring her here?’ And maybe, you know, women would volunteer to help that way.”(p.7)¹¹

Finally, in some populations, there could be potential language barriers preventing women from feeling comfortable attending screening on their own (without someone to translate) and could ultimately discourage them from attending.^{10,16}

Awareness of the availability of breast cancer screening programs, the recommended guidelines for screening timeframes, and how screening could impact their lives varied

Several study participants indicated confusion over breast cancer screening guidelines, the availability of screening services, and what screening could do or detect. Some women and providers experienced screening guidelines as somewhat of a moving target.^{10,14,16} As one provider put it, “We as healthcare professionals, we can’t get the message straight. You’ve got one group saying every other year. You’ve got another group that says no, every year. You’ve got a group that says you’ve got to have an abnormal so that you can get a diagnostic.”(p.729)¹⁴. Conflicting messages make it difficult from women to feel comfortable with their own screening behaviour and decision making.

Some women, predominately from marginalized communities, indicated that people may not be aware of the screening services available to them or how screening could impact their lives.^{10,11} Even when people were aware of breast cancer screening services, there was concern about misinformation. “I think a lot of the community is misinformed about the education about preventative care, before you actually get the entire cancer or whatever. So I think education is the most important thing.”(p.6)¹⁰

In light of perceived limited levels of education regarding breast cancer screening, several participants suggested that flyers or brochures about breast cancer screening and the services available should be distributed to churches, grocery stores and other places that people frequent, rather than medical clinics. Women in these studies explain that while messaging is present within healthcare clinics, people who may not have access to clinics or do not attend may be less aware than others.^{10,11}

Some women from marginalized communities pointed out a reality that their communities are not the communities with screening centres in them.¹⁰ This, paired with a described underrepresentation of marginalized populations in breast cancer messaging, created a sense of not belonging in cancer care. As one African-American woman stated, “This is just my opinion – I think for the most part, breast cancer is seen as a White woman’s disease. So, it’s not something that we feel that is running rampant in our communities at least.”(p.730)¹⁴

How people understand their own bodies and their control over what happens to them could impact decisions to screen

While education about screening and its availability could certainly frame decisions to undergo screening (or not), women also described navigating their own perceptions of their bodies as a way of deciding on the importance of screening.^{8-10,12,15,16,19} As one woman put it, “I haven’t done the screening. I do not feel anything wrong with my breast, so why should I do the screening?”(p.S36)¹⁶ Conversely, women also described not trusting their knowledge of their bodies, “Yes, [screening] is important. It is often too late to receive treatment if we discover it by ourselves.”(p.S36)¹⁶

Some women described having other things going on in their lives that were more pressing than screening. This was especially the case for women living with mental health issues, living through phases of homelessness, or from typically marginalized groups.^{9,15,19} For women living with mental health issues, this could mean that while they valued what screening could offer, it was important to feel well or healthy in other aspects of life prior to pursuing screening.

And my body was going through a whole bunch of different changes through that. And so my logic was with what I’m going to through right now any tests that I have now is not going to be completely correct no matter what, because I’m not completely in a healthy status. So my logic was until you get yourself a little better and stronger, when you do, when you feel like you’re somewhere in an average ... something you feel that’s back to the normalization then you can go back to doing again your yearly check-ups. Whereas it’s not the best way to look at it but it’s less stressful and less pressure in thinking that right now I have a ton of things I’m worried about. If something is bad I really will not be able to handle that.”(p 5)¹⁵

The importance of feeling well otherwise took precedence in this woman’s life. Perceptions of risk, or the likelihood of having a negative screening result could also play into the decision to pursue screening or not. One woman put it this way,

I have the financial means, but don’t want to go back. I felt a little stupid for getting [a mammogram] done because I thought, ‘I’m fine.’ The next time ... I felt even dumber, ‘I’m fine.’ So, it’s harder for me to go back knowing that I’m fine. I know I’m supposed to do it, but I don’t feel there’s anything wrong. You’d almost rather have them say, ‘There’s a little something there, it’s probably not cancer.’(p.180)¹²

Repeated and consistent negative results helped this woman feel comfortable with her decision to stop pursuing screening. Had there been something abnormal found through screening, even if ended up not being cancer, this woman may have been more encouraged to continue. If otherwise well, it can be difficult for some women to find value in repeated and ongoing screening.

Trust in the health care system broadly, and primary care providers specifically, played a pivotal role in the decision to pursue screening, or not.

Women often trusted their primary care providers’ recommendations for screening and their ability to navigate how this fit within their lived realities.¹⁰ While, as has already been described, women suggested that support personnel do the brunt of the work guiding women through the screening process (e.g., setting up appointments, ensuring they were attended, following up with results and next steps), a positive relationship with one’s primary care provider could encourage confidence and comfort. As one woman indicated, “I appreciate

that my doctor goes through every – what I’ve done and what’s coming up. It’s just a conversation. I know in the summer I’m getting all my exams taken ...”(p.8)¹⁰

Similarly, clinical encounters with primary care providers could also feel out of touch with the lived realities of many women. This was particularly true for women from marginalized groups who described situations where their health concerns had previously been, intentionally or not, written off as inconsequential by their providers.^{9,15,16} While these may not have occurred in conjunction with their providers’ suggestions to attend screening, they could leave women questioning the value of their providers’ recommendation. One woman who lived with a mental health disorder described this by saying:

And so I couldn’t do what ... You know, worried about pains or ... when you can’t even walk, you know. And I can’t even concentrate – watching TV. And you’re telling this doctor that, and she doesn’t give a damn. And why go get a Pap smear or mammogram when they’d probably ruin you more. ... I don’t trust doctors. Doctors are not gods. And they don’t have wisdom. I doesn’t matter if they have years and years of experience.(p.8)¹⁵

While it is difficult to draw out exactly what this woman might have meant by wisdom, one way of interpreting this could be that the doctor in question lacked the ability to see her as a whole person. An attuned focus on the particularities of bodily health (e.g., it’s time for your Pap smear or mammogram) may not necessarily be felt as care. For example, this same woman continued, “... five years ago my [general practitioner] (GP) passed away, and he was a very old man. And he was the best. And you know, he was a gentleman. And he treated me like a lady. And ... now I don’t have anybody.”(p.8)¹⁵

Decisions to engage in breast cancer screening (or not) were often framed by others’ cancer or screening experiences

Many women described the ways that family members’, friends’ or acquaintances’ cancer stories impacted their own decisions to pursue screening (or not).^{10,12} Regardless of the form of cancer, seeing others around them and their bodily breakdowns could push women to pursue screening.¹²

My son’s stepmother ... was diagnosed with bilateral breast cancer. So, she had both breasts removed ... and that’s really made me come aware. It has even grounded me more as far as getting my yearly exams. ...[Breast cancer] brought up a lot of fear for myself because the first thing I thought about it, ‘My god, it spread to the lymph nodes and it’s pretty serious.’ ... I don’t know if I could handle that.(p.179)¹²

Unlike the way in which some women may decide to forgo screening out of a fear of not being able to handle a possible diagnosis, this individual uses the fear of treatment to pursue screening. This could also incorporate guilt for those who skipped out on early screening that may have been able to catch their cancer earlier.¹²

It was not always through watching someone live with cancer and its treatment that women were influenced to pursue screening, though. Others reflected on the strong example their own mothers or grandmothers had set regarding the importance of self-examination and mammography.^{13,15} Several women internalized this as similarly wanting to provide an example for their own children.^{13,17}

Some women talked about family history, either known or unknown, as influencing their decisions to engage with breast cancer screening.¹⁰ Some described themselves as coming

from families or backgrounds in which physical health, much less cancer, was not a welcomed point of conversation. As family history is one of the basic GP check points, this made some individuals feel as though they were flying blind. “My family is from Latin America and ... they don’t talk about anything in the past – which means I have no family history – which means I have no idea who died of cancer – who died of this, who died of that. ... So I’m flying blind.” (p.6)¹⁰

Breast cancer screening may be felt as responsibility rather than freedom

For many of the included participants, the idea of breast cancer screening was a norm.^{10,13} Screening had become so normalized for many that considered their biannual participation “a given” and “had never considered not to participate.”(p.4)¹³ That being said, it was also important for these same women to have the freedom to refrain from screening.

Perhaps due to the normalization of breast cancer screening, several women expressed the felt pressure and responsibility to pursue screening as a way of taking care of one’s self. For some who had not attended screening recently, or were not up-to-date, they described their decisions as stemming from laziness.

I make up excuses just to keep from going when I know it needs to get it [sic] done; I don’t go do it like I should. I complain, but ... I think it’ just laziness. If you care about you, then you should go and do it. It’s always excuses and always something that comes up. You can always find time to have things that are important done.(p.330)¹⁷

People’s experiences with breast cancer screening

It was important for people to feel comfortable with the individuals conducting the screening and the attention paid to their concerns while undergoing screening

Many women expressed discomfort with the screening procedure, both in terms of the physical pressing and prodding as well as who might be pressing and prodding. It was particularly important for many of the women to receive care from other women that were attentive to their concerns for modesty.

One woman spoke to the lack of respect she felt throughout a couple of her screening interactions. “It was let’s get the breasts in there, let’s get it done, let’s get it over, it’s like lunchtime, let’s go. She’s already had her first one and she knows what to expect. Bye-bye. ... It does mean it gets shoved in the priorities. Because it’s, OK I have to psych myself up for that kind of clinical approach.”(p.9)¹⁵

Limitations

One of the key limitations for this review stems from the low number of included studies that explored perspectives and experiences of women living in rural or remote locations. While the intent of this review was not comparative in nature, we had hoped to be able to describe points of divergence or convergence regarding screening between rural/remote and urban populations. Though this in no way minimizes the validity of the findings described above, their utility for jurisdictions interested in understanding how rural populations engage with breast cancer screening may be minimized.

Another key limitation is the limited reflection by many of the studies’ authors on how their approach (e.g., assumptions about screening, line of questioning, mode of analysis) may have impacted their results. As has already been described in the critical appraisal, this

lack of reflexivity has been judged to affect the credibility of some of the included studies – particularly those engaging with typically marginalized populations. This is primarily concerning in the sense that many of the included studies described their goals as being oriented toward changing the behavior of non-adherent peoples. Framed this way, the responsibility to adhere to screening could be felt as squarely on the shoulders of the people being engaged rather than health care systems.

While many of the studies came from jurisdictions with public screening programs, several also came from the US. This has some implication on the transferability of some of the findings as some concerns expressed by women included in these studies dealt with things like the ability to afford screening that do not apply to public screening programs.

Furthermore, while this review was meant to focus on both population level screening for breast cancer and follow-up diagnostic mammography, no eligible studies were found that focused specifically on diagnostic mammography. As such, though some studies included minor comments concerning experiences with or perspectives of diagnostic mammography, this review was unable to fully address that portion of the research question.

Conclusions and Implications for Decision or Policy Making

This review used a descriptive thematic analysis to synthesize the results of 12 included studies and described key facets of people's decision making around and experiences of breast cancer screening. Some of the logistical concerns associated with breast cancer screening included location of the screening centre, scheduling options, availability of support systems. When deciding to undergo screening, people's lives and the work it takes to attend screening appointments cannot be minimized in either rural/remote or urban settings. This is particularly important to understand for population level screening but may also be a factor for diagnostic mammography. While difficult to resolve all these concerns, it may be possible to mitigate them somewhat by providing access to patient navigators and by broadening locations where screening takes place.

While screening is not mandatory, many women described feeling as though they were expected to undergo screening in order to be viewed as responsible (both by themselves and by others). Decisions to undergo breast cancer screening may be dependent on the forms of knowledge people privilege. By and large, when aware of breast cancer screening programs, women indicated understanding their importance and potential to catch cancer earlier. When unaware, women described the importance of improving education on screening. Nonetheless, some women also indicated privileging their own knowledge and experiences of their bodies over general recommendations. This privileging could influence their decision to refrain from screening as they already believed nothing was there. As such, it would be important for screening programs to provide the space to refuse screening without minimizing women's experiences of their bodies.

Similarly, while breast cancer screening programs may be standalone services in some jurisdictions, several women described the ways in which experiences with other health care services influenced their decisions to pursue screening (or not). As such, it is important for providers and their jurisdictions to remember that health care may be experienced holistically rather than as discrete services. People who choose to refrain from screening may not be doing so simply out of fear or because they are unaware of the value of screening. Their refusal may be indicative of deeper concerns or general mistrust of their

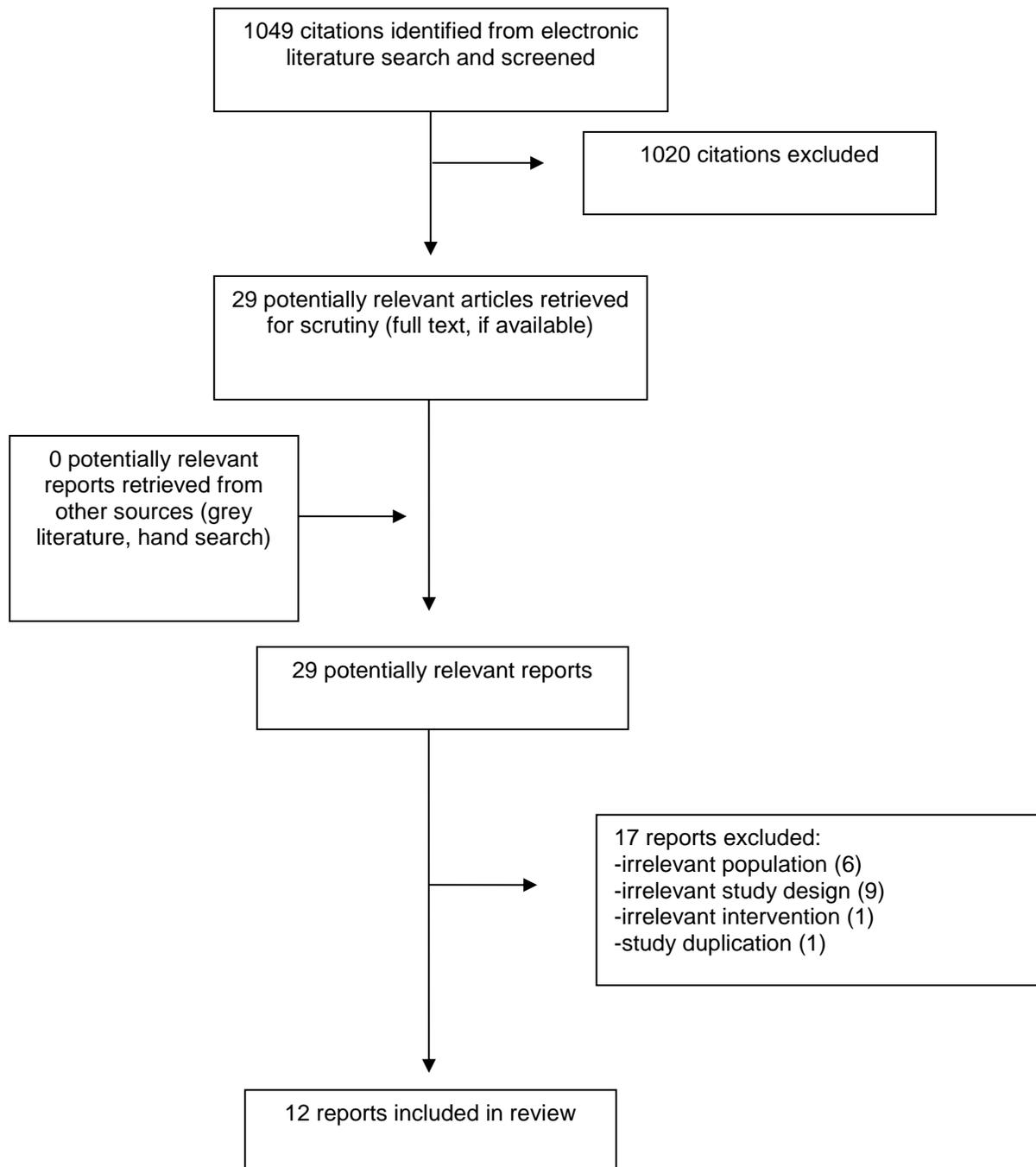
health care system. Thus, it may be valuable for screening programs to reflect on how they can foster trust among those eligible for their services.

While this tends to be well acknowledged within the literature, some women described feeling uncomfortable receiving care from male providers. Due to the intimate nature of breast cancer screening, it would seem important to ensure people have the option to engage in screening with providers of their choice.

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Appendix 1: Selection of Included Studies



Appendix 2: Characteristics of Included Publications

Table 2: Characteristics of Included Studies

First Author, Publication Year, Country	Study Design (Data Analysis)	Study Objectives	Sample Size	Inclusion Criteria	Data Collection
Moravac 2018, Canada ¹⁵	Exploratory and reflexive (thematic analysis)	To explore the factors influencing breast and cervical cancer screening decisions among homeless women and women with mental health challenges living in Toronto, Canada	13 women age eligible for breast cancer screening	Women aged 24-74 living in the homeless shelter system or in assisted living residences (due to mental health challenges) in the Central Toronto area who provided informed consent and spoke English	Interviews
Norfjord Van Zyl 2018, Sweden ¹³	Qualitative descriptive (content analysis)	To describe the experiences and perceptions about mammographic screening of participating women from three municipalities in a Swedish county	27 women	Women aged 40-74 residing in one of the three municipalities under examination, fluent in Swedish and had been invited to a mammographic screening in the county's facility	Focus groups
Marcu 2017, UK ⁸	NS (inductive, followed by deductive thematic analysis)	To understand socioeconomic status differences in the delay of diagnosis for breast cancer	30 participants	Women aged 47 years or older who had experienced at least one breast cancer symptom in the previous six months to the interview	Interviews
Passmore 2017, USA ¹⁴	Qualitative research design (grounded theory)	To explore the factors that influence decision to screen or not to screen among African American women in Prince George's County, Maryland	56 participants	NS	Focus groups
Pilkington 2017, Australia ⁹	NS	To examine perspectives on breast screening among Aboriginal women in WA, exploring the factors which impact on their	65 participants	NS	Interviews, focus groups, yarning circles

First Author, Publication Year, Country	Study Design (Data Analysis)	Study Objectives	Sample Size	Inclusion Criteria	Data Collection
		participation in breast screening			
Simon 2017, USA ¹⁶	Cultural Framework for Health (thematic analysis)	To describe the attitudes toward, and barriers and facilitators of, breast cancer screening among Chinese women in Chicago's Chinatown	47 women	Females aged 45 or older who self-identified as Chinese, could speak Cantonese or Mandarin Chinese, and lived in Chicago's Chinatown	Focus groups
Wells 2017, USA ¹⁷	Information-Motivation-Behavioral skills model (grounded theory)	To theoretically and collectively understand low-income African-American women's absence of mammogram screening	28 women	Women, unscreened or not current, who self-identified as African American, age 40-70 years old, who had not had a mammogram in the past 12 months, and were low-income and underinsured or uninsured	Interviews
Brandzel 2016, USA ¹⁰	NS (thematic and contextual analysis)	To obtain the perspectives of Black and Latina women on Group Health's (insurance provider) prevention reminder letter as well as their personal and cultural perceptions of cancer risk, cancer screening and general health care seeking	39 women	Self-identified as either African American, Black, or Latina; enrolled as a Group Health (insurance provider) patient for at least a year; no previous history of cancer; no hysterectomy before the age of 40; had not requested translation services for their health care	Focus groups
Padela 2016 ¹⁸	Theory of planned behavior (qualitative content analysis)	To identify within a diverse Muslim sample, salient behavior, normative and control beliefs impacting mammography intention and among these beliefs closely	69 participants	NS	Focus groups and interviews

First Author, Publication Year, Country	Study Design (Data Analysis)	Study Objectives	Sample Size	Inclusion Criteria	Data Collection
		examining those related to Islam			
James 2015, USA ¹⁹	Participatory model (content analysis and grounded theory)	To understand why previously researched issues related to breast screening for AIAN persisted and to identify factors that influenced how a subset of older women have responded to outreach and screening opportunities offered by tribal NBCCEDPs	33 AIAN women 12 NBCCEDP staff	NS	Focus groups and interviews
Purtzer 2014 ¹²	Qualitative descriptive (constant-comparison)	To use transformative learning to investigate what experiences serve as catalysts for mammography screening, the cognitive and affective responses that result from the catalyst, and how screening behavior is impacted	25 participants	Low-income women aged 40 years or older	Focus groups
Ragas 2014, USA ¹¹	NS (inductive methodological approach)	To help bridge the gap in patient-driven perspectives by gathering patient's recommendations for improving access to breast and cervical cancer screening and follow-up care.	52 women	Low-income women how had received an abnormal breast or cervical cancer screening result or a positive cancer diagnosis	Interviews

NS = Not specified; NA = Not applicable; AIAN = American Indian and Alaskan Native; NBCCEDP = National Breast and Cervical Cancer Early Detection Program

Appendix 3: Characteristics of Study Participants

Table 3: Characteristics of Study Participants

First Author, Publication Year, Country	Sample Size	Sex (% female)	Age range in years	Screening history (n=)
Moravac 2018 ¹⁵	13 women eligible for breast cancer screening	100%	24-74	Never screened (5) Underscreened (4) Up-to-date (4)
Norfjord Van Zyl 2018 ¹³	27 women eligible for breast cancer screening	100%	42-74	Irregular screening (2) Up-to-date (25)
Marcu 2017 ⁸	30 women	100%	47-81	Screened (15) Not-screened (15)
Passmore 2017 ¹⁴	56 participants comprised of: 26 African-American women 6 health care navigators 24 stakeholders or leaders on breast cancer in African American community	African American women: 100% Navigators: NS Stakeholders: NS	African-American women:42-64	Screened at least once in last five years
Pilkington 2017 ⁹	65 participants made up of: 35 AHW 29 Consumers 1 supporter	91%	24 – 64	NS
Simon 2017 ¹⁶	47 women	100%	46 - 65	NS
Wells 2017 ¹⁷	28 women	100%	40 – 70	Screened within last 13 – 24 months (21) Underscreened (6) Never screened (1)
Brandzel 2016 ¹⁰	39 women	100%	30 – 60	NS
Padela 2016 ¹⁸	59 participants	100%	40 – 74	Have had a clinical breast exam (60) Have had a mammogram (51) Mammogram within last two years (40)
James 2015 ¹⁹	33 AIAN women 12 NBCCEDP staff	AIAN women: 100% NBCCEDP staff: NS	AIAN women: 40 – 80 NBCCEDP staff: NS	AIAN women: NS NBCCEDP staff: NA

Purtzer 2014 ¹²	25 participants	NS though assumed to be 100% women	43-77	Never screened (3) Underscreened (9) Up-to-date (13)
Ragas 2014 ¹¹	52 women	100%	21 – 65	Screened (52)

NS = Not specified; NA = Not applicable; AIAN = American Indian and Alaskan Native; NBCCEDP = National Breast and Cervical Cancer Early Detection Program

Appendix 4: Critical Appraisal of Included Publications

Table 4: Critical Appraisal of Included Publications

Qualitative Studies Assessed Using CASP Qualitative Checklist ⁴										
First Author, Year	Clear statement of the aims of the research?	Qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participants been adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?	Clear statement of findings?	Relevant to the current review?
Moravac 2018 ¹⁵	+	+	+	+	+	+	+	+	+	+
Norfjord Van Zyl 2018 ¹³	+	+	+	+	+	+	+	+	+	+
Marcu 2017 ⁸	+	+	+	+	+	-	+	+	+	+
Passmore 2017 ¹⁴	+	+	+	+	+	-	+	+	+	+
Pilkington 2017 ⁹	+	+	NS	+	+	+	+	+	+	+
Simon 2017 ¹⁶	+	+	+	+	+	-	+	-	+	+
Wells 2017 ¹⁷	+	+	+	+	+	-	+	+	+	+
Brandzel 2016 ¹⁰	+	+	NS	+	+	+	+	+	+	+
Padela 2016 ¹⁸	+	+	-	+	+	-	+	-	+	+
James 2015 ¹⁹	+	+	+	+	+	-	+	-	+	+
Purtzer 2014 ¹²	+	+	+	+	+	+	+	+	+	+

Table 4: Critical Appraisal of Included Publications

Qualitative Studies Assessed Using CASP Qualitative Checklist ⁴										
First Author, Year	Clear statement of the aims of the research?	Qualitative methodology appropriate?	Research design appropriate to address the aims of the research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed the research issue?	Relationship between researcher and participants been adequately considered?	Ethical issues been taken into consideration?	Data analysis sufficiently rigorous?	Clear statement of findings?	Relevant to the current review?
Ragas 2014 ¹¹	+	+	+	-	+	-	+	+	+	-

+ = yes; - = no

Appendix 5: Additional References of Potential Interest

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