

# Access to Cancer Screening for Women with Mobility Disabilities

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**Abstract** Women with mobility disabilities are less likely to access cancer screening, even when they have a primary care provider. The Gateways to Cancer Screening project was initiated to document the challenges for women with disabilities in their access and experiences of screening for breast, cervical and colorectal cancer. The study followed the tenets of participatory action research. Five peer-led focus groups were held with 24 women with mobility disabilities. Study participants identified multiple and interacting institutional barriers to cancer screening. Their discussions highlighted the complex work of (1) arranging and attending health-related appointments, (2) confronting normative assumptions about women's bodies and (3) securing reliable health care and information. These overlapping, mutually reinforcing issues interact to shape how women with disabilities access and experience cancer screening. We explore implications for redesign of cancer screening services and education of health providers, providing specific recommendations suggested by our participants and the findings.

**Keywords** Cancer screening · Community based research · Focus groups · Women with disabilities

## Introduction

Cancer screening is offered for the prevention or early detection of breast, cervical and colorectal cancers. Adherence to breast and cervical screening guidelines in Canada has resulted in declines in mortality [17]. There is evidence of less participation in cancer screening among certain populations [8, 15]; people with disabilities are four times more likely than non-disabled people to report inability to obtain necessary medical care, including screening [3]. Adult women more frequently report disability than men [26] and they face systemic, architectural, procedural and attitudinal barriers to cancer screening [5, 24]. Fewer disabled than non-disabled women receive Pap tests, clinical breast exams or mammograms, faecal occult blood tests (FOBT) or sigmoidoscopy [6, 19, 20].

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The apparent mismatch between available health services and the needs of subpopulations [11, 21] calls attention to the structural barriers posed by the health care system and the ability of providers to offer appropriate care to individual patients [1]. Detailed descriptions of people's experiences in seeking and obtaining health care offer insights into access to and exclusion from health services [2, 21]. Recent Canadian studies suggest that the institutional organization of health care may contribute to social relations of marginalization experienced by lesbians [22], women with low incomes [9], women of colour [18], older women [23] and aboriginal women [10]. While a publicly funded health care system arguably contributes to *availability* of treatment, these studies illuminate women's agency in *accessing* this care within a context of asymmetrical opportunities, but no similar studies have documented issues of access to cancer screening for women with disabilities.

### Project Purpose

Community-based participatory research (CBPR) methods are used to understand issues with current health services, obtain insider perspectives and stimulate knowledge exchange by facilitating collaborative dialogue between researchers, clinicians and members of specific consumer communities [12, p. 1,215]. CBPR studies are often generated by community members who confront gaps in health services [12, 14]. The third author, a woman with mobility disabilities and a peer support coordinator, encountered extraordinary social and physical discomforts in accessing breast cancer screening, so she collaborated with a clinical nurse specialist in breast health and a community worker with the Canadian Cancer Society to develop a funded project. The research team grew to include additional disability rights activists, community workers, health care providers and community- and university-based health researchers. The project goals were to (1) obtain views from women with mobility disabilities about breast, cervical and colorectal cancer screening and (2) illuminate constraints and facilitators to screening access.

### Methods

CBPR takes a pluralistic approach to research methods, with emphasis on judicious selection from the range of available techniques that suit the research purpose [14]. The research team decided to conduct focus group discussions because they (1) are suited to exploration of participants' views, (2) allow participants to share ideas and generate new insights together and (3) offer flexibility to probe unexpected directions taken during discussions

[7, 16]. A key principle of CBPR is equitable involvement of community members in all stages of the research process [12, 14]. All members of the research team, including three women with mobility disabilities, contributed to problem identification, methods design, data collection, analysis and dissemination of findings. The project team also consulted an advisory panel of key community informants at major points in the study. These key informants were women with mobility disabilities who were involved in health services, disability studies, advocacy, policy analysis and peer support, and all were experienced health care consumers. Another characteristic of CBPR is its action orientation and "commitment to the translation and integration of research results with community change efforts" [14, p. 51].

### Outreach and Recruitment

Ethics approval was obtained from the University of Toronto Research Ethics Board. We conducted outreach to a range of over 44 community organizations, including advocacy and support groups, to invite women with mobility disabilities from various demographic backgrounds. Partner organizations supported recruitment through newsletter articles, website postings, circulation of outreach flyers and word-of-mouth. We recruited women older than 18 years who had no previous history of breast, cervical or colorectal cancer. We did not define mobility disabilities in terms of specific diagnoses or health conditions; rather, we invited participation of women who self-identified as living with mobility disabilities.

### Data Collection

Five focus groups were held with 24 women with mobility disabilities. Of these, two were identified as lesbian, seven were identified as belonging to a non-dominant ethno-cultural group and seven stated they were living in poverty or financial hardship (see Table 1). Discussion topics, questions and the approach to discussion were informed by a systematic literature review and suggestions offered during a round table discussion with key informants.

We planned for focus group environments where participants could openly share their views. The groups met in accessible locations in one of three areas of the city. Arrangements were made to accommodate access needs identified by the women, such as attendant services, food allergies and childcare. Two team members with mobility disabilities and extensive experience in peer support and disability advocacy facilitated the discussions. Key informants and team members expressed concern that some participants might be silenced by lack of previous exposure

**Table 1** Demographic characteristics of focus group participants

Demographic characteristics	Number of participants ( <i>n</i> =24)
Age	
20–39	7 (29%)
40–59	12 (50%)
60–76	5 (21%)
Mobility disability	
Congenital	12 (50%)
Acquired	12 (50%)
Identification	
Non-dominant ethnoracial membership	7 (29%)
Lesbian/bisexual/transgender	2 (8%)
Living in financial hardship	10 (42%)

to information about cancer screening, so meetings began with a brief educational presentation by the clinical nurse specialist. This provided a common base of information as a point of departure. Questions were posed verbally and projected simultaneously on a screen to allow participants to re-read and reflect on them as desired (see Table 2—Focus Group Questions). Discussion points were written on a flip chart, and reviewed at the conclusion of discussion to validate understanding, ensure all ideas were captured in discussion and invite further comments. At the end of each session, participants received a package of informational resources and a \$50 CDN honorarium.

**Table 2** Focus group discussion questions

1. People maintain their health in different ways. What do you do to try to stay healthy?
2. Where does cancer screening fit in with your overall healthy living?
3. Now let's talk about mammography for a little while. What experiences have you had with mammography?
  - a. Probe: what might limit your access to mammography?
  - b. Probe: what accommodations would help you feel more comfortable in accessing mammography?
4. Let's move on to discuss pap tests, or cervical screening. What experiences have you had with this? (same probes)
5. Last but not least, what about colorectal screening? Could you tell us what experiences you've had with that? (same probes).
6. Women with disabilities are not all the same; they come from very rich and diverse backgrounds of culture, sexual orientation, age, and income. In what ways has your unique background contributed to your experiences with (or access to) cancer screening?
7. In a perfect world, what would exist to make cancer screening a positive experience?
8. What are some strategies the healthcare system could use in order to reach more women with disabilities?

## Data Analysis

Similar to many CBPR projects [4], the university and community team members all worked together on analysis of the focus group transcripts, beginning with regular debriefing meetings to review new information after each focus group. Analysis involved regular group meetings to read, annotate and reflexively discuss transcripts; develop a coding scheme; and interpret data filed under each code [4, 16]. Each team member offered unique insights to the interpretive analysis. Findings were presented to members of the key informant panel, who verified and elaborated on the themes.

A major emergent theme was the emotional, physical and coordinative work done by women with disabilities to circumvent barriers and connect with opportunities for health care. Focus group participants described their efforts to overcome complex and overlapping institutional structures. During review of the transcripts, the team noticed that focus group participants offered rich descriptive detail about the work involved in managing their health needs in general, and cancer screening in particular. This reminded some team members of the writings of many social scientists, who recommend that researchers pay attention to individual agency (what people do in response to contextual problems). Analysis was deepened by drawing on Smith's call for a generous understanding of work [25]. Work is anything people undertake that is intentional, takes time, “under definite conditions and with whatever means and tools, and that they may have to think about” [25, p. 152]. Thus, work is context-based, often grounded in cognitive or affective processes. It may be invisible and undervalued, even by those who participate in it. This lens enhanced our understanding of access to cancer screening for women with mobility disabilities.

## Results

Focus group discussions indicated that many women had an ongoing interest in personal health. They actively avoided episodes of ill health because of past negative experiences (including physical and psychological trauma), as well as the additional effort involved in seeking care and treatment when ill. Access to cancer screening involved three areas of complex work: (1) arranging and attending health-related appointments, (2) confronting assumptions about women's bodies and (3) seeking reliable health care and information.

### Arranging and Attending Screening Appointments

Participants described their encounters with architectural barriers to health care, but described many additional

constraints, which often combined to create frustrations when they sought cancer screening or other forms of health care. First, a primary care provider was required to perform or order the screening procedures, yet some women had difficulty overcoming this gatekeeping phenomenon: *Right now I'm my own advocate. If I want a test now, I have to literally go and beg. The politics I've had to play to get tests are ridiculous. When you're disabled, I find you're put on the lowest part of the list.* Furthermore, many women had complex medical conditions, requiring attention to multiple issues during health appointments, additional time and assistance to move about and communicate. Participants' anecdotes suggested that providers might assign low priority to health promotion or screening under these circumstances. For example, one woman was refused a colonoscopy because of her history of respiratory illness: *I requested a colonoscopy and I had a doctor that I wasn't impressed with to say the least. He basically said, "I don't want to do this because of your disorder and I'll have to sedate you and you may not come out of this alive." But I'm really proactive about my respiratory health and I go to sleep studies every other year but that was never asked.*

To attend health appointments, other resources were required but these could be difficult to obtain or coordinate. For example, transportation was a major problem for most. Transportation systems for citizens with disabilities bear several similarities to institutionalized health services: both are structured around the requirements of service providers, subject to unpredictable delays and unable to accommodate last-minute rescheduling. Women could be late for appointments because of delayed pick-up and they sometimes missed connections with return transportation because of long waits in clinics. Both systems interacted to create stressful and marginalizing experiences, as one woman described, based on her visits for mammograms: *Another thing is not having accessibility to change rooms. The women change in little cubicles but there are none for me [that accommodate her scooter]. It can take a half hour to find another room, or I end up changing in the ultrasound room or x-ray. All of this takes time and then I can't catch Wheel Trans on time.* Another woman experienced appointment cancellations on short notice and was penalized for cancelling her transportation arrangements: *A lot of people who go for doctor's appointments take Wheel Trans and doctors don't take that into consideration. They cancel within 24 h and the person who booked [transportation] gets hurt. And it's difficult to book rides, anyway.* Severe weather conditions intensified transportation challenges. Even the focus groups were organized around such considerations; although they were given clear information about the time schedule when invited to focus groups, the participants still reminded facilitators to finish the sessions well in advance of their scheduled pickup times in case

transport arrived earlier than expected and left without them. They remained engaged in the work of timing and being "on time".

Attendant services were often required for women to attend health appointments and prepare for procedures. These arrangements also had to be carefully coordinated and scheduled. They sometimes involved social discomforts or invasions of privacy that participants preferred to avoid, if possible: *I live in a building that provides support, but it's very difficult to get a staff person available for the length of time [to attend medical appointments]. So I don't ask for that type of assistance unless I absolutely need it. I've gone to all of my doctor's appointments by myself also due to the privacy issue.* Strategic restriction of her use of attendant services enabled her to protect her privacy, but also demonstrates a rationing of services to ensure availability when need is greatest. Access to attendant services for assistance with screening activities such as breast self-examination or stool testing was limited by payment structures, job descriptions and scheduling restrictions. However, one woman found a clinic where extra time and assistance were available to make her comfortable during a Pap test: *No one was willing to give me one because of my spasticity... It's hard to find someone willing to go the extra mile. But [at new clinic] there were nursing assistants to help and they gave me extra time so they didn't have to rush. My muscles become more spastic if I'm rushed. So they made accommodation for me.* Colonoscopy preparation and obtaining specimens for FOBT produce challenges for women who use wheelchairs and require attendant support for toileting assistance as handling of stool specimens varied with each attendant and agency. In such situations, the women worked within the boundaries of others' schedules, but bodily functions and health appointments are not easily synchronized with attendant availability.

Ultimately, participants were responsible for the coordination of services required to prepare for and attend screening appointments. This coordination had to be responsive to the sometimes-conflicting operating principles of different institutions. This could involve initial contact with primary providers for referral; multiple telephone contacts to arrange appointments for screening, transportation and attendant care services; envisioning, organizing and following up with any required bodily preparation; and then communicating required accommodations to providers. This additional work could deter women from uptake of cancer screening.

### Confronting Assumptions About Women's Bodies

The women who had received screening or other procedures described emotional, interpersonal and physical work



to prevent embarrassments, vulnerabilities and bodily predicaments. Many issues arose from normative assumptions about the function and form of the female body. These were inscribed within referral, intake and appointment scheduling; the type and placement of furniture within waiting rooms; expectations and knowledge of providers; and design and use of equipment for screening. Like several others, this woman found that the design of mammography equipment placed her in a precarious and embarrassing situation, which she wryly commented “*could have been a sitcom*”: *The assumption was that I could stand. I used my walker and I found that I stood and this thing came down on my breast and I was okay, but this was uncomfortable. At one point I was so off balance that I thought, ‘I’m going to fall and my breast will remain in this machine!’ It was definitely difficult.... I thought I should maybe go on a stool. I’m a short person so it was already hard because of that. So I was dangling on my tippy-toes as well. I don’t know if there’s a wheelchair accessible one...or one that goes lower.* Thus, inscribed within this machinery was the expectation that all women’s bodies conform to certain dimensions of height, flexibility and balance. Furthermore, this standardized design required the speaker in the above anecdote to do the physical work of accommodating the machine, rather than the machine accommodating her. Women (including seniors) who have tremors, experience spasms or who lack the stamina to stand at an imaging machine would also benefit from being securely and safely seated for more accurate screening.

In focus groups, participants shared anecdotes about health providers’ responses to questions about screening. A frequent topic was the frustration of not being listened to, despite experiential knowledge of their bodies and health needs. As one woman explained, clinical interactions contributed to a silencing of her questions and a disregard for her accumulated knowledge about her own body and health: *I find that doctors are just as cold as regular people and they talk to the person with you instead of yourself. It’s like you’re invisible and it’s not a good thing because it doesn’t give us a level of comfort. It’s our body and we can sense what’s wrong and we know what is normal and what is not normal.* An attendant accompanied one woman to the focus group session to assist with communication. The attendant described her client’s treatment by a technician during a mammogram and her own efforts to advocate: *[client] was getting dressed and the technician started cleaning the machines while we were still there. She also was talking to me in front of [client] about how bad she feels about people with disabilities. I told her that I think it’s inappropriate to have this conversation in front of [client].* Such situations resonated with many of the women who repeatedly encountered similar interpersonal issues on a daily basis in other sectors of society.

According to some, tensions over these everyday occurrences tended to accumulate. This woman described wanting to hide at home when she was made to feel socially conspicuous in her struggles with architectural barriers: *Even with a walker, there’s a little step and you stand there and people look at you. It’s a very tough world out there and I’m beginning to feel I should stay home, but I don’t want young disabled people to feel like that.* Participants continuously navigated paradoxical intersections of visibility and invisibility, where they were at some times silenced and at others, traumatized by unwelcome scrutiny. Their numerous examples showed us that there were no “*isolated instances*” of marginalizing experience. Instead, we saw that normative assumptions about bodies are deeply enfolded within material culture, scientific knowledge and social relations across multiple institutional sites.

From this experiential perspective, the women offered their insights into the assumptive basis of cancer screening. One woman commented that an “*assumption about asexuality around people with disabilities*” was no less problematic than the heteronormative biases she encountered with queer sexuality: *Having a more open concept of gender identification and sexuality is important. There are the general categories, but there are also other categories.* Participants expressed surprise and disappointment that the professionals whom they most expected to understand the issues of disability seemed complicit in social relations of marginalization. Within the primary care encounter, the focus on standardized physiological indicators and functions can map onto existing social expectations about women’s bodily appearance and sexual comportment. Participants found this disturbing and some responded by abandoning efforts to self-advocate or by avoiding situations where they required health care.

### Securing Reliable Health Care and Information

During initial educative segments of the group meetings, the frequent questions indicated that many women were not receiving sufficient information from their primary care providers. Also, past negative experiences with health care, when combined with social exclusions and ill treatment encountered in everyday settings, led to a cautious and strategic approach. Several participants described themselves as proactive in protecting their health needs. While many were not engaged in regular cancer screening, they were knowledgeable about their own health issues and highly attuned to the shifts in their bodily wellbeing: *I do take medication for the things that really matter but I always check before I take something. Both times I’ve been offered medication I’ve checked the side effects. There were side effects sometimes that I hadn’t been told about. If you have neurological problems you tend to be very sensitive to*

*side effects. Health strategies were learned through trial and error, active engagement with a wide variety of information sources, contact with peers and, occasionally, individualized teaching by health professionals. As one woman indicated, this work supported her survival and involved selective attention to various sources of knowledge. I don't rely on my doctors for up-to-date information. I very much rely on what I hear from others, and the radio and internet. For me it's reflexive because if I hadn't been that way from a young age—we were all supposed to be dead. Another woman explained that she had access to multiple sources of information about health issues, but still was waiting for materials specifically addressed to people with disabilities: I know about screening because I found out about it through other sources, not specifically a doctor. I work for the federal government and they have a lot of health related events where people come from different organizations. But there's nothing I've seen in print yet specifically oriented towards people with disabilities.* At many points, the focus group discussions turned to information exchanges among participants, confirming the importance of peer health teaching and support. However, peer exchanges could also discourage women from seeking screening, because negative experiences were sometimes shared between friends: *My girlfriend went and when she told me about the power going off while she had her boob in the machine. Now I don't want to go!*

In some cases, participants described encounters with providers that were receptive to self-advocacy and engaged with clients in a dialogic manner to understand their health needs. This set the tone for what one woman described as *pro-active* care in which her knowledge was heeded and recognized; another woman valued providers' willingness to “brainstorm” with her to tailor interventions to suit her bodily responses. One woman grew tired of being given “off the rack advice” and found a doctor who *...did not think like everyone else.... like if I had a side effect or something, he would care to investigate why. I am so thrilled, as in the past I didn't even want to go the doctor and had to do things a particular way and couldn't get my legs to stay straight or whatever and it was an ordeal when going to the doctor. Now the doctor thinks of different ways to examine me.* This woman's previous pattern of avoidance was changed by her new provider's efforts to collaboratively learn with and from her, illustrating the value of information exchange and dialogue between health providers and women with disabilities.

Some participants had connected with accessible health centres. These settings offered longer appointments to reduce pressure and provide ample time for questions. Accessible rooms and equipment, as well as attendant care enhanced comfort: *Joining [accessible health centre] was very good for me... I feel very comfortable going there. The*

*doctors I've dealt with, and the nurses are amazing. One lady comes to help you dress... This takes the stress off me for going to the doctor.* Yet one woman questioned the logic of creating designated health facilities for women with disabilities: *My doctor's really good about accommodating me and positioning and that's really all I need. But I like the idea of....a utopian vision, I don't like the idea of going to a place just because it's the most accessible.* Her position was that all providers and clinics ought to be astute to the needs and situations of people with disabilities; architectural accessibility was a secondary (but still important) consideration. Unfortunately, accessible, astute health services and providers were themselves invisible, because they were not widely publicized. The women wanted help to find reliable health care, but their major strategy was word-of-mouth information from peers.

## Discussion

The study's findings offer insight into challenges that may partially account for lower levels of cancer screening in women with disabilities [6, 19, 20]. Participants' health-seeking activities and struggles pointed to the accumulation of marginalizing social relations within, and external to, institutional health care [25]. Basing analysis in Smith's [25] conceptualization of work illuminates the multiple ways that women with mobility disabilities negotiate access to health care and cancer screening. Women were active in arranging and attending health-related appointments, counteracting assumptions about women's bodies in cancer screening and securing reliable health care and information. Participants met challenges by marshalling what resources were available (such as designated transportation services), but they encountered further barriers and performed additional work in the process. These chains of activity point to a context of overlapping, mutually reinforcing constraints that complicate access to cancer screening for women with mobility disabilities. Women with mobility disabilities may be deterred from seeking cancer screening by the additional effort required, providers' lack of preparedness, silencing of questions or suggestions, normatively designed procedures and equipment and scarcity of barrier-free primary health providers or clinics.

Screening procedures create sensitive social experiences that involve bodily exposure and varying degrees of physical and interpersonal discomfort [13]. Stories shared by our focus group participants suggest that clinical encounters are structured by assumptions about the form and function of women's physiological and social bodies. Unpleasant experiences around screening resonated with other similar situations encountered by participants across a range of everyday sites. These situations had the disconcerting

effect of simultaneously silencing participants and subjecting them to intense scrutiny. Health services and providers may therefore be complicit in social relations that marginalize women with mobility disabilities.

### Limitations of the Study

Women with disabilities may be isolated from social participation and may experience intersecting forms of marginalization, based on additional axes such as race, ethnicity, class and/or sexuality. Concentrated and inclusive recruitment strategies are required to reach them. We used multiple forms of outreach, with modest success in recruiting a diverse sample, but more marginalized and isolated women may not have been represented. Participants' descriptions of work and self-advocacy may not be representative of all women with disabilities, but they illustrate the effort required to navigate the health care system. Given the importance of peers as a source of health information, isolated women may encounter greater barriers. Further research is needed with more diverse samples.

### Recommendations

Access to cancer screening services for women with mobility disabilities can be facilitated by primary care facilities with multidisciplinary team-based practice, especially when accessible equipment and screening technology is complemented by on-site attendant care. These facilities should be widely publicized to women with disabilities, tapping into communication networks established by peer support and community organizations for people with disabilities. Designated providers could address disability-related needs prior to screening procedures and offer health promotion sessions for women with disabilities. However, some women may not live close to or prefer not to use designated primary care facilities. Training for health providers could also aim to create safe spaces for women with mobility disabilities, recognizing that these women may also claim diverse ethno-racial, socioeconomic and sexual identities. Women with disabilities value providers who share the work of developing expertise in their health needs. In a dialogic spirit of knowledge exchange, providers could elicit women's health priorities and acquired expertise in bodily responses, but be prepared to offer new information when it is required.

Cancer education messaging should include disability-positive images and information that supports self-advocacy. Women could show these materials to their primary care providers when initiating discussion of cancer screening. Furthermore, professional education is essential. Members of the Gateways Team have forged successful partnerships between health educators and supportive

community organizations to offer information workshops and are currently conducting a knowledge transfer study with health professionals at local hospital breast health clinics. Finally, patient-centred and integrated preventive cancer care should aim to recognize and reduce coordinating work for patients with disabilities. These recommendations may serve to interrupt chains of work that challenge access and deter participation in cancer screening.

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