

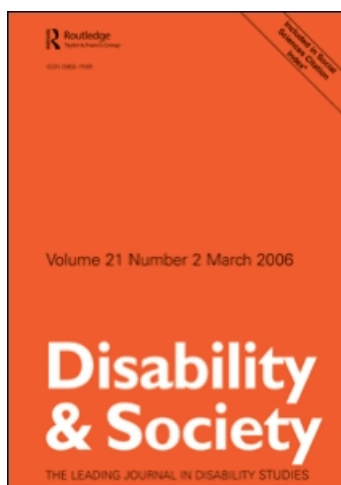
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Navigating healthcare: gateways to cancer screening

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Navigating healthcare: gateways to cancer screening

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This article is the first phase in the Gateways to Cancer Screening project – a user-driven participatory research project that examines barriers and facilitators to preventive cancer screening for women with physical mobility disabilities. Through a systematic review of the existing literature on this subject we discover that, despite the fact that women with disabilities have the same biological risk of developing cancer as non-disabled women, women with mobility impairments face systemic, architectural, procedural and attitudinal barriers to preventive cancer screening. Our goals are to identify barriers and facilitators to screening, identify the gaps in the existing literature related to issues of diversity and ultimately set the stage for disabled women to effect change through the telling of their own stories.

Keywords: cancer screening; women's health; participatory research; health policy; intersectional oppression; health care services

Introduction

All physical bodies are vulnerable. As human beings we are continually threatened by disease, breakdown and loss of function. In Canada universal healthcare is a social and political right and a founding principle of the Canadian healthcare system. Healthcare access can be included as a basic tenet of human rights and social inclusion and a guarantee for full participation. Yet, despite these ideological principles, many people in Canada continue to experience marginal status in their access to healthcare based on disability, race, sex, gender, sexual orientation, income, geographic location and/or resulting from experiences of trauma, violence, immigration or colonization (Pederson and Raphael 2006). In Canada there are over four million people with some kind of disability (Statistics Canada 2007). Preventive health services are offered routinely to individuals by healthcare professionals and are designed to prevent illness or detect it at the earliest possible time so it can be treated. Despite the fact that women with disabilities² have the same biological risk of developing all cancers as non-disabled women, women with mobility impairments face system, architectural, procedural and

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attitudinal barriers to preventive cancer screening (Nosek *et al.* 1995; Welner 1998). As a result, women with disabilities are frequently excluded from the care that most Canadians experience as a basic right.

In this article we draw upon existing literature to examine current screening patterns for women with disabilities. Our goals were to identify barriers and facilitators to screening and identify the gaps in the existing literature related to issues of diversity. We focus on cervical, breast and colorectal cancer screening of women with physical mobility disabilities. We also draw on international sources and studies to contextualize and theoretically ground these barriers on the macro scale. We employ the structural critiques offered by the social model of disability to expose gaps in public health data collection that obscures social and political variants in access to healthcare. Our starting point in this analysis is that healthcare experiences are ultimately embodied experiences. To address the issues surrounding these clinical encounters we begin at the micro level by exploring the interactions between disabled women and their healthcare providers through the lens of feminist frameworks about our bodies (Price and Shildrick 1999). We take the position that women's stories about their experiences can elucidate the intersectional nature of identity (Bloom 2002; Thomas 1999) and the implications of different types of oppression on the macro scale. In doing so, we recognize the emancipatory potential of flesh and bones stories in qualitative analysis to facilitate social change.

Project beginnings and participatory method

The project began when Linda Muraca, a nurse clinician at Mount Sinai Hospital in Toronto, Canada, joined Nancy Barry, a peer support coordinator at the Centre for Independent Living in Toronto, to provide a workshop on breast health for disabled women. During the session several women commented on the various barriers and frustrations they faced when they strove to look after their overall health needs. Some women commented that their doctors told them 'not to worry about these non-urgent health issues', while others described demoralizing experiences they faced physically (being forced to stand) and emotionally (not being directly communicated to) when they had a mammogram. The issues that participants identified formed the basis for the Gateways to Cancer Screening project. Sharmini Fernando, a diversity consultant at the Canadian Cancer Society (CCS) also joined as a community partner with the belief that effective cancer prevention programming requires community participation and service collaboration.³

The study was conceptualized as a qualitative needs assessment to identify the barriers faced by women with mobility disabilities in accessing screening and existing services, as well as identifying specific gaps in services. In response, the Gateways to Cancer Screening project brought together disability rights activists, community workers, healthcare providers and women's health researchers to assess these barriers and to stimulate change. The term 'gateways' was specifically chosen to denote facilitators to access care, rather than just identifying barriers. In view of critiques of research that excludes the voices of disabled people (Oliver 1998), Gateways took a participatory, user-driven approach. While this strategy is not new in social science research, it is still relatively uncommon in health services inquiry. Central to this project is the notion that small focus groups led by research team members who are also wheelchair users will empower the voices of disabled women to tell their own stories in their own language (Bloom 2002; Thomas 1999) about their experiences

with breast, colorectal and cervical cancer screening. Furthermore, an advisory panel composed of stakeholders from consumer and health services groups regularly met with the team to review progress.

As researchers we recognized the need to examine the impact diversity has on the experience of screening among women with disabilities and sought to include women who identify as ethno-racial, aboriginal, lesbian/bisexual/transsexual/transgendered and/or may be living on fixed incomes. The research team included women with and without mobility disabilities, as well as women identifying with other marginalized communities. The feminist disability literature is rich with analysis of the intersectional nature of embodied experience, as well as the silencing and systemic violence women with disabilities encounter in clinical settings (see, for example, Crow 1996; Frazee, Gilmour, and Mykitiuk 2006; Wendell 1999). Theorists of the social model of disability point out that a process of medicalization – where disability is framed as a ‘medical’ rather than ‘social’ issue – situates physicians as experts in the lives of disabled people and undermines self-determination (Barnes 1997; Braddock and Parrish 2001; Oliver 1990; Rioux and Bach 1994). A gendered disability analysis (Sampson 2006; Thomas 1999) highlights that, for disabled women, both the historical medicalization of disability (Barnes 1997; Rioux and Bach 1994) and the devaluation of women’s voices about their own bodily experiences (Wendell 1999; Thomas 1999) combine to create a series of distinct and interlocking barriers to healthcare access. In contrast, existing statistics compiled by Canadian and international health organizations fail to account for the multiple factors that influence disabled women’s access to cancer screening. Similarly, none of the research and prior studies we were able to access through an extensive literature search provided this kind of intersectional analysis of embodied experience.

Cancer and disability in Canada

Examining the basis of the public health data that determines health policy reveals the social values of a given society (Bryant 2006). The population health research we have compiled forms the basis of social policy on the macro scale, which in turn filters down to inform physician priorities and contour clinical practice on the micro scale. In this sense, the social values reflected in broad population data research become continuous with the day-to-day clinical interactions between disabled women and their doctors. Currently there is a lack of statistical data on women with disabilities, cancer rates and screening rates. Also, the paucity of research in this area means that practice is not adequately informed and may reinforce attitudinal barriers due to lack of knowledge.

In Canada cancer accounts for almost 27% of deaths annually (Statistics Canada 2005). Cancer control, strategies for cancer prevention and early detection and management are priorities for population health. There are estimated rates for cancer incidence and mortality available for Canadian women in general (see Table 1). Yet,

Table 1. Estimates for cancer incidence and mortality for women in Canada (2007).

Cancer type	Incidence	Mortality
Breast	22,300	5300
Colorectal	9400	4000
Cervical	1350	390

Adapted from Canadian Cancer Society/National Cancer Institute (2007).

no statistical information is available on the prevalence of cervical, breast or colorectal cancer among Canadian women with disabilities. This gap implicitly assigns value to bodies that are socially defined within normative standards as able-bodied.

At the same time as their social status is devalued, women with disabilities are just as likely to be at risk of developing cervical, breast and colorectal cancer as women without disabilities. Women with disabilities may actually be at an increased risk because they are more likely to be exposed to frequent X-rays, prolonged use of medications and differences in exercise, nutrition and childbearing practices (Mele, Archer, and Pusch 2005). If women do not participate in screening programs they may present with more advanced illness, which leads to fewer treatment options and a poorer survival outcome. Cancer is one of the leading causes of premature death in Canada and takes the lives of more people than strokes, respiratory disease, pneumonia, diabetes, liver disease and HIV/AIDS combined (Canadian Cancer Society/National Cancer Institute 2007). As such, barriers to participation in screening programs have a profound impact on the health of disabled women.

In the 2006 Canadian census 4.4 million adult Canadians reported having activity limitations, of whom approximately 2.4 million were women (Statistics Canada 2007). The disability rate increases with age, and women (15.2%) are more likely to report a disability than men (13.4%) (Statistics Canada 2007). Almost 2.9 million (11.5%) adult Canadians reported mobility-related disabilities, more of whom were women than men (Statistic Canada 2007). The profile of disability in Canada did not include statistics on minority representation. So, while statistics are separately available on cancer rates among women as a general population category, and on general rates of disability, no specific statistics are available for either variation within these populations generally or on cancer rates among disabled women specifically. Conceptualizing disability as a homogeneous category, without addressing additional experiences of difference, such as race, income and sexuality, is ultimately inadequate to fully describe the state of the entire population's health, and the health of disabled women in particular. If the goal of a universal healthcare system includes providing equal access to protection such as cancer screening for all members of society, an adequate foundation of information about the population is essential.

Rates of cervical, breast and colorectal screening

In the early stages of the Gateways project a review of existing studies on cancer screening for disabled women was undertaken. A systematic review of the literature was conducted to find existing studies on preventive cancer screening in women with physical disabilities. An online search was conducted to review information accessible through websites and to access electronic literature produced by, for example, government agencies, professional organizations, non-profit organizations and research centres. Electronic literature was sought because information on the Internet has become a major means of dissemination for many organizations. Electronic resources may also be easily accessed by women with disabilities. For some women with disabilities online access to cancer screening information may be the preferred way of accessing medical information (Crooks 2006). A search was also conducted of published literature using Medline, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Scholars Portal. The studies we found produced some useful statistics about rates of cancer screening that were highly relevant to our research project.

Of specific interest was a report released by the British Columbia Centre of Excellence for Women's Health in 2003 (Riddell *et al.* 2003). The document reported findings from a community action research project examining the barriers women with disabilities face in accessing gynecological and breast healthcare. One of the purposes of the study was to examine the extent to which women with disabilities receive cervical and breast screening. Surveys were sent out to women with disabilities in the community, providers known to provide services to women with disabilities and institutions that provided care to women with disabilities. Of the 278 women that responded to the survey (response rate 40%), 75% were between the ages of 31 and 60 years and 81% identified as having a mobility-related disability (Riddell *et al.* 2003). The results indicated that 11% had never had a Papanicolaou test (Pap test) or vaginal examination. Forty-three percent had not had a Pap test in at least 2 years and 18% in more than 5 years. Most went to the physician's office or hospital to have their examinations, while a few indicated that it had been done at home. The main reasons given for not having a vaginal examination in the last 5 years were: no one suggested it, inaccessible examination table, doctor said it was not necessary and not being sexually active. Although the majority of the women (89%) thought it was important to have regular Pap tests, it was evident that many of them were not receiving regular cervical cancer screening. In addition, most of the studies we assessed found that women with disabilities were less likely to receive cervical cancer screening than women without disabilities (Diab and Johnston 2004; Iezzoni *et al.* 2000; Nosek and Howland 1997; Nosek *et al.* 2001; Ramirez *et al.* 2005; Schootman and Fuortes 1999). Women identified by studies as having 'severe' or 'very severe' disabilities were among the most vulnerable groups and were least likely to receive cervical cancer screening (Chan *et al.* 1999; Nosek and Howland 1997).

The study by Riddell *et al.* (2003) further revealed that 30% of women with disabilities had not had a breast examination in at least 5 years and 12% indicated never having had a breast examination. The physician's office was the main site for examinations. The main reasons identified by the researchers regarding why women had not had breast examinations were an inability to do self-examinations and the fact that physicians were not suggesting this as part of their practice. However, the majority of women (96%) surveyed believed it was important for women with disabilities to have regular breast examinations (Riddell *et al.* 2003). Other studies also found that breast cancer screening rates are lower among women with disabilities (Diab and Johnston 2004; Iezzoni *et al.* 2000; Nosek *et al.* 2001; Ramirez *et al.* 2005; Schootman and Fuortes 1999; Schootman and Jeffe 2003; Verger *et al.* 2005). Women identified in the studies as having 'severe' and long-term disabilities were least likely to have breast cancer screening (Chan *et al.* 1999; Iezzoni *et al.* 2000; Schootman and Jeffe 2003).

Only two studies could be located that examined colorectal screening rates among people with disabilities. Diab and Johnston (2004) found that 'severely' disabled persons were significantly less likely to receive a proctoscopy and sigmoidoscopy, but did not speak specifically about women with disabilities. The researchers did state that women tended to receive these tests less frequently than men, but it was not explicit whether this statement applied to women with disabilities as well (Diab and Johnston 2004). In the study conducted by Ramirez *et al.* (2005), using data from the 2001 California Health Interview Survey, the researchers found that there were no significant differences in colonoscopy and sigmoidoscopy screening rates among people with and without disabilities. Again, there is no information about screening rates specifically for women with disabilities.

Biomedical language and methods perfuse these studies. Researchers ranked study participants based on medical diagnoses that conflate impairment with disability. Other more recent social science studies (see, for example, Crooks and Chouinard 2006; Driedger, Crooks, and Bennett 2004) have pointed out that the experience of disability is embodied and socially and spatially situated. So where traditional research methods might label a woman as 'severely' disabled (Diab and Johnston 2004), the woman herself might not describe her experience using such terms. In this example, after asking a series of questions to determine 'severity' of disability, this study went on to ask participants to identify activity limitations (Diab and Johnston 2004). The researchers then described a contradiction between the 'severity' of disability perceived by researchers and the level of activity limitation self-described by participants. The social model of disability (Oliver 1990) separates biomedical notions of impairment from social experiences of disability. Researchers using the methods outlined by the social model of disability (Barnes 1997; Braddock and Parrish 2001; Oliver 1990; Rioux and Bach 1994) and feminist theory (see, for example, Crow 1996; Frazee, Gilmour, and Mykitiuk 2006; Wendell 1999) might not perceive a contradiction in the answers of the participants. Questions that pathologize and rank the disabilities of participants do not translate easily into the experience of disability (in this case 'activity limitation') without reference to social supports, accommodations and the accessibility of one's living and working environments. Further, in order to rigorously examine the relationship between people's bodies and their screening patterns, research questions and practices need to draw on qualitative methodologies that empower participants to tell their own stories (Frazee, Gilmour, and Mykitiuk 2006; Thomas 1999; Bloom 2002). The findings on rates of screening for women with disabilities illustrates a pressing need for more information about the experiences of the women, as well as further investigation of the complexities that keep screening rates low among this population.

The next step is to move beyond homogenizing accounts of women's experiences and consider differences in age, race and sexuality in the context of disability. Only one study has reported on the differences in screening rates between women from various ethnocultural backgrounds. In the study by Diab and Johnston (2004), using data from the 1998 and 2000 Behavioral Risk Factor Surveillance System (BRFSS) nationwide telephone survey, the researchers found black and hispanic ethnicity, greater education and greater income were associated with higher odds of receiving a Pap test. The researchers also found that women with disabilities were more likely to receive a mammogram if they were hispanic, educated and had a higher socio-economic status. The higher rate of screening amongst these groups is potentially important, because it may provide an understanding how some women with disabilities from different ethnic backgrounds are able to navigate through and work with the system to meet their preventive healthcare needs. Unfortunately, these findings about racialized women are not framed within a social context. While higher levels of education and socio-economic status have been commonly identified with higher screening rates throughout the literature over the last several decades, racialized women have traditionally had significant barriers in accessing healthcare. Community health activists have launched many initiatives as a result, opening clinics and running screening programs specifically for black and hispanic women in the USA (Bickell 2002). If this is in fact the context in which these higher rates among racialized women exist, perhaps it suggests a potential strategy to advocate for increased services for all socially marginalized groups, and specifically for women with disabilities.

Clinical relationships in existing studies

Barriers to effective screening for women with disabilities include a lack of knowledge among women themselves of the need for preventive screening, neglect on the part of healthcare providers and physical access barriers (Nosek *et al.* 1995; Welner 1998). First, we will focus on clinical relationships between providers and women with disabilities. In the study by Riddell *et al.* (2003) focus group findings revealed four main themes: safety, accessibility, physician and information and attitudes. Some women addressed issues of safety, speaking of the need for healthcare providers to be knowledgeable and sensitive to childhood sexual abuse and violence against women with disabilities and the importance of creating a safe environment for these women. The women's characterizations of the physicians ranged from caring, creative and supportive to inflexible and insensitive. Locating a suitable physician was problematic for many of the women. Women indicated that they wanted physicians to be knowledgeable and comfortable with cervical and breast cancer screening, taking into account the woman's particular disability.

Furthermore, when women did find a good physician they attributed this to 'good luck' (Riddell *et al.* 2003). Health professionals' attitudes to screening had an impact on whether women received Pap tests or breast screening. The women acknowledged that they should share responsibility with healthcare providers in actively pursuing and advocating for accessible screening services. Surveys were also sent to 34 physicians known to provide care for women with disabilities. Eleven surveys were returned. All 11 reported that they performed breast examinations on all women with disabilities (Riddell *et al.* 2003). Thus, there seems to be a discrepancy in what is reported by the women and what is reported by the physicians. However, because the physicians that were surveyed were known to work with women with disabilities, they may be more aware of the screening needs of women with disabilities than other physicians.

In a telephone survey of 564 physicians in France, 27.3% reported screening women with disabilities less often than women without disabilities (Verger *et al.* 2005). The study identified certain characteristics of physicians that were associated with providing poorer screening among women with disabilities. These factors include the clinician being male, working in nursing homes, not belonging to health networks, lack of training and feeling discomfort with patients with disabilities. Physicians' own feelings of discomfort were strongly associated with providing less breast cancer screening to women with disabilities. Lack of assistance during consultations to move women with disabilities to examination tables and lack of adequate equipment were also associated with less frequent breast cancer screening. Other systemic barriers such as inaccessible toilets in offices, lack of consultation time, lack of assistance and communication difficulties were identified.

Physician responses in this survey by Verger *et al.* (2005) provide a rich source of data for our purposes. Significantly, they identified the micro relations of clinical encounters, where individual doctors identified feeling uncomfortable, with broader systemic issues of oppression, such as gender relations that resulted in male doctors being less likely to screen disabled women, and broad scale gaps in medical training. While 'lack of training' is identified in the study as socially and politically neutral and simply an individual issue, in fact, it points once again to the systematic undervaluing and silencing of women's bodies and our embodied experiences in clinical encounters (Frazee, Gilmour, and Mykitiuk 2006). A failure to 'suggest' screening cannot simply be understood as a clinical mis-step. Communication between patients and doctors

reflects the political and social context of medical training, which consolidates the role of doctor as expert (Foucault 1963; Couser 1997) as opposed to a mutual collaborator. In addition, macro structural barriers in healthcare itself, such as a lack of staff, resources and time, clearly have an impact on the interactions between women and their doctors in these clinical encounters.

Screening barriers

In a phenomenological study Mele, Archer, and Pusch (2005) found that women with disabilities expressed concern over physical and structural barriers to accessing breast cancer screening. Structural barriers included lack of health insurance and lack of a reliable, accessible transportation system. Physical barriers included inaccessible parking, heavy doors, inaccessible bathrooms at the provider office and lack of support and assistive equipment. In another qualitative study Becker, Stuifbergen, and Tinkle (1997) examined access to reproductive healthcare. The women discussed how the following issues acted as barriers to accessing preventive screening: inaccessible offices and equipment, lack of space in offices to maneuver, lack of accessible parking spaces and inadequate transportation.

In terms of barriers to communication, some women expressed concern that many providers' offices did not know how to use telecommunications devices for the deaf (TDD) and relayed anecdotes about other communication challenges (Mele, Archer, and Pusch 2005; Thierry 2000). In addition, most articles and guidelines recommended extending appointment times to accommodate the needs of women with disabilities (Becker *et al.* 1997; Day 2006). A recurrent theme in this research is that negative healthcare encounters have a profound effect on how women view the healthcare system. The knowledge and attitudes of medical professionals were the main issues identified by the women in the Mele, Archer, and Pusch (2005) qualitative study. The women felt that providers spent little time with them or were evidently uncomfortable with their disabilities. Many women expressed issues of inappropriate etiquette at provider offices and their desire to be partners in their health with the providers (Mele, Archer, and Pusch 2005). Women in the study also felt they could not count on healthcare professionals to advocate for their needs and felt that their non-disability needs were ignored, such as preventive care (Mele, Archer, and Pusch 2005).

Women in the Becker, Stuifbergen, and Tinkle (1997) study also discussed their negative interactions with providers. These women spoke of insensitive healthcare providers who lacked an awareness of disability issues (Becker, Stuifbergen, and Tinkle 1997). Some of the women felt that providers did not listen to them and provided inadequate explanations of their conditions. Women also described poor communication, a lack of discussion of prevention issues and a lack of access to preferred providers (Becker, Stuifbergen, and Tinkle 1997). Interestingly in the Mele, Archer, and Pusch (2005) study, attitudinal barriers existed not only in healthcare providers. Rather, the women indicated that they held certain beliefs that also acted as barriers. Women in the study believed that preventive health screening was important, but often did not engage in the behavior (Mele, Archer, and Pusch 2005). Many of these women indicated that they would only ask for a mammogram if they felt a lump or if a member of their family was diagnosed (Mele, Archer, and Pusch 2005). There was a contradictory belief that although screening was important, the women did not think that they were at risk of getting cervical or breast cancer.

In the qualitative study by Becker, Stuifbergen, and Tinkle (1997) many of the women indicated that they had been treated as asexual by healthcare providers and society in general. Therefore, it is possible that the erroneous belief that women with disabilities are less susceptible to breast and cervical cancer may stem from discriminatory preconceptions of their asexuality on the part of providers. In addition, the ongoing treatment women with disabilities receive from medical professionals throughout their lives based on ableist attitudes such as these clearly has a significant impact on the beliefs and attitudes held by disabled women about medical procedures and practices. Therefore, women's own attitudes towards healthcare and decisions regarding the necessity of accessing screening services can be viewed through this lens of social interaction and with an understanding of the structural barriers routinely faced in these contexts.

Of the two research summaries found online that addressed these barriers, one was Canadian and the other from the US. The US research paper summarized results from analyzing survey data collected from the 2002 California Behavioral Risk Factor Survey (King 2004). The researchers concluded that women with disabilities were less likely to have had a recent mammogram as part of a routine check-up. Women with disabilities, especially those labeled by researchers as having 'severe' disabilities, were more likely to get a mammogram due to a breast problem rather than as part of routine preventive care (King 2004). The Canadian study was a participatory action project that had evaluators visit 11 mammography centers to assess accessibility (Barile 2003). Evaluators were women with various disabilities, representatives from the community and support agents/interpreters. The evaluators assessed location of centers, access to public transit, parking, entrances, doors, signs, elevators, waiting rooms, changing rooms, washrooms, mammography rooms, mammography equipment, biopsy rooms, consent forms and telephones. Overall, the evaluation identified several issues with accessibility. The locations of some centers were not easily accessible as they were in remote areas or located inside malls. Accessible parking spots were either too far or there were none at the centers (Barile 2003). Waiting rooms, washrooms and changing rooms tended to be too small to maneuver around in a wheelchair. Most of the mammography machines descended for women who had to remain seated in a wheelchair, but not all descended enough for smaller wheelchair heights (Barile 2003).

Some women with disabilities noted economic barriers, specifically lack of medical insurance coverage in the context of the US, preventing some women from accessing preventive cancer screening (Mele, Archer, and Pusch 2005). In addition, women reported a lack of knowledge required to correctly perform breast self-examinations (BSE) and wanted to know alternative methods that took into account sensory impairments. Despite decades of disability rights advocacy, structural and attitudinal issues remain the biggest barriers women with disabilities must contend with in exerting their rights to adequate healthcare. All of these studies illustrate how healthcare remains literally and physically inaccessible. The prevailing attitudes of providers reflect the systemic nature of cancer screening provision that excludes and marginalizes disabled women.

Facilitators to screening

Only one study (Becker, Stuifbergen, and Tinkle 1997) directly asked participants what facilitated their access to cervical and breast cancer screening. The main facilitators included a positive attitude from providers, providers' openness to questions and

learning and patience on the part of the provider. Other facilitators included being partners in the decision-making process, using a holistic approach and making offices and equipment physically accessible (Becker, Stuijbergen, and Tinkle 1997). In a pre and post study by Schopp *et al.* (2002) the impact of comprehensive gynecological services on health maintenance behaviors among women with spinal cord injury was examined. Women with spinal cord injury were recruited from a specific clinic. The clinic had increased accessibility having purchased a special examination table, trained practitioners in reproductive healthcare for women with disabilities, increased appointment lengths, taught women with disabilities to do BSE, offered appropriate disability-relevant sexuality information and counseling and educated women regarding BSE, mammography, exercise and dietary changes. It was found that the overall frequency of health-promoting behaviors of women with spinal cord injuries increased over the 12 month period (Schopp *et al.* 2002). There was a trend towards increased willingness to engage in monthly BSE for those women who continued to participate (Schopp *et al.* 2002). This study showed that increasing accessibility may have a positive influence of health promotion behaviors of women with disabilities.

Discussion

The research we have addressed in this paper marks the first phase of the Gateways to Cancer Screening project. After completing the literature review we went on to organize a group with 'key informants' in Toronto. We met with disabled women who were also established community activists and/or experts in the field of disability health. After an extremely rich theoretical discussion we formed our focus group protocol and developed the lens through which we would analyze the existing literature in this paper. Our key informant group highlighted experiences of disabled women in clinical encounters where professionals did not address preventive healthcare at all. Instead, the focus was on the disability as the 'presenting issue', regardless of whether or not the women were seeking medical advice about disability. In addition, after describing a lifetime of challenges with medical professionals based on attitudes and approaches to disability these women were very unlikely to seek any kind of medical support unless it was absolutely necessary.

This perspective from our key informants identifies a major gap in the existing literature on preventive care. Because none of the studies we found actually allow women the opportunity to tell their stories, they miss the fact that previous experiences that are apparently unrelated to cancer screening on the surface have a profound impact on whether or not disabled women will advocate for and/or choose to engage in preventive healthcare services. In addition, by designing this project as user-driven, we very consciously allowed the stories and healthcare experiences of our facilitators to engage with the stories of our participants. Interestingly, the tensions that exist within the broad scope of research between community-based and traditional research methods were reflected in the early stage of our group process. The disability rights activist members of the research team mentioned that they experienced an initial reticence about joining a nurse clinician and a nursing professor to carry out research about disability health. Their past experiences of such engagements were often challenging and not always respectful of the particular expertise that lived experience as disabled women produces. The nursing professionals involved in the research were very much aware of this history, and also of the current inadequacy of healthcare research that uses old methods that do not engage with the community.

As we have demonstrated throughout this paper, quantitative research is the predominant method used to examine screening rates and provision of cancer care to women with disabilities. There are several limitations to such an approach. The 'neutral' language of quantitative research fails to adequately describe the contexts in which women with disabilities experience barriers to cancer screening. Results are often represented numerically, which altogether uncomplicates experiences and obscures the actual physical bodies that have endured the barriers. In its goal to generalize, quantitative studies often homogenize experiences of women with disabilities, systematically erasing ethnocultural, sexual and socio-economic characteristics of those surveyed and studied. In doing so, such studies can ultimately reinstate the notion of a normative body that is apparently unracialized, ungendered and not affected by economics, disability or any other social factors.

As it is our goal to unpack the day-to-day navigations of disabled women in the healthcare system, exploring and documenting both barriers and facilitators, it was necessary to find a way to do this research differently. Ultimately, we found that as a research team this form of collaboration between community activists, professionals and academics can actually work. We are currently carrying out a data analysis phase that contrasts with traditional approaches by looking at the issues of how bodies are valued and undervalued, and what the impact of time, space and economic and structural realities are on disabled women's healthcare experiences. Perhaps most importantly, we are looking at what has worked well and how we can build on the things that already facilitate healthcare access. Through the entire research process, both within our research team and through the inclusion of multiple women's voices from diverse milieu, we have forefronted disabled women's expertise about their own bodies and experiences. With this focus, we reinforce our belief and our starting point that disabled women need to be supported as active agents in their own healthcare.

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Notes

1. Principal co-authors.
2. We use the phrasing 'women with disabilities' interchangeably with 'disabled women' throughout the manuscript. Our research team recognizes the tensions and ongoing debate regarding language – our stance is that 'people first' language speaks to the specificity of each individual's intersectional experience and narrative expressions at the same time as the language choice of 'disabled women' highlights the structural realities of social disablement.
3. At this point individuals from the Lawrence S. Bloomberg, Faculty of Nursing, Springtide Resources and Ismaili Cancer Support Network joined the research process. A number of other community organizations joined the advisory process, including representatives from Anne Johnston Health Station, St Michael's Hospital and George Brown College.

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