Listening to Marginalized Women in Toronto: A Dialogue about Breast and Cervical Cancer Screening

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science
Institute of Medical Science
University of Toronto

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2015

Abstract

This study explored the perceptions of women living in homeless shelters and women with severe mental health challenges about the factors influencing their decision-making processes regarding breast and cervical cancer screening. Twenty-six qualitative interviews were conducted and analyzed using thematic analysis. The aim of this exploratory study was to focus on meanings and actions with a broader view to identify the interplay between participants’ narratives and social structures, medical praxis and policy implications.

Results provided insights on both positive and negative prior cancer screening experiences, the role of power and trust in women’s decision-making, and areas for improvement in health care provider/patient interactions. Outcomes of this investigation contribute to the future development of appropriately designed intervention programs. Tailored and effective health promotion strategies leading to life-long cancer screening behaviours among marginalized women may improve clinical outcomes, decrease treatment costs and save lives.
Acknowledgments

I would like to express my sincere appreciation to my thesis supervisor, Dr. Katherine Boydell for her encouragement, support and editorial advice. Warm thanks are also extended to Drs. Cory Borkhoff and Lori Ross, program advisory committee members who provided helpful feedback on early drafts of this manuscript. All three guided important decisions as they were being made during the conceptualization of this research endeavor and during the writing stage. For their time, contributions and guidance I am truly grateful.

I am sincerely grateful to each of the women who participated in interviews and shared their stories and insights with me. I hope that I have conveyed their messages well and that the outcome of this endeavor will bring about improvements to the well-being of many women in Toronto and beyond.

I would also like to express my profound gratitude to my brother, Kevin Alary who patiently supported me in countless ways throughout my time in graduate school. Special thanks also to my parents Teresa and Vince Alary for their ongoing support of my academic studies. I am also grateful to my sister Glenda Crocco who inspired a childhood love of reading that led me to be curious about the world. That curiosity many years later led to an interest in research, a desire to improve health outcomes, and the confidence to explore challenging issues.
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Chapter 1

Background: Breast and Cervical Cancer Screening among Homeless Women and Women with Mental Health Challenges

Project Summary

This study explored the perceptions of women living in homeless shelters and women with severe mental health challenges about the factors influencing their decision-making processes regarding breast and cervical cancer screening. Twenty six in-depth qualitative interviews were conducted. The objectives of this investigation were:

(i) to provide new insights about women’s decision-making processes,

(ii) to describe the barriers to and facilitators for breast and cervical cancer screening, and

(iii) to offer recommendations for future outreach, education and screening initiatives developed specifically for under/never-screened marginalized women living in urban centres.

This exploratory study utilized thematic analysis to broaden our understanding about women’s decision-making processes. A constructed ontology was used in an attempt to understand and describe participants’ constructed realities while referencing my own constructed reality and appreciation for the complexity of the topic. The epistemological framework was subjective and reflected co-created knowledge. The approach was hegemonic, values-based and context-specific. The aim of the analysis was to focus on meanings and actions with a broader view to identify the interplay between participants’ narratives and social structures, medical praxis and policy implications.

1 It is understood that there is an overlap between these two populations. Many women residing in homeless shelters have mental health issues and/or substance use issues. Many women residing in assisted living residences as a result of mental health issues also have had histories of homelessness or housing challenges; some have also had addiction issues.

2 Ontology refers to the study of the nature of being. It explores the nature and form of social reality and from that what can be known.
Results provided insights on both positive and negative prior cancer screening experiences, the role of power and trust in women’s decision-making, and areas for improvement in health care provider/patient interactions. Outcomes of this investigation contribute to the future development of appropriately designed intervention programs for marginalized women, as well as for sensitivity training for health care providers. Tailored and effective health promotion strategies leading to life-long cancer screening behaviours among marginalized women may improve clinical outcomes, decrease treatment costs and save lives.
BACKGROUND

Breast Cancer Screening: Nationally, Provincially and Locally

Breast cancer can sometimes be identified through breast self-exam, clinical breast exam or through regular participation in mammography screening procedures. Since the advent of breast screening programs across Canada in the late 1980’s, mammogram use has increased significantly. Although breast cancer prevention initiatives have largely been successful, more than one quarter of Canadian women aged 50-69 report that they have not had a mammogram in the previous two years. (1) Non-use of mammography has been associated with: being an immigrant (in Canada less than ten years), living in a low-income household, not having a regular physician, and/or smoking. (1) Low social economic status (SES) has been associated with: i) the belief that having a mammogram is unnecessary, and ii) failure to return for subsequent breast cancer screening. (2)

The current guidelines in Ontario recommend asymptomatic women participate in mammography every two years starting at age 50 for early detection of breast cancer. According to Cancer Care Ontario, breast magnetic resonance imaging (MRI) and mammography are considered the best screening methods for women ages 30-69 who are known to be high risk for breast cancer (family history of breast cancer or experiencing breast problems). The Ontario Breast Screening Program (OBSP) provides written reminders for upcoming screening to women age 50 through to age 74. The OBSP also sends written reminders to women considered high risk.

According to Canadian Cancer Statistics 2014(3), it is estimated that there will be 9,500 new cases of breast cancer detected in Ontario this year and that 1,950 Ontario-residing women will die from the disease. The number of predicted new cases and deaths in Ontario is higher than in any other province. It is believed that once the national breast screening target of 70% is reached, one-third of breast cancer deaths could be prevented within the next 7-10 years. In 2010-2011 61% of women in Ontario between the ages of 50-74 were screened for breast cancer using mammography. (4)

The Cancer Quality Council of Ontario provides surveillance data for each of the 14 Local Health Integration Networks (LHIN). Their most recent reports indicate that 55.5% of women residing
in the Toronto Central LHIN participated in mammography once in a two year period between 2011 and 2012. This rate was lower than the 2011-2012 provincial average at 60.3%, underlying the need for enhanced outreach and educational initiatives.

**Cervical Cancer Screening: Nationally, Provincially and Locally**

Cervical cancer is caused by the human papillomavirus (HPV), a common sexually transmitted infection. Of the 100 types of HPV, 15 are considered high risk. Types 16 and 18 are causally related to 70% of cervical cancer cases. Although many types of HPV infections clear naturally from the body on their own, some women experience persistent infections. The average length of time from contracting HPV to the development of a pre-cancerous lesion is two years. Given that the development of invasive cervical cancer may take another 8 to 12 years, routine screening for cervical cancer can be highly effective in identifying early pre-cancerous lesions leading to appropriate treatment.

Cervical cancer can be prevented through participation in regular Papanicolaou (Pap) tests. The Pap test can show abnormal changes in the cells of the cervix. Colposcopy, which provides a magnified view of cervical cells, can identify pre-cancerous lesions. These lesions can be treated to prevent the development of cervical cancer. The current guidelines for cervical cancer screening in Ontario recommend that screening commence at age 21 among sexually active women and that Pap tests be conducted every three years when results are normal. Abnormal Pap test results should be followed up on a case by case basis depending on the classification of abnormality. Cervical cancer screening can cease at the age of 70 if three or more Pap tests conducted in the past 10 years yield normal results.

According to 2006-2008 data reported by the Canadian Partnership Against Cancer (2011) between 72.4% - 79.6% Canadian women ages 20-69 participated in at least one Pap test within a three year period (corrected for hysterectomy). Based on data available for 2004-2005 in this 2011 report, 79.6% of Canadian women were re-screened within three years of receiving a normal test result.

With respect to the prevalence of cervical cancer in Ontario, Canadian Cancer Statistics 2014 estimates that approximately 630 women will be diagnosed this year and approximately 150 women will die from the disease. Between 2009-2011 only 65% of women between the ages
of 20-69 living in Ontario were screened for cervical cancer. This rate is significantly below the provincial screening target of 85%. It has been shown that women living in the lowest income neighbourhoods have a cervical cancer screening rate of 58%, substantially lower than the 70% screening rate of women residing in the highest income neighbourhoods.(11) Between 2009-2011 the cervical cancer screening rate in the Toronto Central Local Health Integrated Network (LHIN) was 61%.(4) This was the lowest screening rate of all LHINs and therefore an appropriate geographical region to target for this investigation.

**Populations of Interest**

The present study focused on homeless women living in the shelter system and women with severe and persistent mental health challenges residing in assisted living residences. A review of the literature on cancer screening practices of homeless women, low income women and women with mental health challenges revealed a number of gaps: contradictory patterns of screening uptake, few Canadian-based studies, and statistics which were more often based on self-report rather than on clinical records. The majority of health-based research on these populations was quantitative in nature focusing on general physical health, including pre and postnatal health, mental health, substance use, and past physical and/or sexual abuse. Investigations about breast and cervical cancer screening among women living in homeless shelters and women with severe mental health challenges are fairly sparse, as will be discussed. Only two qualitative studies were found pertaining to cancer screening among women with mental health challenges and/or substance use issues.(12,13) One other study examined access to general health care services among women with mental health issues.(14) No qualitative studies were found concerning cancer screening and homeless women.

**Breast and Cervical Cancer: Under/Never-Screening among Homeless and Low Income Women**

To gain an understanding of cancer screening activities of homeless and low income women, an international literature search was conducted utilizing resources available through the University of Toronto’s library collections. Theses archived at Library and Archives Canada and at T Space at the University of Toronto were also reviewed. Relevant studies are described to provide information on screening prevalence and facilitators and barriers to breast and cervical cancer
screening. These studies were conducted in Canada and the United States using both quantitative and qualitative methodologies. The paucity of qualitative research conducted on this topic highlighted the need for the present investigation and supports the rationale for the current study design and methodology.

**Screening Prevalence**

Heyding et al. (15) conducted a study in Toronto with marginalized women attending an inner city drop-in centre. Over the course of a one-year period, women were invited to a local inner city hospital for mammography accompanied by a staff member of the drop-in centre. The hospital clinic reserved three appointments each week for women from the drop-in centre. The purpose of the study was to examine the effectiveness of this intervention on breast screening uptake by women using the drop-in centre. In the seven years preceding introduction of this intervention (1995-2001), the average annual mammography rate among women using the centre was 4.7%. In 2002, 29.2% (26 out of 89 women) participated in mammography, representing a significant increase. Heyding et al. (15) described the population using the centre as older women between the ages of 50-70 years, approximately half of whom had a major mental illness. Approximately one third of the women were either homeless or living in supportive housing. While these outcomes were promising, this study highlighted the tremendous challenge facing health care providers, community agency staff and health promotion specialists when trying to engage vulnerable, highly marginalized women in cancer screening programs.

Another study (16) compared breast and cervical cancer screening rates among Ontario women and women living in the United States who were 18 years of age or older. This research team found that the availability of health insurance in Ontario did not positively affect screening uptake among women of low socioeconomic status. The trend of under/never-screening among low-income women in both Ontario and the U.S. was consistent. It appeared that the removal of this financial barrier for Ontario women of low socioeconomic status did not make a difference in cancer screening behavior.

A 2007 Toronto-based study, The Street Health Report (17) found low cancer screening rates among homeless women. Authors of the report, Khandor and Mason, surveyed 368 homeless people during a three-month period between November 2006 and February 2007. Twenty-six percent of the sample was female. The Street Health Report (2007) revealed that 14.7% of
women surveyed (14 out of 95) had received Pap tests in the past year compared to 62% among the general population in Toronto. This study also indicated that 29% of women aged 40 or more (27 out of 95) reported having had a mammogram in the past year, compared to 65% of women aged 35 and over in the general population in Toronto. Twenty-one percent of homeless women interviewed reported having been sexually assaulted or raped in the past year. Fifty-five percent (11 respondents) of those women (who were sexually assaulted in the past year) reported that they had been sexually assaulted more than once in the past year, putting them at greater risk for sexually transmitted infections (STIs) including Human Papillomavirus (HPV).

The Worcester Family Research Project conducted in Worcester, Massachusetts between 1992-1995 by Weinreb et al.(18) compared Pap screening uptake between a sample of sheltered homeless mothers and a group of very low income housed women. A thorough approach was used to assess and describe the population based on 10 hours of interview time with each study subject involving three or four sessions each. Information gathered included: general demographics, social supports, health status, mental health functioning, risky behaviours relative to health, childhood and adulthood victimization, use of medical services and history of Pap tests. The authors reported that 75% of participants had received Pap testing in the past year and 90% of participants had received Pap testing within the past two years. No differences in screening rates were found between the low income housed and homeless women. These rates were significantly higher than reported elsewhere concerning homeless and low income women(19,20) which called into question the notion that homeless women are among the under/never-screened for cervical cancer.

The high rate of cervical cancer screening reported by Weinreb and colleagues(18) may largely be due to the fact that almost half of the women in their study had given birth to a child in the previous year. Given that participation in screening was provided by self-report, it is also possible that these rates were inflated. The accuracy of self-report has been both questioned(21-24) and justified(25-28) in the literature. In the discussion of their findings, the authors of the Worcester Family Research Project noted that the successful results may have been impacted by the strong collaboration between homeless shelters, community based agencies and health care institutions in the area.
In San Francisco, California, Long and colleagues(28) reported on screening rates of 105 women living in two homeless shelters in the area. Participants self-reported screening rates were comparable to the general population at 47% with recent mammograms and 54% having had a Pap test in the past year. It is not known why such inconsistency among screening rates exists. This may be due to regional differences or variables that were not examined and reported on. Another study of 221 homeless adults from nine locations in Los Angeles county explored cancer screening behaviours among men and women. One hundred and one homeless women participated in this study conducted by Chau et al.(29). This investigation found that among women over 40 years, 55% had had a Pap test while 32% had had a mammogram in the past year. These cervical screening rates were similar to those reported by Long et al.(28) while the mammography rates were slightly lower.

In 2005 and 2006 Ogilvie and colleagues(30) evaluated the feasibility of using self-collection for HPV testing among marginalized women in Vancouver’s downtown eastside area. They recruited women from women’s centres, shelters and alleys in the area. One hundred and fifty-one women participated; 43 samples tested positive for high risk types of HPV. Outcomes supported the feasibility for self-collection of HPV test samples. Of particular interest to the current study, 13.9% of the women in Ogilvie’s study reported never having had a Pap test. This rate was higher than that of the general population in British Columbia at 8.3% never having been screened. More than half of participants (53.6%) reported having had a Pap test in the past three years. This rate was consistent with the past 12 month screening rates reported by Long et al.(28) and Chau et al.(19).

It is difficult to access accurate figures about breast and cervical cancer screening uptake among homeless women and women living in shelters partially due to the fact that many studies rely on self-report rather than on clinical records. Some studies involve questionnaires only, while others have an intervention component. Despite this, there is a generally held belief that homeless women, many of whom have mental health challenges, are at high risk for several types of cancers(19, 28-29) and carry a disproportionate burden of breast and cervical cancer.(20, 30-31)
Facilitators to Breast and Cervical Cancer Screening among Homeless and Low Income Women

The review of extant literature provided insights about factors influencing participation in cancer screening, including access to health care providers and health insurance, level of education and income, use of substances, attitudes and beliefs about screening, and quality of life. One’s housing status, physical and mental health condition, frequency of visits for primary health care and/or facilitated access to screening appointments each play critical roles. The directionality of each of these factors as screening facilitators will be explored next.

Having a Regular Health Care Provider

Weinreb, Goldberg and Lessard(18) found that the strongest predictors of having had a Pap test in the past year were i) having a regular care provider; ii) having given birth in the past year or, iii) having been hospitalized in the past year for reasons other than childbirth. An implied facilitator for cervical cancer screening in this study was access to health insurance which the majority of participants had. No differences were found in screening uptake between housed and homeless women. Social and mental health factors were not associated with cervical cancer screening.

While there is a prevailing assumption that homeless women including those with mental health and/or substance use issues are among the under or never-screened for breast and cervical cancer, Weinreb et al.’s 2002 study(18) findings contradict that assumption. As noted previously, their high cervical cancer screening rates may be attributed to the fact that almost half of their participants had given birth in the past year. During early prenatal care, the opportunity to have a Pap test was likely offered. The reproductive age of this study group may have contributed to higher screening rates than studies inclusive of women past their childbearing years.

A Canadian study(32) found a positive relationship between having a regular care provider and medical visits during the past year with participation in cervical cancer screening. Visiting one’s health care provider also results in increased screening participation. Participation in both mammography and Pap tests is associated with having more medical visits in the past year compared to women who are under/never-screened for these cancers.(28) Additionally,
women are more likely to be up to date with cervical cancer screening if they have received health care in the same setting with the same health care provider during the previous twelve month period.

Further evidence that access to a health care provider facilitates cancer screening was provided by Diamant et al.(33) This research group investigated the use of preventive services among very low income women living in Los Angeles County and found low screening rates for breast and cervical cancer among their sample of almost 3,000 women. When asked about type of health care access in the past year, 68% of participants reported clinic use; 14% utilized hospital emergency departments; and 18% went to a private physician. Lack of routine access to a primary care provider was associated with non-participation in cancer screening.

A study published in 2013 on homeless people in Vancouver, Toronto and Ottawa also found evidence for one’s general health care needs being met when one had a primary care provider.(34) The authors reported the following facilitators for health care needs being met: i) higher health-related quality of life, and ii) improved mental or physical health compared to participants whose health care needs were unmet (based on scores on the 12-item Short Form Health Survey). Over 1,000 people participated in this study, 37% of whom reported that they had unmet health care needs. This was a higher rate than had been reported by Hwang et al.(35) in which 22% of single adult homeless women reported having unmet health care needs.

The importance of having a regular source for health care was also emphasized by Lewis and colleagues in their 2003 study.(36) Among 974 homeless women aged 15-44 living in Los Angeles, 37% reported not having their medical care needs addressed in the past two months. Sixty-five percent of this sample responded by survey that having all their health care needs and treatments provided at the same place was the most important facilitator for having their care needs met.

**Positive Attitudes toward Screening**

Long et al.(28) found that homeless women had very positive attitudes towards cancer screening particularly if the testing was free. The majority of women indicated that they would want to
know if they had cancer or not. This was true for both women who were up-to-date with cancer screening and women who were not. Chau et al. (19) found that about three-quarters of their participants indicated that they believed in the benefits of screening and 79% were not fatalistic about cancer. This contradicts other studies which found that fatalist attitudes and not wanting to know one’s cancer status were barriers to cancer screening among homeless and marginalized women as well as among the American public in general. (37-42)

**Demographics and Lifestyle Factors**

Although statistical significance was not reached, one study (28) found a trend indicating that women who had twelve or more years of education were more likely to be up-to-date with breast and cervical cancer screening compared to homeless women with less education.

Research has found that women are more likely to have participated in mammography within the past year if: they rate their health status as being very good or excellent, are not currently smoking or using alcohol, and are housed (33). There is a relationship between being up-to-date with cervical cancer screening and rating one’s health status as being excellent. (33) Younger women are more up-to-date with Pap tests than older women. (33) There is also a correlation between non-smoking status and being up-to-date with breast cancer screening. (28)

**Interventions as Facilitators for Mammography**

As discussed previously, Heyding et al. (15) found that group accompaniment to mammography appointments facilitated mammography uptake among highly marginalized women. As the study authors noted, important components of this model of engagement was the development of trust between the drop in staff and the women being served. Having protected appointment slots, sensitive and welcoming behavior on the part of clinic staff, and flexibility from week to week in the breast clinic all contributed to the success of this intervention.

Weber and Reilly (43) also reported on a multi-faceted approach to engaging under/never-screened women in mammography. They utilized a multi-site database to remind physicians about patients who were overdue for mammography. Reminder letters were sent to under-screened women. A peer model of support was implemented in which community health educators (CHEs) liaised with the women, provided basic education, encouragement and
navigation through the health care system. Peer community health educators were also matched to women based on ethnicity. It was found that in less than four months, 41% of the under-screened women who received assistance from CHE’s participated in mammography, whereas only 14% of under-screened women who only received reminder letters from their physicians actually followed through with mammography. This study highlighted the effectiveness of peer models in facilitating cancer screening.

In summary, facilitators for both breast and cervical cancer screening include: i) having ongoing access to a health care provider, ii) having a positive attitude towards cancer screening, iii) having twelve or more years of education, iv) being a non-smoker, v) not using alcohol, vi) being housed; vii) rating one’s health as very good or excellent, viii) participating in an effective intervention program. While access to health insurance is likely an important facilitator to screening, Katz, et al.(16) did not find statistically significant evidence for this in their study comparing access by low income Ontario-residing women with low income American women who were under/never-screened for breast cancer. Long et al.(28) only found a statistical trend for having health insurance as being a predictor of women being up-to-date with clinical breast exams. This illustrates that other complex factors are involved in the cancer screening decision-making process beyond financial or health insurance considerations.

**Barriers to Breast and Cervical Cancer Screening among Homeless and Low Income Women**

Factors which discourage or impede participation in cancer screening activities among homeless and low income women have been investigated primarily through quantitative research studies. Currently published research offers information about the role of social support, motivation, ability, attitudes toward screening and knowledge about cancer, on screening uptake. Whether or not a woman’s care provider encourages screening, if she has the funds for screening, if she is afraid of the test or the outcome, all can play a part in the decision-making process. The quality of interactions with health care providers and the health care system may also influence these decisions. Women who perceive that they are being treated with respect may be more inclined to participate in screening compared to women who experience discrimination. A history of sexual abuse may inhibit participation in Pap tests or mammograms. Many women may have other pressing life circumstances that require their
attention. The next section provides evidence for specific factors in some women’s lives which may act as deterrents to cancer screening.

The main barriers to all types of cancer screening in Chau et al.’s(19) study with homeless adults were: i) not having enough money ii) lack of knowledge about how to access screening, or difficulty accessing screening, iii) anticipation of discomfort, and iv) not feeling that it was necessary because respondents did not feel sick.

A 1993 study on mammography utilization among the poor and medically under-served in the United States concluded that fear of finding breast cancer was an important barrier to breast cancer screening.(43) No other studies have been found which support this finding pertaining specifically to homeless and/or low income women.

Weber and Reilly(44) reported that many under-served American women indicate that they have never had a mammogram because their physicians did not recommend it, however the references provided for this claim were from the 1980’s and early 1990’s. In recent years with the increased prominence of cancer agencies and efforts in North America to engage primary care physicians in promoting cancer screening, this may no longer be a significant barrier to mammography.

**Discrimination in the Health Care Setting**

A qualitative study was conducted with childbearing-aged women living in a homeless shelter to explore womens’ knowledge, attitudes and beliefs about health promotion including healthy pregnancy.(45) Among the themes which arose, women spoke about being treated differently in health care settings because they were uninsured. The (Toronto) Street Health Study(17) also reported that 40% of participants who experienced homelessness reported that they had been ‘judged unfairly’ or had been disrespected by a doctor or a medical staff person at least once in the past year.(17) Of this group who reported feeling discriminated against, 66% said that they felt the discrimination was due to the fact that they were homeless.

**Competing Needs and Subsistence Issues**

One hundred and eighteen women using emergency shelters in Seattle, Washington participated in a study examining how often women followed through on referrals and which factors were related to attendance or non-attendance at appointments. The research team(46) found that
personal stress and competing priorities were reasons cited by women who did not participate in referrals. Sixty-two percent of referrals for medical appointments were kept while only 22% of referrals for preventive care appointments were kept by women in the study. Participants reported that issues of housing, employment, access to welfare payments, and child care issues superseded health care needs. Some women reported that they were feeling too depressed or disoriented to follow through with the referral they had been given.

Stressful life events prevented women from returning for follow-up after an abnormal Pap test result.(47) Women defined stressful life events as: having difficulty at work, experiencing severe physical violence by one’s partner, being homeless, or having an unplanned pregnancy.

Additional though less strong evidence for this barrier to health care was presented by Gallagher, et al.(48). This evidence is considered less relevant given that the majority of homeless people in this Los Angeles County study were male. Gallagher and colleagues found that individuals who had a lower likelihood of having a regular care provider frequently had difficulties with sustenance issues, lengthy periods of homelessness (i.e. five years or more), experienced challenges trying to navigate health and social service systems, and reported low levels of social support.

**Lack of Self-Care Agency**

Self-care agency refers to an individual’s inner resources which allow one to initiate and sustain activities to maintain one’s health and well-being. Judith Anderson(48) conducted 150 semi-structured interviews with homeless men (75% of sample) and homeless women (25% of sample) in an effort to explore the relationships between self-care agency, self-care and wellbeing. She found that low self-esteem and reliance on alcohol or substance use as coping mechanisms reduced participants’ self-care agency. Low or no levels of social support were also found to be related to low levels of self-care agency. Statistically significant findings demonstrated a relationship between self-care agency, self-care and wellbeing which was influenced by personal variables including affect. Anderson stated that self-esteem and general affect were foundational components of self-care agency. As a result, Anderson advocated for nurses to endeavor to strengthen the self-care agency of homeless persons as a means of promoting self-care behaviours.
History of Sexual Abuse

Wenzel and colleagues(49) conducted a study with 974 homeless women residing in Los Angeles. They found that 13% of the study sample reported having been raped in the past year, and half of those women reported being raped at least twice in the past year. Homeless women who had experienced rape were more likely to report having used substances other than alcohol. Women who had been raped had poorer scores on every physical and mental health measure, compared to homeless women who had not been raped. Women who had been raped indicated that although they needed to see a physician in the past year, they were less likely to have done so compared to non-victims.(49,50) Other research has also found that adult survivors of childhood sexual abuse experienced uncomfortable feelings and trauma-type responses during gynecological examinations compared to women who did not experience sexual abuse in childhood.(50)

Robohm and Butterheim(51) reported similar results when conducting research with women in the general population who had experienced childhood sexual abuse. When accessing gynecological services survivors reported significantly higher levels of pain, and more negative emotional feelings such as embarrassment, shame, vulnerability and fear compared to controls who had not experienced childhood sexual abuse. When asked about re-traumatization experienced during or after the gynecological exam, almost two-thirds of the survivors indicated that they had felt overwhelmed by emotions. The range of emotions experienced included: grief, rage, fear, panic, terror, shame, disgust, humiliation and helplessness. Some female survivors of childhood sexual abuse also experienced uncontrollable crying and 47% reported unwanted or intrusive thoughts during the gynecological exam. Robohm and Butterheim(51) also found that 82% of survivors and 87% of controls in this study were not asked about prior sexual abuse by gynecological care providers. Based on these and other studies, it is clear that a history of sexual abuse is a barrier to participation in cancer screening, particularly cervical cancer screening.

According to the current literature, homeless and low income women experience several barriers to breast and cervical cancer screening. Some women lack health insurance or the funds to pay for cancer screening (particularly in the U.S.); some women do not know how to access cancer screening services, while others worry about discomfort during the procedures. An attitude that screening is not necessary, or fear of the results also serve as barriers. Women who have
experienced being judged, stigmatized or discriminated against while interfacing with health care professionals may be less inclined to seek general health care let alone preventive health services. Many homeless and low income women have competing needs that are prioritized more highly than cancer screening activities, including subsistence needs such as food, shelter, clothing, work and/or childcare responsibilities. Women who do not possess self-care agency are not able to participate in preventative health activities. Lastly many women who have experienced sexual abuse in childhood or in their adult lives find gynecological examinations including Pap tests and clinical breast exams to be frightening, potentially triggering and emotionally distressing. Any or all of these circumstances act as barriers to cancer screening for homeless and low income women.

**Breast and Cervical Cancer: Under/Never Screened Women with Serious Mental Health Challenges**

Recent literature searches of the University of Toronto’s library collection of electronic journals, Theses Canada, as well at T Space at the University of Toronto on women with mental health challenges and their uptake in breast and cervical cancer screening revealed very little Canadian data. The majority of relevant studies were conducted in Australia, Britain and the United States. All studies were quantitative with the exception of three American studies, which utilized qualitative methodologies. The degree to which women with mental health challenges are under or never-screened for breast or cervical cancer will be explored followed by a review of facilitators and barriers to screening for these cancers.

**Screening Prevalence**

A study conducted in Sydney, Australia reported on interviews with 100 women who were accessing mental health services.(52) Eighty women were randomly selected from databases at four community-based mental health centres and 20 were selected from recent admissions to an acute care psychiatric unit of a hospital. The average age of the women was 46.3 years. The majority had mood disorders, while 19% had schizophrenia and 9% had general anxiety disorder. Data was available on eighty-two of the 100 women given that 18 women had previously undergone hysterectomies. Based on self-report: 36 women had had a Pap smear in the past year; 26 had a Pap smear in the past 1-2 years; 13 had a Pap smear more than two years ago; and 7 reported never having had a Pap smear.
Following an analysis of interviews, this Australian research team(52) coordinated a pilot study in which cancer screening tests were offered to women with mental health challenges in community based mental health care centres and in hospital. As a result of this initiative, 78 appointments were made. Greater uptake in cancer screening was found within the hospital setting (18/24) than within the community setting (11/54). Among those women who attended these clinics: 40% had not had a Pap test for five years or more; 54% had not had a breast examination for five years or more. Of the latter group 50% had never had a breast examination conducted by a primary care provider. Further, it was reported that 17% had abnormal findings on breast examination and 7% had abnormal Pap smears.

Another Australian study(53) reported on baseline cancer screening rates among mentally ill women living in boarding houses or living independently in Australia. Women were invited to participate in breast and cervical cancer screening. Thirty-three women living in boarding houses agreed to participate in Pap tests (90% of those eligible based on age and history of hysterectomy) and 116 women living independently agreed to participate in Pap tests (12% of those eligible). Of the boarding home women, 22 (66%) had never been screened. With respect to mammography, none of the women living in boarding homes had previously been involved in a breast screening program, and only 10% of the women living independently had accessed this program. While this initiative increased screening rates for both cancers among both groups, it is clear that improved outreach strategies are needed for women with mental health challenges.

In London, England a study was conducted comparing breast cancer screening records of 933 female psychiatric patients and 44,195 women without mental health challenges.(54) The age range was 50-64. Of particular interest to this discussion, comparable screening rates were found among the psychiatric patients and the reference group.

A research team in Cleveland, Ohio found that women with mental health challenges had lower rates of ongoing breast cancer screening compared to women who did not have mental health challenges.(55) Medicaid records were examined from 2002-2008 resulting in a sample size of 130,088 women. Women with mental health challenges were 32% less likely than women without mental health challenges to participate in at least one mammogram.

Researchers in Sacramento County, California examined cancer screening practices of men and women with serious mental illnesses.(56) In records from 2005-2007 it was found that among
123 women, 83 had had a Pap test in the past 3 years; 34 had had a Pap test more than 3 years ago; 2 had never had a Pap test and 2 did not respond to the question. With respect to mammography: 30 had never had a mammogram; 33 had had one within the past year; 16 had had one between 2-5 years ago; 18 had not had one in more than 5 years and 1 gave no response. While these findings support the need for life-long cancer screening interventions with women who have mental health issues, it is worth noting that 95% of this sample did receive at least one Pap test in their lifetime. The fact that the average age of participants was 40 likely contributed to lower rates of mammography use.

There is very little Canadian literature on this particular topic, underscoring the need for further research. Chochinov and the Need to Know Group(57) conducted a population based study in Manitoba examining the impact of a diagnosis of schizophrenia on participation in breast cancer screening. Using the Population Health Research Data Repository they reported on a sample size of 1,448 women in the schizophrenia group and 108,792 women in the Manitoba-residing non-schizophrenic group. Chochinov and colleagues(57) found that 44.8% of the group with schizophrenia had received a mammogram in the past two years while 58.3% of the general Manitoban population had received a mammogram in the same time period. This 13% difference was clinically significant.

While the majority of available studies concluded that women experiencing mental health challenges are under-screened for breast and cervical cancer, one study(54) found no difference between psychiatric patients and controls. It is difficult to compare studies given that the criteria for mental illness (i.e. level of severity) varied between studies, as did sample sizes. Further research into the prevalence of under/never-screening among women with mental health challenges in the Canadian context is clearly needed.

**Facilitators to Breast and Cervical Cancer Screening among Women with Mental Health Challenges**

To find out if women with mental health challenges experience similar facilitators for cancer screening participation that women with housing challenges face, the extant literature was reviewed. The next section summarizes what was found with respect to the role of communication between care providers, continuity of care, social and financial supports, and family history of cancer on screening uptake. Only one study explored the impact of different
levels of severity of mental illness on screening participation. No research was found on the use of supportive accompaniment to screening, innovative outreach strategies, or the use of peer models.

**Continuity of Care**

As was the case with homeless and low income women, the Canadian Need to Know Group(57) found that the strongest indicator for participation in mammography among participants with schizophrenia, was continuity of care. This group found that among women with a diagnosis of schizophrenia who reported receiving good continuity of care, there was a 52% probability of participation in mammography. They predicted however that only 35% of women diagnosed with schizophrenia who did not have good continuity of primary care services would participate in breast cancer screening.

Borba and colleagues(58) reported on an American study with thirty low income, urban women of predominantly African American descent who had serious mental health issues. Participants were involved with telephone and in person qualitative interviews about perceived barriers and facilitators to accessing medical health care services. Among the 30 participants only three resided in a homeless shelter and one in a halfway house/residential program. Their findings indicated that access to general health services was facilitated by access to mental health treatment services. Women who had built trusting relationships with their mental health providers reported that they were subsequently able to access primary health care services. Many participants in this study indicated that they preferred to have all their health care needs provided by one primary care provider whom they trusted.

Researchers in Boston, Massachusetts(59) explored the importance of improving communication and collaboration between primary care providers and mental health care providers. Qualitative interviews with female consumers of mental health services revealed that a central facilitator for both breast and cervical cancer screening was having a trusting relationship with a primary care provider. Another facilitator was the perseverance of primary care providers in repeated recommendations for screening. Borba et al.(58) also advocated for more communication between care providers and/or the implementation of integrated models of care to improve overall care as well as to promote preventative health care activities for patients.
Social Support

During qualitative interviews with women, evidence was found supporting a relationship between receiving encouragement from family members and participation in cancer screening. Having social supports including ties with faith organizations is associated with access to medical services by women with mental health challenges. Women who are involved with faith communities report that the environment and the people help them to cope with the stresses and difficulties in their lives. Some commented that attendance at church provides a sense of belonging and inspiration to keep trying and to have hope. Family members are also reported to be instrumental in providing emotional and financial support to access health care services. Some women receive social support from other women who have serious mental health challenges. Women sometimes help each other to locate physicians who provide good care. The importance of social support highlighted by these two studies focused on familial and spiritual supports as well as friends who shared similar life challenges.

Family History of Cancer

A study conducted in Buffalo, New York by Khan and colleagues used focus group methodology with women who primarily had co-occurring mental health issues and substance use issues. Twenty-six women aged 40 to 65 who were enrolled in Medicaid-managed programs volunteered to participate in one of four focus groups. The goal of the study was to explore the barriers and facilitators to mammography screening in order to increase screening rates among the target populations. All but one of the interviewees had had a mammogram in the past eighteen months. This research team used a grounded theory editing approach to analyze the data. Results indicated the following facilitators to breast cancer screening uptake: (i) family history of breast cancer, (ii) physician recommendations and referrals, (iii) connection with mental health facilities, and (iv) connection with faith-based communities (which functioned as both a facilitator and a barrier). At least one woman in each of the focus groups said that they were motivated to have mammograms because their mothers had either had breast cancer or some other type of cancer in the past. Among the facilitators identified, family history was reported as being the most significant motivator for participation in breast cancer screening.
In summary, facilitators to accessing medical care and/or cancer screening included: continuity of care, having a trusting relationship with a primary care provider, ongoing recommendations for screening by primary care providers, receiving encouragement from family members, having social supports including friends and ties with faith based organizations, and/or having a family history of breast cancer.

**Barriers to Breast and Cervical Cancer Screening among Women with Mental Health Challenges**

The degree of severity of mental illness may impact on women’s interest, capacity and willingness to engage in cancer screening activities. Concerns about discomfort, anxiety about results or lack of awareness about preventive care may act as deterrents to screening as is the case with some women in the general population. Difficulties navigating the health care system, lack of: health insurance, trust in care providers, transportation or social supports might also impede screening uptake.

**Depression and Emotional Factors**

Among the general population (non-psychiatric) an association was found between depression and low use of mammography in a sample of women over 40 years of age residing in Kentucky(61). The aim of this study was to assess the relationship between self-reported mental health status and mammography screening using information from the Behavioral Risk Factor Surveillance System (BRFSS). A significant association was found between women’s self-report of poor mental health days, being depressed, or being anxious for a continuous period of thirty days with lower rates of mammography compared to women who did not self-report on these variables.

Another American study found that women with high levels of depressive symptoms were less likely to participate in mammography; however this was not the case for Pap tests.(62) Socioeconomic status played a larger role in non-adherence to mammography than serious depressive symptoms.

American researchers Carney and Jones(63) reported that women with any type of mental illness were less likely to receive mammograms than controls, and that among those women with mood disorders or women with a history of psychosis, alcohol or substance abuse there was a further
decrease in likelihood of mammography participation regardless of the level of severity of mental illness. Similar findings were reported in the United Kingdom. (54)

A qualitative study (60) reported the following barriers to breast cancer screening uptake: (i) fear of pain, (ii) anxiety about the possibility of receiving a cancer diagnosis and (iii) shame and embarrassment particularly if technicians were male.

Feelings of fear and discrimination were reported as barriers to accessing health care services (58). Miller et al. (59a) identified the potential for re-traumatization of patients during cancer screening procedures as one of the barriers to screening participation among women with mental health challenges.

**The Health Care System**

As was the case with women experiencing homelessness, lack of continuity of care providers was reported as a barrier for women with mental health issues (58). Miller and colleagues (59a) reported that their study participants spoke about the following barriers: long wait times, lack of follow-up from missed appointments, unhelpful front desk staff, and a lack of communication between primary care providers and mental health professionals. Medical professionals participating in interviews also emphasized the need for improved education and sensitivity training among primary care providers about the potential for re-traumatization of women during cancer screening procedures. Lastly, Khan et al. (60) reported barriers to cancer screening included the waiting period for screening results and lack of empathy and communication by/with health care providers.

**Women’s Personal Circumstances**

Lack of health insurance, low income and lack of transportation to access services were also identified as barriers to cancer screening in the American studies previously discussed. (58, 60) Borba, et al. (58) also found that many women in their study had limited knowledge about breast cancer and mammograms and required more education.

Barriers to health care access and participation in cancer screening activities included: a history of depression, fear of pain, anxiety about the possibility of receiving a cancer diagnosis, shame and embarrassment especially if technicians were male, fear of discrimination, concern about the
potential for re-traumatization, issues within the health care system and personal factors such as being uninsured, not being able to afford the procedures, not having access to transportation and not having received adequate education about the subject.

**RATIONALE**

A comprehensive search of the literature and published theses failed to result in locating any qualitative studies concerning homeless women and breast and/or cervical cancer screening. The present study is a first attempt at addressing this gap in the literature. While more quantitative research efforts have been directed to women with mental health challenges, very few have used qualitative methods to understand what women think about cancer screening and how they make decisions about whether or not to participate. Unfortunately Miller et al.’s (59a) qualitative study did not provide rich contextual information which would allow for a more comprehensive understanding of women’s attitudes towards and experiences with cancer screening. For example, a portion of Miller et al.’s (59b) study outcomes were summarized as follows:

Table 1 (59b)
Participant Quotations from Miller, Lasser and Becker (2007)

<table>
<thead>
<tr>
<th>Reason for decisions not to receive mammography screening among women with known mental health diagnosis (no mammogram or cervical cancer screening and no Primary Care Provider (PCP) in Community-Based Health Care System (CHCS) database (N=3)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mental disorder affecting ability to follow through with appointments</strong></td>
</tr>
<tr>
<td>58-year old with “agoraphobia”, states “I set up appointments then cancel.” Close relationship with her mental health counselor who has helped her get to appointments by coaching her, constantly reinforcing the need to follow up, and encouraging self-care.</td>
</tr>
<tr>
<td><strong>Pain associated with procedure</strong></td>
</tr>
<tr>
<td>“The mammogram was just too painful” (58-year old, last MMG about 10 years ago; outside PCP scheduled MMG for next week, but doubts she will go).</td>
</tr>
<tr>
<td><strong>Fear of finding a problem</strong></td>
</tr>
<tr>
<td>“I always worry about myself and I don’t know why I don’t make the appointments. I’m so afraid.” (48-year old, last MMG 4 years ago, last PAP 2 years ago, has PCP in CHCS, will discuss with her provider at next follow up visit scheduled for day after interview to discuss a recent Hepatitis C diagnosis).</td>
</tr>
</tbody>
</table>
Unable to articulate any reason

47-year old had MMG 4 years ago out of state and PAP smear during a psychiatric hospitalization ("because something was wrong"), no reason for not following through, states will plan to discuss with her PCP (in CHCS).

These short quotes do not provide sufficient detail about mitigating circumstances, reasons underlying concern about pain during the procedure, or the quality of previous screening experiences as they may be related to fear and worry. Although 16 interviews were conducted only three women with mental health diagnoses were found to be under-screened. Perhaps more time should have been allocated for these conversations, which ranged from five to 20 minutes on the phone or 30 minutes during in-person interviews. Rigorous and methodologically sound qualitative research studies need to be conducted to understand how and why cancer screening decisions are made so that women’s specific needs can be effectively accommodated.

Each of the studies reviewed highlighted the importance of enhancing our understanding about the particular barriers and facilitators to breast and cervical cancer screening that homeless women and women with severe mental health challenges (hereafter referred to as WMHC) experience. It is important to learn about women’s perceptions about health care in general, cancer screening in particular, including their thoughts about systemic issues which impact on their willingness to be screened and/or their actual screening behaviours. Women who have never or seldom been screened make up more than 50% of all new cervical cancer diagnoses among Canadian women.(64) It is likely that some of these women are homeless or WMHC. As noted previously, the Toronto Central Local Health Integrated Network (LHIN) has the lowest cervical cancer screening rates compared to the rest of the LHINs in Ontario, and breast screening rates in this region are also lower than the provincial average. Early detection of cervical and breast cancer through routine Pap tests and mammography is supported by the Canadian Cancer Society, Cancer Care Ontario, Toronto Public Health, family physicians, nurse practitioners, gynecologists and oncologists.

Local efforts are needed to discover better strategies for reaching women with housing and mental health issues, and to improve their screening uptake. Any such advancement can only be made through consultations with the women experiencing these circumstances. Taking the time
to converse with women on a one-to-one basis about their life situation, their health beliefs, access to health care, and attitudes towards breast and cervical cancer may be the only way to begin to understand why some individuals are rarely or never screened, what motivates others to be screened and why some women miss health promotion initiatives altogether.

**Theoretical Framework: Behaviour Change**

Several theoretical models of behavior change were reviewed and evaluated for their applicability and usefulness to the current investigation. The Health Belief Model, the Transtheoretical Stages of Change Model and the Integrated Behaviour Model informed the development of a semi-structured interview guide and reflections on the qualitative data collected. These well-known models referenced collectively provided foundational knowledge for this inquiry. McLeroy et al.'s(65) robust ecological model however was best suited to explore the vast array of inter-related variables which impact on access to cancer screening activities. This model acknowledges that individual behavior is affected by the social environment. The ecological framework proposed by McLeroy et al.(65) was adapted for the current study and greatly influenced evolving questions with participants, data interpretation and analysis, and recommendations offered at the conclusion of the study. Each of these models will be reviewed and critiqued.

**The Health Belief Model**

Interviews with study participants considered the five constructs of the Health Belief Model (HBM) including: participant’s *perceived susceptibility* for developing cervical or breast cancer, *perceived severity* of these diseases, *perceived benefits and barriers* to breast and cervical cancer screening, and *perceived self-efficacy* to follow through with screening. Many studies have reported using HBM constructs to predict breast or cervical cancer screening behaviours.(66-73) While the HBM provides a useful framework for developing educational interventions and understanding some aspects of behavioural change at the individual level, it is not successful as a stand-alone model for understanding the underlying mechanisms at work with respect to behavioral change, nor has it been shown to consistently and accurately predict future screening behaviours. The model is limited by its focus on individual level factors to the exclusion of socio-cultural and familial influences, and community and systems level factors such as local availability of screening, knowledge about screening, and availability of emotional and financial
support to access and maintain screening behaviours. The model assumes: ready access to screening information, health literacy, and that health and wellness are universally valued.(74) Among homeless women and WHHC in this study, there were instances in which some and sometimes none of these assumptions were true. While the HBM takes into account barriers such as beliefs about the tangible and psychological costs of the advised action(75) it does not consider other significant barriers such as fear, previous negative experiences with breast or cervical screening, philosophical ideation, cultural or religious beliefs about mortality, or the impact of community or institutional level factors on non-participation in screening such as discomfort with male physicians performing Pap tests.

The HBM over the past 50 years has not evolved with respect to: explaining the relationships between the constructs(74); the salience of individual constructs in relation to each other, changes over time with respect to the salience of each construct for an individual or indeed if they do change over time; or how cues to action impact on compliance with health behaviours. The HBM does not account for the impact of health educators and health care providers not being sensitive to certain barriers which might exist such as a trauma or previous sexual assault. Attention to the construct ‘barriers’ in this model focuses on perceived barriers as presumed to be experienced by target populations, while overlooking the fact that interventions which are developed without knowledge of some of these perceived barriers are likely to fail in meeting their objectives. In the current study, particular attention was paid to these barriers. This included an acknowledgement of emotional factors such as fear, changes in mood, apathy, fatalism and greater concern with more pressing life issues.

**Transtheoretical Stages of Change Model**

Intuitively it makes sense that not all individuals adopt new behaviours in a singular step. Rather, change and readiness for change occurs in stages for most people depending on the targeted behavior, the context, and a variety of other influential factors. The Transtheoretical Stages of Change Model was described by DiClemente and Prochaska in 1982 relative to smoking cessation. It involved six states of change, decisional balance (pros and cons) and self-efficacy. The core constructs related to stages of change included: pre-contemplation, contemplation, preparation, action, maintenance and termination.(76) Interventions which narrowly define success by the outcome measure ‘participation in breast and/or cervical cancer screening’ fail to
acknowledge the stages of change along the continuum from pre-contemplation to contemplation over time which also may reflect the impact/effectiveness of a given intervention strategy. Many intervention studies fail to address or measure participants’ maintenance or relapse behaviours with respect to breast and/or cervical cancer screening. Consequently, interventions should be designed whenever possible in successive phases to sustain changes which impact on screening decisions and behaviours and which acknowledge and accommodate participants’ varying states of readiness for screening.

With respect to the theory’s application to cervical cancer screening, the stages of change as delineated by Tung and Cook(77) in their intervention with Vietnamese American women were:

<table>
<thead>
<tr>
<th>Stage of Change</th>
<th>Definition Relative to Readiness/Status for Cervical Cancer Screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-contemplation</td>
<td>A woman who never had a Pap test and has no intention to have one within the next six months</td>
</tr>
<tr>
<td>Contemplation</td>
<td>A woman who has never had a Pap test but intends to have one within the next six months</td>
</tr>
<tr>
<td>Preparation</td>
<td>A woman who has never had a Pap test but intends to have one within the month</td>
</tr>
<tr>
<td>Action</td>
<td>A woman has had one Pap test in the past year and intends to continue getting regular Pap tests</td>
</tr>
<tr>
<td>Maintenance</td>
<td>A woman has had regular Pap tests and intends to continue to do so</td>
</tr>
<tr>
<td>Relapse Risk</td>
<td>A woman is on schedule but has no intention to get a Pap test in the future</td>
</tr>
<tr>
<td>Relapse</td>
<td>A woman has had Pap tests but none during the past (3) year(s) and does not intend to get one</td>
</tr>
</tbody>
</table>

Many studies support the use of the TTM for cancer awareness and screening interventions.(66,78-81) A closer examination of research studies which have specifically tested the application of the TTM in predicting cervical cancer screening behaviours have revealed inconsistent results. While studies conducted in Australia, the United States and Korea have reported empirical evidence supporting the TTM,(79,82-83) other investigations have not found consistent evidence supporting the stages of change constructs and the decisional balance.
construct (weighing of pros and cons) of the TTM in predicting screening intentions or behaviours. Tung, and colleagues(84) in their investigation with Taiwanese women living in Taiwan found that participants in the relapse stage perceived more barriers than women in the action/maintenance stage, however no significant differences were found among other stages. This finding contradicts what has been proposed by the TTM. The authors concluded that the predictive aspect of the TTM with respect to weighing benefits and barriers was not supported in their study.

Tung(77) in her study with Vietnamese American women living in the United States found that participants in the maintenance stage had lower levels of perceived barriers and higher levels of perceived benefits compared to participants in the pre-contemplation stage which is what one would expect. A surprising and contradictory finding however was the fact that maintenance stage participants reported lower levels of self-efficacy than pre-contemplation stage participants. Similar to findings by Tung and colleagues(84), this may be a reflection of problems or discomfort experienced during previous Pap tests. If so, this supports the need for sensitivity training for all health care professionals conducting Pap tests and confirms the notion that other barriers may persist post-initiation of cervical cancer screening which impact on decisions concerning future and life-long screening behaviours.

Eiser and Cole(85) conducted a study with young women attending university in England to test the relationship between stages of change constructs as defined by Procheska and DiClemente(86) and risk factor awareness, interest in knowing Pap test results, and barriers to testing. These researchers found that women’s ratings of their perceived level of risk for cervical cancer were not associated with their stage of readiness for change or maintenance of behaviours. In fact their perceived level of risk for cervical cancer was not found to be associated with knowledge about factors which might put them at greater risk. Eiser and Cole(85) had hypothesized that women with higher levels of perceived risk for cervical cancer would be more ready and willing to participate in Pap tests and follow through with them. Their hypothesis based on the TTM was not confirmed.

Despite its limitations, the TTM informs our understanding of processes of change at the individual level and expands on the concepts provided by the HBM in important ways. It recognizes the impact of emotional factors as well as social and familial support on screening
decisions. The model’s acknowledgement that social norms can change and that individuals engage in a weighing of pros and cons related to screening behaviours elaborates meaningfully on the decisional process. Building on the concepts of ‘cues to action’ and ‘self-efficacy’ from the HBM, the TTM more thoroughly considers key components which relate to cancer screening decisions and behaviours. The TTM also takes into account the unique challenges of working with at risk populations, marginalized groups and ‘non-compliant’ individuals in a way that most action-oriented behavior change paradigms do not.(87)

**Integrated Behaviour Model**

The Integrated Behaviour Model (IBM) combines elements of both the HBM and the TTM and takes into consideration additional factors which influence screening behaviours such as feelings about the behavior, behavioral beliefs, others’ expectations and behaviors, attitudes and norms, self-control, perception of control and self-efficacy.(88) Importantly however this model also acknowledges one’s knowledge and skills to perform the behavior, the importance of the behavior to the individual, one’s intention to perform the behavior, one’s habits and environmental constraints. Each of these elements impacts on screening behavior. This model appears to be more robust and more promising than using either the HBM exclusively or the TTM exclusively. Although helpful as a framework, it seems lacking with respect to the construct of self-motivation.

**Andersen’s Behavioral Model of Health Services Use**

Andersen’s development and refinement of the Behavioral Model of Health Services Use is frequently used by researchers examining multiple factors which impact on the facilitators and barriers to health care utilization by marginalized groups of people(89). Initially developed in the late 1960’s the model outlined predisposing characteristics (demographic, social structure and health beliefs), enabling resources (personal/familial and community), perceived need and evaluation of need as factors relating to use of health services. Andersen attempted to identify global measures of health access which would serve to both inform health policy and evaluate the effects of policy change. One of the model’s strengths is the concept of mutability, which recognizes the varying degree to which variables can be altered. For example, personal health beliefs or medical resources can be changed – are mutable, whereas demographic variables such
as gender or ethnicity are not. The fourth iteration of the model in 1995 includes feedback loops which demonstrate the interaction between consumer satisfaction, for example, and subsequent use of health services. Researchers utilizing this model as a framework for studying highly specified topics (access and care for particular diseases) as well as general topics (access to hospital emergency departments) may have to implement longitudinal studies, complex study designs and sophisticated statistical analyses, and/or have access to pre-existing, large data sets. This model was not used in the current study given that the research enquiry was qualitative, time-limited, with less emphasis on the collection of demographic characteristics and more focus on the decisional process of cancer screening.

**McLeroy et al.’s Ecological Model:**

Ecological models acknowledge that there are multiple levels of influence on specific health behaviours. Attention is paid to diverse environmental factors and the role of policy on health behaviours. Ecological models move away from a ‘blame the individual’ approach which has been associated with individual level interventions, insurance company policies, and judgmental attitudes within a broader social context (for example with respect to smoking cessation or substance use). The current study has been strongly influenced by the ecological model presented by McLeroy and colleagues(65) which in turn was inspired by Broffenbrenner’s model(90) and the work of Belsky(91). In McLeroy et al.’s model(65), behavior is understood to be influenced by five factors: i) intrapersonal; ii) interpersonal; iii) institutional; iv) community; and, v) public policy as shown in Figure 1.
Figure 1

MOHLTC: Ministry of Health and Long Term Care
CCO: Cancer Care Ontario


Note: These 5 components should be understood as nested within each other.
‘Intrapersonal’ in this model refers to individual level factors such as knowledge, attitudes, beliefs, behaviours, self-efficacy, self-concept, and skills, while ‘interpersonal’ factors relate to formal and informal social support systems such as families, professional colleagues and circles of friends. Intrapersonal factors were explored in the qualitative interviews in the current study. Institutional factors refer to ‘social institutions with organizational characteristics and formal and informal rules and regulations for operation’, while community factors refer to ‘relationships among organizations, institutions and informal networks with defined boundaries’.(65) Given that women were recruited to participate from homeless shelters and assisted living residences in the current study, the impact of institutional culture was explored in the conversations. The collaboration between myself as student researcher and participating sites reflected both interpersonal and institutional aspects of the model. Consulting with members of the homeless and mental health ‘communities’ in this study facilitated shared ownership and control of the information to be discussed and ultimately shared. This breaks away from paternalistic, hierarchical approaches which have been used in the past by some health promotion programs. McLeroy et al.(65) discuss the impact of public policy on health behavior change with regard to local, state, and national laws and policies. The current study aimed to address health inequities by providing information about what homeless women and WMHC say about their access to quality health care, interest in and access to cancer screening services, and their recommendations for improvements at the individual, community, institutional and policy levels.

Clearly individual level interventions aimed at increasing breast and cervical cancer screening rates among under/never screened populations cannot succeed without complementary interventions at the community, institutional and policy levels. Offering educational programs in community settings without the provision of travel, child care or interpretation costs, supportive accompaniment to screening, close proximity of screening sites to where people live or gather, support upon receipt of test results and access to follow up care, simply does not make sense. Support systems need to be in place at all levels to promote screening uptake.

The strengths of this ecological model are that it recognizes that: multiple level interventions are more likely to be successful in the long term compared to single or dual level interventions; and individual level changes generally cannot be achieved without consideration of the impact of environmental factors. Interventions which are tailored to specific health behaviours using
multiple system approaches can guide future research. Another asset of the McLeary et al. model(65) is its uni-directional impact. For example, individuals and communities can have impact on public policy and public policy can have impact on individuals and communities. This point of view offers a more hopeful interpretation of how changes can be made in the future towards the provision of equitable health care and advances in health promotion.

This chapter provided background information on breast and cervical cancer at the national, provincial and local levels underlining the prevalence of under/never-screening among homeless and low income women and women with mental health challenges. The known facilitators and barriers to breast and cervical cancer screening among these populations were discussed. Only two qualitative studies have been published exploring the views of women with mental health challenges concerning cancer screening, and no qualitative studies are currently known which explore homeless women’s thoughts on this topic. The need for a deeper and more richly-textured and nuanced understanding of the context in which women make screening decisions and the factors which shape those decisions are quite evident.

Acknowledging that behavior change and/or behavior maintenance is not driven solely by individual level factors, McLeary et al.’s ecological model(65) was used to frame the study design, interpretation of results and formulation of recommendations at multiple levels including institutional, community and public policy spheres. The next chapter outlines the study methodology, theoretical framework for the qualitative inquiry and analysis, and ethical issues.
Chapter Two

METHODOLOGY

Primary Research Question

The primary research question for this undertaking was:

What factors influence breast and cervical cancer screening decisions among homeless women and women with mental health challenges?

Secondary Research Questions

Secondary research questions were:

1) What are the barriers to and facilitators for breast and cervical cancer screening among women living in the shelter system or in assisted living residences (due to mental health challenges) in Toronto?

2) What recommendations can be made for future outreach, education and screening initiatives developed specifically for under/never-screened women living in urban centres at the individual, organizational, community and systems levels?

Inclusion Criteria: Women aged 24–74 living in the shelter system or in assisted living residences (due to mental health challenges) in the Greater Toronto Area who provided informed consent and who spoke English were recruited to the study.

Exclusion Criteria: Women under 25 years of age and women over 75 years of age were excluded from the study. Individuals who did not provide informed consent were not included in the study. Individuals who were not able to communicate verbally in English were not included in the study.

In this study ‘under-screened’ is defined as:

i) any individual who has a cervix who has ever been sexually active who is aged 24 or older and who has not been tested for cervical cancer in more than three years
ii) any individual over the age of 52 years who has not had a mammogram in the past two years
   (exception: breast cancer survivors who have undergone double mastectomy)

**Ethics Approval**

The research protocol for this study originally received approval from the Research Ethics Board at Women’s College Hospital on August 29, 2012 (2012-004B). A revised research protocol received approval from the Research Ethics Board at Women’s College Hospital on May 2, 2013. REB renewal for 2013-2014 was received on August 29, 2013 and for 2014-2015 on August 29, 2014. Administrative approval of the protocol was provided by the Office of the Vice President, Research at the University of Toronto on September 28, 2012 (protocol reference # 28163).

**Recruitment & Informed Consent**

The majority of participants in this study were recruited from a larger study Cancer Awareness: Ready for Education and Screening (CARES). CARES Project activities were initiated in September 2011 and concluded in March 2014. This was a joint project between St. Michael’s Hospital and Women’s College Hospital representing the Toronto Regional Cancer Program within the Toronto Central Local Health Integrated Network. CARES was one of five projects funded by Cancer Care Ontario to reach under-screened and never-screened populations. This health promotion project utilized a multi-lingual peer leader model to provide community-based information sessions to women about breast and cervical cancer. Target populations included: newcomers, refugees, immigrants, low income women, women living in homeless shelters, sex trade workers and women with mental health challenges (WMHC). To address known barriers to education and screening activities, women were provided with local travel costs, child care as needed, oral and written information in their first language as well as facilitated access to screening through project staff and peer leaders. Paid peer leaders facilitated two hour information sessions which were sensitive to varying levels of literacy as well as culturally-specific norms and beliefs. From May 2012 to January 2014 over 2,000 women participated in educational sessions in twenty languages.

Six sites were selected for the present study including homeless shelters and assisted living residences for WMHC. Approximately one month after a CARES information session was
offered on site, recruitment flyers were posted (Appendices A and B) about the current study. I was interested in having the opportunity to interview women who elected not to attend the information session as well as women who did attend the on-site session. My plan was to interview women who were under/never-screened for either breast or cervical cancer who had decided not to be screened after the education session as well as those who did follow through with screening after the education session.

In some cases women directly called the phone number provided on the flyer. After discussing the study and answering any questions which arose, arrangements were then made for the interview to take place. All interviews were scheduled at the site where the CARES educational session had originally been offered. A private room was arranged for all interviews. At one of the homeless shelters, after discussions with staff, I held office hours on-site during which women could enquire about the study or participate in an interview.

At the outset of each proposed interview, the purpose of the research study was outlined and what was being asked of each participant was discussed. Next the written information and consent form was reviewed, either independently by the participant or with my assistance. Consent for audio-taping the interview was also discussed and provided by all participants. All questions, if any, were answered; each participant signed and dated two consent forms (Appendix C). Each participant was provided with a consent form; I retained original copies of consent forms in a locked file cabinet in a locked office.

**Sampling**

A stratified purposeful sampling framework(92-94) was used in an attempt to reach the quotas for both target groups as listed in Table 2. Potential participants who met the inclusion criteria and who provided written informed consent were sequentially accepted into the study. It was initially proposed that 24 women be interviewed representing both of these target groups and each of the following categories: (i) invited to participate in a CARES information session and declined (ii) participated in a CARES information session, was eligible for breast and/or cervical cancer screening and decided not to be screened (iii) participated in a CARES information session, was eligible for breast and/or cervical cancer screening and followed through with screening.
Stratified Purposeful Sampling Framework

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<th>Target Groups</th>
<th>Declined Education through CARES Project</th>
<th>Attended Education &amp; Decided Not to be Screened</th>
<th>Attended Education &amp; Decided to be Screened</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homeless shelter residing women</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>WMHC residing in assisted living residences</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 2

In qualitative enquiries only estimates of sample sizes can be given, which are usually based on a researcher’s previous experience, theoretical orientation and research goals and objectives. It is not possible to know in advance how many interviews will be required to meaningfully answer one’s research questions. Normally when a level of saturation has been reached it is no longer necessary to conduct further interviews or other forms of data collection (95-98). Saturation is reached when the analysis of data no longer yields new thematic concepts or new information about the phenomenon under study. It should be emphasized however that interviewing should not cease merely because new information is not arising. New questions can be posed based on the analysis in progress, relationships between themes or emerging concepts, all of which may bring forth new insights and information. Cresswell (99) suggests that grounded theorists conduct between 20-30 interviews. While guidelines have been developed within a few theoretical orientations, the issue of sample sizes in qualitative research remains controversial. Mason (100) conducted a study examining sample sizes of 560 PhD qualitative research studies which used interviews as the method of data collection. He sorted studies into 26 qualitative approaches and found that:

Eighty per cent of the total proportion of qualitative studies met BERTAUX’s (1981) guideline [15 is the smallest acceptable sample size]; while just under half (45%) met CHARMAZ’s (2006) guidelines for qualitative samples, with up to 25 participants being "adequate" (p.114). A third of the studies (33% or 186) used sample sizes of 20 or under (GREEN & THOROGOOD, 2009 [2004]). Finally, 85% met RITCHIE et al.’s (2003) assertion that qualitative samples "often lie under 50" (p.84).

As the current study design is stratified, I estimated that a sample size of 24 would be sufficient to provide theoretical insights, which would allow projection to comparable contexts. (101)
Lincoln and Guba(102) provided support for this practice which they described as the ‘transferability of findings to other contexts”. Analysis of the data explored the potential broader relevance of this topic within these populations and aimed to identify the grounds upon which generalizations could be made.(103) Ultimately 26 interviews were conducted at which point saturation was confirmed. No new thematic concepts arose after the twentieth interview had been conducted and analyzed. Interviews 21-26 were arranged to ensure that thematic saturation had been achieved and also to continue ongoing efforts to recruit women with severe mental health challenges residing in assisted living residences. A greater number of women residing in homeless shelters agreed to participate in interviews compared to women residing in assisted living residences. Although this impacted the intended purposeful sampling framework, the fact that the majority of homeless women interviewed had moderate to severe mental health challenges compensated for this methodological difficulty. The extent to which participants represented each of the three proposed categories is explored in the discussion chapter.

**Qualitative Interviews**

One to one qualitative interviews were selected as the method of data collection for this research inquiry given the sensitive nature of the topics and the life circumstances of the women. Focus groups would not have been an appropriate method of data collection as this approach would not have allowed for privacy and confidentiality, could have inhibited disclosure of personal views and experiences, and been uncomfortable for participants.

While the focus of this enquiry was on women living in the shelter system and WMHC, I regarded the interviews as conversations with women. A conscious and deliberate effort was made to ‘see’ the whole person and to diminish the salience of the labels and categorizations which had in fact led to these particular meetings taking place. I would be meeting with women with complex histories, multiple facets, diverse personalities and varied worldviews. Their current life circumstances were considered integral to the data analysis phase and potentially knowledge generation, however during the process of listening to women and learning about their thoughts and experiences the focus was on the ‘whole person’ rather than on her housing or mental health status. I did not wish to create distance between the interviewees and myself. The
goal was to create a safe and comfortable space for women to talk freely without feeling self-conscious.

After reviewing the purpose of the study and before the interview began, I thanked each woman for her time and assistance. I explained that I was there to learn from them and that I did not have views one way or the other about their cancer screening decisions. I acknowledged that women make their own decisions about their bodies, health care and cancer screening. I explained that the interview was an opportunity to talk freely about experiences and opinions. Participants were also told that I was interested in hearing about their suggestions, if any, for how improvements could be made to the health care system generally or to cancer screening practices specifically.

Although all interviews took place in a private room on-site at each location (i.e. homeless shelters and supportive residences) there were a few instances in which interruptions took place. Whenever that occurred, the conversation ceased until the interloper left the room. A semi-structured interview guide was used during the initial interviews (Appendix D) and adapted during the course of the study based on a preliminary analysis of early interviews. Questions explored individuals’ thoughts about their own health care in general (both physical and mental), current life stressors, knowledge, attitudes, beliefs and personal experiences with cervical and breast cancer, Pap tests and mammograms. The role of fear, fatalism and apathy in decision-making was also examined. Socio-cultural, institutional and familial influences on decision-making were explored along with perceived barriers and facilitators to cancer screening.

All interviews were audio taped and professionally transcribed verbatim including sighs, laughter, or other forms of expression(104). Each participant was assigned a participant identification code. All audiotapes and transcriptions bore the participant identification code; no actual names were used. The interviews ranged from 20 minutes to 90 minutes, with an average length of 45 minutes.

During interviews I positioned myself in the role of learner so that participants could take up the role of teacher. This approach facilitated an interaction that was, on the whole, relaxed, informal and comfortable. My attentive listening, eye contact, facial reactions, encouragement, empathy and understanding also aided creation of this safe space for conversation. My body posture,
variation in my physical proximity to interviewees during an interview, my sensitivity to emotions, soft voice and gentle approach all may have contributed positively to the atmosphere of the interview setting.

Some women who were coping with mental health challenges engaged in tangential dialogue. Consequently those interviews were longer in duration; however key questions were ultimately responded to and enriched the data set. Among all participants, there were many instances of personal story-telling unrelated to key questions. I listened to these stories, extended the interview time and only re-directed the conversation when I felt it was appropriate and respectful to do so. Some women had greater ability and ease than others to communicate verbally, reflect, and engage in critical thinking.

With regard to the learner/teacher dichotomy of roles, it was fluid at times. For example when interviewees had specific questions during the interview, particularly about cancer screening, I shared factual information at that point and then proceeded to the next question. If however a participant wished to have a conversation about her future decision-making with respect to breast or cervical cancer screening, I suggested we speak about that at the conclusion of the interview. (When that occurred I assisted by asking questions to help the woman decide for herself. When asked, I did provide further resources such as lists of Ontario Breast Screening Program (OBSP) sites or lists of City of Toronto public health clinics.) Apart from these exceptions, the role of participant as teacher was maintained.

At the conclusion of the interview each participant completed a demographic questionnaire (Appendix E), which took approximately seven minutes. The sole purpose of using this questionnaire was to allow for a description of participants’ demographic characteristics and cancer screening history. This information was collected at the end of each interview rather than at the beginning in an effort to obtain honest responses free from potential ‘researcher-pleasing’ answers, particularly with respect to the ‘willingness’ questions. The tone and conduct of the interviews appears to have facilitated honest responses.

Field notes were completed shortly after each interview was conducted. Field notes were unstructured in format and detailed: key observations, notes about further questions which could
have been posed during the interview, my emotional reactions to the narrative, concerns about answering the research question(s), reflections on the process and other thoughts deemed important to document. Field notes were reviewed during the analysis, providing additional context to interviews, inspiring critical reflection and guiding the interpretation of meanings and connections between codes.

**Theoretical Approach to Qualitative Inquiry**

This was an exploratory reflexive study which utilized thematic analysis to broaden our understanding of women’s decision-making processes concerning breast and cervical cancer screening as well as the facilitators and barriers to screening. A constructed ontology was used in an attempt to understand and describe participants’ constructed realities while referencing my own constructed reality and appreciation for the complexity of the topic. The epistemological framework was subjective and reflected knowledge that was co-created. The approach was hegemonic, values-based and context-specific. The term exploratory is used to describe this study as there is very little information available in the literature about the decision-making processes of women living in these circumstances, and a paucity of qualitative investigations on this subject.

Consideration was given to the use of grounded theory for this investigation, however the current state of knowledge about the research topic made it unsuitable for the development of mid-range theories or fully-developed theories. While grounded theory focuses on actions and processes during analysis, concentrating on themes and inter-relationships between themes using thematic analysis was a more appropriate strategy for this research enquiry.

**Thematic Analysis**

Braun and Clarke(105) define thematic analysis as a method for identifying, analyzing and reporting patterns (themes) within data. They explain that thematic analysis organizes and describes data sets in rich detail which the researcher then uses to interpret various aspects of the research topic. Boratzis(106) defines thematic analysis as more of a tool than a specific method, however it is a tool which can be employed across many methods. In the context of this study it is being used as a flexible tool within a constructivist paradigm exploring lived experiences,
meaning, decision-making and the influence of external factors on constructed realities (for example social, historical or political structures). Researchers using thematic analysis make important decisions prior to data collection, during data collection, during analysis and when reporting findings. These decisions should be articulated and explained when reporting results. The data collection and analytical phases of thematic analysis involve reflexivity. Researchers employing this tool ideally move beyond mere description of themes to explore potential explanations or underpinnings of thematic concepts. Braun and Clarke provide a six step framework for conducting a thematic analysis yet emphasize that the process is not linear. The six steps include: i) becoming familiar with the data, ii) generating initial codes, iii) searching for themes, iv) reviewing themes, v) defining and naming themes, and vi) producing the final report. One moves back and forth between data sets and between steps in an iterative fashion. Thematic analysis offered a useful tool in the quest to answer the primary and secondary research questions of this investigation.

**Methodology: Thematic Analysis**

The thematic analysis began with reading and re-reading the interview transcripts and field notes making written notes on the hard copies. Portions of audio tapes were also reviewed to examine the quality of the transcriptions and to clarify words that the transcriptionist had difficulty deciphering. All interviews were then entered in NVivo 10 software. This software was used as a tool to organize and review the data. Field notes were maintained in hand written form. After reading and re-reading all of the transcripts several times an initial coding strategy was formulated (Appendix H) consisting of 19 nodes and 16 sub-nodes. Each node and sub-node usually consisted of a “chunk” of data rather than individual sentences. This initial coding strategy was an attempt to organize the large quantity of data consisting of 473 pages of transcripts and 34 pages of field notes. Although constant comparison between cases was used to create the coding, the result was fairly basic, more reflective of category groupings. All nodes and sub-nodes were reviewed again and a second coding strategy (Appendix I) attempted to collapse codes. This resulted in ten parent codes being identified with 24 child codes. Although this seemed to be an improvement over the first attempt at coding, it was recognized that a deeper analysis was needed, so I returned to the data once again. Ultimately one over-riding concept was identified with three major themes. The over-riding concept was named
‘internal/external continuum of decision drivers’; the three primary themes were contextual factors, power and trust.

This approach was selected for several reasons. One being the recognition that multiple realities exist, another being that subjectivity is integral to the approach, and that I was attempting to understand the studied phenomenon ‘from the inside’(107). The analysis was influenced by social constructivism and included reflexivity throughout the process. Acknowledging that realities are socially constructed by interviewees as well as by the interviewer, a constructivist approach aided the search to understand the meaning behind and beneath participant’s comments. I also recognized that I brought my own experiences, values, beliefs and understanding of the world to this process and that I needed to be mindful of the impact that this could have on the interpretative process. Interviewees use words to describe their lived experiences which reflect personal understanding, interpretation of others, social contexts and language which has been socially constructed. I recognized that I needed to take into account my own understanding of socially constructed meaning in relation to words and social contexts both historical and contemporary while reflecting on the data and analyzing the data.

Reflexivity is involved throughout the research process to continually question and problematize the data, to continually question one’s own values and involvement in co-creating data and to critically appraise what underlying mechanisms exist that shape people’s words, meaning, and meaning-making. Knowledge is understood to be fluid and changes over time. As Guba stated: “Realities are taken to exist in the form of multiple mental constructions that are socially and experientially based, local and specific, and dependent for their form and content on the persons who hold them.”(108)

**Researcher Values**

While designing the study and throughout the process of liaising with study sites, interviewing women, analyzing the data and summarizing the findings, I reflected on my intent and the values which guided this undertaking. First and foremost was my respect for the women being interviewed as well as for the staff affiliated with the six study sites. My intent was to enrich our understanding of women’s experiences and thoughts about cancer screening, and to work towards equity in access to health and social services. My aim was to actively listen and learn from participants in a non-
judgmental manner and to do my utmost to create a safe and comfortable space for the conversations
to take place. I recognized that I needed to be cognizant of the inherent power imbalances in the
interview setting and to diminish any power differential to the best of my abilities. I committed to
maintaining and protecting the privacy and confidentiality of participants as well as interview sites,
and to share learnings broadly.

**Researcher’s Positionality, Perspective and Beliefs**

As a woman over the age of 50, I believed that the interviewees would be comfortable sharing
with me and allowing me to communicate their experiences. I was trained in psychology and
sociology, worked in health-based research for approximately sixteen years with a primary focus
on women’s health and marginalized/under-serviced communities. I believe that multiple
realities can and do co-exist, that one’s understanding of reality and meaning are shaped by the
social settings in which one grows up and experiences the world. Constructions of meanings are
also shaped by historical, political, religious, familial and social factors, and can change
throughout one’s lifetime. Individuals are complex. Identities are multiple and fluid. People
can be adversely affected in many ways by experiences of marginalization, stigmatization and
prejudice. Human beings have the capacity to be resilient even during times of hardship.
Individual lives and communities are affected by systemic and political factors as well as meso
and micro level factors as outlined in McLeroy’s(65) ecological model.

When we are engaged in this type of qualitative work we reflect on ourselves, how we see the
world, how participants may perceive us and the impact we may have on the interview
experience. I strove to reduce any power dynamics during interviews and demonstrated my
genuine respect for the women I interviewed. I was able to obtain permission to conduct this
study partially based on staffs’ assessment of me while involved with the CARES Project. I met
with managers and staff on a one to one basis to discuss the objectives of the current research,
how to operationalize it, to discuss safety plans, to consult about the honoraria and to hear about
any concerns they might have had. The fact that I have been working with homeless women of
all ages for several years, was already known to some staff, and that I demonstrated
thoughtfulness and sensitivity in my past work, all contributed I believe to staff trusting me to
conduct this research. I had also worked at the former Clarke Institute of Psychiatry for six years
and was comfortable interacting with women living with severe and persistent mental health challenges. At least to the extent that one can be comfortable witnessing poor mental health, loneliness, isolation and frustration. This speaks to concrete experience but what is more important are the values which are brought into the setting and the intention of the research as discussed. My intention in conducting this research was to better understand how women living in these circumstances make decisions about cancer screening with the aim of sharing that knowledge with others in the hope that future cancer screening opportunities and services would be more accessible and tailored to women’s needs. By hearing what women had to say, listening to their ideas for improvements and carrying their stories and recommendations forward, I hoped to make a positive contribution with lasting results.

It is the researcher’s responsibility to be attentive to ethical issues inherent in conducting research, both anticipated and unanticipated. I agree that all researchers should be clear about their intent before initiating any research enquiry and should contemplate how research participants could benefit from their involvement. Through the use of clear methodologies, rigorous and thoughtful analysis, I aimed to present participants’ views in a representative, truthful and clear manner. My theoretical perspective is post-modernist, social constructivist and grounded in the participants’ representations of themselves and their points of view. The methodology used as previously discussed is hermeneutic and dialectic. The epistemology is subjectivist; the ontology is constructivist. (102, 107-116)

Scientific rigor has been applied with respect to the design of the research undertaking, the procedures utilized, and the quality of the analysis. The justification for the research enquiry was clearly outlined and a rationale was provided for the development of research questions (115). The selection of one-to-one interviews as the method of exploring the phenomenon was justified; the theoretical framework guiding the enquiry was explained in detail. The number of interviews conducted and the length of interviews ensured sufficient data for a thorough analysis to be conducted. The approach to interviews and the rapport built with participants has been described; my values and positionality within the research context has been stated. An exploration of study strengths and weaknesses are detailed in the discussion chapter. The procedures utilized for data collection have been clearly explained along with a discussion of ethical issues. A transparent outline of the procedures for the analysis was offered. While
reviewing the results chapter, the reader may evaluate the analytic rigor of this study with respect to the transferability of findings to other contexts, including education for all under/never-screened women (101). The quality of the analysis can be assessed based on the audit trail including field notes, reflective notes, stages of coding and documentation on the decision-making process during analysis. (115) Validation checks were conducted in the analysis in which any potential biases were sought which could invalidate the findings; extreme cases were examined and evidence of cases in which the proposed conceptual code did not apply were also sought. A decision about when saturation occurred was also outlined for the reader. It was not feasible to follow up with participants to verify or discuss interpretations, however feedback and guidance from my thesis committee members were instrumental to decisions concerning analysis and interpretation of the data.

**Participant Honoraria**

At the conclusion of the interview, all participants were provided with a $20.00 honorarium in recognition of their time and contributions. Payment was provided in cash. Participants signed a sheet confirming receipt of the honoraria (Appendix F). Participants were also offered bottled water or juice and a snack.

**Data Storage**

Study information and consent forms were stored in a locked cabinet in a locked office. Information and consent forms will be kept for a period of seven years following completion of the study after which time they will be destroyed by shredding. The audio tapes and transcriptions have been stored on an encrypted USB (Data Traveler Vault Privacy 3.0) and backed up on my home computer as encrypted files (using Folder Lock 7 software). The hard copies of transcriptions have been stored in my home office in a locked cabinet. The audio files, electronic copies of transcripts and hard copies of transcripts will be maintained for a period of seven years after which time they will be destroyed. An electronic file with the participant log book will be destroyed one year after completion of the study.
Privacy and Confidentiality

Participants were informed verbally and in writing through the information and consent form that the personal information provided on those forms would be securely stored and that their names would never appear in any publications or forums about the study without their prior consent. Participants were informed that selected quotes appearing in any writing or in any presentations about this investigation would not include any information which might inadvertently identify them. As noted earlier, each participant was provided with a study identification number. Study identification numbers were used in place of participant names on audio recordings of interviews and on the transcriptions of interviews. To protect participants’ privacy pseudonyms have been used in the discussion of study results.

An electronic file was created listing participant names and participant identification numbers. This was done in the event that it became necessary to contact participants following interviews to verify accuracy of audio recordings. This electronic file is currently stored as an encrypted file on my home computer and also on an encrypted USB for back-up purposes.

Ethical Considerations

When working with vulnerable populations there are many ethical issues, which need to be considered. Of utmost importance is ensuring that participants understand their right to choose to participate or to choose to decline participation at any stage of the research project. Potential participants must understand what will be involved if they participate and that their participation is wholly voluntary. As with any research participants they must be informed about how their personal information will be used and who will have access to it. Ample time was provided during the consent process for potential participants to think about their decision to participate or not, and to ask questions.

Talking about personal issues can bring about emotional feelings. Participants were informed that they could skip any questions they did not wish to answer, that they could stop the interview at any time and that a referral to a social worker or social service agency could be arranged if desired (Appendix G). I also recognized that individuals who are uninsured or undocumented
may have serious concerns about maintaining their privacy and fear of being reported to immigration officials. I was prepared to deal with these issues.

The use of honoraria in research remains controversial. This was given due consideration. Ultimately I felt strongly that the women’s’ time and participation should be acknowledged in some tangible way. Study posters did not advertise that an honorarium would be provided. The honorarium was noted only in the consent form. At each site I consulted with staff concerning their policies and procedures about clients receiving money. All staff strongly supported honoraria being provided to participants. It was my intent to interview women who genuinely wanted to discuss the topic and for whom the honoraria was not the motivator for participation.

This chapter provided an overview of the methodology employed in the current study which was influenced by the review of literature and identification of gaps in knowledge. The research questions, recruitment, consent and sampling methods were discussed. I explored the theoretical approach to this qualitative enquiry and analysis of data. My values, positionality to the research, personal perspectives and beliefs were followed by a discussion about scientific rigor and ethical issues. The results of this investigation are described in the next chapter. For clarity, some of the analysis undertaken has been included with the results, and will be further elaborated upon in the discussion chapter.
Chapter Three

RESULTS

Introduction

Study results are presented including a review of participants’ demographic information, cancer screening status, willingness to engage in future cancer screening procedures, and details of their participation in information sessions on the topic. The primary theme concerning the proposed ‘internal/external continuum of decision drivers’ which resulted from the thematic analysis is explored. Contextual factors and issues of power and trust in health care providers are discussed in relation to decision-making about cancer screening. Women’s perceptions about power and trust in health care providers are shaped by communication and behavior. Women also experience empowerment and self-trust through their social interactions and through supports provided by social networks. Further analyses of study outcomes are discussed in chapter 4.

Study Sites and Participants

Between September 2013 and March 2014 26 qualitative interviews were conducted in four settings in Toronto. Two sites were homeless shelters designated for women only. Another site was mixed housing for homeless women along with rental units geared to income with on-site professionals available to assist with substance use and mental health issues. The fourth site was a supportive residence for women with severe mental health challenges who had also experienced housing challenges and homelessness. Invitations to participate in interviews a month after delivery of educational sessions at two other sites did not yield any participants. Both of these sites provided housing and support services for women with mental health and substance use issues.

Summary of Demographic Questionnaire Data

Based on the demographic questionnaires administered following each interview, participant ages ranged from 27-67 with a mean age of 47 years. Nineteen women were Canadian born; six women reported living in Canada for more than five years, while one woman reported living in Canada for less than five years.
Fifty percent of the participants reported some post-secondary education; 46% reported some high school education and 4% reported no education. All participants spoke English. One participant noted her first language as being Amharic and another participant explained that she also spoke several African languages. Half of the women had given birth to one or more children. All twenty-six women said that they had Ontario Health Insurance Program (OHIP) coverage. Eighty-eight percent (88%) of the participants reported that they had seen a physician or nurse practitioner in the past year. Of importance however was the fact that at the time of the interview 23% did not have a primary care provider, most of whom were actively seeking one and experiencing difficulties in that quest. Five participants reported having male physicians; fourteen had female physicians/nurse practitioners, five had no primary care provider and two reported more than one provider representing both genders. Information about screening status and overall health status are summarized in tables 3-4. A total of 13 women were over the age of 50 and age-eligible for breast cancer screening.

**Breast and Cervical Cancer Screening History**

<table>
<thead>
<tr>
<th>Cervical Cancer Screening History</th>
<th>N=26</th>
<th>Breast Cancer Screening History</th>
<th>N=13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never Screened</td>
<td>1</td>
<td>(3.8%)</td>
<td>Never Screened</td>
</tr>
<tr>
<td>Under-Screened</td>
<td>6</td>
<td>(23.0%)</td>
<td>Under-Screened</td>
</tr>
<tr>
<td>Up-to-Date</td>
<td>19</td>
<td>(73.0%)</td>
<td>Up-to-Date</td>
</tr>
<tr>
<td><strong>Total UNS</strong></td>
<td>7</td>
<td>(26.9%)</td>
<td><strong>Total UNS</strong></td>
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</table>

Table 3
UNS – Under/Never Screened

**Self-Reported Overall Health Ratings**  N=26

<table>
<thead>
<tr>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>8</td>
<td>12</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 4

The majority of participants (77%) rated their overall health as being either fair or good.
When asked about level of willingness to have Pap tests in the future 14 indicated that they would be ‘very willing’, seven were ‘willing’, one was ‘somewhat willing’, one was ‘not sure’, and two said they would be willing if they were sexually active. One woman who had undergone a hysterectomy did not require cervical cancer screening. One participant indicated that she would be willing to have a Pap test one year after she has been off all her psychiatric medications.

Thirteen women over the age of 50 were asked about their level of willingness to have mammograms in the future. Seven said that they would be ‘very willing’, three indicated that they would be ‘willing’ and one said that she would be ‘somewhat willing’. One woman was ‘not sure’; one woman was ‘not willing’. One participant indicated that she would be willing to have a mammogram five years after she has been off all her psychiatric medications. Details are provided in Appendix J.

Of particular interest in Appendix J is the fact that two women who were under-screened for cervical cancer were very willing to have Pap tests in the future; others stated conditions under which Pap tests would be considered, and no under/never-screened women refused future cervical cancer screening. Among the five women who had never been screened for breast cancer only one woman was not willing to participate in mammography in the future while four women were either ‘very willing’ or ‘willing’ to have mammograms. None of the four women who were under-screened for breast cancer indicated that they had no intention of participating in future mammography: one was very willing, one was somewhat willing, one was unsure and the fourth stated conditions under which she would consider it.

With respect to the distribution of participants who attended CARES information sessions versus those who did not, a summary is provided in table 5. In one homeless shelter a decision was made to offer information about cervical cancer on one date and information about breast cancer on a subsequent date. Shelter staff recommended this approach due to their perceptions that residents would only be able to sustain focused attention for forty-five minutes to an hour.
### Attendance at CARES Information Sessions

<table>
<thead>
<tr>
<th>Attended Both Sessions</th>
<th>Attended One Session</th>
<th>Did Not Attend Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>13 (50%)</td>
<td>6 (23%)</td>
<td>7 (26%)</td>
</tr>
</tbody>
</table>

Table 5

Seventy-three percent (73%) of participants received some education about breast and cervical cancer and cancer screening through the CARES Project, while 26% did not. Those that did not participate in educational sessions either decided not to attend or had moved into the facility after the education sessions had taken place. This fulfilled one aspect of the stratified sampling framework, which proposed that approximately two-thirds of the sample would have attended information sessions and one third of the sample would not. Appendix K provides information about participant cancer screening status and attendance or non-attendance at CARES information sessions.

Appendix K shows that three women who were under-screened for cervical cancer did not attend any information sessions. One participant who had never had a Pap test and one who was under-screened for cervical attended the full information session, while two other under-screened women attended half of the information session. Two women who were under-screened for breast cancer and one woman who had never been screened for breast cancer did not attend any information sessions. Five women (4 under-screened and 1 never-screened) attended the full information program. One never-screened woman (mammography) attended an information session on breast cancer screening. In summary 3 out of 7 women who were under-screened for cervical cancer did not participate in information sessions, while 3 out of 9 women who were under/never-screened for breast cancer did not attend information sessions. A detailed summary of responses to the demographic questionnaire is outlined in Appendix L.

### Thematic Analysis

The third level of coding resulted in the identification of a primary concept ‘Internal/External Continuum of Decision Drivers’. Internal/External Continuum of Decision Drivers is envisioned as being influenced by sub-themes of power, trust and complex contextual factors, all of which are in continual movement.
Internal/External Continuum of Decision Drivers

Figure 2
Internal/External Continuum of Decision Drivers

When examining participants’ decision-making processes as literally stated and beyond what was literally stated, decisions appeared to be self-directed, externally-directed or avoided altogether. Individuals can be conscious of the driving force behind decision-making or unconscious of its origins. Decision drivers are fluid, change naturally over time and vary by situational context. At the two extremes, decisions can change quickly during a conversation, or slowly over many years of experience and reflection. Assimilation and assessment of new information can solidify or alter the decision making process and outcomes. I recognized that some participants appeared to be self-directed with respect to screening decision-making, regardless of the decision to screen or not screen at that particular juncture in time. Some women actively decided not to make decisions and simply avoided it. There were many instances in which decision-making appeared to be externally driven. Examples of this were statements indicating that if the family physician said a woman should be screened, that was presented as the basis for her decision to be screened.

The thematic analysis highlighted many contextual factors that impacted on women’s intentions, decisions and/or follow-through with cancer screening. These included perceptions about their mental and physical health status, housing concerns, substance use or stage of recovery from substance use, poverty, social isolation, and access to transportation. Other critical contextual factors were a history of sexual abuse, having a family physician or nurse practitioner, the quality of relationships with health care providers, and feelings about previous interactions with health care providers and the health care system. Trust in self was implied by self-directed decision-making, taking an active role during interactions with health care providers and in self-care. Trust in health care providers, in the health care system and in social networks was influenced by communication and actions or behaviours in each of these spheres. Participants’ sense of power or lack thereof appeared to be directly related to communication and actions/behaviours of health care providers and/or experiences with the health care system. Possession of power in oneself was implied by self-directed decision making, pride in past accomplishments, and acceptance that one had to advocate for oneself in order to have specific health care needs met.
Contextual factors will be explored followed by the impact of power and trust in cancer screening decisions. The influence of communication and behaviours among health care providers and staff working in health care settings on women’s perceptions of power and trust will then be elaborated upon. Relevance of the internal/external continuum of decision drivers in the present context will then be reviewed at the conclusion of this chapter.

**Contextual Factors**

**Mental Health**

Among participants in this study, mental health factors were sometimes barriers to participation in cancer screening, while in others; mental health challenges did not seem to play a significant role in decision-making for or against cancer screening. Andrea, a 55-year-old woman with serious mental health challenges living in a homeless shelter spoke with me about her cancer screening history and thoughts about future screening. Andrea’s last Pap test was 13 years ago; she’d had a mammogram in her forties due to a family history of breast cancer. Her last mammogram was more than two years ago. When asked about her willingness to have another Pap test, she explained that she would probably be willing but only once she has been off her psychiatric medications for a full year. Likewise she thought she would consider having a mammogram but only after she has been off her medications for a full five years. In her perspective her body had to be clear of all medications to show accurate results.

Another participant, Sophia, a 50-year-old woman with mental health challenges, living in a homeless shelter, shared this perception. She explained that her food disorder interfered with regular Pap testing: “I kind of let that go a bit.” Like Andrea, she had an idea that she needed to ‘get normal’ or ‘get healthier’ before she would consider going back for this type of check-up:

“And my body was going through a whole bunch of different changes through that. And so my logic was with what I’m going 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…”

“And [I tried] to keep up until that problem [food disorder]. And so that was my logic in saying when you get to, you know, something you feel that’s back to that 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.”

Despite this point of view Sophia indicated that she would think about having a mammogram in the future. Sophia had attended the information session and commented that the experience made her think about screening more seriously:

“When you talked about the mammogram and Pap test I think, you know, logically I should and it is correct, and there’s a fear of not knowing exactly, but, you know, you are at an age that it might be a good idea to do it. So when I do my check-up … I’d like to include those two tests in there and sort of have them included.”

It appears in this example that access to the information session assisted Sophia in thinking about cancer screening differently, and facilitated openness to the idea. Her emphasis changed from the necessity of having a healthy status first to the importance of screening based on age and wanting to know what is going on inside her body.

Jackie, a 35-year-old woman with severe mental health challenges residing in an assisted living residence, explained that she was behind in going to see her family doctor for physical check-ups because she had great difficulty leaving the building. She shared that she has difficulty taking showers, putting on clothes and maintaining her room. It had been two or three years since she had been to see her doctor; she has never had a Pap test but did have a clinical breast exam. Jackie indicated that she would be willing to have a Pap test in the future if she became sexually active. In this case her mental health status impacted her ability to participate in routine health care, however her history of sexual inactivity precluded the need for cervical cancer screening. During the interview Jackie expressed her view that physical check-ups and health related tests are important to maintaining good health. She said:

“…But just to give you an example, even if I did hear that it [the Pap test] went horribly for someone else, that wouldn’t alter or affect my decision to have [one]. Because to do any test, either a mammogram or (pause) I would like to experience or take the test because I might not have a bad experience…. Because obviously I would care more to perform or do the test just to make sure my health is [good].”

Andrea’s decision about screening appeared to be self-directed based on her perception of what state her body needed to be in before testing should occur. Sophia seems to have moved along the
continuum from being self-directed to delay screening to being influenced by external information that moved her self-directed decisions to be more open to the idea of participating in cancer screening. Jackie’s attitude towards cancer screening appears to be self-directed even though her current mental health challenges prevent her participation in routine health care.

For other participants, mental health status appeared to be unrelated to cancer screening decisions. Leslie, a 55-year-old woman living in a homeless shelter who told me she had been diagnosed with schizophrenia at the age of 18, has had yearly Pap tests all her life. About 14 years ago she had an abnormal result and consequently had a biopsy to remove the cancerous tissue. She has never had a mammogram because she is afraid of the pain. Leslie told me that she has very sensitive breasts and that the only thing that would motivate her to have a mammogram would be if she discovered a lump. Leslie’s mental health status did not appear to influence her decisions about cancer screening; her self-directed decision not to have mammograms was connected to her fear of pain, although she willingly participated in routine cervical cancer screening.

The range in severity of mental health challenges participants experienced may have played a role in cancer screening decisions for some, but did not play a role in decision-making for others. The interplay of multiple factors makes this a complex phenomenon to ‘unpack’ and understand.

**Substance Use**

Dorothy, a 56-year-old woman living in supportive housing for people with mental health and/or addiction issues, and/or previous histories of homelessness, talked about how her attitude towards health has changed over the years:

“You know, before, I mean all I thought about is how I’m going to make money and how am I going to buy heroin and just.... No life you know?”.... You just sleep, get up, do your hair and then you go to work to make money [exotic dancing]. That was my life.”

She reflected on the fact that when she was addicted she never thought about sickness or about health. In recent years Dorothy has been taking an active interest in her health, particularly with respect to good nutrition, and has been trying to find a family doctor without success. She had a Pap test two years ago at a walk-in clinic, has never had a mammogram but she said she would like to arrange one as soon as she finds a primary care provider willing to accept her as a new
patient. Dorothy’s mother had her leg amputated due to bone cancer when she was in her thirties which Dorothy says makes her worry about her own cancer risk especially now that she is older. She spoke about how her priorities have changed in recent years:

“Well you know because I’m really starting to … you know my life is more organized now, you know, I have a roof over my head, I have some money coming in and…. I’m not into drugs or I don’t even hang around with any people that (pause) so my mind is on things that are important to me.”

With respect to mammograms, Dorothy indicated that it doesn’t matter to her if it hurts a little bit. She views mammograms as being necessary. Clearly Dorothy’s past substance use negatively impacted her participation in health care and in cancer-screening activities, however now that her life is more stable she is motivated to access health care and open to these preventive health practices. Her attitude toward future mammography appears to be internally-driven, but has also likely been influenced by external factors such as her mother’s bone cancer.

I met Rita, a 51-year-old woman residing in an assisted living residence who talked about the impact of many years of drug use on her life. She said:

“… It was like when I got into drug use, it [health] didn’t matter to me. I don’t know how long I went [without health care]. I started going to Toronto Health and they started giving me boosters and shots and protection and yeah I knew all that. They would come to me, you know at, in certain places I was at. And I’m like, you know, I’m going to be like this, so I started safety with my drug use and who I was with, so I started learning all that. But that didn’t come until later.”

Rita told me that while she was using she was not aware of the deterioration of her health. After quitting smoking, drinking and doing drugs she discovered the amount of pain in her body. She asked herself “When did I break that wrist? When did that, you know happen to me where, I can’t get out of bed to even go to the bathroom and it’s right there? Like anxiety was just grabbing at me.” Rita admitted that she never knew how much her children looked after her until she stopped using. Now that she is receiving support and addressing her physical and mental health issues, she is making decisions about how to prioritize all the areas requiring attention. Rita told me that she was going to have a mammogram the following week. An on-site nurse made the arrangements for her. The OBSP clinic is very close to her residence, which is helpful due to her
anxiety and difficulty attending appointments. It is difficult to discern whether her decision to be screened was internally or externally driven:

“So we’re at 50, so we need to have the stage of looking after the cancer and the mammograms. So that’s a whole circle of care and education. It’s a must.”

I interviewed Judy at a homeless shelter. She was 27 at the time. When asked what was most important to her about her health she said she was concerned about her mental health, diabetes, physical fitness and being able to eat healthy foods. Judy divulged that she had been using crystal meth for several years, but had been clean for the past four months. She explained that when she was high she would go a week or two without eating. That impacted her blood sugar levels and made her feel unwell. Judy told me that when she was high she was not hungry. For a period of time she was in a supportive residence but would not leave her room. She said at that time she didn’t want to talk to anyone and was always depressed.

During her addiction she did not seek health care, but Judy told me that she had a Pap test a few months ago and was very willing to keep having them in the future. In Judy’s case her years of addiction interfered with her overall health care, however very shortly after she quit using she decided to be screened for cervical cancer and went through with it. This decision appeared to be self-directed. It may also have been motivated by the fact that both her mother and her grandmother had experienced breast cancer and she had an ‘older’ friend who had cervical cancer twice. Judy told me that she assisted this friend ‘like a nurse’ because the woman was in a lot of pain and needed help getting to the washroom. These external drivers likely played a significant role in her cancer-screening decision.

**Safe Housing**

Judy spoke to me about the impact of her housing situation on her overall health:

“Because before I was at another shelter, women’s shelter, called [shelter name]. And ... it’s like it’s a nice place. The people are nice. But the activities there (pause) for drug users are very triggering and very addictive.”

Even though social workers, addiction counsellors, and nurses were available on site at this particular shelter, Judy continued to use crystal meth and stayed isolated in her room. When street
involved women or women who are ‘roughing’ it outside do make it into the shelter system, some settings do not facilitate stability. As Judy explained, other women at the facility can negatively impact efforts to abstain and recover from addictions. Women experiencing high levels of stress who are in these situations have to find the strength within themselves to gain access to shelters which are better suited to their needs. Sometimes there is a considerable wait for a long-term bed to become available at a shelter of their preference. In the interim it can be very difficult for women to sustain the path that they have established for themselves to move towards greater health and wellbeing.

During our conversation Judy shared with me what worries her most:

“My stability health-wise. And… my housing. Because I know if like this place doesn’t work out and say I end up on the street, I’m pretty much just digging my own grave. You know?”

Maureen, a 42-year-old woman living in the same homeless shelter as Judy commented on her previous housing situation:

“And I’m on anti-depressants. But where I was staying wasn’t very good for me. I was at a shelter before this, it was co-ed and I couldn’t stand it. My depression was really bad. Yeah, I finally got back in here and now I’m much better.”

Not just housing, but safe housing was a critically important factor to many women who participated in interviews. Kelly, a 60-year-old woman living in a homeless shelter who had HIV, a life-long history of drug use and other challenges explained that she did have a home but she could not go back to live there. She had been the victim of a horrendous physical assault in her home, which resulted in a debilitating fear and a high level of anxiety. A housing worker accompanies her to her previous home once a month to pick up her ‘stubs’ and to pay her rent. The housing worker is helping her to find a new place to live. She commented on her circumstances:

“And it’s so easy for people to say you got a place go back to it, you know like he’s not there anymore. Well there are a lot of factors, he’s not there because maybe I’m not, you know. Like I know he’s gotten on with his life because that’s his lifestyle you know and gone to the next, you know, victim. But I don’t want to see him again ever if at all possible.
... You know that’s why my worker he’s working with me to help me find a safe place because that’s why I won’t live on Regent Park and I won’t live on Sherbourne Street and I won’t live on the corners and I won’t live in places that are right now available. Well maybe I’m going to have the same issue because like there are places available but that … No they’re not healthy places and so yeah speaking about myself it’s got to be a safe environment for me.”

What many members of the general public don’t realize is that there is a time limit on length of stay in most shelters. Women have to contend with the uncertainty of this tenable position as Kelly went on to explain:

“… there are women here that are here and they become so complacent that you know they’re not even looking you know, but they’re in for a rude awakening because housing and case workers are clamping down and women are being given letters like every day, you know, you got to go, you know, like you got a week. Some get a week, some get a month. I don’t want to leave that way, I want to be able to leave on my own, knowing that I’m going to a place, you know, and I don’t want to be transferred to another shelter. That’s what bothers me the most …”

When safe or stable housing is not available, it is difficult to think about preventive health care. Despite this Maureen reported having had a Pap test within the past year; she did not need a routine mammogram as she was under 50 years of age. Kelly who was living at the same homeless shelter as Judy and Maureen also had recently had a Pap test on-site by the visiting physician. Kelly couldn’t remember when her last mammogram was but she indicated that it was many years ago. She was unsure about whether or not she would have one in the future. Having Pap tests available on-site likely facilitates uptake for some women, however the need to make an appointment and go to a potentially unfamiliar site to have a mammogram may be a barrier for some women living in homeless shelters.

**Sexual Abuse**

A history of sexual abuse is a contextual factor in women’s psychological health and engagement in health promotion activities. The Pap test in particular can often be re-traumatizing and lead to avoidance of these cancer checks. Four of the 26 women interviewed disclosed past sexual abuse, four others mentioned a history of physical abuse and one woman referenced past trauma.

Nicole, a 34-year-old woman with multiple physical and mental health challenges living at a homeless shelter mentioned that she had been sexually abused as a child. When I asked her about
her first Pap test experience and what the health care provider had explained to her, she said that she ‘wasn’t going to let a man touch me’ and:

“So I was glad that it was a female doctor. And she didn’t say oh, it’s in case you get cervical cancer or anything, she didn’t really say why we get one. She just said when you’ve been sexually active. And I didn’t know whether I should include my sexual abuse in that sexually active, because it wasn’t me … you know, participating.”

Nicole explained that she didn’t know for a long time if she could get a Pap test. She had her first one when she was 25 shortly after she married. Nicole told me that she didn’t know what to expect, that she found it painful and that she bled afterwards. She wasn’t sure if bleeding was normal or not. Despite this she continued to have Pap tests usually every year but had recently lost track of when her next one should be. When I asked Nicole what motivated her to have her first Pap test she explained that her doctor told her she should have one. With the information available it would seem that this decision was externally-driven. It is not known what motivated Nicole to engage in subsequent Pap tests, however it may have been related to her positive approach to health care and self-care which was evident during the interview:

“I am informed of any kind of tests or kinds of medications or things like that, so that I can live as full a life as possible.”

In Nicole’s case, childhood sexual abuse did not interfere with her participation in cervical cancer screening.

Paula, who was 48 years of age, had a different life story. A breast cancer survivor who calmly dealt with surgery and chemotherapy; she handled it well she said ‘mainly because I’ve been through a lot already in my life.’ In our conversation it was implied though not directly stated that her father had sexually abused her. When broaching the subject of Pap tests Paula told me that she was sent to have one when she was a teenager and she didn’t know why or what to expect:

“And I didn’t know. And I cried through the whole thing. I just cried. I’ll never forget that. And after that, I thought never again, not a male doctor. [A moment later]: … and he wasn’t (pause) he kept hurting me, and like … I don’t want to talk about it. It was just so – ugh.”

After the breast cancer was resolved, Paula’s family doctor wanted her to have a Pap test, but
Paula explained to me that she had not had sexual intercourse so it was decided that she would have the Pap test done under anesthesia at a local hospital. I wonder however if the real reason for needing the anesthesia was due to her bad memories of the first Pap test and/or her memories of the sexual abuse. One can only speculate. The impact of sexual abuse on cervical cancer screening in this case is less clear. During the administration of the questionnaire at the end of the interview Paula indicated that she would not be comfortable having another Pap test but she would be willing if it was absolutely necessary.

Rita, who I referred to previously with respect to her recovery from addictions, was also sexually abused in both her childhood and adult life. Her parents died at a young age; she was in foster care where she was ‘continually abused’. She shared with me that she had delayed having her ‘physicals’ done, that she didn’t like certain procedures; that she ‘wasn’t comfortable with it.’ She admitted to using stall tactics which she ultimately found to be exhausting. When we spoke about her first Pap test she said that it was very painful. She didn’t want to experience Pap tests after that:

“I guess it was the bleeding and the uncomfortable of it all. Like I wasn’t-, you know, typically when you go home and you don’t have to worry about any harm coming to you, I was always sexually abused. So I knew if somebody was going to do something or check my body; that it was going to be more painful. So a Pap was more like it’s going to hurt for something else. That’s how I identified.”

Despite her feelings, Rita was able to continue to have annual Pap tests during the years when she was raising her children. She said that she recognized the importance of being there for her babies, ‘so that kind of clicked in, the responsibility of being that.’ Even though she had found the procedure to be uncomfortable and somewhat traumatic she was able to tolerate Pap tests for the sake of her children. Later when she started using alcohol and drugs to numb her emotional pain she no longer cared about her health and understandably her attendance and interest in annual physical examinations declined. An internal mechanism seemed to be driving her decision to participate in Pap tests in her early years of motherhood. Contextual issues of substance use, prior sexual abuse, homelessness and poverty impacted on her ability to care for herself and engage in general or preventive health care. Now at the age of 51 and in a multi-step process of healing and recovery, Rita’s health care decisions appear to be strongly internally driven and buoyed by her love of life. For example when asked what good health means to her, Rita responded:
“I think really taking care of my spirit … my whole being, and that means being able to wake up and live and learn!”

Among the women whom I interviewed who disclosed past sexual abuse I did not find clear evidence of its negative impact on breast and cervical cancer screening participation. That is not to say that women did not find these procedures difficult. They did however participate in screening. It is not known how many other women in this study may have experienced sexual abuse and been affected differently than the cases discussed.

**Impact of Poverty on Healthy Lifestyle**

Living in the context of poverty makes it very difficult to maintain good nutrition, exercise and a healthy lifestyle as recommended by health care providers, health promoters and cancer prevention agencies. One’s ability to maintain good health is often fraught with challenges. Teresa, a 52-year-old woman living in a homeless shelter explains:

> “Yeah, so I [used to] do all kinds of exercise. My body wasn’t like this. I am in good shape because I do exercise. And I’m trying to watch my food, try to eat healthy food. But the problem right now I cannot go for exercising because I’m in assistance right now. So I cannot go. And depressed, it’s hard doing, going and doing like YMCA. Even somebody give me the money, there is no…”

Apart from not being able to afford to go to the YMCA and not feeling like exercising due to depression, Teresa explained to me that one of her breasts is so painful she cannot jog or walk fast. She recently had a mammogram and was told the pain is due to calcification. She was directed to return for another mammogram in six months. Teresa plans to attend her follow-up appointment even though she has limited funds for local transportation to get there.

Several women I interviewed had diabetes; they said it was difficult living in homeless shelters because there weren’t enough healthy sugar-free food substitutions for them at meal times. Frances, a 56-year-old woman living in a homeless shelter talked about the challenges of being diabetic and not being able to prepare her own food:

> “Yeah it is [challenging] because I’m supposed to have – diabetes people are supposed to have seven small meals a day. Like breakfast and then a snack, and
then lunch, a snack, supper, then a snack. You get the three meals, but you don’t get the snack in between, only after supper.”

Women in poverty who are housed or marginally housed sometimes have to rely on food banks, which means canned goods and non-perishables. It is very difficult to access fresh fruits and vegetables. Simple health promotion messages that fail to attend to these realities can be ineffective and discouraging to marginalized poor women.

**Access to Health Care Providers**

Quantitative studies have shown that having a regular primary care provider is often a key facilitator to participation in cancer screening. Women who have difficulties securing dedicated health care providers may have pressing health care needs which are unmet, and are at a disadvantage with respect to reminders, encouragement and support for cancer screening participation. Twenty-three per cent of the women in this study were currently seeking health care providers and experiencing difficulty.

Dorothy who has been drug-free for the past eight years spoke about her current situation:

“So that’s another thing I think about now. I don’t have a family doctor. My doctor, my methadone doctor, he was doing everything for me. Which he shouldn’t have to, you know, because he’s (pause) my drug doctor, right?”

Dorothy talked about her difficulties in finding a family doctor who would accept her. She called several clinics and personally dropped in to several more and was told that they weren’t accepting new patients. She went to one medical building and knocked on doors, floor by floor to no avail. She did this while experiencing a significant level of pain that impairs her ability to walk. She has been without a primary care physician for eight years and uses walk in clinics occasionally as needed.

Maureen who spoke about coping with depression in the section on safe housing also encountered difficulties when she did not have a primary care provider yet needed to continue with her regime of anti-depressants. She would go from one walk-in clinic to another until she was able to have
her prescription filled. It is certainly understandable that physicians working in walk-in clinics might be reluctant to prescribe a medication potentially without prior medical documentation and no guarantee of patient follow-up. Maureen had been trying to secure a primary care provider for a year and a half and had been routinely turned away:

“Yeah, especially and a family doctor - I had a hard time finding because I said (pause) I say right up it’s important for me to say I’m an alcoholic. Because I was in recovery for years, but it’s important that they know so that what they prescribe me and all that kind of stuff.”

“I was turned away by a few. They said they just can’t deal with even in recovery, and the same thing with the psychiatrist. So that was hard to access.”

Ultimately a physician at a walk-in clinic took her on as a patient when she presented with a broken wrist. In these examples in which women were willing to participate in cancer screening activities yet faced systemic barriers, we see that other measures are needed to support them, which will be addressed in the discussion chapter.

Kelly who was referred to previously, has an ‘HIV doctor’ and occasionally sees a ‘liver specialist’. During the interview she told me that she was currently looking for a new family physician because she was so ‘turned off’ by the impersonal nature of the intake process, which was conducted by the physician’s nurse:

“Oh to the point where I don’t want to go see the doctor. You know I’ve met her, she’s got my whole history now, I signed the consent forms for all my other health history issues to be sent over to her, like you know my file from [hospital]. But I wouldn’t even call her if I was sick that’s how turned off I was you know.”

The intake process was very thorough but took what the participant felt was a very long time. She was also disturbed about the fact that she was given a list of tests she would have to undergo before the doctor would see her again. This included among other things, a fecal occult blood test (FOBT) kit and a mammogram:
“You know like I saw the paper, the form upstairs for the mammogram. I don’t know when I was supposed to have gone, I think it was within a week of having seen her, you know, but then that day has come and gone and I still have it upstairs and I’m not going. I’m not doing it and I’ll wait and find a doctor that knows how to treat me better.”

Kelly resented the assembly-line approach and having to share personal information with a ‘stranger’ who was not the physician. The tension between the physician’s prerogative to run her clinic the way that she wanted to and the patient’s prerogative to resist that approach is embedded in a lack of trust on both sides. Unfortunately when an impasse like this one is reached, an opportunity for cancer screening is lost.

Social Isolation and Social Networks

When speaking with Paula who was a breast cancer survivor, I asked whether her experience motivated her to talk with other women about breast cancer and perhaps encourage them to get checked, or if that was something that she really didn’t talk about. She responded, ‘No, no my mother goes. My sister goes. They go.’ When asked about friends, her answer was:

“And if I have friends, yeah. I would tell them to go, definitely I would tell them to go.”

This statement exemplifies a lack of social support and difficulties maintaining lasting friendships which was common throughout many of the interviews in this study.

Participants rarely spoke about friends, however reference to mothers (and grandmothers) arose in several of the conversations with respect to their personalities, inner strength, past achievements, and also with respect to their influence on screening decisions. In most of these cases participants’ mothers were no longer alive; they were reflecting on memories. For example, when speaking about cancer screening, Gwen commented:

“And that’s my mother. You know, you, this is what you must do, and do it. And so I never was afraid or anything. It’s [screening] important.”

Women sometimes spoke about hearing other women say that Pap tests are difficult or mammograms are painful and this sometimes acted as a barrier to screening. Only one example was found in which the influence of others facilitated screening. Frances, a 56-year-old woman
residing in a homeless shelter, had never had a mammogram and was quite afraid to have one. However, during the interview she stated that she was going to try to overcome her fear and speak with her doctor about arranging one. When asked how she made this decision, Frances told me that she spoke with other people who said it did not hurt. She said that she was still afraid, but that she should go.

Teresa was the only other interviewee besides Frances who spoke about social support she received from her community and her church. Even then, she shared that it was difficult to find people who truly understood her situation, and sometimes her depression prevented her from going to church. Having social networks can be very helpful to women’s overall sense of well-being; however, women marginalized due to their mental health or housing status often lack social connections and social support. This contextual factor can impact cancer screening decisions, which might otherwise be made with input from peers. Depending on the attitude of peers, this input could facilitate or impede cancer screening activities.

**Power and Trust**

**Lack of Trust in Health Care Providers**

Andrea, the 55-year-old woman residing in a homeless shelter who identified herself as having been diagnosed with schizophrenia, spoke about Pap tests:

“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 a mammogram when they’d probably ruin you more.”

Andrea was clear about her decision not to have a Pap test or a mammogram and that decision was embedded in a lack of trust in her current physician and a suspicion that the tests could harm her. She added:

“I don’t trust doctors. Doctors are not Gods. And they don’t have wisdom. It doesn’t matter if they have years and years of experience. And also, the reason why … five years ago my GP (general practitioner) 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.”

While Andrea’s mental illness affects her judgement it is interesting to note that she was able to discern the difference between what she perceived as caring and uncaring physicians. Her current decision against screening appeared to be internally driven yet shaped by prior experiences. On the other hand, as mentioned earlier, Andrea indicated that she would be open to cancer screening once she has been off her medications for particular periods of time. In this example we can see the continuum upon which decision drivers move based on contextual factors.

Maureen, discussed previously, explained that she had to have Pap tests every six months because she had endometriosis. She relayed that the results were always positive so she routinely undergoes biopsies ‘just to make sure’. I asked for more details about the biopsy procedure and how she felt about it:

“My first one was horrible. It was done by a man who is… it was just the most horrid experience I’d ever had. So it was when they said the next time they wanted to send me for a biopsy I was really skeptical. But it was with my woman gynecologist and it was a much more – I can’t say pleasant. But it was much better handled. She didn’t leave the forceps in me to take a phone call or anything like that. That was horrible.”

According to Maureen, she was left with the speculum in her for half an hour while the physician took a phone call. She told me that the physician wasn’t gentle, the speculum was cold; he just seemed to be going through the motions. She was able to overcome her reaction and memory of this bad experience. Maureen ensured that the next time she had to have a biopsy done, she was seen by a female gynecologist who warmed up the speculum and had a more gentle approach. Other women who may have undergone an experience like this might never have returned for care.

Vanessa, a mature woman who did not disclose her age was living in supportive housing. She was physically well but experiencing mental health challenges following a violent assault. Vanessa shared with me her recollections about poor experiences with both Pap tests and mammograms:
“I noticed that in one of the cases there was not a woman with me, the nurse did not come in. So I asked the doctor where was the nurse? And he said things are okay. Don’t worry, don’t worry. So he proceeded with the test. But I decided not to go back to him.”

The physician disrespected Vanessa resulting in her having a lack of trust and understandably not wanting to return. Vanessa was eventually able to go on to have Pap tests in spite of this experience. She was resilient and determined to maintain her good health. Unfortunately for her, she continued to have negative experiences:

“But also I find Pap testing can be very uncomfortable. You know the instrument is extremely cold, frozen. And then most of the gynaecologists, we go there when we are not sure of ourselves. We are exposed, you know. And they don’t -- like gentle -- ask us to spread more, relax, you know. Much like -- relax, you know. What are you afraid of? Because I don’t know if it's me, it's my character that -- you know.”

“But because I will ask him, I said could he -- because I know that they can warm the instrument a little bit. But he took it from wherever it was. I think it was sterilization. It can be sterilized in heat or in cold I guess. Yeah, he didn’t. It just shocked me. And then with that you know, he didn’t even ask me. I tried to be relaxed. I even talk to myself, relax, relax ... But then when the cold came, I just like tightened. Yeah, he kind of told me off. But there have been some good experiences. So I'm not saying that all of them were bad.”

The next time Vanessa’s physician sent her to a gynecologist for a Pap test she told me that she had the form but told herself that she would not go; then she went home. She explained that she still had a lingering discomfort that was difficult for her to overcome. Vanessa also spoke about her experiences with mammograms:

I actually four times [had] experiences that technicians are very rough. And so when the test ended I did go to the reception and let them know that I was not happy with the technicians.... They [said] they would look into it. But I wonder when they’re doing training if that’s something, you know, could be touched upon.

She had different technicians each of the three times that she was treated roughly. In one instance, apart from rudeness, the technician positioned her improperly so that she had to stand on her toes to reach the height of the mammography plate. Vanessa delayed having her fourth mammogram as a result of these disturbing experiences:
“The fear of the first three stayed with me. So then I was skipping the appointment because the fear was still there.”

I met Eleanor, a 47-year-old woman with multiple mental health challenges, at a supportive residence. When I enquired about her Pap test experiences she said:

“No, they wanted … this was the first time it was done and it hurt like hell and they wanted … they felt I needed it. And then okay, but then the last time I was supposed to have it done they started it and I kept saying I hadn’t had sex. I’ve not been sexually active so they said … the lady stopped it. They wouldn’t give it to me. She said you can’t give her this because it’s too painful for her ‘cause she hasn’t had … been sexually active.”

When asked for clarification about her first Pap test and whether or not there had been any conversation beforehand, Eleanor responded:

At the time I wasn’t told that I wasn’t supposed to have it if I didn’t have sex. I was told I had to have it and it really hurt. It hurt more than when you go into the backside of somebody. It really, really hurt. I never wanted it again. ….. They didn’t say that I didn’t have to …. They didn’t ask me oh did you have sex. I would have said no and then they wouldn’t have … it wasn’t like that. It was insisted on doing it and she did it and it hurt like hell.”

Clearly disrespectful interactions with health care providers discourage some women from accessing preventive care, general health care and/or treatment. While these examples have highlighted misuse of power resulting in mistrust, there were also many examples from the interviews which reflected positive interactions with health care providers based on solid foundations of trust.

**Trust in Health Care Providers**

Teresa a 52-year-old woman living in a homeless shelter spoke with me about stresses in her life, her struggles with depression, medication, and her social supports. When talking about Pap tests she said:

“Pap tests, my doctor she told me to take. But, you know what; I am not like go (pause) going with the man because of my religion. And because I’m not in a marriage now, I’m
single and I’m reserved. I don’t worry about it. But still she encourages me to check and I check. I don’t know, it’s an annual check, but… (pause)

I tried to clarify by saying: “So what I’m hearing is even though you didn’t feel you really needed it - for good reasons - your family doctor said let’s do [it] and you agreed”?

“Yeah, and I’m happy to, yeah. And the comfortable, the testing I don’t have any issue. I’m comfortable…”

In this example Teresa appears to have diminished her opinion about the necessity of cervical cancer screening in favour of compliance with her physician’s direction. The continuum of decision drivers appeared to move from internal to external where power and trust likely came into play. Teresa trusted her care provider and followed her advice. Later when she spoke about how extremely painful she found mammograms to be, I asked Teresa if she planned to continue to return for six-month check-ups as had been suggested by her care providers. She replied that yes of course she would. “It’s better to go through that process rather than end up with cancer…. I don’t mind that I’m going.” She continued to trust in her care providers and in her own decision-making.

Teresa also spoke about the fact that her family doctor had encouraged her to have a mammogram even though she was under 50 years of age. (Teresa had previously had a brain tumour):

“She actually … my family doctor once again bad with the follow through, it was bad timing. She had scheduled me for a mammogram. She wants me to have one, but I didn’t follow through.”

I asked Teresa to elaborate further so that I could understand if she was reluctant to have one and if so why:

“Well, I heard they hurt. So I wasn’t all that excited to go. But I’m like this is something I need to do. But then everything else kind of snowballed in my life and that just fell to the backburner as well.”

“… It’s just been me with the follow ups, so just bad timing. But I’m willing to go. That’s one thing; it’s on my list of things I need to do. If she says I should get it done then I trust her.”
Teresa’s trust in her family doctor will likely outweigh her concerns about the discomfort she has heard about from other women. She went on to explain that since she had already dealt with a broken wrist, a broken leg and other things, the mammogram shouldn’t be too bad.

Linda, a 31-year-old woman living in a homeless shelter recounted that when her male physician suggested that she have a Pap test, she insisted on having it done by a female practitioner. Her doctor accommodated this request. She continued being cared for by this physician and trusted him. Nicole recounted that she liked her family physician because she was discreet and respectful. Maureen spoke about a former doctor who helped her to receive treatment for alcoholism and also introduced her to Alcoholics Anonymous (AA). This physician took the time to arrange for another patient of his to accompany Maureen to her first AA meeting. She said he was a wonderful doctor.

Lack of Trust in the Health Care System

Some interviewees had negative experiences when interacting with the health care system. Judy, the 27-year-old woman who disclosed her addiction to crystal meth, related a story about being treated rudely by hospital nursing staff who failed to take her symptoms seriously. She felt that they had made assumptions about her and judged her – thinking that she was ‘high on drugs or whatever.’ I enquired if she found that that happened in other places too (i.e. being judged in places other than hospitals). She replied:

“Yeah, I heard a lot of stories like that from my friends, you know. Once they ... they think that you’re on the street, you’re doing drugs, you’re like ... not important to them.”

While this is one side of a narrative without full context, it does illustrate the power of health care institutions and health care providers to differentially dispense medical care. When women perceive that this is happening it decreases their trust in care providers and in the health care system generally. Judy said: “A lot of people hate hospitals because of that.” She went on to explain that the paramedic who assisted her was very nice and seemed to care. Once they reached the hospital and he explained the symptoms to the nurse, though: “As soon as he left it was like it went through one ear and out the other you know? It’s like nobody cares about you.” Judy
explained that another woman in the waiting room in the hospital emergency department went to the nurse and said she was concerned that Judy might be having a heart attack and that she needed help right away. The nurse then came out and apparently said:

“What the hell are you yelling about, shut up and sit down, you’ll get called.”

Judy couldn’t breathe, her left side went numb and she thought she was going to die. When a heart monitor was finally set up, her heart rate was 178 beats per minute. She spoke about the discrimination she faced and said: ‘That’s not a way to treat people.’

In an unrelated incident Judy was referred to a mental health facility for an assessment. She found that ‘...even there I don’t feel like they actually took their time to sit down and listen to me. So I’m going to have to go for another assessment soon’.

Dorothy also spoke about negative experiences she had in hospital emergency departments when she was accompanying her daughter:

“They were very rude to me … I said to him afterwards, I said that I should report you, I said that was very rude the way you talked to me … And he said go report me, he said.”

Nicole recounted that she suffered from post-traumatic stress disorder from hospital experiences she had as a child. She underwent several surgeries and found the use of the gas mask to be extremely frightening. When she was ten years old being prepared for surgery she requested a needle for the administration of anesthesia rather than the gas mask. Hospital staff reassured her that she would be given a needle, yet when she was on the surgery table the surgeon began putting a gas mask on her. She said, at that point I lost it:

“I freaked out, I rolled off the table and was trying to get up and run out of the room. I had no glasses on because they didn’t let me keep them in the OR, so I couldn’t see very much. And they grabbed me, held me down on the table, like on my arms and legs. I was naked because the gown that I was wearing fell off. And they put the mask on me and I feel asleep that way. And I was crying, I remember. And then I woke up and I was sick, because it was the smell and the feeling of it, the fumes of it.”
Later in Nicole’s life when she had a psychotic incident she had to be restrained, and the experience was even more traumatic for her given her childhood experiences. Nicole also commented on under-staffing and staff burn-out in mental health institutions. She was assaulted by another patient while in care; Nicole thought the incident might not have happened if the unit had been fully staffed. Nicole also shared this story from one of her stays in a mental health facility:

“And when I was in the adjacent unit to that unit I remember that I was in the middle of a crisis, I was suicidal, and I was trying to talk to the nurse, and then the other side (pause) other side of that unit where there’s very many, many very sick people, they had a crisis there and they [staff] all went away to take care of that while I was still suicidal. And another patient helped me. And they said, oh you shouldn’t talk to other patients about your stuff, Yeah, but you guys all left me. I could’ve freakin hanged myself.”

These types of experiences erode women’s confidence and trust in the health care system. The consequences of these types of interactions can seriously impact both their physical and mental health and willingness to seek health care in the future.

Self-Trust in Decision-Making

Gwen, a 67-year-old woman living in a mixed-use facility with rents geared to income, a homeless shelter and extensive on-site resource staff, reflected on a Pap experience she had had many years earlier:

“I’ve had a lot of doctors over the years, and the only one I remember was a young male doctor - and I am very clinical about tests. I do it. I need to do it. I’m not embarrassed about it. I have no qualms. It’s in my interest so I want to participate. But I was just thinking about this recently. A very young doctor, I think he - we were both young and I think he was embarrassed. But he said now this may hurt, and I said well, it never has before so I’m assuming it won’t. And that kind of broke the ice, because I wasn't a nervous Nellie and I think he relaxed and we just, it’s just um … it’s nothing, you know, to do it. But a lot of women are very squeamish. I’m not.”

Gwen presents this scenario in a way that depicts a strong internal mechanism, not only about the decision to be screened, but the way in which the screening occurs. She appears to have been as concerned about the physician’s level of comfort as her own. Gwen’s commitment to screening was also clearly reflected in her comments about mammography:
“The one thing I will say is I did hear women say when they had their mammogram, that the squeezing of their breast really bothered them. It didn’t bother me, and even if it had it wouldn’t have mattered. I need this.”

Later in the interview while discussing different thresholds of pain women seem to have during childbirth and also during mammography she said:

“It must be something to do with um … the fact that, I think every woman anticipates some pain associated with child birth. And I guess certain women – as I say – it wasn’t painful for me so I’m a biased person already. But I often thought – and I reproach myself – what are you talking about? I mean it takes so short an amount of time. How can it be so …”

“… but I find that here … I mean it’s like the women sort of aren’t comfortable within their own bodies. And I think the whole idea, part of this breast screening thing, maybe there’s some type of strange touching their breasts or something. I can’t figure it out.”

Gwen emulated complete confidence and self-trust in her health-based decisions. Her positive attitude towards screening appeared to be influenced by her mother’s opinions as noted earlier. She believes that even if some discomfort is experienced, the benefits of knowing one’s cancer status outweigh any short-term discomfort. She was surprised by other women’s difficulty with it. During the interview she spoke about her contemporaries who shared her point of view. It may be the fact that some of the women living in the facility had previous histories of sexual abuse, which influenced their feelings about their bodies and reactions to cancer screening procedures. Gwen did not seem aware of this possibility; at least it was not discussed.

Gwen also talked about the importance of advocating for oneself in health care. She had not had her information needs met with respect to other areas of her health, but was determined to keep trying different avenues. A recent attempt to obtain a second opinion from an orthopaedic surgeon resulted in an appointment in 2016. She said:

“In other words, we don’t want to be bothered with you. (Later: ) But I’m not giving up. I’m just waiting because I don’t want to slip and fall again.”

Gwen has accepted that she must advocate for herself; she recognizes that the landscape of health care has changed over the years. She’s disappointed yet determined to fight for what she needs.
During the interview with Noreen, she spoke about her health issues including the need for one-to-one counselling to help her manage her diabetes. While waiting to hear back from a hospital she had been referred to, Noreen conducted her own research on natural remedies. She explained to me what she had learned about flax seed oil, chia seeds, magnesium and butterfly tea. As a result of her research and consumption of specific foods and herbs, Noreen said that her breathing had improved significantly and that her high blood pressure had dropped by 30%. She was confident in her ability to learn about and integrate alternative ways to improve her health, and was very satisfied with the results. Both Noreen and Gwen exhibited self-trust in decision-making.

**Physician’s Power**

Susan, a 31-year-old woman residing in a homeless shelter told me that she had had a Pap test a few months before the interview. I enquired if in the past she initiated Pap tests herself or if she had them when her doctor reminded her it was time. She replied laughing:

“No the doctor made me do it.”

When asked about the experience she said:

“It was uncomfortable, but I knew it’s best for me.”

Then I asked her whether she planned to continue having Pap tests approximately every three years, she said that she was not really willing to do it:

“I prefer not to think about it, but Pap is important.”

This scenario demonstrated an external influence on her decision-making just prior to having the Pap test in which she may have felt somewhat coerced into cooperating. Earlier in the interview she spoke about her father succumbing to stomach cancer and her mother’s history of an ovarian cyst, which made Susan fearful of cancer in general. Her unwillingness to be screened seemed contradictory to her statement about her fear of cancer. Perhaps her level of fear was impacting on her decision-making process. Despite further discussion it was not possible to gain further insight about the rationalization for her decision about cancer screening. This may be an example of avoiding decision making by not thinking about it.
When I asked Katherine, a 44-year-old woman living in a homeless shelter if there was ever a time that she needed help with health problems that she was not able to get the assistance she needed, she said “Everything’s fine here.” Later she indicated that she only needed “shampoo and stuff.” When I asked if there was anything she wished was different in the health care that she received, again she said, “No, everything is fine.” To which I asked, “You don’t have any complaints?” Katherine replied:

I don’t complain to nobody. To doctors or anything. Because I try to be on my best behaviour with doctors and stuff.

This comment made me wonder about what may have previously transpired during medical appointments that made her feel that she had to be on her ‘best behaviour.’ Other examples of physicians’ use of power both positively as a facilitator for cancer screening and negatively are discussed in the next section.

**The Impact of Communication on Power and Trust**

An examination of communication during screening will further explore the connection between the quality of interactions during screening and subsequent decision-making, both internally and externally driven. Women’s sense of trust or distrust, power or powerlessness is strongly influenced by the communication that takes place during interactions with the health care system generally and also during cancer screening procedures.

Louisa, a 60-year-old woman whose physical disabilities require the use of a wheelchair, recounted that her very first mammogram experience was ‘Actually quite good. It was exceptional.’ When asked what made the experience exceptional she explained that the technician took the time to find out that it was her first mammogram and spent more time with her, ‘compared to today’s standards.’ She went on to say that her second and third mammogram experiences were ‘not so good.’ Asked to elaborate:

“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, she knows what to expect. Bye-bye. Both times.” …. (and later in the conversation) “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.”
Louisa also noted that she did not experience pain with her first mammogram but did experience pain during her second and third mammograms when technicians were rushed, inconsiderate and not very communicative. Her initial decision to have a mammogram appeared to have been internally directed and yet the treatment she received in subsequent mammograms caused her to reduce the priority of being checked for breast cancer. At the time of the interview she was behind in her breast cancer screening:

“I mean if someone doesn’t shove it down my throat and call and say look, can we make this appointment and I’ll meet you at the front door kind of thing, you just don’t bother.”

Louisa also spoke about the difficulties of arranging and paying for WheelTrans to attend medical appointments.

Rita, who was recovering from addictions, physical and mental health challenges, spoke candidly about her life and current circumstances. When asked about what communication took place during previous Pap tests she responded:

“Nothing was ever explained to me. Like I think too that there was a lot of blame, because I wasn’t asking, and I was that woman. So I took that a lot of, ‘Why didn’t I ask when I left?’ But it was more or less explained to me, actually after [emphasis added] I’d had all my children. So what I thought was just usual to get up there; they’re going to do what they’re going to do. They’re going to call me back in if there’s something wrong. That’s all they ever said. It was like in and out. It wasn’t them. I think it was weird too that I just didn’t care. I just didn’t [ask], just now I ask everything. That’s maturity.”

I asked Rita:

“So did you realize it might have been like a cancer check or you weren’t sure if it was an STI (sexually transmitted infection) test or, because many women I talk to sometimes didn’t know what was actually happening. Were they checking one thing or … so you knew? Did you know?”

Rita: “No, didn’t know nothing. All I knew that is they’re going to tell me if something is going on inside my body.”

The lack of communication and explanation offered by health care providers over a period of several years in this example could have led to a lack of trust and feelings of disempowerment. Upon reflection about these experiences however, Rita questioned her own role in not having asked for more information and not having cared more. She seems to excuse the lack of
communication by health care providers in saying ‘It wasn’t them’ and blames herself. Some study participants also expressed the feeling that they should be empowered to speak up when communication has not been clear or adequate. When they recalled not having been able to do so, they chastised themselves rather than identifying the factors in the interaction which may have prevented them from feeling comfortable to ask for more information.

Sophia, the woman previously discussed who struggled with a food disorder, spoke with me about her first Pap test and what communication took place:

“… and he did my first Pap test. And I remember explaining to him kind of the way we’re talking right now, how I was afraid of it. And how it’s going to hurt. And the people talk about the pain and everything. And he was very … before we actually went into the test he actually got a little bit more into the detail about how it was… you know, it’s going to feel like pressure, it’s not going to hurt. (Later:) I think because he sat down with me and talked to me and kind of prepared me. Really really it was good and important for a doctor to do that.

Through our conversation during the interview it seemed that Sophia was able to go regularly for Pap tests earlier in her life because her first Pap test went so well. The communication that occurred instilled trust; she was then able to overcome her initial fears. She commented on how quick it was and that she didn’t feel anything except a bit of pressure.

“So when I had the Pap test I thought, wow, everybody’s been complaining about how painful it is. And you know, it took them so long to get over it. And it’s a terrible test. And it wasn’t like that for me. It was scary before and then after it was like, yeah, I could go back next year and have a Pap test – no problem with that.”

The importance of taking the time to engage in a dialogue about the procedure and to prepare the patient, particularly for a woman’s first Pap test cannot be overstated. This investment of time by the physician can build trust and pave the way for life long screening decisions.

Frances was up to date with Pap tests but had never had a mammogram. She spoke about her mother’s mental health problems, which resulted in her being put into child protection services at the age of nine. When asked about her first Pap test: ‘Oh it hurt. Yeah when they put that silver thing. That really hurt.’ I enquired if she was able to say that it hurt. She replied that she told him:
“I told him to take it out. He said oh I’ll just be a – it was a man doctor. But he was very gentle. He said it’s just going to be a minute, then I’ll take it away.”

Later in the conversation she was asked if anyone explained beforehand what was going to happen during the Pap tests. She said no. ‘I know the Pap test is just to prevent having cancer or something. Yeah.’ She explained that even though it was a very unpleasant experience, she was able to continue having Pap tests and was no longer ‘scared’ of having them. She was asked if she had to think about it much, to which she replied ‘No’. Frances was able to communicate her experience of pain however the doctor proceeded with the exam anyway. Although it appears that he exerted his power over her, she readily forgave that saying he was gentle. She had very little understanding of what was being done to her yet did not seem concerned about that. In this scenario it seems that in subsequent Pap tests she deferred to the doctor and did not question the procedure. Her decision making appears to be externally driven. Her response to potential discomfort was to try to be calm. After exploring this further it became clear that she did not have any strategies to employ to actually help herself remain calm.

From each of these examples it is clear that the quality of patient/physician communication impacts on women’s sense of trust or distrust in care providers. When women perceive that health care providers are exerting power and control over situations or decisions, they may feel disempowered or they may resist or reject care. Based on unpleasant mammogram experiences Louisa stopped going for mammograms, while Francis appears to go along with the care she is provided with, putting the responsibility on herself to stay calm. Rita, who did not receive appropriate information nor effective communication during several Pap tests could have experienced a loss of personal power, however, she ultimately blamed herself for not asking more questions and asserting more control during those interactions. Rita’s expectations about the quality of health care providers’ communication may have been low given that she had low expectations of herself during her years of substance abuse. The excellent communication and reassurance that Sophia experienced with her care provider on the other hand, facilitated her trust in the procedure and the practitioner, which facilitated future cervical cancer screenings.

**Summary**

Cancer screening decisions among homeless women and women with severe mental health
challenges are multi-faceted and extremely complex. Generalizations cannot be made as each woman has a unique history, and circumstances change over time which impact on one’s attitudes towards health care generally and cancer screening specifically. There was great variation among this group of women with respect to their rationalizations about screening decisions. Some provided coherent, thoughtful responses to questions while others gave brief answers, which perhaps over-simplified the process or represented an accurate picture of uncomplicated, straightforward decision making. During some interviews points of view expressed on the topic were subsequently modified, making categorizations impossible. This happened more frequently among women with mental health challenges. The findings demonstrated that some contextual factors analyzed on their own incurred disparate outcomes with respect to decision-making. This highlights the importance of considering multiple variables simultaneously and speaks to the complexity of the phenomenon.

The range of mental health challenges facing different women impeded participation in cancer screening among some, and appeared to have no impact on screening decisions or participation among others. Active engagement in substance use negatively impacted screening activities; however, once in a stage of sobriety, uptake of cancer screening did occur. Not having stable, safe housing interfered with some women’s ability to engage in screening; however, on-site Pap tests at shelters facilitated screening among others. A past history of sexual abuse can be a barrier to some women participating in routine cervical cancer screening. Despite this, however, examples were presented of women with sexual abuse histories who found undergoing Pap tests to be difficult, yet they were able to participate in regular screening.

Women living in poverty have higher priorities to contend with, which over-shadow thoughts about cancer screening. These may include housing needs, need for particular foods or personal care items, access to Ontario Works or the Ontario Disability Support Program or other health care needs. Access to a health care provider was shown to facilitate participation in breast and cervical cancer screening, while lack of access was a barrier to screening. Social isolation may inhibit involvement in cancer screening, while having access to a social network could influence decision-making in either direction.
Lack of trust in health care providers or in the health care system was presented as a barrier to screening for some women. Other interviewees expressed distrust of some health care providers; however, they were able to persist with their commitment to cancer screening by changing physicians. Fear of screening was overcome through trust in care providers; trust in the notion that “it’s for my own good” and self-trust that one could handle it. Communication, both poor and excellent, influenced women’s sense of trust in care providers and in their perceptions about physicians’ greater position of power relative to their own.

The data presented illustrate the fluidity of decision-making and the ways in which power, trust and complex contextual factors impact on internally and externally driven screening decisions. One’s perception about internal and external sources of power is influenced by trust. Trust is cultivated in oneself, in health care providers, in health care systems and in social networks. Contextual factors play a key role in cancer screening decisions both for and against.

Based on this model, facilitators to cancer screening included: having access to a family physician; being satisfied with one’s family physician; having had previous Pap tests and/or mammograms that went reasonably well; being encouraged or influenced by mothers, friends, or others in one’s social network; and valuing cancer checks as routine activities that help to maintain good health. Barriers to screening identified were: not having access to a family physician, other life issues being more highly prioritized, mobility issues, transportation issues, not being well enough psychologically to leave the facility, social isolation, and varying levels of knowledge and understanding about cancer checks. Cancer screening decisions among this group of women were varied and complex.
Chapter Four

DISCUSSION

Introduction

The breadth of data collected from the 26 interviews was sufficiently broad to enhance understanding of the complex factors influencing women’s decision making about breast and cervical cancer screening. In this chapter the reasons for participants’ screening rates will be explored along with a discussion about the feasibility of utilizing mobile mammography units in Toronto. Given that some participants experienced negative interactions with health care providers, strategies to improve health care provider communication skills are explored along with a discussion of the mitigating factors behind patients being turned away from practices accepting new patients. The finding that some women with mental health challenges believe that they need to be healthy before they can participate in cancer screening activities is discussed along with the implications of this perception and how it may be addressed. Acknowledgement of and responses to systemic barriers are examined; the usefulness of the behavior change models for this study are then discussed. Recommendations by participants as well as synthesized recommendations that I co-developed with participants are presented, followed by a discussion of study limitations. The chapter concludes with lessons learned about the barriers and facilitators to cancer screening.

Cancer Screening Rates

Results of the demographic and screening history questionnaire were encouraging in that only 26.9% percent of women were under/never-screened for cervical cancer. Given the complex and challenging life circumstances of most of the women interviewed, combined with unpleasant screening experiences by some, this was a surprising outcome. It may reflect the 2012 change in guidelines from annual Pap screening to every three years when results are normal. That 80% of women reported being either very willing or willing to have Pap tests in the future correlates with what would be expected given prior cervical screening behaviours. Another reason for these findings may be that on-site health services were available (even if only occasionally) at most sites, including access to Pap tests. The 73% cervical cancer screening participation rate in the
past three years among the women in this study was primarily higher than the cervical cancer screening uptake rates among homeless women reported in the literature reviewed in chapter one.

Thirty percent (30.9%) of age-eligible participants in this study reported being up to date with mammography, i.e. they had had a mammogram within the past two years. This rate was lower than the majority of studies previously discussed in chapter one concerning homeless women. Mammograms require women to travel to OBSP clinics and this may explain in part the high rate (69.1%) of under/never screening for mammography among the women participating in this study. Lower screening rates may also be attributed to the older ages of the women, some of whom may be fatigued by difficulties they’ve experienced interacting with the health care system over the years. Despite this it was an encouraging finding that only one of the never-screened women rejected outright the idea of participating in future mammograms.

Consideration should be given to the use of mobile mammography units so that medically under-served women including women with disabilities, mental health and housing challenges, and women without primary care providers could more easily access screening services in their neighbourhoods. Mobile screening programs have been in existence in North America for more than 20 years, although service delivery is usually focused on remote geographical areas (117-125). A group of researchers in Quebec (126) recently published a study comparing the effectiveness of mobile mammography programs to fixed site mammography clinics. Between 2002-2010 the authors reported that 42,279 mammograms were conducted by mobile units in Quebec accounting for 1.8% of the total number of mammograms conducted in the province. The mobile unit program raised participation in mammography by more than 80% in the regions where no fixed centres existed. Outcomes of this study demonstrated similar estimated sensitivity for detecting cancer and a lower number of false positive results at mobile units compared to fixed site locations.

Another study published in 2013 (127) reported on the impact of a mobile mammography program in Jefferson County, Kentucky. Between 2008-2010 3,923 mammograms were conducted in approximately 200 under-served locations. Twenty-nine percent of the women accessing mobile units had never had a mammogram or had not had one for more than five years. The study authors noted that 56% of women screened in mobile units were uninsured and 25% did not have primary care providers. The participation rate in areas served by mobile units reached 63.4% on average.
between 2006-2010, compared to 54.7% in fixed clinic settings. All women who were found to have cancer were successfully reached and assisted with navigation for follow-up care.

The Saskatchewan Cancer Agency uses mobile buses to reach rural women and women living in the northern part of the province. The British Columbia Cancer Agency supports three mobile vans that travel to 120 small communities including First Nations communities. Cancer Care Ontario has a Screen for Life coach that visits communities in Northern Ontario and also the Hamilton region. While mobile clinics can be expensive to operate, they offer a viable solution to engage hard-to-reach women, even in urban centres. A cost effectiveness analysis should be conducted to compare operating costs of such a program in Toronto with diagnostic and treatment costs for under-served women whose cancer is detected at a late stage.

As previously discussed, fear and lack of trust are significant barriers to breast cancer screening uptake. Despite this, almost 77% reported that they were ‘willing’ or ‘very willing’ to have mammograms in the future. A possible explanation for this may be the impact of having attended an information session on the topic, and/or the impact of discussing breast cancer and mammograms during the interview. Another explanation may be that some women who did not have primary care providers intended on having mammograms once they had located one who was willing to take them on as new patients.

One might have expected more than 40% of women to have rated their health as fair or poor given their revelations about current health conditions (Appendix M). That all women interviewed had OHIP cards was a surprising finding. It is not uncommon for personal identification to be lost or stolen when moving from shelter to shelter or back and forth from the streets. The Street Health Study(17) reported that 34% of homeless individuals participating in the study did not have OHIP cards; 50% did not have a social insurance number card and 29% did not have a form of identification such as a passport, birth certificate or proof of citizenship. The majority of women interviewed in the current study had complex medical problems. It is possible that women were very careful with their health insurance being dependent on the health care system for prescriptions and other types of care. It may also be that staff at these residences assisted women with the replacement of lost OHIP cards. Whatever the reason, this was a reassuring finding. Most women had accessed health care services over the past year, including those who used walk-in clinics or hospital emergency departments when they were without a primary care provider.
Internal/External Continuum of Decision Drivers

In this study decision-drivers were contextual factors in women’s lives and issues of power and trust in health care providers. This model envisioned internal and external sources of influence shaping decisions and proposed that these influences including sub-themes holistically change over time. When I reflected on these interviews and how I envisioned an organically changing continuum of factors driving decisions, I thought further about the underpinnings of internal and external drivers and meaning making. This led me to interpret the concept differently. Even when it may appear that decisions and behaviours are internally driven, many external factors over a period of time influence and shape that positionality. For example when women spoke about their mothers’ points of view about cancer screening, they were reflecting whether consciously or unconsciously, on how their own views were shaped. Mothers’ representation of meaning and the importance of these cancer checks seemed to play a significant role in their daughters’ attitudes towards these health promotion activities. As we construct meanings for ourselves throughout life we may not recognize the process as it is happening or realize the external cues that accumulate and contribute to our meaning making. Our understanding of the world and ourselves is socially constructed. The physicians and gynaecologists who appeared to exert power and control over their patients, seemed to operate from a position of privilege that has been cultivated by their profession for many years. Health care professionals are shaped by their individual life experiences, social structures, professional cultures, and other influences resulting in different styles of interacting with their patients (including differential interaction between patients). Viewed through this lens, perhaps all decision-making about health as well as other issues originates from external cues, which help to manufacture meaning.

Negative Interactions with Health Care Providers

The number of accounts of poor interactions with health care providers including breast imaging technicians which arose during the interviews was concerning. Stories about some physicians exerting power and control over patients, failing to stop Pap tests when women expressed pain, failing to obtain a sexual history before proceeding with Pap tests, and lecturing women when they tensed up during those exams are inexcusable. Much work needs to be done to provide awareness and sensitivity training to existing physicians and gynaecologists as well as those currently being trained in their respective professions. There are of course systemic factors that
cause health care providers to feel rushed and pressured, however consideration should be given to marginalized women who require special care and more time. Failing to do so may result in women not returning for basic health care needs or health promotion activities.

The scenario in which the gynecologist performing a biopsy left the speculum in Maureen while he answered the phone was an extreme example. Given this extremely negative experience, it is not difficult to understand why Maureen was skeptical about going for her next biopsy appointment. Clearly during this procedure Maureen did not feel any sense of power or control over what was happening. The physician on the other hand held all the power and control. How Maureen had the fortitude to return for care following her next positive result on a Pap test is hard to imagine. It seems as though the knowledge that she would have a female gynaecologist performing the biopsy helped her to find the courage to return for follow-up care and diagnostics. Power and trust are entwined not only in decision-making about cancer screening but also in other decisions about health care in general.

Katherine, the woman who was reluctant to critique either her health care provider or the health care system who said “I try to be on my best behaviour with doctors and stuff” is an example of someone who does not appear to feel safe to express herself. Had she been told in the past that she was not exhibiting good behaviour? According to whom? What does best behaviour mean? Why was she more concerned with pleasing the medical staff and engaging in self-silencing than with the assertion of her own needs? Was she concerned about some type of retribution if she made any negative comments? This story exemplified the intersection of power, communication, and behaviour self-modification as a woman with mental health issues interfaced with the health care system.

A scenario warranting further discussion involves Kelly, the woman who did not like her new physician’s intake system. She said: “I’m not going [to the mammogram]. I’m not doing it and I’ll wait and find a doctor that knows how to treat me better.” In this anecdote the physician had a system that she likes to employ with new patients. This system may be well intended and perhaps well accepted by some; however for this woman it was impersonal and rather autocratic. Kelly resented the assembly-line approach, having to share personal information with a ‘stranger’ who was not the physician, and that participation in screening tests were mandatory. Lack of communication about the context for cancer screening also likely played a role in this story. This
particular physician implemented a system that may have been efficient for her, however it may have inadvertently discouraged some women from cancer screening activities.

Vanessa, the woman who asked her gynecologist to warm up the speculum before her Pap test was shocked when he ignored her. Then he scolded her when she tightened at the feel of the cold speculum. He asked her sharply: “What are you afraid of?” When a physician is this disrespectful, how could a woman ever develop trust or feel any sense of power in the situation? It is certainly no surprise that, when her family physician referred her to a gynaecologist for her next Pap test, Vanessa was unwilling to go. The excessive and unnecessary use of power with which this gynecologist handled his patient, completely destroyed any possibility of trust. As a result of experiences like these, women suffer on many levels.

More evidence of abuse of power and control by health care providers was found in Eleanor’s case, the young woman who was not yet sexually active but was coerced into having a Pap test. This was an example of carelessness and neglect in not having had prior dialogue with the patient before a decision was reached to do a Pap test. When a patient feels powerless, there is absolutely no trust. It is not known what role her mental illness played in the physician’s decision to precede with cervical cancer screening without the patient’s understanding or consent. There is however no excuse or rationalization that could justify skipping such an essential dialogue from having taken place.

Effective and thoughtful communication by health care providers demonstrating respect for their patients impacts women’s decision-making and willingness to be life-long screeners. Having heard countless stories about painful mammograms through the CARES project as well as through these interviews, I am left wondering about the skills of breast imaging technicians, why many of them seem unperturbed about the level of patient discomfort during the procedure, and why many women do not feel respected during their mammography appointments. If substantial improvements could be made with regard to the quality of technician/patient interactions, uptake in breast cancer screening would likely rise.
There is a substantial body of extant literature on patient/physician communication, the impact of communication on issues of patient trust, and approaches for providing patient/woman-centred care (128-131). Despite this, there has been growing concern in recent years about the level of patient dissatisfaction with provider communication. Levinson and Pizzo addressed this issue in a commentary published in the Journal of American Medicine (128) in which they stated that medical schools and residency programs focus the majority of time on science and technology and minimal time on skill development for effective communication. They also commented on the impact of some physician incentive systems which reward efficiency and patient volume resulting in brief appointments and sometimes dissatisfied patients. Recommendations have been made to substantially improve the situation, albeit this will take many years and require concerted, collaborative and dedicated effort. Some suggestions included: allocating more time for patient-centred communication skills in medical schools and residency programs, providing incentive-based professional learning opportunities for practising physicians, regularly implementing patient satisfaction surveys, and conducting annual physician evaluations using 360º models incorporating peer and patient feedback. Levinson et al. (130) also suggested that patient surveys be included in the recertification process for physicians, and insurers consider including payment codes for time spent educating or counselling patients.

Establishing or maintaining patient trust in health care providers is a complex undertaking. A 2013 Cochrane review including 10 randomized control trials did not produce sufficient evidence that any of the interventions impacted on an increase or decrease in patient trust in physicians. (131) Several studies have been conducted on physician attitudes towards homeless and low income individuals (132-134) as well as attitudes of drug users towards physicians. (135-139) Unfortunately many of these studies highlighted a perception by drug users that they were disrespected and experienced prejudice. Lack of physician knowledge or interest in addictions accounted for some of these difficulties. On the other hand, Reilly and Schiff (133) authored an excellent article on how to provide primary care for the medically underserved; it was a meaningful contribution towards ameliorating disparities in receipt of quality care. Also encouraging was Malika Sharma’s (134) description of an innovative curriculum for medical trainees about provision of health care for marginalized people which was implemented at St.
Michael’s Hospital in Toronto, Canada in 2010-2011. Although much work needs to be done in this area, some progress has been made which others may model in the future.

Given that family physicians play a key role in the promotion of cancer screening, having a primary care provider is another contextual factor in decision-making and screening uptake. Primary care providers through their power and control to accept or deny new patients both directly and indirectly affect marginalized women’s access to cancer screening. Unfortunately many women are unaware of the fact that they can self-refer for routine mammography after the age of 50. A qualitative study conducted in British Columbia (140) with un-attached marginalized patients who had one or more chronic illnesses found that participants worried about lost opportunities for preventive care, not having a consistent medical record, being excluded from care because they were perceived by physicians as being ‘difficult’ cases, and their inability to access referrals to specialists. Focus group participants believed in the benefits of having a family physician and wanted to have the opportunity to develop trusting relationships with care providers. Participants using walk-in clinics reported being treated by different providers each visit, with the result that physicians did not have the continuity of contact to properly assess health care deterioration over time. To partially address these difficulties an effort could be made by health care providers working in walk-in clinics to review preventive care needs after dealing with the primary reason for the visit.

As a result of the number of complaints by the public about the perception of being ‘screened’ by physicians and subsequently not accepted as new patients, the College of Physicians and Surgeons of Ontario (CPSO) created a new policy in 2009. (141) The policy advocated a ‘first-come-first served’ approach to accepting new patients, although in reality surveillance of the implementation of this directive is not wholly feasible. The public may file complaints if they are turned away from a practice accepting new patients without a reasonable explanation. Unfortunately some family physicians may be reluctant to take on patients with complex medical needs or psychiatric conditions as was the experience reported by some participants in the present study.
A significant finding in this study was the concept some women with mental health challenges hold, that they cannot participate in cancer screening activities until they feel that they are well, healthy, or normal. This has implications for future practice. Health care providers should of course respect their client’s decisions, but on the other hand, this insight may inspire more fulsome conversations with clients about their decision-making. Care providers should consider taking the time to listen to women’s rationalizations about cancer screening decisions and help them to better understand how their bodies work. This is not to suggest that physicians should coerce women into compliance with screening practices. Listening and really hearing how women think about these issues and make decisions may facilitate a different kind of conversation. Such a conversation may also provide great insight into other aspects of women’s health decision-making.

Sophia, the participant who spoke about delaying her annual physical exams until she felt that she was back to normal, made the following comment: “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.” This statement echoed by other women, particularly those coping with mental health issues, poignantly conveyed a critical teaching point. Women intuitively know what they can handle. Preventative health care decisions are sometimes made with coping skills and resilience in mind. Internally driven decisions like this one, may act as a protective feature by insightful women who feel they know their own limitations. Putting off potentially important screening or diagnostic tests due to an inner belief that one has to be ‘normal’ or ‘well’ or ‘healed’ before having those tests could however result in poor clinical outcomes. This is especially significant given that many women with mental health challenges report being reluctant to continue taking medication once they feel better and as a result of this are often caught up in repetitive cycles of improvement and worsening of symptoms. Many years might pass before a woman holding this perspective reaches a point of considering herself ready for cancer screening, or she might never reach that place.

While women shared stories of great hardship in their lives, they did not speak about suffering per se. This does speak to the resiliency of the human spirit of course, yet at the same time, patterns
emerged of numbing out pain and placing suffering on ‘mute’ to maintain an outward appearance and dialogue that was devoid of suffering and emotional pain. This may be a coping mechanism employed during periods of high stress and difficulty. It’s impossible to know if and how much women’s inner dialogue contrasts with these external presentations of self. With this knowledge health care providers might consider asking follow-up questions to more accurately assess the severity of problems women are experiencing, given their down-playing of serious concerns.

**Addressing Systemic Barriers**

An important outcome of this study for health promotion specialists, health care providers, professional governing bodies, cancer agencies and policy makers is the need to move away from assumptions about individual-based deficiencies in under-screened women to acknowledging that poor physician/patient encounters are partially responsible for some women’s discontinuation of cancer screening activities. It is frequently presumed that women are deficient in knowledge, awareness, understanding or the resources needed to attend screening activities. Public messaging, health promotion activities and educational events assume that once women have the information they will follow through with cancer screening.(142-146) Poor interactions with health care providers are not discussed, nor is the fact that some women are not able to secure primary care providers to attend to their health care needs in the first place.

As a consequence of this, even programs that address barriers to screening such as the provision of child care, transportation costs, multi-lingual resources or even facilitated accompaniment to screening appointments assume a system is in place that works relatively well. The focus is on raising awareness and on educating women, which naturally is important, but for those women who have had poor screening experiences, a different approach is needed. Experiencing pain, rudeness, or disrespect cultivates distrust in health care providers and the health care system as a whole, which has larger implications for general health care needs. These comments are not intended to discount the positive experiences many women have receiving high quality care, nor the advances cancer agencies have made to reach out to marginalized populations. There is work to be done however with respect to sensitivity training, communication skills and technical skills for professionals. This includes receptionists, administrative assistants, breast imaging
technicians, family physicians, gynecologists, oncologists and other specialists involved in cancer treatment. Increased rates of cancer screening among under/never-screened women will not be achieved until inadequacies in the health care system are addressed in conjunction with improved health promotion strategies.

**Revisiting Behaviour Change Theories**

Some components of the Health Belief Model did arise during the interviews including: discussions about perceived benefits, perceived barriers, perceived susceptibility for developing breast or cervical cancer, as well as perceived self efficacy to continue or initiate cancer screening. The construct ‘perceived severity’ was not articulated during the interviews. Many interviewees seemed to think about cancer as you either have it or you do not; there were no discussions about some types or stages of cancer as being more serious than others. The key health promotion message that finding cancer early offers a better chance of a good outcome than when cancer is found at a later stage was understood by approximately half of the interviewees. Those for whom that messaging resonated however, did not speak about different degrees of severity of cancer. As noted in chapter one this theoretical model assumes that people have ready access to cancer screening information, that levels of health literacy are sufficient to process available information, and that health and wellness are universally defined, understood and valued. This was not necessarily the case among women participating in qualitative interviews.

The Transtheoretical Stages of Change Model with its focus on the individual without consideration of contextual factors was not useful in this investigation. I could have classified participants as being in pre-contemplation, contemplation, preparation, action, maintenance, relapse risk or relapse categories, however this would have been based on an interpretation of what women shared during interviews and might not in fact have been accurate. Even if interpretations of women’s stage of readiness for screening could be assured, there was very little use for this information on its own in the context of this study. Where it could be useful to educators and health promotion specialists would be with respect to the development of focused messaging for women who are at risk of relapse (thinking about not returning for screening) or who have actually relapsed (decided not to return for screening and have not returned for screening.) Addressing the fact that some women described by these two categories may have had
unpleasant experiences either with health care in general or with cancer screening in particular would open up the opportunity for dialogue. This would allow discussion of alternative options available to women and would also validate their past experiences.

Some components of the Integrated Behaviour Model (IBM) arose during the interviews. The most important contribution this model made to the analysis was the consideration of environmental constraints, which included access to health care providers, contextual factors and systemic issues. Other components of the model that were reflected in the interviews included: feelings about screening, other’s expectations and behaviours concerning screening, self-control, perception of control and self efficacy, knowledge, skills and ability to follow through with screening, and intention to be screened. Ability has been emphasized because it has been added to the IBM given that some women had the knowledge and the skills to continue or initiate cancer screening yet their mental health challenges precluded them from being able to leave their place of residence to do so (e.g. severe anxiety).

McLeroy et al.’s ecological model provided an excellent framework for the analysis of interview data, my reflections, and the development of recommendations. This model, as well as other social ecological models, has been employed in health promotion practice and community capacity building for the past 20 years.(147-153) The strength of these models is their departure from a focus on individual-based behaviour change to recognition of the impact of the social environment on the individual, resulting in behaviour change strategies being employed at multi-levels. Social ecological models have been most successful in the field of HIV prevention. In their review of community based health promotion programs using social ecological models Merzel and D’Afflitti(154) conclude that many interventions aimed at entire communities failed to attain stated project goals. They attributed this to the difficulty of measuring behavioural change while other trends are occurring in society. Another difficulty has been low statistical power to detect changes. Mezel and D’Afflitti(154) suggest that new metrics are needed relative to the scale and time frame in which interventions take place. High expectations for significant results in short periods of time in which funding is available also impacts meaningful evaluations. They have suggested a three-tier approach for health promotion activities: i) tailored educational interventions with high risk individuals ii) mass media campaigns directed at large communities to help shift social norms, and iii) activities to influence change at the policy level. Mezel and
D’Affitti(154) also emphasize the importance of engaging and involving communities with ongoing social change. While most interventions based on social ecological frameworks have only been able to demonstrate modest levels of behaviour change, the conceptual use of such models for designing interventions has been beneficial.

Given that evaluations of community-based health promotion projects using social ecological models over the past 20 years have resulted in only modest levels of success, it would be prudent to use ecological models in the planning stages of interventions. An environmental scan should first be conducted followed by active engagement with individuals, communities, institutional and other stakeholders as well as policy makers prior to planning interventions. In the present context McLeroy et al.’s ecological model provided a robust framework for understanding the multiple influences which shape women’s decision-making processes about access to preventive health services and active involvement or disengagement with those services. Figure 3 provides a visual representation of additional and/or more specific components, which were developed and articulated during the current investigation. These components are listed below the original ecological model.
Figure 3: Application of McLeroy et al.’s Ecological Model to Study Findings

**Public Policy**
- MOHLTC
- CCO
  - Recommendations for system-level changes
  - Access to Health Insurance

**Community**
- Health Clinics
- Neighbourhoods
- Poverty
- Health Literacy
- Health Insurance Status

**Institutional**
- Homeless Shelters
- Supportive Residences
- Hospitals
- Screening Programs

**Interpersonal**
- Researcher
- Interview Participants
- Staff Members
- Family Members
- Social Networks

**Intrapersonal**
- Knowledge, Attitudes, Behaviours, Beliefs, Perceived Perceived Barriers, Susceptibility
- Self-Motivation
- Poverty-Related Stressors
- Language Issues
- Social Isolation
- Mental Health
- Stigmatization
- Prejudice
- Gender Identity Issues

**Community**
- Access to OBSP for mammograms and access to Pap tests for women without a PCP
- Living in a safe neighbourhood
- Impact of poverty on overall health, access to health care, access to accurate information, transportation costs & plain language materials with images

**Public Policy**
- Advise women without OHIP and women with IFH about access to mammography
- Advise uninsured women about access to community based clinics for Paps with choice of female or male practitioners
- Specific recommendations from the study

**Institutional**
- Assistance acquiring OHIP
- Sources of accurate information, encouragement and support
- Impact of hospital experiences on attitudes towards HCP and HCS
- Power and trust in health care system

**Interpersonal**
- Family Physicians
- Gynecologists
- Breast Imaging Technicians
- Reception Staff (OBSP & community-based clinics)
- Mothers / Memory of Mothers
- Other Residents
- Friends
- Power & trust in HCPs
- Communication with HCPs including breast imaging technicians and support staff

**Intra-personal / Contextual Factors**
- Substance Use
- Fear
- Internal/External Decision-Drivers

HCS: Health Care System
IFH: Interim Federal Health
OBSP: Ontario Breast Screening Program
PCP: Primary Care Provider
HCP: Health Care Providers
Barriers and Facilitators to Screening

Analysis of the interview data revealed the following barriers to cancer screening: fear of the procedure, fear of pain, fear of hearing the results, not having access to a family physician, history of unpleasant/unsatisfactory Pap tests or mammograms, lack of trust in health care providers, other life issues being more highly prioritized, mobility issues, transportation issues, not being well enough psychologically to leave the facility, experiences of discrimination, history of sexual abuse, dis-interested attitudes, and varying levels of knowledge and understanding about cancer checks.

The majority of these issues have been cited in quantitative studies, however the present study contributes important information about women’s lived experiences, illuminating patient/provider interactions which resulted in feelings of empowerment, disempowerment, trust, distrust, shame and embarrassment. The reasons underpinning women’s cancer screening decisions have been underscored with greater clarity and breadth of understanding. This investigation also highlighted new insights that some women with mental health challenges may hold a belief that they cannot participate in cancer screening activities until they are physically or mentally well or have discontinued use of psychiatric medications. This insight may inform future discussions between care providers and patients who may hold this type of perception.

Facilitators to screening included: having access to a family physician; being satisfied with one’s family physician; having had previous Pap tests and/or mammograms that went reasonably well; being encouraged or influenced by mothers, friends or others in one’s social network; and valuing cancer checks as routine activities which help to maintain good health.

The current study provides new knowledge about women’s personal experiences trying to access health care services while dealing with housing and/or mental health challenges in a context in which some physicians selectively choose new patients, barring others. Scenarios describing successful patient/provider interactions demonstrated that simply taking a few extra minutes with a patient can positively impact on trust-building, compliance, and life-long screening behaviours. The impact of mothers’ positive attitudes towards cancer screening on adult daughters own screening decisions has not previously been elaborated upon in the literature. This may be a
generation-specific artefact given that prior to the 1960’s women were socialized not to talk about the female anatomy at all, and certainly not in public. Those conversations were privately held between sisters or between mothers and daughters. Present day mothers may still influence their daughters’ attitudes towards cancer screening, however decisions are likely also shaped by mass media, social media and other sources of information and influence.

**Participant Recommendations**

*I think we’ve really lost our social fiber and that perspective that if we don’t lift the lowest people up we don’t all go up. And it’s kind of like each man for themselves and the strongest survive again. And that’s so wrong.*

Gwen, 60-year-old woman residing in an assisted living residence

Towards the end of each interview participants were asked if they had any suggestions for improvements which could be made to cancer screening practices specifically or to the health care system more generally. The majority of women were brief with their answers. It may be that many women were unaccustomed to being asked for their opinion particularly on such a broad topic. Perhaps it is difficult to offer suggestions about the health care system without more detailed knowledge about the intricacies of that system. The comments and suggestions which were received are described below. My own synthesis of co-created recommendations at the individual, organizational, community and system levels is then presented followed by a discussion of future research directions and closing remarks.

**Clinical Recommendations**

Participants offered the following recommendations for health care providers who conduct Pap tests:

- Ask about sexual history first
- Explain what will happen during the procedure
- Provide reassurance and help to reduce the patient’s fear
- Arrange for a female nurse to be in attendance
- Enquire if the patient would like the speculum warmed up
- Make suggestions about how the patient can relax
- Be gentle when performing the procedure
- Explain what is happening during the procedure
- After the procedure ask the patient how it went
- After the procedure ask the patient if there is anything that could have been done differently.

While it may not be possible in every practice to have a female nurse in attendance, it may be possible to inform women that they can bring a friend or a support person with them while the procedure is being done. Notices to this effect could be placed in physician waiting rooms so that women become aware of this option and plan ahead according to their needs. The recommendation about sexual history taking was related to the fact that some women have not been sexually active for many years and therefore may experience greater difficulty with the procedure. In these circumstances application of a lubricant may be helpful. In other contexts this would be important to discuss prior to initiating the procedure when it may be a woman’s first Pap test or in the case of a woman who has not yet been sexually active, revealing that the procedure is unwarranted. Several participants emphasized the importance of being gentle and a preference for the speculum to be warmed up.

With respect to mammograms the majority of participants wished that the procedure were not so painful. They looked forward to future improvements being made to the equipment. Vanessa in particular suggested that breast imaging technicians be provided with training on communication skills and empathy. She commented that technicians should be gentle with patients. Other participants described scenarios in which breast imaging technicians did not explain the procedure and spoke very little during it. These participants did not make concrete recommendations for improvements.

Several participants spoke about the need for physicians and other health care providers to be more respectful towards them and to provide more time during appointments. One woman explained that doctors should ‘allow people more time to communicate better.’ This would indicate that more time is needed for both the patient and the physician to have a dialogue. Dorothy commented:
A lot of-, I’ve heard that people talk about that. There are a lot of doctors, you know... they don’t have time for you, they just say, you know, here’s your script, get the hell outta here.

Many participants expressed the wish that doctors were more compassionate and patient as voiced here:

I think doctors had more compassion [in the past]. And everybody’s so busy today. It’s like I always feel they’re rushed, you know.

Some participants implied by their comments that sensitivity training for support staff would be helpful. Rita spoke about her telephone interactions with doctors and medical receptionists:

I have to really verbally tell them that I don’t like to cancel appointments or not show up, but sometimes my anxiety keeps me. So I wish that people would really have that. I don’t expect them to come to me. But I really want them to work with me and not give up on me. And I’ve had to constantly redo it, and it’s exhausting when you have anxiety. For some reason they don’t really hear you.

It could be where that person’s the secretary. That’s her job. You know what I mean. “I don’t want to hear you, I need to do my work.” … usually I have to now get somebody that helps me, supports me. I won’t need it all the time ‘cause it really takes me a lot to say: You know what, I need help to go to this appointment. Can you support me by going there?

The second comment implies a need for volunteer or staff accompaniment to appointments. This would be a helpful resource to many women with mental health challenges, especially women with anxiety disorders.

Several participants spoke about the difficulties they had experienced trying to find a family physician willing to provide care. Family physicians need to be open to accepting some new patients on their rosters who have complex problems even though these patients may require more time and energy. Changes to current fee schedules for physicians will be needed to facilitate this.

Yeah, it was all of a sudden well I’m not taking on any new clients right now. And there’s a big sign in the window saying accepting new clients.
They’d say they’re all full right now, I had to keep looking. So some of them refusing to give me the anti-depressants because they didn’t want to be prescribing no more.

Maureen

Public Education / Health Promotion

There was some, though limited discussion about future awareness-raising strategies and educational programs on cancer screening. One participant encouraged the use of visual imagery in educational sessions and materials and indicated appreciation of pamphlets being available in doctor’s offices. Another participant who was deaf and almost completely blind suggested that educational materials be made accessible in plain language and in different languages. She recommended producing materials in large print, in Braille, on audiocassettes or on DVDs.

Information about breast and cervical cancer screening is available in Braille in Ireland, England, Wales, Australia and the United States. The Canadian National Institute of the Blind (CNIB) does not list resources on cancer screening being available in Braille or on audio tapes on their website. Cancer Care Manitoba has a limited collection of audio and video tapes available for on-site use only.

In summary participants recommended:

- Health care providers follow guidelines for conducting Pap tests as outlined
- Creating less painful procedures to check for breast cancer
- Providing empathy and communication skills training for breast imaging technicians
- Training health care providers to be more respectful, to have more empathy and to provide more time during appointments
- Clerical staff should receive sensitivity and awareness training
- Create volunteer and staff opportunities to provide supportive accompaniment for clients attending medical appointments who need it
- Family physicians should be open to accepting new clients who have complex histories
• Resource materials should be produced in plain language, multiple languages and in large print

• Resource materials should be produced in Braille, on audio cassettes or on DVDs

**Listening to Women: Synthesized Recommendations**

The following recommendations were derived from the interviews with women participating in this study and my own reflections on ways to address the issues women had raised. This discussion, based on McLeroy et al.’s ecological framework is presented in four parts: at the level of the individual, organization, community and systems.

**Individual Level**

The individual level being referred to includes both intrapersonal and interpersonal factors. Initiatives at the community level, for example public education must take into consideration intrapersonal and contextual factors to be effective. All four domains are inter-connected and inter-dependent and should be conceived of as components of a holistic framework. In the most basic sense, funding at the systems level allows communities and organizations to function in ways that directly impact individuals.

Marginalized women base their cancer screening decisions on many factors as previously discussed. The timing of when a woman is invited to consider cancer screening can play a significant role in her decision-making relative to current life circumstances, level of stress and competing priorities. The decision-making process is also different for women who have already experienced the procedure versus those who have not, and the quality of the interaction which occurred for those who were screened. Poor experiences are often recounted to other women which in turn impacts those women’s decision-making processes. Health professionals conducting Pap tests should ask women at the outset if there is anything they can do to make women more comfortable. This may allow for an opportunity for women to disclose prior sexual abuse or prior difficulties experienced during cervical cancer screening. Appropriate accommodations can then be made.
A strategy should be developed to encourage physicians and nurse practitioners employed at walk-in health clinics to enquire about preventative health care needs during routine appointments for other presenting issues.

One of the most salient outcomes from the present study is the need for health care professionals to interact with women in a respectful, professional and sensitive manner. Many physicians already practice in this way, as much as they can under existing time constraints. Others use power and control when interacting with patients, negatively impacting on women’s health-based decisions and subsequent access to care. A sensitivity training and communication skills course should be made available to all health care providers along with an incentive for educational credits. An awareness of the fact that many women who have suffered significant hardships do not speak openly about the impact of those hardships on their physical, mental and emotional health may encourage health care providers to listen to women more closely and ask different questions. Some health care needs may be left unmet as a result of some women’s normalization of traumatic experiences and reluctance or discomfort to engage in a dialogue about the impacts of those experiences on their health and well-being. The cultivation of attentive, patient, empathic and interpretive listening skills among health care providers will begin to improve this situation and uncover hidden suffering.

**Organizational Level**

The organizational level refers to institutions such as homeless shelters, supportive residences for WMHC, hospitals and cancer screening programs. Homeless shelters should be provided with adequate funding to periodically offer educational sessions on breast, cervical and colorectal cancer specifically tailored to the contextual factors that women are dealing with while residing there. These sessions should expand on standard cancer awareness programs to acknowledge poor interactions which sometimes happen with care providers, prejudice and stigmatization, issues of power and trust, trauma, and effective communication strategies when interacting with health care professionals. Suggestions could be made for women who have had negative Pap test experiences to consider: going to a public health unit, to a female provider, or to a community-based clinic and to bring a friend or a person they trust. Women who have had negative mammography experiences could be encouraged to go to a different OBSP site, to discuss with
the technician beforehand what issues they experienced previously, and to ask the technician for specific accommodation. Messaging about early detection of cancer should explain in clear language the continuum in which cancer grows and indicate that different outcomes can occur depending on when women participate in cancer screening should they happen to have cancer. Women may be reassured to know that cervical cancer is preventable when pre-cancerous lesions are found. Helping women to understand that having breast cancer does not necessarily mean removal of the entire breast can reduce fear of breast cancer. Images are important to include in educational presentations for all women. Thoughtful use of imagery is particularly important when sharing information with women of varying levels of literacy. Photos and images should be relatable to the women participating so that they personally identify with the relevance of the information to their own lives.

Ideally this education would be offered as a component of a series of discussions on topics pertaining to women’s health and well-being. These sessions could be co-facilitated by women who have experienced homelessness, substance use or mental health issues who are interested and stable enough to participate in training to build capacity to fulfill this role. Efforts could be made to engage volunteers and/or staff to coordinate appointments and provide supportive accompaniment to group appointments for cancer screening. Modest success with this model to engage marginalized women in mammography has been reported by Heyding et al.(15) and others.(155-158)

Hospitals should consider offering sensitivity training to health care providers, support staff and breast imaging technicians. An effective format for these educational tools would be the use of film. Several short vignettes featuring women talking about their lives, health conditions, thoughts and feelings before going for a Pap test or a mammogram, could be followed by an enactment of both a poor provider/patient interaction and an ideal provider/patient interaction. The third portion of the story would consist of women’s reactions and reflections on their experiences and the impact that it had on them. Comments from the women on what could have improved the interaction could be made as well as comments on what factors made an ideal interaction successful and comfortable. This could be created with the Standardized Patient Program at the University of Toronto or directly with women with lived experiences who are motivated to be involved with professional education. The scenarios could include interactions
with support staff, family physicians, gynecologists, breast imaging technicians and hospital-based volunteers. The educational package could be viewed in DVD format on personal computers. With hospital support, the DVDs could be shown in interprofessional group settings with facilitated group discussion. Individuals who have participated in the program could elect to wear a button indicating that they are ambassadors of sensitive patient care. Funding for this initiative could be sought from Cancer Care Ontario with involvement of the Primary Care Leads (There are two primary care leads in the Toronto Central LHIN who have been hired on a part-time basis by Cancer Care Ontario to work with physicians to promote cancer awareness and screening.) Funding may also be sought from the Ministry of Health and Long Term Care and the College of Physicians and Surgeons of Ontario. Distribution of the DVDs along with a Facilitator’s Guide could be province-wide. The scenarios involving support staff and breast imaging technicians could be distributed to OBSP sites and diagnostic imaging sites throughout the province. These teaching tools would assist individuals providing services to marginalized women to be cognizant of contextual factors in women’s lives and the importance of effective and sensitive interpersonal interactions.

Community Level

Cancer awareness educational programs as described above should also be offered in community settings such as drop in centres and special programs for street-involved women, WMHC, substance use issues and other women who experience marginalization. Information sessions tailored to contextual factors in their lives will likely have greater impact and success than information sessions which have been designed for the general public. As in institutional settings efforts should be made to provide assistance with scheduling appointments and supportive accompaniment to screening. Individuals in this support role should understand and expect that some appointments may be cancelled, however consistent follow-up should be encouraged. Group scheduling of appointments is an efficient approach to use however it may not always be feasible. Adding a pleasant activity to the group scheduling may be helpful. Groups could also be organized according to the months of women’s birthdays with a small celebration afterwards. Funding could be sought from the Ministry of Health and Long Term Care for a bus with mammography equipment to provide breast cancer screening in urban communities as is currently done in remote communities in Northern Ontario and also in the Hamilton region. The
bus could visit homeless shelters, residences for WMHC, residences for women with physical disabilities, programs for women with developmental disorders and other places where women are who may find it difficult or impossible to attend OBSP sites. The bus should be outfitted with adjustable equipment for women using wheelchairs and other women who require modifications in breast screening procedures.

**Systems Level**

Permanent ongoing funding for implementation of community based and institution based cancer awareness education programs for marginalized women should be advocated for and obtained. Funding from either Cancer Care Ontario or the Ministry of Health and Long Term Care should be sought for the production of sensitivity training tools for health care providers, administrative staff and volunteers as described earlier. Funding from the Public Health Agency of Canada might ensure national distribution of resource tools.

In summary, the synthesized recommendations are to:

- Provide messaging to health care professionals to encourage them to interact with marginalized women in a respectful, professional and sensitive manner
- The Ontario College of Family Physicians and the Nurse Practitioners’ Association of Ontario co-develop a strategic plan to encourage medical professionals at walk-in health clinics to enquire about preventative health care needs during routine appointments
- Develop, pilot and produce a sensitivity training and communication skills course for health care providers with filmed scenarios
- Provide homeless shelters with adequate funding to periodically offer educational sessions on breast, cervical and colorectal cancer specifically tailored to the contextual factors that women are dealing with while residing there
- Provide adequate funding to community-based drop in centres and special programs for marginalized women to participate in tailored educational sessions on breast, cervical and colorectal cancer awareness as outlined above
• Secure support from hospitals, OBSP sites, diagnostic imaging sites and professional organizations to implement training programs designed to increase sensitivity skills and improve effective communication skills when interacting with marginalized clients

• Secure ongoing funding for facilitated access to cancer screening services for marginalized clients in both community-based and institution-based settings (scheduling appointments, accompaniment and support)

• Secure funding for a mobile mammography unit to serve marginalized women in urban settings

While many of these recommendations may take years to implement now is the time to begin the process. Concerted efforts to address these gaps at the individual, institutional, community and systems levels will increase the involvement of under/never-screened women with cancer screening and improve the quality of life for many people who experience marginalization.

**Study Limitations**

At the outset of this investigation it was thought that it would be possible to compare women across three categories related to attendance or non-attendance at cancer information sessions and subsequent cancer screening activities among both women living in homeless shelters and WMHC. Ultimately this was not possible. First, many women who were up to date with cancer screening had participated in screening prior to attendance at a CARES information session. Therefore it was not possible to evaluate the impact of the information session on screening decisions and follow-through. Second, it was difficult to recruit participants based on these pre-conceived categories. Ultimately I was pleased to have the opportunity to interview all women who met the eligibility criteria to learn about their attitudes and experiences with cancer screening. Third, as discussed previously, issues of homelessness, mental health challenges and substance use issues overlapped among participants precluding any comparison between shelter-residing women and women living in supportive residences due to serious and persistent mental health issues. In early interviews, questions were posed about the educational session, however I subsequently refrained from doing so, focusing on other topics of importance. I no longer sought to evaluate the effectiveness of the program with respect to awareness raising or with regard to
impact on screening uptake. This shift to focus primarily on answering the research questions arose somewhat organically. The ensuing conversations shed light on the research questions and satisfied the primary goals of the study.

All the women who participated in this study had health insurance and the majority of them had been able to access some form of health care in the past year. This may not be representative of the population of women living in homeless shelters and women with severe mental health challenges some of whom do not have health insurance and are not engaged with the health care system. Further qualitative research should be undertaken to expand on this work and to explore what factors distinguish between women who receive health care services and women who do not.

During the interviews and the collection of demographic information, details were not sought concerning length of period of homelessness, history of past psychiatric hospitalizations, or type or severity of mental health problems. In some cases participants volunteered this information; however, it was not systematically collected. Given the information that was shared and my impressions from the interviews however, I believe interviewees were broadly representative of shelter-residing homeless women and women with severe and persistent mental health challenges. Study findings are transferable not only to the target populations but also to underserved women in the general population.

In terms of trustworthiness of the findings it would have been ideal to have had more than one person analyze and interpret the data. As this was a masters’ level research project involving others with the coding, interpretation and analyses was not possible. It may however be possible in the future.

Some may question whether or not the interview can be seen as an intervention. As I initially conceived the study I would have said at the outset that it was not an intervention. The intention of the interviews was to listen to what women said about their experiences, to begin to understand how and why they made the decisions that they did. I was very clear in the protocol that interviews were not intended to influence women’s decisions; that my role was not to encourage or discourage cancer screening activities. Now that I have conducted the interviews and reflected on this, I concede that inadvertently women may have been influenced with respect
to thinking about cancer screening more than they would have had they not participated in an interview. The act of being interviewed squarely put the topic into focus. It may be that some women went on to be screened subsequently or made decisions whether or not to return to either type of screening in the future. I would not use the word intervention to describe the interview process at all, however I now see that the act of being interviewed on a given subject in and of itself may influence later decision-making.

I was not able to engage as many women as initially planned from supportive residences for women with severe and persistent mental health challenges. The fact that many participants interviewed in homeless shelters were coping with mental health issues largely made up for this limitation.

The fact that the interviews were conducted exclusively in English may be seen as a weakness given that some women living in homeless shelters and in assisted living residences naturally include non-English speaking women. As English is the only language that I speak, this could not have been avoided. The results of this exploratory study however may lead to further investigations, which will include other language groups, multi-lingual research staff and multi-lingual transcribers.

As this study was conducted in the Greater Toronto Area, some of the recommendations outlined in upcoming sections may not be appropriate or realistic for rural or small town settings. This exploratory project was specifically designed however for urban settings. Future studies should be conducted in geographical regions where populations are smaller and where access to care providers and cancer screening services are more limited.

**Summary**

Women with housing challenges and mental health challenges experience similar fears and worries as women in the general population do about breast cancer, cervical cancer, mammograms and Pap tests. Specific contextual factors however add to the complexity of engaging under/never-screened women with these issues in health checks for early detection of these two cancers. The impact of being homeless and/or dealing with serious mental health issues (often in combination with other health problems) on a woman’s interest, willingness and
ability to engage in screening is significant. Women living in homeless shelters and WMHC often have competing priorities; some do not have primary care providers; and some women experience discrimination when interacting with the health care system. Some women have had previous experiences with health care practitioners that were unsatisfactory or unpleasant. These interactions resulted in a lack of trust in care providers and a devalued sense of personal agency and power. Some women have histories of sexual abuse which interfere with their interest and willingness to participate in Pap tests, and in some cases with mammography. Having depression, anxiety disorders or mobility issues can also impact participation in cancer screening activities. Unless staff in shelters and supportive residences provide information about breast and cervical cancer and actively encourage women to think about cancer screening, many women are unlikely to initiate screening on their own. Some type of motivation must be in place, whether in the form of simply reminding women about it, providing education, offering to assist with tangible supports to ease the inconvenience of screening, by role modelling or in some other form. Once women have accurate information and have made their own decision about screening, the health care system needs to do its part by providing sensitive and high quality service. Primary care providers and gynecologists need to take the time to communicate with patients, be gentle and remember that the quality of their interactions affect women’s future decisions about accessing health care and health promotion activities. Family physicians need to be open to accepting some new patients who have histories of homelessness, mental illness, substance use, sexual trauma, and/or co-morbid conditions, otherwise many women will only be able to access ‘band aid’ care through walk-in clinics and hospital emergency departments. Women with these issues do take more time, but they deserve the same standard of health care that the rest of the population enjoys. Some breast imaging technicians and clerical staff also need sensitivity and awareness training, improved communication skills, patience and empathy. Finally, improvements to cancer screening systems currently in place are needed so that homeless women and women with mental health challenges are not discriminated against, so that all women are treated equally and with respect.
Chapter Five

FUTURE RESEARCH DIRECTIONS AND CONCLUSION

Future Research Directions

To continue a program of research in this area, several directions could be taken. A qualitative study using either focus group or interview methods could be undertaken to share the findings of the current study with homeless-shelter-residing women and WMHC. The experiences, themes, interpretations and recommendations arising from the current study could be explored with women for validation, expansion of ideas, criticism and further interpretation. The results of such an investigation would inform future research, advocacy work, health promotion strategies and possibly professional development programs for health care providers.

An environmental scan should be conducted to identify existing educational resources for health care providers, support staff and volunteers which provide sensitivity training and awareness of contextual factors when interacting with marginalized women. Classen and her colleagues(159) conducted a study which sought to improve healthcare delivery by increasing the knowledge of health care providers about interpersonal trauma. Resources developed in that study may have application for the recommendations in the current study. The search for relevant resource materials should be international in scope. A literature search could also be conducted to investigate if any of the recommendations emanating from the current study have been implemented elsewhere and if so how effective they have been in achieving their stated goals.

Once the environmental scan research has been completed and resources have been assessed, a multi-disciplinary team including marginalized women could be formed with the aim of developing an educational program for health care professionals and other service providers. The proposed program could have three streams: one for health care providers and social service providers, one for breast imaging technicians and administrative staff at OBSP clinics, and another for clerical staff and volunteers working in health or social service settings. Educational DVDs could be created as described earlier and pilot tested with learners. Based on feedback provided through piloting, the DVDs could be improved and expanded. A Facilitator’s Guide
could be developed to accompany the DVD set. A plan would need to be established for knowledge translation and exchange, distribution of materials and evaluation. Support would also need to be sought from hospitals, professional organizations, OBSP sites, diagnostic imaging clinics, community-based health care organizations and social service organizations. An incentive for participation in the educational program may also be considered.

Concurrently or subsequent to the development of the educational program for care providers, a tailored educational program could be developed specifically for under/never-screened marginalized women as part of a research study. The program would be informed by the results and recommendations of the current study and shaped by an interprofessional team including representation from the target audience. The program could include a visually based PowerPoint slide deck, newly developed DVDs and hand-out materials in plain language (multi-lingual). Apart from supporting the main topic area, the DVDs could focus on effective communication with health care providers, tips to prepare for medical appointments, and strategies to consider using when women feel that they are not heard or understood when interfacing with the health care system. All resources should be pilot tested in varied settings and modified accordingly. A plan for distribution of resources, training of facilitators and evaluation should also be developed.

A qualitative pilot study could also be launched to evaluate the effectiveness of a training program for co-facilitators of the cancer awareness program for marginalized women. Facilitators could be staff or volunteers working in shelters, drop in programs, residential programs etc. along with women with lived experiences of homelessness, substance use, mental health challenges and/or marginalization. One of the research objectives would be to observe and describe the process of this training, including the documentation of arising issues. The primary outcome would be the evaluation of the training experience in effectively preparing facilitators to deliver the educational program. A secondary outcome of that investigation could be the development of a Facilitator’s Training Guide.

Research should also be conducted into strategies that health care professionals can employ to help reduce patient’s fear and anxiety about cancer screening procedures. Evidence-based strategies are needed for all women, but especially for women with mental health issues and/or histories of trauma and sexual abuse.
Conclusion

This study provided unique insights into the factors which influence decision-making about breast and cervical cancer screening among homeless women living in the shelter system and women with serious mental health challenges residing in assisted living residences. While a review of the existing literature provided foundational information on the topic, this qualitative enquiry offered a more detailed and intimate description of women’s thought processes and personal circumstances. For example, in Materson et al.’s (2010) quantitative study which found a significant association between women’s self report of poor mental health days, depression or anxiety and lower rates of mammography compared to women not experiencing these difficulties, we can only imagine what ‘depression’ or ‘anxiety’ looks like or feels like. When we hear Jackie talk about her struggles getting out of bed, showering, getting dressed and maintaining her room we have a much richer picture of what depression looks like for her, and a keener understanding of why her engagement in cancer screening is so challenging. When a person has difficulties leaving her ‘home’ for any reason, even a pleasant outing, we have a much clearer understanding of the challenges.

I found that complex contextual factors, power and trust strongly influenced breast and cervical cancer screening decisions among homeless women and women with mental health challenges. We now have a much clearer understanding of the facilitators and barriers to breast and cervical cancer screening among these populations of interest. Facilitators to cancer screening included: having access to a family physician; being satisfied with one’s family physician; having had previous Pap tests and/or mammograms that went reasonably well; being encouraged or influenced by mothers, friends, or others in one’s social network; and valuing cancer checks as routine activities that help to maintain good health. Barriers to screening identified were: not having access to a family physician, other life issues being more highly prioritized, mobility issues, transportation issues, not being well enough psychologically to leave the facility, disinterested attitudes, social isolation, and varying levels of knowledge and understanding about cancer checks. Cancer screening decisions among this group of women were varied and complex.
The stories that women shared in this study also provided new insights into both negative and positive interactions with health care providers and the health care system in the context of cancer screening. Witnessing some of these scenarios was shocking and disappointing, while others confirmed that many health care providers are doing an excellent job of caring for their patients. The information gleaned from the unsatisfactory interactions is the basis for recommendations for sensitivity and communication training for health care providers, including breast imaging technicians. This research further informed recommendations at the level of the individual, community, institution and public policy. While some of the recommendations may be challenging, at the very least it is hoped that they serve to ignite conversations and at the very best it is hoped that they inspire focused and determined action towards improving women’s health and wellbeing.
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Appendix A
Recruitment Poster for Women Not Participating in CARES Project

WOMEN AGES 24 -74

You are invited
to participate in a confidential interview about breast & cervical cancer checks

With: A mature master’s student studying at the University of Toronto

Why: To understand why some people participate in breast and cervical cancer checks (screening) while others do not and how cancer prevention programs could be improved

How long: 30-45 minutes

When: Between now and May 2013

Never had a Pap Test?
Never had a mammogram?
We would like to talk with you!

Contact: Catherine
Cell: 647-628-6793
Monday – Saturday between 10:00 am – 7:00 pm

This is a student research project affiliated with the CARES project
Appendix B
Recruitment Poster for CARES Participants

Did you attend a CARES information session?

Is it time for you to have a cancer check?

We would like to talk with you:

√ if you decided not to go for a cancer check

√ if you are thinking about it

√ if you did go for a cancer check after the information session

Why: To understand why some women participate in breast and cervical cancer checks (screening) while others do not and how cancer prevention programs could be improved

With: A mature master’s student studying at the University of Toronto
How long: 30-45 minutes

When: Between now and May 2013

If you are interested in participating in a confidential interview call:

Catherine
Cell: 647-628-6793
Monday – Saturday between 10:00 am – 7:00 pm
APPENDIX C

INFORMATION ABOUT A RESEARCH STUDY

Title of Project / Research Study:

Listening to Women in Toronto: A Dialogue about Breast and Cervical Cancer Screening

Master’s Level Student

Catherine Moravac
Masters of Science Student, Institute of Medical Science, University of Toronto
Phone: 647-628-6793

Academic Supervisor

Dr. Katherine Boydell
Scientific Director, Qualitative Inquiry, Child Health Evaluative Sciences, The Hospital for Sick Children
Associate Professor, Dept. of Psychiatry and Dalla Lana School of Public Health, University of Toronto
Phone: (416) 813-8469

Introduction

Before agreeing to take part in this interview, it is important that you read this information sheet. It includes information that we think you need to know in order to decide if you want to participate in an interview. If you have any questions ask the person who gave this form to you. You should not sign the consent form until you are sure you understand the information. All research is voluntary.

Purpose of the Research

The purpose of this research study is to better understand why some women participate in educational sessions about breast and cervical cancer while others do not, and why some women participate in breast and cervical cancer screening while others do not. We would like to find out how and why women make these decisions. We are also interested in finding out what changes could be made to make breast and cervical cancer screening easier to access for those women who want it.
Description of the Research

Some women who are invited to participate in the educational sessions and the screening opportunities provided by the CARES project are being asked to participate in one-to-one interviews. We would like to interview women who choose not to participate in educational sessions and also women who do participate in educational sessions. We are also interested in interviewing women who go to educational sessions but decide not to go for breast and/or cervical cancer screening. Lastly, we would like to interview women who participate in both an education session and cancer screening. These interviews will help us to understand how and why women make these decisions. The information we collect might also help others to improve the way education and screening services are offered to women in the future.

Interviews

If you answer ‘yes’ to any of the following questions you may be able to participate in an interview:

√ Were you invited to come to a CARES information session but decided not to go?

√ Did you go to a CARES information session and decide not to go for a mammogram or Pap test even though you were due to go?

√ Did you go to a CARES information session and then went for a Pap test or mammogram that you needed?

You are being asked if you would like to participate in a one-to-one interview about your health and about your attitudes and ideas about breast and cervical cancer in particular. The interview will take between 30-45 minutes depending on the length of your answers. Examples of the type of questions which will be asked include:” What is most important to you about your health?” “When someone says breast cancer, what do you think about or feel?”

You do not have to answer any or all of the questions – just the ones you want to. You are free to leave the interview at any time. Interviews will take place where you are currently living or at a community-based agency – whichever you prefer. A private meeting room will be arranged.

We would like to audio tape the interview so that we don’t miss any of your comments. If you do not want the interview to be audio taped, the interviewer will make written notes instead. Your name will not be recorded on the audio tape. A participant identification number will be used instead of your name. After the interview, the tape will be transcribed (the spoken words will be put down on paper). The paper version of the interview will also have the participant identification number on it instead of your name. There is a possibility that the masters student will follow up with you some time after the interview to verify if her summary or interpretation of your interview accurately reflects what you said during your interview. The researcher will review all of the interviews and write a report about what she learns. This
report may include quotes from your interview however you will not be identified in any way. If the researcher goes to conferences or meetings where they discuss the results of this research study, you will not be identified in any way. Care will also be taken not to include any information in any quotes which have the potential to reveal your identity.

**Potential Harms (Injury, Discomforts or Inconveniences)**

There are no known harms (bad things) that can happen to you because you participate in an interview. Talking about personal issues may bring about emotional feelings. It is possible that you may feel upset when answering questions. If you feel upset at any point, you may stop the interview or ask for a break.

**Potential Benefits**

There are no direct benefits for you if you participate in an interview.

**Confidentiality and Privacy**

Your participation in an interview will be anonymous. That means you will not be identified in any written reports, public talks or in any form. As noted above, a participant identification number will be used instead of your name both on the audio tape and on the paper copy of your interview.

The contact information sheet which you completed, a copy of this consent form, the audio tape and the paper copy of the interview will be kept in a locked cabinet in a locked office of the primary investigator, Catherine Moravac. Once you have been contacted by Catherine Moravac, the contact information sheet will be destroyed. Seven years after the research study has been completed the consent form and the audio tape will be destroyed. The paper copy of the interview will be kept in a locked cabinet in the locked office of the primary investigator for seven years after the completion of the research study, then it will be destroyed (by shredding.)

**Publication of Results**

At the end of this research study the Master’s student will write up what was learned. The results of this research study may be shared at conferences or in academic journals that health care providers read. Your name or any information which could identify you will not be revealed. If you would like to receive a copy of the results just let Catherine Moravac know. The results may be available in January 2014.

**Participation and Withdrawal**

Participating in an interview is voluntary. You can leave at any time.

**Reimbursement**

A $20.00 honoraria will be provided to you at the end of the interview. The honorarium is a token of appreciation for your time.
Research Ethics Board Contact

If you have any questions about your rights as a research subject you may contact Ms. Sue Williams, RN,BNSc, Chair, Women's College Hospital Research Ethics Board at (416) 351-3732 Ext. 2723.

Project /Research Contacts:

If you have any questions about this research project you can call any of the people listed on the front page of this information sheet.
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Research Study:

Listening to Women in Toronto: A Dialogue about Breast and Cervical Cancer Screening

I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been told that my participation is voluntary. I know that I may ask now, or in the future, any questions I have about the research. I have been told that records related to my participation will be kept anonymous (secret) and confidential (private) and that no information will be released or printed that would identity me without my permission unless it is required by law. No information collected during this study or during this interview will be used for any purpose other than to help the researcher better understand why some women participate in educational sessions about breast and cervical cancer while others do not, and why some women participate in breast and cervical cancer screening while others do not. Or for the purpose of better understanding how and why women make these decisions. The potential harms and benefits (if any) of participating in this research study have been explained to me. I understand that I have not waived my legal rights and I do not release the members of the research team or involved institutions from their legal and professional responsibilities.

I understand that I am free to withdraw from the study at any time. I have been given enough time to read through this information. I [hereby] consent to participate in this study. I will be given a signed copy of this consent form.

I agree to have the interview audio-taped □ Yes □ No

Participant Name ________________________________ Participant Signature ________________________________ Date __________

Printed Name & Position of Person Conducting Consent Discussion ________________________________ Signature of Person Conducting Consent Discussion ________________________________ Date __________
Interviewer’s Preamble

My name is Catherine. I am a masters’ student at the University of Toronto and I am doing these interviews to learn about what people think about their health, why some people are interested in learning about breast and cervical cancer and others aren’t, and how people decide whether or not to be screened (checked) for breast or cervical cancer.

Here are two copies of the consent form. Whenever anyone is thinking about participating in a research project they are given information about the project and what is involved. After they are given time to think about it, the person decides whether or not to participate. If they decide to participate, they sign the consent form and keep a copy for themselves. Would you like me to go through the information with you, or would you rather read it yourself?

[After the information has been reviewed, all questions answered and a decision made, the discussion either ends here or the interview begins.]

As you know, you are doing this as a volunteer. If at any point you feel uncomfortable or want to stop the interview, just let me know. We can stop at any time or skip ahead to another question. You are free to leave at any time. You do not have to provide a reason.

No Education

I’m going to turn the tape recorder on now if you’re ready. Today is [date and time]. I am at [shelter/community living residence] about to interview participant [ID Code].
I understand that:

You were invited to an educational session on breast and cervical cancer and decided not to go. Is that right? I’d like to ask you about that a little later. Right now I wondering:

1. What does good health mean to you?
2. What is most important to you about your health?
3. In the past year or so have you been able to do things to keep healthy? How?
4. In the past year or so have you been able to get your health care needs met by health care providers? Can you tell me about that?
5. When someone says breast cancer what do you think about or feel?
6. When someone says cervical cancer what do you think about or feel?
7. Could you tell me how you made your decision not to go to an information session on breast and cervical cancer?

Potential Prompts:

- Do you feel you already know enough about it? Why is that?
- Are you up to date with screening for breast and cervical cancer? At what age and how often should women be tested for cervical cancer? Breast cancer?
- Do you usually talk about these decisions with someone else? Can you tell me about that?
- Did you have Pap test(s) in previous years that influenced your decision? / Did you have a mammogram(s) in previous years that influenced your decision?
- Does living here make it easier or harder for you to look after your overall health? Why/How is that?
- Does living here make it easier or harder for you to do things like go to the dentist, have your feet checked, or go for a Pap test? Why is that?

8. (Depending on previous responses): If someone offered to arrange for you to have a Pap test or a mammogram, for example two months from now, what would you say and why?

9. Can you imagine a time in the future when you would be willing to have a Pap test? What would be different compared to now?

10. And the same for breast cancer – Can you imagine a time in the future when you would be willing to have a mammogram? What would be different compared to now?
11. Is there anything else you would like to say about screening for breast or cervical cancer? (spiritual beliefs, cultural beliefs, apathy, lack of knowledge, fear …)

**Education Only**

You participated in an educational session on breast and cervical cancer but you decided not to be screened for either breast or cervical cancer. Is that right?

1a. Can you tell me how you made the decision about mammography?

1b. Can you tell me how you made the decision about a Pap test?

Potential Prompts:

- Are you up to date with screening for breast and cervical cancer? At what age and how often should women be tested for cervical cancer? Breast cancer?
- Do you usually talk about these decisions with someone else? Can you tell me about that?
- Did you have Pap test(s) in previous years that influenced your decision? / Did you have a mammogram(s) in previous years that influenced your decision?
- Does living here make it easier or harder for you to look after your overall health? Why/How is that?
- Does living here make it easier or harder for you to do things like go to the dentist, have your feet checked, or go for a Pap test? Why is that?

2. What is most important to you about your health?

3. When someone says breast cancer what do you think about or feel?

4. When someone says cervical cancer what do you think about or feel?

5. (Depending on previous responses): If someone offered to arrange for you to have a Pap test or a mammogram, for example two months from now, what would you say and why?

6. Can you imagine a time in the future when you would be willing to have a Pap test? What would be different compared to now?

7. And the same for breast cancer – Can you imagine a time in the future when you would be willing to have a mammogram? What would be different compared to now?

8. Is there anything else you would like to say about screening for breast or cervical cancer? (spiritual beliefs, cultural beliefs, apathy, lack of knowledge, fear …)
**Education & Screening**

You participated in an educational session on breast and cervical cancer and shortly afterwards you were screened for cervical cancer and/or breast cancer. Is that right?

1a. Can you tell me how you made the decision to go for a mammogram?

1b. Can you tell me how you made the decision to go for a Pap test?

If not already covered: Was this your first mammogram/Pap test or have you had these cancer checks before? How often have you been checked for breast or cervical cancer?

2. What is most important to you about your health?

3. When someone says breast cancer what do you think about or feel?

4. When someone says cervical cancer what do you think about or feel?

5. Will you continue to be regularly screened for breast cancer? (every 2 years until age 74) Why?

6. Will you continue to have regular Pap tests (every 3 years) Why?

7. I understand that you were not up-to-date with screening before you went to the educational session. Is that right? How did your thinking change from before the educational session to after the educational session?

8. Is there anything else you would like to say about screening for breast or cervical cancer? (spiritual beliefs, cultural beliefs, apathy, lack of knowledge, fear …)
Appendix E
Demographic Questionnaire

Participant ID Number: __________  Participant Age: ______

We are asking these questions to try to understand more about women who get checked for breast and cervical cancer and about women who do not get checked. You do not have to answer any questions that you do not want to answer.

1. How are you feeling today? Circle only one answer.
   1. Not good
   2. Okay
   3. Very good

2. How long have you been in Canada?
   1. All my life
   2. Less than 5 years
   3. 5 years or more
      _____________ weeks

3. What language do you speak at home?
   1. English
   2. French
   3. Other

4. What health insurance do you have?
1. Ontario Health Insurance Program (OHIP)

2. Interim Federal Health (IFH)
3. Other
4. None

5. Have you seen a doctor/nurse for your own health in the last year?
   1. Yes
   2. No

6. Is your doctor/nurse:
   1. Male
   2. Female
   3. I do not have a regular doctor/nurse
7. **Does your doctor/nurse speak your first language?**  
   1. Yes  
   2. No  
   3. I do not have a regular doctor / nurse

8. **Have you given birth in Canada?**  
   1. Yes  
   2. No

9. **Have you ever had a Pap test?**  
   1. Yes  
   2. No  
   3. Not sure

10. **When was your last Pap Test?**  
    1. Within the last 3 years  
    2. More than 3 years ago  
    3. Never had one  
    4. Not sure

11. **On a scale from 1-5 how willing are you to have Pap tests?**  
    1. Not willing  
    2. Somewhat willing  
    3. Not sure  
    4. Willing  
    5. Very willing

12. **What level of education do you have?**  
    0. No education  
    1. Up to grade 5  
    2. Between grade 6 and grade 8  
    3. Between grade 9 and grade 12  
    4. Higher
13. How would you rate your overall (mental and physical) health?

1. Poor

2. Fair

3. Good

4. Very Good

5. Excellent

Women who are 49 years old or younger you are finished the survey.

Thank you!
14. Have you ever had a mammogram?
   1. Yes
   2. No
   3. Not Sure

15. How long ago did you have a mammogram?
   1. Never had one
   2. Within the last 2 years
   3. More than 2 years ago

16. On a scale from 1-5 how willing are you to have mammograms?
   1. Not willing
   2. Somewhat willing
   3. Not Sure
   4. Willing
   5. Very Willing

Thank you!
Title of Project / Research Study:

Listening to Women in Toronto: A Dialogue about Breast and Cervical Cancer Screening

I __________________________ received a $20.00 cash honoraria from Catherine Moravac to thank me for my time and participation in an interview for the study “Listening to Women in Toronto: A Dialogue about Breast and Cervical Cancer Screening.”

_________________________________________    ________________________________
Signature                                      Date

_________________________________________
Location / Site
Appendix G
Referral Plan for Social Work Follow-Up / Counselling if Needed

The student researcher will consult with management at partner agencies concerning existing practice for providing emotional and psychological counseling and support to residents. If appropriate, a list of the following agencies will also be provided. The student researcher will liaise with staff and with study participants concerning any assistance which may be required to arrange appointments.

RESOURCES FOR WOMEN WHO HAVE BEEN SEXUALLY ASSAULTED

Assaulted Women’s Helpline
Phone: (416) 863-0511
Toll Free: 1-866-863-0511
TTY: (416) 364-8762
Toll Free TTY: 1-866-863-7868
Mobile: #SAFE (#7233)

The Schlifer Commemorative Clinic
489 College Street, Suite 503
Phone: (416) 323-9149
www.schliferclinic.com
www.schliferclinic.com/vars/help/creating_a_safety_plan.pdf

Toronto Sexual Assault/Domestic Violence Care Centre
Women’s College Hospital
76 Grenville Street
416-323-6040

Education Wife Assault Canada
427 Bloor Street West
Phone: (416) 968-3422

Scarborough
Sexual Assault/Domestic Violence Care Centre
The Scarborough Hospital
Grace Campus
3030 Birchmount Road
416-495-2555

Springtide Resources
215 Spadina Avenue, Suite 220
Phone: (416) 968-3422
TTY: (416) 968-7335
Email: info@womanabuseprevention.com

Mississauga
Peel Region Sexual Assault/Domestic Violence Program
Sexual Assault Care and Counselling Centre
The Trillium Health Centre
100 The Queensway W.
905-848-7580, ext. 2142

Women’s Legal Education and Action Fund
60 St. Clair Avenue East, Suite 703
Phone: (416) 595-7170
Toll Free: 1-888-824-5323
Appendix H
First Level Coding Strategy for Thematic Analysis

Good health means
Most important about health
Things to change to improve health
Maintaining good health
Mental Health
Pap Tests:
  Knowledge
  Communication
  Attitude
  Experience
Mammography:
  Knowledge
  Experience
  Attitude
  Communication
  Pain
  Willingness to have mammograms
Emotions:
  Upset
  Scared
  Worry
  Stress

Family Doctor
  Nurses
  Specialists
Mothers
Personal experience with cancer
Trauma and abuse
Poverty / Uninsured
Housing
Knowing other women with cancer
Personal stories
Gender
Recommendations for improvement
Colorectal cancer
Appendix I
Second Level Coding Strategy for Thematic Analysis

1. **Perceptions of Health**
   - Good health means - health changes - reflections
   - Most important about health
   - Things to change to improve health
   - Maintaining good health
   - Mental health

2. **Reflections on Pap Tests**
   - Knowledge
   - Communication during Pap tests
   - Attitudes
   - Experience
   - (Willingness)

3. **Talking about Breast Cancer and Mammograms**
   - Knowledge
   - Communication during mammograms
   - Attitudes
   - Experience
   - Willingness

4. **Range of Experiences with Care Providers**
   - Family doctors
   - Nurses
   - Specialists
   - Circles of care

5. **The Role of Mothers**

6. **Personal Experiences with Cancer**
   - Benign cancer experiences
   - Emotional Support

7. **From the Margins**
   - Trauma and Abuse
   - Poverty / Uninsured
   - Housing

8. **Impact of Knowing other Women with Cancer**
   - (Impact on decision-making, attitudes, knowledge, emotional reaction)

9. **Gender**

10. **Recommendations for Improvements**
Appendix J

Cervical Cancer Screening Status and Level of Willingness to Participate in Future Screening  
N=26

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<th>Very Willing</th>
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<td></td>
<td>**1</td>
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*One under-screened participant indicated that she would be willing to have a Pap test if she became sexually active. One other participant indicated that she would be willing to have a Pap test after she has been off her psychiatric medications for one year.

**One never-screened participant indicated that she would be willing to have a Pap test if she became sexually active.

Breast Cancer Screening Status and Level of Willingness to Participate in Future Screening  
N=13

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Appendix K

Cancer Screening Status and Attendance at CARES Information Sessions

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<th>Psuedonyms</th>
<th>Cervical Screening Status</th>
<th>Breast Screening Status</th>
<th>Education</th>
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<tr>
<td>Linda</td>
<td>UTD (few months ago)</td>
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<tr>
<td>Susan</td>
<td>US (more than 3 yrs ago)</td>
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<td>None</td>
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<tr>
<td>Mary</td>
<td>UTD</td>
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<td>Cervical</td>
</tr>
<tr>
<td>Nicole</td>
<td>UTD</td>
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<td>Breast &amp; Cervical</td>
</tr>
<tr>
<td>Lorna</td>
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<td>UTD (2 months ago)</td>
<td>Breast</td>
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<tr>
<td>Katherine</td>
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<td>Cervical</td>
</tr>
<tr>
<td>Judy</td>
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<td>Cervical</td>
</tr>
<tr>
<td>Frances</td>
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<td>Breast &amp; Cervical</td>
</tr>
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<td>Leslie</td>
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<td>Breast</td>
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<tr>
<td>Anna</td>
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<td>Fiona</td>
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<td>Dorothy</td>
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<tr>
<td>Eleanor</td>
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<td>None</td>
</tr>
<tr>
<td>Andrea</td>
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<td>US (more than 2 yrs ago)</td>
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<td>Maureen</td>
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**Summary:**

Cancer Screening Status and Attendance at CARES Information Sessions

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<th>UTD: Up to date</th>
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N=26

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<tr>
<th></th>
<th>UTD: Up to date</th>
<th>US: Under-screened</th>
<th>NS: Never-screened</th>
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<tr>
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N=13
## Appendix L
### Responses to Demographic Surveys
#### Part 1 of 2

<table>
<thead>
<tr>
<th>Psuedo-Nyms</th>
<th>Age</th>
<th>Time in Canada</th>
<th>Language</th>
<th>OHIP</th>
<th>Seen a MD/NP in the past year?</th>
<th>Gender of MD/NP</th>
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<td>Linda</td>
<td>31</td>
<td>5+ years</td>
<td>English</td>
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<td>Yes</td>
<td>Female</td>
</tr>
<tr>
<td>Susan</td>
<td>31</td>
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<td>English</td>
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<td>Yes</td>
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</tr>
<tr>
<td>Mary</td>
<td>47</td>
<td>5+ years</td>
<td>English</td>
<td>Yes</td>
<td>Yes</td>
<td>Female</td>
</tr>
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<td>34</td>
<td>Life</td>
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<td>Yes</td>
<td>Female</td>
</tr>
<tr>
<td>Lorna</td>
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<td>English</td>
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</tr>
<tr>
<td>Judy</td>
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<td>Frances</td>
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<td>English</td>
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<tr>
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<td>Female</td>
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<td>Time in Canada</td>
<td>Language</td>
<td>OHIP</td>
<td>Seen a MD/NP in the past year?</td>
<td>Gender of MD/NP</td>
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</tr>
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<td>Life</td>
<td>English</td>
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<td>Life</td>
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N/A: Participant does not have family doctor/nurse practitioner

Both: Participant has more than one care provider representing both female and male genders
### Responses to Demographic Surveys

### Part 2 of 2

<table>
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<tr>
<th>Pseudo-Nyms</th>
<th>Age</th>
<th>Does your MD/NP speak your first language?</th>
<th>Have you given birth in Canada?</th>
<th>Level of Education</th>
<th>Rating of Overall Health</th>
</tr>
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<tbody>
<tr>
<td>Linda</td>
<td>31</td>
<td>Yes</td>
<td>No</td>
<td>9-12</td>
<td>Fair</td>
</tr>
<tr>
<td>Susan</td>
<td>31</td>
<td>Yes</td>
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<td>Post Secondary</td>
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<tr>
<td>Mary</td>
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<td>No</td>
<td>Post Secondary</td>
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</tr>
<tr>
<td>Nicole</td>
<td>34</td>
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<td>No</td>
<td>Post Secondary</td>
<td>Good</td>
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<td>Lorna</td>
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<tr>
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<td>44</td>
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<td>No</td>
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<td>Judy</td>
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<td>Yes</td>
<td>9-12</td>
<td>Very Good</td>
</tr>
<tr>
<td>Dorothy</td>
<td>56</td>
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<td>Yes</td>
<td>9-12</td>
<td>Good</td>
</tr>
<tr>
<td>Eleanor</td>
<td>47</td>
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<td>No</td>
<td>9-12</td>
<td>Fair</td>
</tr>
<tr>
<td>Andrea</td>
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<td>Yes</td>
<td>Post Secondary</td>
<td>Poor physically; Good mentally</td>
</tr>
<tr>
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<td>42</td>
<td>Yes</td>
<td>Yes</td>
<td>Post Secondary</td>
<td>Fair</td>
</tr>
<tr>
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<td>Yes</td>
<td>Yes</td>
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<tr>
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<td>No</td>
<td>9-12</td>
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</tr>
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<td>Vanessa</td>
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<td>Psuedo-Nyms</td>
<td>Age</td>
<td>Does your MD/NP speak your first language?</td>
<td>Have you given birth in Canada?</td>
<td>Level of Education</td>
<td>Rating of Overall Health</td>
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<td>------------------------------------------</td>
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<tr>
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<td>Yes</td>
<td>Post Secondary</td>
<td>Fair</td>
</tr>
<tr>
<td>Noreen</td>
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<td>Yes</td>
<td>Yes</td>
<td>Post Secondary</td>
<td>Varies: Fair, Good &amp; Very Good</td>
</tr>
<tr>
<td>Gwen</td>
<td>67</td>
<td>Yes</td>
<td>Yes</td>
<td>Post Secondary</td>
<td>Very Good</td>
</tr>
<tr>
<td>Jackie</td>
<td>35</td>
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<td>No</td>
<td>Post Secondary</td>
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</tr>
<tr>
<td>Paula</td>
<td>48</td>
<td>Yes</td>
<td>No</td>
<td>Post Secondary</td>
<td>Very Good</td>
</tr>
<tr>
<td>Rita</td>
<td>51</td>
<td>Yes</td>
<td>Yes</td>
<td>9-12</td>
<td>Good</td>
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<tr>
<td>Nancy</td>
<td>45</td>
<td>Yes</td>
<td>Yes</td>
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</table>
### Appendix M

**Participant Physical / Mental Health Conditions with Ratings of Overall Health**

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<tr>
<th>Pseudonym</th>
<th>Physical / Mental Health Conditions</th>
<th>Rating of Overall Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linda</td>
<td>No information volunteered</td>
<td>Fair</td>
</tr>
<tr>
<td>Susan</td>
<td>Muscular Dystrophy, epilepsy, colitis</td>
<td>Good</td>
</tr>
<tr>
<td>Mary</td>
<td>Sleep apnea, mental health challenges</td>
<td>Good</td>
</tr>
<tr>
<td>Nicole</td>
<td>Blindness, deafness, childhood sexual abuse, PTSD, Diabetes, Bipolar Disorder</td>
<td>Good</td>
</tr>
<tr>
<td>Lorna</td>
<td>Asthma, glaucoma, arthritis, former abuse of alcohol</td>
<td>Good</td>
</tr>
<tr>
<td>Katherine</td>
<td>Cancer – unspecified; mental health challenges</td>
<td>Fair</td>
</tr>
<tr>
<td>Judy</td>
<td>Diabetes, use of crystal meth, mental health challenges</td>
<td>Fair</td>
</tr>
<tr>
<td>Frances</td>
<td>Diabetes, Arthritis</td>
<td>Poor</td>
</tr>
<tr>
<td>Leslie</td>
<td>Asthma, schizophrenia, plaque in legs/trouble walking</td>
<td>Fair</td>
</tr>
<tr>
<td>Anna</td>
<td>Brain cancer, mental health challenges</td>
<td>Good</td>
</tr>
<tr>
<td>Fiona</td>
<td>Brain cancer, endometriosis, alcohol abuse</td>
<td>Very Good</td>
</tr>
<tr>
<td>Dorothy</td>
<td>HIV, former drug addition, former alcohol abuse</td>
<td>Good</td>
</tr>
<tr>
<td>Eleanor</td>
<td>Mental health challenges (schizoaffective), mobility problems</td>
<td>Fair</td>
</tr>
<tr>
<td>Andrea</td>
<td>Stoke, mental health challenges</td>
<td>Poor physically; Good mentally</td>
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<tr>
<td>Maureen</td>
<td>Former substance abuse (heroin); hip/leg pain/mobility problems</td>
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<td>Serious physical assault, depression</td>
<td>Excellent</td>
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<tr>
<td>Louisa</td>
<td>Mobility issues – use of wheelchair; “mental disabilities”</td>
<td>Fair</td>
</tr>
<tr>
<td>Noreen</td>
<td>Previously broke tailbone, Fetal Alcohol Syndrome, trauma, former alcohol abuse, Diabetes, Post Traumatic Stress Disorder</td>
<td>Varies: Fair, Good &amp; Very Good</td>
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<tr>
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<td>COPD, osteoporosis, environmental allergy</td>
<td>Very Good</td>
</tr>
<tr>
<td>Jackie</td>
<td>‘Severe’ mental health challenges (anxiety &amp; depression); past trauma</td>
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<tr>
<td>Paula</td>
<td>Breast cancer survivor, mental health challenges, childhood sexual abuse, substance use</td>
<td>Very Good</td>
</tr>
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<td>Rita</td>
<td>Anxiety, Type II Diabetes, substance use, alcohol use, childhood and adult sexual abuse</td>
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</tr>
<tr>
<td>Nancy</td>
<td>Diabetes, asthma, former substance use, physical pain, emotional pain</td>
<td>Good</td>
</tr>
</tbody>
</table>

**Note:** Participants were not asked about physical and mental health histories. This information was volunteered by participants during the interviews. Descriptions are in their own words.