

**RECENT CANCER SCREENING AMONG WOMEN: A  
CRITICAL EVALUATION OF WHY CANADIANS AREN'T  
GETTING REGULAR CLINICAL BREAST EXAMS AND  
PAP TESTS**

by

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## **ABSTRACT**

Preventive cancer screening is effective for early detection of many cancers, however many Canadians fail to participate in screening programs. This paper critically evaluates the results of an analysis of Canadian Community Health Survey data relating to women's cancer screening behaviours. The most commonly reported reasons by Canadian women for not being screened by clinical breast exams (CBE) and Pap tests are discussed in relation to their ability to provide insight into why women do not participate in cancer screening. Limitations of current data on cancer screening behaviours are discussed along with recommendations for their improvement.

**Keywords:** breast cancer, Canadian Community Health Survey, cancer screening, cervical cancer, clinical breast exam, Pap test

**Subject Terms:** Public health -- Social aspects -- Canada; Breast -- Cancer - - Social aspects; Cervix uteri -- Cancer -- Prevention; Preventive health services; Pap test; Women's health services -- Canada

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## INTRODUCTION

Cancer screening is effective for early detection of many cancers, resulting in better prognoses for individuals with cancer and precancerous lesions. In Canada, cancer screening programs have been implemented nationally, however many Canadians fail to participate in such programs. A recent study found that nearly one quarter of Canadian women aged 18-69, for example, had not been screened for cervical cancer in the recommended previous three years (Kaida, Colman, & Janssen, 2008).

The reasons for individuals not participating in screening programs are commonly referred to as barriers. Barriers to screening can be personal or structural, and often multiple factors intersect to create complex barriers. Consider, for instance, an elderly recent immigrant woman with limited mobility who does not speak English well. She may not be screened for cervical cancer because Pap tests are not common in her home country and so she is unfamiliar with what they are and why they are important. Perhaps she also generally avoids seeking medical care because she is unable to navigate the Canadian health care system as a result of poor English abilities. Additionally, she may not access preventive care because of mobility difficulties and transportation challenges. Having a thorough understanding of the barriers that individuals, or populations as a whole experience can assist public health practitioners in addressing barriers and making meaningful improvements to appropriate aspects

of cancer screening programming to increase rates of cancer screening and ultimately reduce cancer mortality.

This paper builds on previous research that used national data from the Canadian Community Health Survey (CCHS) to identify the most common reasons given by women for not participating in routine breast and cervical cancer screening, and the common characteristics among women reporting certain reasons for not being screened (Bogaert, 2008).

This previous research prompted questions about how screening programs could be improved to address the disparities in screening that are associated with individual sociodemographic characteristics, structural factors, and factors relating to the health care system. It also brought about some concern about the way in which data relating to cancer screening is currently being collected through the CCHS. Using data from the CCHS (2005) data, this paper seeks to address two questions: 1) What are the main barriers to preventive cancer screening experienced by Canadian women; and 2) Is the CCHS an adequate tool for identifying barriers to screening for cancer experienced in women?

This paper will begin with a description of the ways in which cancer is an important public health challenge and a discussion of breast and cervical cancer screening for the prevention of cancer cases and the reduction of cancer mortality. A discussion of the current screening recommendations and their implications will follow, then the common reasons that women report for not being screened by clinical breast exams (CBE) for breast cancer and Pap tests

for cervical cancer will be explored followed by a critical evaluation of the use of the CCHS survey to provide information about the reasons for not participating in preventive health programs. Recommendations for further research and improved data collection relating to cancer screening will conclude this paper.

## **BACKGROUND**

### **Cancer as a Public Health Problem**

Worldwide, cancer causes one in eight deaths (Garcia et al, 2007).

Although some of the relatively recent increase in global cancer incidence and mortality can be attributed to population growth and aging, and improved diagnosis and reporting, the actual incidence of cancer is also increasing due to greater exposure to cancer-causing agents (IARC, 2008). In low-to-middle income countries, infections, increased life expectancy, and the adoption of a westernized lifestyle, such as changes to diet, increased obesity, physical inactivity, and tobacco smoking are driving cancer rates up in regions where cancer has not been a significant public health problem in the past (IARC, 2008).

In economically developed countries, cancer has already become a leading cause of death, second only to heart diseases (Garcia et al, 2007). Rates of cancer incidence and mortality in Canada are on the rise; currently one in three Canadians will develop cancer in their lifetime and one in four will die from cancer (Canadian Cancer Society, 2008). Cancer has become a major public health challenge in Canada, and cancer rates are expected to continue to increase.

Globally, breast cancer is the most common cause of cancer mortality in women followed by cervical cancer (IARC, 2008). In Canada, breast cancer is by far the most common form of cancer in women, accounting for nearly 30 percent

of all new cases of cancer in women in 2008 (Canadian Cancer Society, 2008). Cervical cancer, far less common than breast cancer but still responsible for a significant number of new cases and deaths, is the thirteenth most common cancer in Canadian women and accounted for 1.7 percent of new cancer cases in Canadian women in 2008 (Canadian Cancer Society, 2008).

### **Cancer Screening for Early Detection and Reduced Mortality**

While much of cancer prevention remains unknown, the balance of the literature acknowledges that early detection through screening can prevent some cancers from progressing and in many cases increases probability of survival (IARC, 2008; Garcia et al, 2007).

When determining if screening programs are appropriate for a specific disease there are a number of basic principles to consider. The target disease should be common in the population, with high mortality (or morbidity), effective treatment capable of reducing mortality (or morbidity) should be available, and the test used for screening should be safe, relatively inexpensive, and considered acceptable by the target population (WHO, 2009).

In economically developed countries such as Canada, both breast cancer and cervical cancer are ideal for screening programs based on these principles. Clinical breast exams (CBE) and Pap tests are both simple screening techniques that can be done at regular doctors' offices and health clinics; they do not require that women seek specialized health professionals.

With early detection, cancer survival rates increase significantly. In Canadian women, currently the estimated five-year relative survival ratio for breast cancer is 87 percent, meaning 13 percent of those diagnosed with breast cancer die within five years of their diagnosis. The estimated five-year relative survival ratio for cervical cancer is 74 percent, meaning 26 percent of those diagnosed with cervical cancer die within five years of their diagnosis (Canadian Cancer Society, 2008).

Risk for breast cancer and breast cancer mortality increase steadily with age (IARC, 2002). Breast cancer is most commonly diagnosed in Canadian women aged 50-59 and breast cancer mortality is highest for women aged 80 and above (Canadian Cancer Society, 2008). Risk of cervical cancer generally increases with age beginning at age 20 and drops again after age 45 (IARC, 2005). Cervical cancer mortality also increases with age (IARC, 2005) and cervical cancer is most commonly diagnosed in Canadian women aged 20-49 (Health Canada, 1998).

### **Clinical Breast Exams for Breast Cancer Screening**

Clinical breast examinations are physical exams done by trained health professionals to identify physical changes to breast tissue, including signs of lumps and other abnormalities (IARC, 2002). Research has shown that CBE have generally moderate sensitivity and high specificity (IARC, 2008). It is commonly recommended that CBE be used in addition to mammography to improve early detection rates of cancerous lesions and increase probability of survival (Jatoi & Miller, 2003).

The Canadian Cancer Society (2009a) recommends that women aged 40-69 be screened by CBE at least once every two years. The Breast Cancer Society of Canada (2009) recommends that women talk to their doctor to determine if CBE should be included in their regular health check-ups at a younger age than 40. The American Cancer Society recommends that women have a CBE at least once every three years beginning at age 20 and at least once per year beginning at age 40 (Smith, Cokkinides, & Brawley, 2009).

### **Pap Tests for Cervical Cancer Screening**

The Papanicolaou (Pap) smear test, the conventional cytological screening method for cervical cancer, has been hailed as the single best human cancer screening procedure (IARC, 2008). The Pap test is responsible for a marked decrease in invasive cervical cancer incidence and mortality rates in developed countries where screening programs exist, including Canada (Liu, Semenciw, Probert, & Mao, 2001). Trained health professionals take a swab of cells from the cervix to be examined under a microscope in order to look for abnormalities.

Mild abnormalities and slowly progressing pre-cancerous lesions can be detected by the Pap test and therefore treated early to prevent the progression to cancerous cells. Similarly, early cancerous cells can also be detected and treated to prevent progression to invasive cervical cancer (IARC, 2005; IARC, 2008). Carcinoma *in situ*, the earliest stage of cancer, is detectable 8-10 years before it progresses to invasive cervical cancer (IARC, 2005). This significant time period allows for regular screening to identify cancer before it becomes severe so that it

can be treated with a greater chance of survival. Not having routine Pap tests is the single greatest risk factor for developing cervical cancer and also negative outcomes among women who develop cervical cancer (Health Canada, 1998).

The Canadian cervical cancer screening recommendations vary by province but generally it is recommended that sexually active women and women over the age of 18 should have a Pap test at least once every three years until age 70 and those with greater risk or those who have had abnormal Pap test results in the past should have more frequent Pap tests as often as once every 6 months. (Canadian Cancer Society, 2009b; Health Canada, 1998). In the United States, it is generally recommended that healthy women be first tested within three years of first vaginal intercourse but no later than age 21, followed by annual Pap tests until age 30 and then every two to three years until age 70 (Smith, Cokkinides, & Brawley, 2009).

### **Factors Influencing Screening Recommendations**

The screening recommendations for breast cancer and cervical cancer vary depending on which body is providing the guidelines. Competing political and economic agendas create a confusing mix of preventive screening recommendations. The political economy of cancer complicates the issue of appropriate recommendations because there is profit to be made in cancer screening, and so the recommendations may be influenced by the potential for some stakeholders to make a profit (Zones, 2002). In a country such as Canada, with a universal health care system that covers cancer screening methods for all citizens, the recommendations are likely to be more conservative in order to

reduce the size of the population 'needing' screening, and therefore reducing the cost of screening to the health care system.

### **Canadian Population-Level Health Data**

In Canada, population-level health data is collected through a national population-based survey called the Canadian Community Health Survey (CCHS). The CCHS is a cross-sectional self-reported household survey conducted by Statistics Canada. According to Statistics Canada, the primary objectives of the general content cycles of the CCHS are to provide timely, reliable estimates of health determinants, health status, and health system utilization across Canada (Statistics Canada, 2006). Although the majority of the survey questions directly relate to these objectives, some questions fall outside of the intended scope of the survey. For example, a question that determines the number of respondents who participate in regular preventive screening assists in meeting the health system utilization objective of the survey. However, questions relating to the reasons why people do not participate in preventive screening programs fall outside the primary objectives of the CCHS and thus, the responses are more limited.

Canadians who participate in the national CCHS respond to questions relating to personal characteristics and health behaviours including questions about their participation in cancer screening programs. The data from the CCHS can be used to make connections between individual characteristics and screening behaviours. For example, recent research using CCHS data found that

women who are overweight and obese are less likely to participate in cervical cancer screening (Mitchell, Padwal, Chuck, & Klarenbach, 2008).

Identifying and articulating common barriers experienced by women that prevent them from being screened could lead to solutions for the removal of those barriers, ultimately increasing screening rates therefore lowering cancer mortality rates. Effectively addressing the underlying barriers to access requires a thorough understanding of the current barriers based on contemporary research, and the implementation of realistic solutions for overcoming those barriers.

### **Factors Influencing Screening Decisions**

Some characteristics are associated with higher rates of cancer and lower use of preventive cancer screening programs. Previous research, for example, has shown that being Aboriginal (Steven et al, 2004), being an immigrant (Hislop, Inrig, Bajdik, Deschamps, Tu, & Taylor, 2003), being an ethnic minority (Moser, Patnick, & Beral, 2009), having an Asian background (McDonald & Kennedy, 2007), suffering from depression (Kaida, Colman, & Janssen, 2008), being obese (Wee, McCarthy, Davis, & Phillips, 2000; Mitchell, Padwal, Chuck, & Klarenbach, 2008), having a low socio-economic status (Lee, Parsons, & Gentleman, 1998; Moser, Patnick, & Beral, 2009), or having a history of sexual assault (Farley, Golding, & Minkoff, 2002; van Til, MacQuarrie, & Herbert, 2003) results in both higher rates of cervical cancer and lower use of Pap test screening. Just as the social determinants of health impact health behaviours and health outcomes, they also impact use of preventive cancer screening (Bryant, Browne, Barton, &

Zumbo, 2002). Not being screened puts these at-risk populations at a further disadvantage since not being screened is the greatest risk factor for cervical cancer.

Previous research (Mitchell, Padwal, Chuck, & Klarenbach, 2008; Wee, McCarthy, Davis, & Phillips, 2000) has shown an association between body mass index (BMI) and preventive cancer screening in women: over-weight and obese women are less likely to participate in both preventive breast and cervical cancer screening programs than normal-weight women. Women with higher BMI scores are less likely to be screened because they often experience other known barriers such as lower education, lower income, and higher rates of illnesses, as well as patient and provider attitudes (Mitchell, Padwal, Chuck, & Klarenbach, 2008; Wee, McCarthy, Davis, & Phillips, 2000). A number of factors likely contribute to this finding, including factors relating to individual women, the health care providers, and the health care system. Specifically, obesity disproportionately affects those of lower socioeconomic status, and economic barriers may be the underlying barriers preventing some women from being screened (for example, being unable to take time off work or unable to afford transportation to attend a preventive health appointment). Also, some health care providers are less likely to initiate screening because of negative stereotypes of overweight and obese patients, or because they have misinformed notions about the effectiveness of screening in above-average weight women (Mitchell, Padwal, Chuck, & Klarenbach, 2008).

The importance of identifying common characteristics of women who experience similar barriers to cancer screening is that recommendations could be made for improving screening programs for a number of women. Removing systemic barriers to care and developing programs to target specific populations of women could increase rates of screening, ultimately leading to positive health outcomes. For instance, a targeted preventive cancer screening program for South Asian immigrants in Greater Vancouver has proved to be successful (Sent, Ballem, Paluck, Yelland, & Vogel, 1998). The Asian Women's Health Clinic in Vancouver is an educational and screening clinic that has successfully raised awareness of the importance of preventive health among Asian immigrants and has effected change in local physician screening practices among the female Asian patient population (Sent, Ballem, Paluck, Yelland, & Vogel, 1998).

Unfortunately, the clinic has experienced some difficulty in maintaining utilization rates (Grewal, Bottorff, & Balneaves, 2004) due to challenges in maintaining long-term stakeholder involvement in community awareness about preventive health care and in maintaining support from local physicians in referring Asian immigrant patients to the clinic. Additionally, the clinic has tended to attract Asian women with a wide range of health issues that the clinic was unprepared to address. Ultimately a more comprehensive approach to health services for this unique population may be necessary to attract and retain patients and to continue to see positive results surrounding their provision of care (Grewal, Bottorff, Balneaves, 2004). These kinds of targeted services may be necessary for specific at-risk populations in order to address the significant

barriers preventing them from accessing care, including preventive cancer screening.

Addressing factors that influence cancer screening decision-making by identifying common barriers to being screened requires data that provides such information. Identifying real barriers that are causing disparities in cancer screening behaviours could lead to more equitable access to preventive cancer screening and improved health outcomes.

## **METHOD**

This project draws extensively on CCHS Cycle 3.1 survey data that was compiled and analyzed in the fall of 2008 (Bogaert, 2008). The methods have previously been described in detail (Bogaert, 2008) but will be summarized here to provide context for this paper.

The CCHS initiative began in 2000 and the survey is conducted to collect information on determinants of health, health status, health behaviours, and health system utilization (Statistics Canada, 2006). Prior to 2007 the survey was conducted every two years but surveys are now conducted yearly, with data for each calendar year released annually. The general health survey consists of core content survey questions that are relatively unchanged between cycles and are asked as part of the .1 cycles, such as the 3.1 used for the previous study. Theme content of the focused topic survey (.2 cycles) provides provincial data on a specific topic (for example, the topic of cycle 1.2 was mental health and well-being) (Statistics Canada, 2008).

Statistics Canada uses a complex, multistage sampling strategy that first identifies randomly selected households from 125 Health Regions and then randomly selects one resident 12 years of age or older from each household to be interviewed for survey completion. Persons living on Indian Reserves or Crown lands, those residing in institutions, full-time members of the Canadian Forces, and residents of certain remote regions were excluded from the survey,

representing about 2% of the entire Canadian population. The survey was designed for computer-assisted interviewing (CAI). Field interviewers visit the dwellings of those individuals randomly selected to complete the survey in order to administer the survey in person. When that is not possible, multiple attempts are made to reach the person by telephone in order to administer a telephone version of the questionnaire (Béland, 2002). The national response rate for cycle 3.1 was 78.9%, which yielded 132, 947 valid interviews. Roughly half of the interviews were conducted in person and the other half by telephone (Statistics Canada, 2006). The methodology of the CCHS 3.1 is fully described elsewhere (Statistics Canada, 2006).

In the previous study that was the impetus for this paper, CCHS Cycle 3.1 (2005) data were used to determine frequencies of the different response categories selected as reasons given by women for not being recently screened by CBE and Pap tests and the different reasons' relationship to demographic, socioeconomic, and behavioural characteristics. Responses to the questions "What are the reasons that you have not had a breast exam in the past 2 years?" and "What are the reasons that you have not had a Pap smear test in the past 3 years?" were analyzed for women aged 18 years or older who had not had a mastectomy or a hysterectomy, respectively. These questions were asked of those women who stated that it had been two years or longer and three years or longer since being screened by a CBE and a Pap test, respectively. Previous literature of similar analyses (such as Kaida, Colman, & Janssen, 2008) was

consulted when determining the study sample for the CCHS analysis being discussed here (Bogaert, 2008).

In the previous study, proportions of responses to the two questions of interest were calculated from the frequencies of responses and then the corresponding reasons for not being screened were rank-ordered accordingly. The results of logistic regression models were used to examine the relationship between reasons for not being screened and various characteristics and were reported elsewhere (Bogaert, 2008). In the previous study sample weights were applied to obtain weighted results. The sample weights provided for the data set by Statistics Canada were used for this calculation. The sampling weights can be interpreted as the number of people each respondent represents in the actual Canadian population (Statistics Canada, 2006).

For the purpose of this paper, the most commonly reported reasons for not being screened that were rank-ordered based on calculated proportions were examined further. In the recent CCHS research (Bogaert, 2008), it was hypothesized that there are commonly reported reasons (i.e., barriers) among groups of women for not being screened by both CBE and Pap tests. CBE and Pap tests were selected for inclusion in the research because of similarities between the two screening methods; both screening methods are safe, uncomplicated procedures that are available at general doctor's offices, they require minimal time commitment for the actual screening procedure, and both are widely accepted as effective preventive cancer screening methods.

Mammography is often included in similar analyses instead of CBE (Blackwell, Martinez, & Gentleman, 2008; Sherman, Abel, & Tavakoli, 1996; Snider, Beauvais, Levy, Villeneuve, & Pennock, 1996; Wee, McCarthy, Davis, & Phillips, 2000), however, CBE was purposefully selected over mammography because mammography programming differs widely across provinces and it is a more involved screening procedure that requires a specialty appointment outside of the standard health care delivery system (Bogaert, 2008).

In attempting to develop a better understanding of the meaning and limitations of the CCHS data, I used my earlier research as a starting point for critically examining the commonly reported reasons for not being screened in order to highlight weaknesses of the information that the CCHS data provides. In conducting this research, I adopted a social determinants lens (Wilkinson & Marmot, 2003), to show that there may be aspects of respondents' social environments that lead to disparities in health, including access to preventive health services, and therefore influence the reason(s) CCHS participants provide for not being screened. That is, what is it about the experiences or characteristics of some women that make them provide one reason for not being screened over another? What barriers do women experience that prevent them from participating in cancer screening?

I also drew from the previous research of Raphael and Wuest. Raphael (2004) argues that the differences in health that are experienced by Canadians are primarily a result and function of different environments, and that social

determinants of health are dependent on the quantity and quality of resources that a society makes available to its members (Raphael, 2004).

Wuest (2006) further complements the social determinants perspective with the argument the best chance for understanding the complex patterns of women's health is within the contexts of family, social, cultural, political, and economic.

## **FINDINGS**

Below is a summary of the key findings from the previous research (Bogaert, 2008) relating to CBE and Pap tests that were the impetus of this paper. A thorough analysis of the key findings, the meaning of these findings and the limitations of the data follow in the Discussion section.

### **Commonly Reported Reasons for Not Being Screened**

Women who reported at least one reason for not having a CBE in the previous two years ( $N = 6,404$ ) and women who reported not having a Pap test in the previous three years ( $N = 16,824$ ) overwhelmingly reported the same top three reasons for not being screened: 1) Respondent did not think it was necessary, 2) Doctor did not think it was necessary, and 3) Respondent has not gotten around to it. Together these three reasons accounted for 94 percent of reasons reported by women for not having a CBE and 79 percent of all reasons reported for not having a Pap test (see Appendix A).

The remaining reasons reported for not having a CBE were split among 11 other response categories, each accounting for less than 2 percent of responses. The remaining reasons reported for not having a Pap test were split among 12 other response categories, each accounting for less than 4 percent of responses, except for “Other” which accounted for nearly 11 percent of responses (see Appendix B).

When the weighted rank was calculated the top three reasons remained; however, for both CBE and Pap test results, the response order changed to: 1) Respondent did not think it was necessary, 2) Respondent has not gotten around to it, and 3) Doctor did not think it was necessary.

## **DISCUSSION**

The section below is a critical discussion of the findings relating to the commonly reported reasons for not being screened from the previous study as summarized above. This discussion is based on my review of existing literature relating to preventive screening and the barriers to screening, and it is also based on my critical analysis using a social determinants lens to reflect on the implications of the previous study's results. Existing literature is used to support my own ideas of the barriers to screening and the weaknesses of the information provided by the CCHS relating to screening barriers. Aspects of the CCHS survey design and its adequacy as a tool to identify the reasons why women are not being screened by CBE and Pap tests are critically discussed below.

After considering the above findings from the previous CCHS research, it became clear that these commonly reported reasons for not being screened do not provide insight into the underlying reasons why women are not participating in preventive cancer screening. The three most common response categories are also the most general and therefore leave much room for interpretation by the respondent, the interviewer, and also researchers.

### **Commonly Reported Reasons for Not Being Screened**

Generally, the three most commonly reported reasons for not being screened (respondent did not think it was necessary, doctor did not think it was

necessary, and have not gotten around to it) provide only basic information about barriers to care. Although these were overwhelmingly the top responses by women, they are too general to make any meaningful conclusions for informing action to address the reasons women are not being screened. These common responses do not give any indication of the underlying barriers that lead women to report these reasons for not being screened.

The high rate of the use of the “Other reason” response category for Pap tests (12.33% of reasons for not being screened) but not for CBE (0.10%) suggests that there is something about Pap test screening that is different than CBE. Unfortunately, the details of the responses that were classified as “Other reason” are unknown. There may be one specific reason that was commonly reported but was not listed as a response category or there could be various reasons for not being screened that did not fit in other categories. Without any specific information about this miscellaneous response category the information this provides is not useful for addressing barriers to screening.

It is well known that the ways in which individuals make health-related decisions, including preventive screening are very complex (Steven, et al., 2004). Theories such as the Health Belief Model (HBM) and the Theory of Reasoned Action attempt to explain personal health decisions. According to the HBM, individuals make health decisions based on perceived susceptibility and severity of disease, perceived benefits of the recommended action and the barriers to that action, and also personal self-efficacy (Austin, McNally, & Stewart, 2002).

Surrounding the results of this study, women who reported that they did not think screening was necessary may be avoiding screening because, for example, they believe their susceptibility to cancer is low, or because they do not believe that preventive screening is effective, or because they feel there is some barriers to screening that is too great to overcome (van Til, MacQuarrie, & Herbert, 2003).

Inaccurate beliefs may be the result of women's social environment and systemic barriers, and therefore be a function of the social determinants of health. For example, a woman's belief that screening is not able to prevent cancer or that her susceptibility to cancer is low could be because of inadequate education about the etiology of cancer or individual cancer risk (McDonald & Kennedy, 2007; Steven et al, 2004; van Til, MacQuarrie, & Herbert, 2003). Similarly, the belief that preventive screening is ineffective could be the result of inadequate education about cancer screening or the progression of cancer, or because of cultural beliefs of health and illness.

Other research (Freeman & Chu, 2005) presents a detailed model of barriers to cancer screening, diagnosis, and care. One interesting piece of the Freeman and Chu (2005) model is their explanation of how cultural factors often act as barriers to screening, such as non-biomedical views of health, lack of community support for preventive screening, cultural perspectives that cause women to avoid screening, and culturally inappropriate approaches used by health practitioners. These kinds of complex barriers to health are not obvious from the three most commonly reported reasons by Canadian women through

the CCHS for not being screened, although, as Freeman and Chu (2005) suggest, they are likely the underlying barriers preventing some women from being screened.

### **Respondent Did Not Think It Was Necessary**

Women who reported that they did not think screening was necessary could have responded that way because they are misinformed about the risks of breast or cervical cancer, because they have beliefs about their own susceptibility to cancer, such as no family history, or a healthy lifestyle, or because they are well educated about the disease(s) and because of their age, or other factors, believe that they do not require screening (van Til, MacQuarrie, & Herbert, 2003). Women who are not being tested by Pap tests because they do not think they are at risk could be accurately making that decision based on the fact that they had a long history of normal Pap test results. Alternatively, women could be making the same decision inaccurately based on the fact that they are no longer sexually active. Without knowing why each respondent does not think screening is necessary for her we are unable to determine if they are making the appropriate decision.

### **Doctor Did Not Think It Was Necessary**

Women who reported that their doctor did not think the screening was necessary could have stated a number of significantly different responses that were ultimately coded by the interviewer as being the same. For example, a woman who had previously had a hysterectomy could have said in her response

that her doctor said a Pap test was no longer necessary, but if she did not explicitly state in her interview response that she had previously had a hysterectomy then her response would be classified the same as a woman who for example, did not want to admit her own negligence in screening and claimed that her doctor had never recommended she be screened.

It could also be the case that doctors are not actively recommending screening and women take that to mean that their doctor does not think screening is necessary. It could be that women who are not being screened and reported this reason because they have only accessed emergency care as a result of poor access to a family physician and those urgent care health professionals have not recommended screening because there was an assumption that she would be seeing a family physician for regular check ups.

Women reporting this reason could have also meant that their doctor advised them not to be screened for a valid reason, or for an invalid reason. As previously mentioned, research has found physicians to hold biases about the preventive screening needs of obese and overweight women (Mitchell, Padwal, Chuck, & Klarenbach, 2008; Wee, McCarthy, Davis, & Phillips, 2000), for example, and so it is possible that health professionals are failing to recommend preventive screening to some women who could benefit from the screening. Again, without knowing details other than that the interviewer categorized their response as their doctor does not think screening is necessary, it is not possible to determine if this reason for screening is appropriate for the women who reported it.

## **Have Not Gotten Around To It**

The response category that is most ambiguous is the reason that the woman has not gotten around to getting a CBE or Pap test. If women are not making screening a priority, there is a reason, or many, for not doing so. Without explicitly stating other reasons for not being screened, women's responses relating to screening being a low priority of theirs would be categorized by the interviewer as having not got around to it.

Women who have not made screening a priority may be doing so because their other priorities are so significant that they have not accessed any personal health services recently, because they are uncomfortable with the screening procedure, fearful of the results, do not believe they are at risk for cancer, or are unable to attend the appointment for any number of reasons. Although many of these more specific problems were listed as separate response categories for the questions relating to CBE and Pap tests, unless the women being interviewed were specific and explicitly named these other reasons, their response would have been categorized as having not gotten around to it.

A recent study in Great Britain, for example, found that women who had access to a car were more likely to participate in cancer screening (Moser, Patnick, & Beral, 2009). Canadian women who do not have access to a car may experience a barrier to health care and may put off preventive health care procedures because of transportation challenges. Transportation was provided as a response category, but unless a woman explicitly indicated that she had a transportation-related reason for not accessing care, then it may have been

categorized as not getting around to having the screening. Again, the ambiguity of this reason for not being screened prevents it from being useful in determining the underlying reasons women are not being screened by CBE and Pap tests.

### **Weaknesses of the CCHS Questions Regarding CBE and Pap Tests**

The CCHS has a number of weaknesses when considering the two questions of interest relating the CBE and Pap tests. Interviewers asked women the CCHS 3.1 survey questions in person or over the telephone. The open-ended questions on the survey were designed for interviewers to check off from pre-determined response categories the responses given by respondents. The questions pertaining to barriers to preventive screening (including CBE and Pap tests) and other medical appointments (such as regular physical checkups and dental appointments) all had a list of 14 common possible response categories (see Appendix B), and some questions had additional unique response categories. The question relating to CBE included the additional response category 'Breasts removed/mastectomy', and the question pertaining to Pap tests included 'Have had a hysterectomy' and 'Hate/dislike having one done' (Statistics Canada, 2004).

Interviewers categorized women's responses as they responded to the question but the interviewers did not probe for further information, so these general response categories may not provide the full story. In this respect, if a woman stated that she was not screened simply because she had not got around to it, the interviewer would have categorized the response as such, without asking the woman to clarify. Clarification could have lead to her response being

categorized into a different response category, such as she was unsure of how to go about making an appointment. This kind of detailed response would indicate that she is not screened because of a weakness of the health care system, not a personal characteristic that has prevented her from participating in screening.

The CCHS (2005) questions that pertained to CBE and Pap tests fail to provide actionable information. The responses to the questions of why women were not screened leave room for an additional question of why (that is, for example, if women reported they do not think screening is necessary, why do those women think screening is not necessary?). While the questions asked provide a surface-level of information, they unfortunately are limited in that they do not provide a clear indication of the underlying barriers that women experience and what could be changed to remove barriers to screening and improve screening rates.

### **Use of the CCHS Survey for Preventive Cancer Screening Data**

In the CCHS 3.1, as respondents answer the questions about failing to be screened it is the interviewer who is responsible for determining which responses category(ies) the respondent's answer most closely matches. Unfortunately, this introduces significant limitations, as it provides no opportunity to ask for further clarification or for the woman to expand on her response while it does provide the opportunity for misclassification of responses. It may be better for women to read the list of response categories, or have the interviewer read all response categories to each respondent and ask if she experiences each barrier in the form of a yes/no question so that women can consider each category without

having to first think of them on their own and then also articulate them to the interviewer.

Some of the common response categories for the CBE and Pap test questions are ambiguous. One of the response categories available to interviewers is “Fear (e.g., painful, embarrassing, find something wrong)”. If the barriers to screening are to be addressed, it is necessary to understand the barriers as best we can. Considering the example of “Fear”, this is a barrier that can be addressed very differently depending on the type of fear women experience. Women who reported not being tested because they find the test painful, because they find the test embarrassing, and because they are worried that the test will find something wrong were all placed into one category in the CCHS 3.1. However, all of these issues need to be addressed in very different ways in order to remove the barrier for women.

### **Implications for Future Research**

The results of this project highlight some of the limitations of current population-level health data in Canada. This paper underscores the importance of quality, detailed data relating to preventive cancer screening behaviours and the barriers preventing women from being screened.

Overwhelmingly, women reported that they have not been screened by CBE and Pap tests because they personally do not think the screening is necessary. Unfortunately, the CCHS 3.1 data is unable to answer the question of why women do not think the screening is a necessity. Future research needs to

determine if women are making educated decisions about their personal necessity of screening or if they are misinformed about their screening needs.

Furthermore, nearly a quarter of all reasons reported noted that their doctor did not think the screening was necessary, and another quarter noted that they had not gotten around to being screened. These reasons need to be fleshed out through future research in order to provide more meaningful information if it is to be used in public health practice for improving preventive cancer screening.

### **Recommendations for Cancer Screening Data Collection**

Generally, the objective of the two questions in the CCHS relating to the reasons women are not getting routine CBE and Pap tests should be re-evaluated. What was the original reason for including these questions in the CCHS .1 cycles? If the purpose is simply to get an idea of why women are not being screened and to track trends in responses over time, then the question may be providing a sufficient level of detail. However, these questions are insufficient if the data are to be used to improve access to screening. Using a conceptual framework that focuses on moving research data into action, as Bazos et al (2001) would advocate for, could allow for the development of survey questions that lead directly to actionable data so that improvements to current cancer screening could be realized.

Survey data alone cannot provide the level of detail required for making recommendations to improve cancer screening rates among Canadian women. The CCHS data could be used to identify under-screened populations by

analyzing characteristics of those who are not screened. Qualitative research methods such as open-ended interviews or focus groups could then be used to provide more detailed information from identified groups of women who are less likely to be screened. Although qualitative research is costly, and at a national level is not feasible, future research that incorporates qualitative methodologies to further investigate the reasons women are not participating in cancer screening programs would better elucidate the underlying issues at hand.

Alternatively, future research could ask what women's reasons are for getting routine CBE and Pap tests. Survey questions could be added to the CCHS to ask those women who have been screened in the recommended previous time period why they were screened. Survey data may provide limited information so qualitative methods could be employed as well to determine the reasons of routinely screened women for being screened.

Previous literature has indicated that pain, embarrassment, and fear are common barriers to CBE and Pap tests (Burak & Myer, 1997; Byrd, 2007; Hislop et al, 2003; Farley, Golding, Minkoff, 2002; van Til, MacQuarrie, & Herbert, 2003). Redesigning the survey questions relating to cancer screening to more specifically include these barriers could help to identify if these barriers are common to Canadian women as well. Or, as discussed above, qualitative research methods could be employed to further examine specific barriers and more specific information.

## **Recommendations for Improved Screening Programs**

Once the underlying barriers to screening are accurately identified and articulated, initiatives to address those barriers must be undertaken to increase cancer screening rates among women across Canada. There are many things that may help to address the reasons related to women's decisions to not be screened, as well as to address the health system-related reasons.

In order to reach the populations who are not being screened, it is critical to understand the reasons associated with lower screening rates. The general response categories discussed previously in this paper do not provide the type of data necessary to improve cancer screening rates. Qualitative research, focus groups for example, could provide much richer data on the topic of barriers to screening than data collected through survey questions.

Recent qualitative research (van Til, MacQuarrie, & Herbert, 2003) using focus groups examined the reasons women from Prince Edward Island aged 45-70 had not had a Pap test in the previous five years (van Til, MacQuarrie, & Herbert, 2003). This qualitative research provides rich information about the barriers that older women experience. For example, many of the women discussed negative personal experiences of previous Pap tests that deterred them from ever having another Pap test, as well as structural barriers and issues related directly to the health care system. One woman demonstrated her lack of knowledge about the etiology of cervical cancer by saying that there is no way to prevent cervical cancer so there is no benefit in being screened.

The women in the focus groups also identified potential ways to influence women's decisions for being screened in the future. For example, the unscreened women felt that learning accurate information about cervical cancer and Pap tests would increase their likelihood of having regular screening, as would improved access to gynaecologists and female physicians (van Til, MacQuarrie, & Herbert, 2003). Additional qualitative research examining the barriers experienced by other groups of women could improve our understanding of the types of barriers that are commonly experienced among Canadian women and those barriers that are specific to certain populations.

Separate clinics that are devoted to prevention and a system for providing patients with reminders for screening have been shown to improve screening rates (Stone et al, 2002). Prevention-based clinics could help to increase knowledge of cancer progression, especially in populations with non-biomedical health beliefs. The success of mammography programming in Canada, for example, is largely due to the fact that it is a widely accepted screening procedure and it is separate from all other health care delivery with patient reminders as part of the programming.

Increasing public awareness of the value of preventive cancer screening and increasing general knowledge about the screening procedures by providing accessible educational material may aid in improving cancer screening rates (Hislop et al, 2003). Because of the multicultural population of Canada, educational material must be culturally and linguistically appropriate in order to reach underserved populations (Steven et al, 2004).

From the health care system side of cancer screening, it could decrease confusion about the screening guidelines if there was a national strategy for preventive cancer screening in place that could be promoted nation-wide. It may also be a worthwhile endeavour to research health professionals' opinions relating to barriers to screening. According to the CCHS CBE and Pap test data, nearly a quarter of the reasons reported by women for not being screened are that their doctors do not think the screening is necessary (Bogaert, 2008). If women are erroneously being told not to be screened, or if health care providers are not actively informing and reminding their patients about the need to be screened then implementing a strategy to increase health professionals' recommendations to women for preventive screening could address up to a quarter of missed screenings.

Earlier research has shown that primary care physicians report forgetfulness, lack of familiarity with current guidelines, and lack of time as reasons for not offering screening to their patients (Kupets & Covens, 2001). Future research in the area could provide insight into the current situation among Canadian health care providers and lead to effecting change among health care providers.

### **Limitations**

This project has several limitations. The self-reported nature of the CCHS data warrants caution. Recall bias may play a role in women's recollection of their last CBE or Pap test, which may reduce internal validity of the responses and may vary systematically by characteristics. The data originally used to

determine the three common reasons for women not being screened is drawn from women who reported not being screened in the previous two or three years. Reporting errors are widely known limitations of retrospective data and should be taken into consideration with regards to the present research.

Certain populations are excluded from the CCHS and are therefore also excluded from the present project. Individuals living on Indian Reserves and on Crown Lands, institutional residents, full-time members of the Canadian Forces, and residents of certain rural and remote regions were excluded from the CCHS sampling frame. The reasons women of these groups are not being screened by CBE and Pap tests may vary from the common reasons found among those women included in the CCHS and should be researched to determine if these groups have unique preventive screening needs.

Because recommendations for screening vary by province future research could stratify the CCHS data by province to determine if there are differences in screening behaviours across the provinces. However, because screening by CBE and Pap test are asked about in the previous two or three years and the CCHS does not provide information on residential history, the women may be new residents to the province from which they reside at time of the survey. It could be valuable to gain information about differences between provinces in order to compare the provincial approaches to preventive cancer screening.

## **CONCLUSION**

Gaining an in-depth understanding of the barriers individuals and populations face when making health-related decisions, including preventive cancer screening, will enable the development of more effective and successful programming and interventions, and ultimately, result in lower cancer mortality rates. If the CCHS is to assist in developing such an understanding, the current preventive cancer screening questions must be reconsidered and data collection relating to reasons for not being screened must be improved.

## **APPENDICES**

## Appendix A

**Table 1. Rank of responses to ‘What are the reasons that you have not had a Pap smear test in the past 3 years?’ and ‘What are the reasons that you have not had a clinical breast exam in the past 2 years?’**

| Reason For Not Being Screened                            | Pap Tests        |                                       |               |                                     | Clinical Breast Exams (CBE) |                                       |               |                                     |
|--|------------------|---------------------------------------|---------------|-------------------------------------|-----------------------------|---------------------------------------|---------------|-------------------------------------|
|  | Rank of Response | Percent of all Responses <sup>a</sup> | Weighted Rank | Percent of all Responses (Weighted) | Rank of Response            | Percent of all Responses <sup>b</sup> | Weighted Rank | Percent of all Responses (Weighted) |
| Respondent did not think it was necessary                | 1                | 38.88                                 | 1             | 38.81                               | 1                           | 46.82                                 | 1             | 47.35                               |
| Doctor did not think it was necessary                    | 2                | 20.23                                 | 3             | 20.56                               | 2                           | 24.49                                 | 3             | 22.61                               |
| Have not gotten around to it                             | 3                | 19.93                                 | 2             | 17.30                               | 3                           | 23.08                                 | 2             | 24.60                               |
| Other reason   | 4                | 10.85                                 | 4             | 12.33                               | 12                          | 0.15                                  | 12            | 0.10                                |
| Hate/dislike having one done*                            | 5                | 3.93                                  | 5             | 3.46                                | —                           | —                                     | —             | —                                   |
| Fear (e.g., painful, embarrassing, find something wrong) | 6                | 2.30                                  | 6             | 2.68                                | 4                           | 1.78                                  | 4             | 1.91                                |
| Did not know where to go/uninformed                      | 7                | 1.11                                  | 7             | 1.68                                | 9                           | 0.47                                  | 7             | 0.59                                |
| Not available at time required                           | 8                | 0.74                                  | 8             | 0.94                                | 6                           | 0.67                                  | 5             | 0.73                                |
| Waiting time was too long                                | 9                | 0.65                                  | 9             | 0.77                                | 10                          | 0.35                                  | 10            | 0.30                                |
| Not available at all in the area                         | 10               | 0.57                                  | 10            | 0.62                                | 5                           | 0.73                                  | 6             | 0.68                                |
| Personal or family responsibilities                      | 11               | 0.37                                  | 11            | 0.34                                | 7                           | 0.61                                  | 8             | 0.51                                |
| Transportation problems                                  | 12               | 0.21                                  | 12            | 0.26                                | 11                          | 0.22                                  | 11            | 0.21                                |
| Unable to leave the house because of a health problem    | 13               | 0.14                                  | 13            | 0.14                                | 8                           | 0.55                                  | 9             | 0.32                                |
| Cost   | 14               | 0.07                                  | 14            | 0.09                                | 13                          | 0.07                                  | 14            | 0.04                                |
| Language problems  | 15               | 0.02                                  | 15            | 0.04                                | 14                          | 0.03                                  | 13            | 0.05                                |

\*only offered as a response option for Pap screening

<sup>a</sup> Respondents could select more than one reason and so this is percentage of all responses given for ‘What are the reasons that you have not had a Pap smear test in the past 3 years?’

<sup>b</sup> Respondents could select more than one reason and so this is percentage of all responses given for ‘What are the reasons that you have not had a clinical breast exam in the past 2 years?’

Source: Bogaert (2008)

## Appendix B

**Table 2. Common<sup>1</sup> Open-Ended Response Categories**

|  |
|--|
| Have not gotten around to it                             |
| Respondent - did not think it was necessary              |
| Doctor - did not think it was necessary                  |
| Personal or family responsibilities                      |
| Not available - at time required                         |
| Not available - at all in the area                       |
| Waiting time was too long                                |
| Transportation - problems                                |
| Language – problem                                       |
| Cost   |
| Did not know where to go/uninformed                      |
| Fear (e.g., painful, embarrassing, find something wrong) |
| Unable to leave the house because of a health problem    |
| Other – Specify  |

Source: Statistics Canada (available online  
[http://www.statcan.gc.ca/concepts/health-sante/cycle3\\_1/index-eng.htm](http://www.statcan.gc.ca/concepts/health-sante/cycle3_1/index-eng.htm))

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<sup>1</sup> Common to the CCHS Cycle 3.1 questions: “What are the reasons that you have not had a breast exam in the past 2 year?”, “What are the reasons that you have not had a PAP smear test in the past 3 years?”, “What are the reasons that you have not had a flu shot in the past year?”, “What are the reasons that you have not had your blood pressure taken in the past 2 years?”, “What are the reasons you have not had [a mammogram] in the past 2 years?”, “What are the reasons that you have not had an eye examination in the past 2 years?”, “What are the reasons that you have not had a [physical] check-up in the past 3 years?”, and “What are the reasons that you have not been to a dentist in the past 3 years?”.

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