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Knowledge of Overdiagnosis and the Decision To Participate in Breast Cancer Screening

Kimberly T. Nembhard
Walden University

Walden University

College of Social and Behavioral Sciences

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Kimberly Nembhard

has been found to be complete and satisfactory in all respects,
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the review committee have been made.

Review Committee
Dr. Lori Demeter, Committee Chairperson,
Public Policy and Administration Faculty

Dr. Victor Ferreros, Committee Member,
Public Policy and Administration Faculty

Dr. Matthew Jones, University Reviewer,
Public Policy and Administration Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Abstract

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by

Kimberly Trudy-Ann Nembhard

MS, University of London, 2009

BS, University of the West Indies, 2006

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

In 2014, breast cancer was the second leading cause of death among Canadian women, with women over age 50 years making up 82% of the identified cases. To address this issue, the Ontario Breast Screening Program developed a media campaign that promoted the benefits of mammogram screening, but not the associated risks (i.e., false-positive, false-negative, radiation exposure, and overdiagnosis). This study was designed to determine whether there was a statistically significant relationship between knowledge of overdiagnosis and participation in mammogram screening. This cross-sectional, correlational study used schema theory supported by the effective health communication model. Forty-one women were invited to listen to a brief presentation on the benefits and risks of screening mammograms and then completed a modified Champion Health Belief Model Scale survey. Two sample *t* tests and logistic regression analyses of the survey scores showed that the data did not support any correlations with education and screening, but did indicate a correlation between overdiagnosis and participation. The less a participant felt that overdiagnosis was a negative consequence, the more likely they were to participate in breast screening. Survey participants also stated that promotions of mammograms should present balanced information about the benefits and risks of screening. The positive social change and policy implications of this study include providing women aged 50–69 years more information on overdiagnosis in mammograms so they are more informed participants in the decision-making process, and educating Ontario government policymakers with information about the barriers that women aged 50–69 years face in getting balanced information on mammography programs.

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Dedication

I dedicate this dissertation to my wonderful parents, Emry-Joy and Cyril Nembhard, without your love, warm embrace, humor and continued support, this journey would have been much harder and less rewarding.

To my loving sister, Mekielia; niece, Danielle; and close friends, Damian A. Clarke, Philip D. Gardner, Patrice L. Gilpin, Mark A. Hill, Delorean S. Klien, Chandler W. Lauzon, Rohan R. Oldacre, Andrea L. Samaru, Yohann G. Simpson and Camille A. Wint; I dedicate this dissertation to each of you. Thanks for keeping me grounded and motivated. Through many long nights of writing, you have all entertained, inspired, and occasionally served as my spiritual guide, sounding board, proof editor, financial advisor, personal chef, fitness trainer, and entertainment coordinator. Cheers!!!

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Chapter 1: Introduction to the Study

Introduction

Breast cancer has no cure and is the most common form of cancer among Canadian women. In Canada, in their lifetime, an estimated one in nine will have developed the disease by the age of 90 years; one in 30 will die (Canadian Breast Cancer Foundation [CBCF], 2014b, Key statistics section, para. 1–3). The Government of Ontario and several public health organizations have dedicated significant research and financial resources to establishing more effective ways of addressing breast cancer. One of the key ways to address breast cancer has been through the promotion of early detection via screening mammography. However, despite the increased focus and media campaigns promoting mainly the benefits (and not the associated risks) of screening programs, the rate of participation estimated in the Province of Ontario has not reached the hoped-for target participation level of 70%–73%, which was set by Cancer Care Ontario (CCO)'s Ontario Breast Screening Program (OBSP) (Breast Cancer Society of Canada [BCSC], 2014a; CBCF, 2014b; Office of the Auditor General of Ontario, 2012). The reasons for this lower-than-expected rate of participation have been attributed to a variety of barriers identified in several different studies. Some of the identified barriers to screening participation include embarrassment, fear of pain, underlying health, lack of access to services, language barriers, lack of knowledge, cultural beliefs, and the unhelpful attitudes of health professionals (Vigod, 2011; Welch, 2004). Of these identified barriers many studies have concentrated on how fear of pain, embarrassment, and lack of access to services have impacted breast screening participation rates.

Other studies addressing breast screening have focused on considerations of the associated risks of screening mammography. Studies conducted by Baines (2005), Brouwers et al. (2011), Elmore and Fletcher (2012), and Nelson and Hagedorn (2011) have looked at issues of (a) *false-positive*, (b) *false-negative*, (c) radiation exposure associated with screening, and (iv) *overdiagnosis*. However, Bleyer and Welch (2012), de Gelder et al. (2011), Duffy et al. (2010b), Elmore and Fletcher (2012), Hellquist, Duffy, Nyström, and Jonsson (2012), Jørgensen and Gøtzsche (2009), Kopans, Smith, and Duffy (2011), McPherson (2010), Welch and Black (2010), and Welch, Schwartz, and Woloshin (2011) focused their respective studies on overdiagnosis in breast screening. These above-mentioned studies and others contribute to existing literature about breast cancer screening, and established context for the specific aspect of mammography screening that was examined in this study.

This study addressed a gap in current literature relating to breast cancer overdiagnosis in Ontario, Canada. Welch et al. (2011) defined overdiagnosis as occurring "when individuals are diagnosed with conditions that will never cause symptoms or death" (p. xiv). Welch et al. further indicated the need for more research that definitively looks at how breast screening programs are impacted by a lack of knowledge of overdiagnosis and by mass media. From the perspective of mass media/ media communications, Favaro (2012) noted that current health communications continue to present unbalanced information about screening. Hersch et al. (2013) emphasized that "great care is needed in communicating this [new] information [about overdiagnosis] as it may influence screening and treatment decisions in unintended ways" (p. 10); Based on

breast cancer statistics in Ontario, Canada and the comments and recommendations from Bleyer and Welch (2012), Favaro (2012), Hersch et al. (2013), Welch and Black (2010), Welch et al. (2011), among others, this research placed emphasis on examining whether knowing about overdiganosis related to breast cancer screening decision-making.

Within the context of Canada, a study by Coldman and Phillips (2013) examined the Province of British Columbia (BC), and estimated the rate of overdiagnosis for breast cancer in women over the age of 60 years at 5.4% for invasive diseases and 17.3% for both invasive diseases and ductal carcinoma in situ (p. E492). However, the literature review for this study did not identify any Ontario-specific data outlining the rate of overdiagnosis in the province. Additionally, no prior studies were found that examined the relationship between documented levels of screening participation and a knowledge of overdiagnosis. To my knowledge, this study was designed as the first that examined this topic in Ontario. It is also the first of its kind to combine schema theory with the effective health communication model to create a new approach for presenting information about breast cancer screening programs and the associated risk of overdiagnosis.

This study was designed to promote positive social change by making future screening participants better-equipped to make informed decisions about participating in screening programs. It specifically responds to the lack of Ontario-specific data on the correlation between overdiagnosis and screening participation. It also facilitates greater understating of how a combined understanding of schema theory and the effective health communication model helps in efficient delivery of information about overdiagnosis. It

will inform screening participants by providing access to comprehensive information on both the benefits and risks of screening mammography. Another predicted positive social change implication is that policy-makers and public health care providers will be able to improve the screening process by creating more comprehensive patient screening. It promotes improvements in screening processes by identifying the best practice strategic tools to track, assess, and enhance the quality and quantity of screening service delivered. In addition, this study lays the groundwork for a critical assessment and consideration of whether the current aggressive (Favaro, 2012, para. 10) and unbalanced promotion of breast cancer screening, as being predominantly beneficial, has a relationship to the reported increase in the rates of screening mammography participation. With a more accurate overview of the rates of screening participation, the Government of Ontario will be better able to establish policies that can address how information is presented about breast screening programs.

The primary research question therefore asked: Is there a relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years? The working hypothesis tested by the study was that the more knowledge a woman has regarding the screening process, the more likely she is to participate in breast cancer screening. To answer the research questions and hypotheses, primary data were collected from a sample of 41 female participants (focus group/cohort, $n = 41$) who collectively listened to a brief presentation on breast cancer screening and its various implications, and then were administered a 45-item survey instrument. The first section of the survey instrument consisted of seven closed-ended

ordered-category items intended to gather preliminary background (contextual) information. This background information served the purpose of identifying/establishing relevant context for the interpretation of the primary data collected. The final section of the survey instrument had 38-items that were 5-point closed-ended Likert-format questions. This section incorporated three of the eight Champion Health Belief Model Scales (CHBMS) developed by Champion (1999), and two new scales created specifically for this study. Each question required responses that ranged from *strongly disagree* to *strongly agree*.

The three Champion scales measured each participant's knowledge of breast cancer screening, its associated benefits and risks, and considerations of what motivates health-related decision-making. The supplementary scales addressed each participant's knowledge of overdiagnosis and their respective opinions on how information related to breast cancer screening was presented. The complete survey instrument had five major scales that respectively addressed:

- *health motivation*, consisting of a preexisting seven-item scale and a one-item scale created for this study (eight items total)
- *benefits–mammogram*, consisting of a six-item scale,
- *barriers–mammogram*, consisting of a five-item scale from the final revised health belief model (HBM) scale and six of Champion's confirmatory factor loading for scale items (eleven items total)
- *knowledge of overdiagnosis*, consisting of a five-item scale, and
- *information presentation*, consisting of an eight-item scale.

The survey instrument is detailed in Appendix A.

Champion (1999) established the reliability of each individual scale on the eight-scale Health Belief Model (HBM) survey (see Appendix B). This enables other researchers to selectively eliminate scales in the HBM survey once it is established that the removed scales are not relevant to the study being undertaken, as was the case with this study. Each included scale was evaluated and deemed relevant because they directly addressed considerations of perceived positive and negative implications of breast cancer screening. Those scales also facilitated an assessment of the motivating factors in health-related decision-making. For those selected scales, adequate reliability was maintained.

The remaining sections for this chapter discuss the study's background, problem statement, theoretical framework, purpose of the study, research question, research method, nature of the study, and definition of terms. It also details the assumptions made, the limitations, scope, and delimitations of the study. The significance of the study is discussed and summary statements are given. Overall, this chapter offers specific details about key concepts related to breast cancer. As well, it provides a brief summary of breast cancer and screening mammography in the context of Ontario, Canada. The chapter further presents an overview of relevant information pertaining to how this research was structured and conducted.

Background

At the time of the study, breast cancer was the second-highest cause of death among women in Canada. In 2014, it was projected that almost 24,400 women would to be diagnosed with the breast cancer and that roughly 5,000 members of the diagnosed

population would die from the disease. This represents an estimated 14 deaths out of every 67 Canadian women diagnosed each day. The estimated cases of breast cancer among Canadian men were noted to be 60 deaths from an estimated 210 diagnosed (BCSC, 2014a; CBCF, 2014b; CCO, 2014a; Canadian Cancer Society [CCS], 2014c). To deal with this issue of breast cancer, screening mammography programs were introduced in the 1988 by the Government of Canada (Canada. Parliament, 2013). The identified improvements in the rate of survival and the rate of mortality (measured in five-year increments) have indicated that screening and early detection programs are somewhat effective in identifying cancers at earlier stages (CBCF, 2014a). Early detection enables the use of less invasive treatment options; however, this detection has also raised the recorded incidence rate of breast cancer in Canada since the 1980s.

Several studies have noted a variety of risks associated with screening mammographies (Brouwers et al., 2011; Coldman & Phillips, 2013; Elmore & Fletcher, 2012). These risks include false-positive, false-negative, radiation exposure, and overdiagnosis. This study focuses on the risk of overdiagnosis. The issue of overdiagnosis is not a new concept in relation to cancer. As noted by Welch et al. (2011) overdiagnosis gained popularity in the context of prostate cancer screening in men aged 50 years and older. In more recent years it has been the focus of many studies (e.g. Bellenir, 2009; Brouwers et al., 2011; de Gelder et al., 2011; Duffy & Parmar, 2013) that address the issue of breast cancer and screening mammography participation.

Several other studies on breast cancer screening programs have evaluated how risk factors increase the potential for breast cancer. Previously examined risk factors

include personal history, smoking habits, family history, ancestry, obesity postmenopause, and lack of physical activity. Many recent studies have also compared breast cancer risk factors and the observed incidence rate of breast cancer (CBCF, 2014a). Others have chosen to address breast cancer screening, not in relation to the rate of incidence, but rather with a focus on the issue of overdiagnosis (Bellenir, 2009; Brouwers et al., 2011; de Gelder et al., 2011; Duffy & Parmar, 2013; Giordano, Webster, Segan, & Austoker, 2006; Gøtzsche, Hartling, Nielsen, Brodersen, & Jørgensen, 2009; Hersch et al., 2013; Jørgensen & Gøtzsche, 2009; McPherson, 2010; Welch et al., 2011). More recently, Bleyer and Welch (2012) found that in the United States of America (U.S.) one in three women with breast cancer had been overdiagnosed. Elmore and Fletcher (2012), Nelson and Hagedorn (2011), and Welch and Black (2010) separately claimed that there is a lack of knowledge about how screening participation levels are impacted when emphasis is placed on overdiagnosis as a consequence of breast screening. Many of the above-mentioned studies focused on overdiagnosis used randomized clinical trials (RCT) and/or lead-time approach research design to examine the rate of overdiagnosis in a given population.

There is very limited information or research conducted on the issue of breast cancer overdiagnosis in the specific geographic context of Ontario. As a result, the impact of this overdiagnosis on the current rate of participation is unknown. However, prior to any examination of a cause and effect relationship between the two study variables, knowledge of overdiagnosis and the decision to participate in breast cancer screening, it was vital that this research first determine the existence of a relationship

between the variables within the context of Ontario. Post data collection, if the study's findings indicate that a relationship exists between the study variables further examination of the cause-effect relationship is merited.

Problem Statement

The Office of the Auditor General of Ontario's (2012) annual report stated that "[breast cancer] screening programs are effective if they reach a sizeable percentage of the target population" (p. 50). A three-year participation target range of 90% to 95% was set in 2003. However, after further assessment, the same office decided to reach this goal via incremental screening mammogram target increases from 66% in 2009 to 73% in 2013/2014 (Office of the Auditor General of Ontario, 2012, p. 50). This participation target range was then further narrowed to focus on females aged 50 years and older, as current statistics (on the incidence of breast cancer, rate of mortality, and rate of survival for Canadian women) identified this age group as requiring particular emphasis. The CBCF (2014b) specifically noted that 82% of the identified cases of breast cancers in the country are found in Canadian females over age 50 years.

The CCO (2014a) also noted that there was no family history of breast cancer for a majority of women identified with the disease, and since there is currently no way to stop breast cancer, if the disease is found earlier the chances for a cure increases. In Ontario, for 2014, about 9,500 women were predicted to develop breast cancer, with almost 1,950 predicted to die from the disease (see Table 1; CBCF, 2014b; CCO, 2014a; CCS, Statistics Canada, Public Health Agency of Canada, & Provincial/Territorial Cancer Registries, 2014). According to the CCO (2011b), CCS (2014b) and the Canadian

Task Force on Preventive Health Care [CTFPHC] (2014), out of every roughly 1,000 women screened aged 50–69 years, 36 (3.60%) would have an unnecessary breast biopsy, and approximately 283 (28.30%) would have a false positive mammography. CTFPHC (2014) indicated that, for each identified case of false positive, the effects on these (overdiagnosed) screened women were "unnecessary anxiety and follow-up testing" (CTFPHC, 2014, "To save one life," p. 1). For every 1,000 women screened, CTFPHC also noted that 5 will undergo unnecessary surgery for breast cancer ("For every 1000 women," p. 1). However, despite (a) the approximately $92 million Canadian dollars spent on screening programs during the 2011/2012 fiscal year (Office of the Auditor General of Ontario, 2012, p. 14), and (b) the robust health care media communication campaign promoting the CCO's Ontario Breast Screening Program [OBSP]—rationalized by the statement breast "cancer screening saves lives" (Ontario Ministry of Health and Long-Term Care [MHLTC], 2014, para. 1)—the information presented by such organizations as CCO, CCS, CBCF and CBCS have not adequately offered a balanced perspective that outlines the benefits as well as any associated risks of screening mammography.

This study was designed to determine the correlation between the variables, knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years. The findings are expected to inform the Government of Ontario in creating more balanced health communication strategies and campaign content for the province's breast screening program. This cross-sectional, correlational (nonexperimental, quantitative) study sought to address the following research question:

Is there a relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years?

Theoretical Framework

The theoretical framework for this study was based on schema theory and the effective health communication model. Grounded in Bandura's (1977) social cognitive theory, schema theory argues that the human mind is organized by a series of schemas that classify and interpret information to create a general picture of how that individual understands specific topics. This picture created is a cognitive construct and a consequence of that individual's use of all the information present and the associations from that present information. According to schema theory, persons use schemata (scripts) to group current information/knowledge and provide a framework for future understanding (Erasmus, Boshoff, & Rousseau, 2002). According to Rumelhart (as cited in Sabella 1999):

> Schemas are the fundamental elements upon which information processing depends. Schema[s] are employed in the process of interpreting sensory data . . .in retrieving information from memory, in organizing actions, in determining goals . . .in allocating resources, and generally in guiding the flow of processing in the system. (p. 8)

Rumelhart further described a schema as a data structure where general ideas are retained in memory. In other words, schemas represent knowledge about "objects, situations, event, sequences of events, actions, and sequences of actions" (as cited in Sabella, 1999, p. 8). The process of an individual's schema is illustrated in Figure 1.

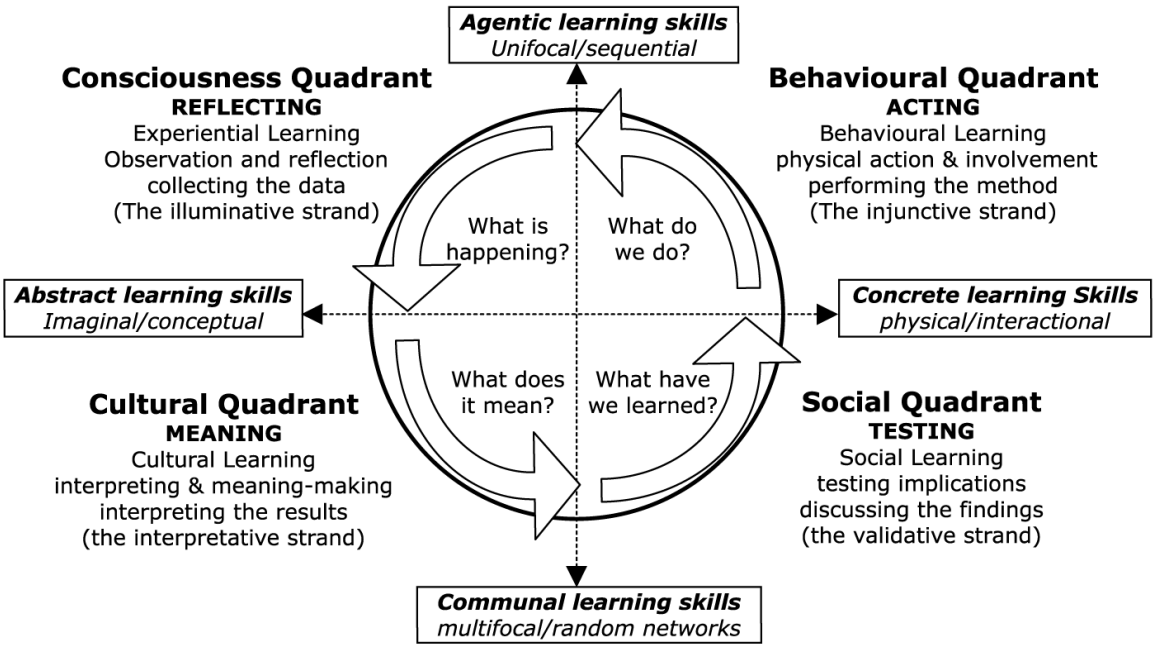

Figure 1. A diagram depicting the integral learning cycle. Each quadrant within the circle represents the four stages of learning. Starting anticlockwise each stage/quadrant addresses in sequential order: What is happening? What does it mean? What have we learned? What do we do? Adapted from "The integral learning cycle and the map," by C Dierkes, 2009, May 23, [Web log post] Retrieved from http://indistinctunion.wordpress.com/category/integral/. Copyright 2009 by Chris Dierkes.

Schema theory was used in the following studies: Anderson and Pichert (1978), Brewer and Treyens (1981), Gara et al. (1993), Georgeon and Ritter (2012), Markus (1977), Nishida (1999), and Onorato and Turner (2004). Each study addressed issues of knowledge and the interpretation of knowledge in relation to cultural learning, social learning, behavioral learning, and experiential learning (see Figure 1). Although not specifically related to this study's focus on knowledge of overdiagnosis, the information presented in each research nevertheless offered relevant insights (about how

information/knowledge is processed and applied on an individual level) that are applicable to this study.

For this study, Giordano et al.'s (2006) effective health communication model was used to support schema theory. According Giordano et al., for effective communication, "health professionals must provide individuals with such information that will allow them to 'knowledgeably' decide whether or not to undergo an intervention, taking into consideration available alternatives, potential risks and foreseeable outcomes" (p. 382). More specifically, Giordano et al. indicated that "appropriate information in suitable formats should be available and accessible to all women who would benefit from breast screening" (p. 384). Giordano et al. further mentioned that:

> Women obtain breast cancer information from a variety of sources, among which health professionals are one of the obvious. The health professionals play a central role in the provision of information. . . .[Therefore] it is important that these people [health professionals] acquire comprehensive knowledge needed to inform women about the pros and cons of screening. (p. 384)

This problem of effective communication in health-related matters (as noted by Giordano et al. 2006) was also addressed by researchers Glanz, Rimer, and Viswanath (2008), Kreuter and Wray (2003), Politi, Han, and Col (2007), and Stewart (1995). Although all these above-mentioned studies did not directly address health issues related to breast cancer, they each demonstrated the significance of considerations such as "physician-patient communication mak[ing] a significant difference to patient health outcomes"

(Stewart, 1995, p. 1429). Politi et al., (2007) specifically noted that care was needed in communicating uncertainties of the harms and benefits of medical interventions (similar to the medical intervention of screening mammography that is addressed in this study).

Within the context of screening mammograms, this study's focus was on understanding the correlation between knowledge of overdiagnosis and decisions about screening participation. As the issue of "overdiagnosis will be new and counterintuitive for many people and may influence screening and treatment decisions in unintended ways, [it underscores] the need for careful communication" (Hersch et al., 2013, p. 1). Therefore, it was relevant for this study that schema theory be used in conjunction with Giordano et al.'s (2006) effective health communication model. Both acted as a guide to understanding not only how individuals interpreted and understood new information in the context of their reality, but also to the consideration that care should be taken in how this new information was presented. With an understanding of both schema theory and the effective health communication model the Government of Ontario, public health policy makers, and other health care providers will be better-equipped to establish screening information guidelines. This can then facilitate a balanced (benefits and risks, including overdiagnosis) approach to how information is presented about screening mammography. This, by extension, also allows participants to make more informed decisions on whether or not to participate in screening. It may also possibly limit negative impacts to screening participation levels.

Further details about schema theory and the effective health communication model are outlined in Chapter 2. This outlined information helped to establish and

contextualize the topic being investigated. Both schema theory and the effective health communication model allowed for an understanding of how theoretical suggestions can offer strategies for real-life social (societal) application. Furthermore, this information will enable readers of this study to learn the connections among (a) notions of cognitive learning (understanding); (b) environmental (social) factors that influence such learning; (c) the development of appropriate solutions (for this public policy-related research question); and (d) implementation methods for those identified solutions.

Purpose of the Study

The objective/purpose of this quantitative study was to determine if there is a relationship (correlation) between knowledge of overdiagnosis (independent variable) and the decision to participate in breast cancer screening (dependent variable) among women aged 50–69 years. This information can be used (by the Government of Ontario, public health policy administrators, public health care providers, people who are at risk of developing breast cancer, individuals deciding whether or not to participate in breast screening programs, and others) to understand the potential consequences of overdiagnosis in screening mammography.

Research Question

This research sought to investigate among women aged 50–69 years if there exists a relationship between knowledge of overdiagnosis and decisions about participating in screening mammography. The primary research question asked: Is there a relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years? Secondary research questions examined

whether relationships exist between thoughts and attitudes on subsections of the survey (such as mammogram barriers) and decision to participate in breast cancer screening. To answer the research question, this study used a cross-sectional, correlational (nonexperimental, quantitative) survey research design (Black, 2012; Salkind, 2010). The nonexperimental approach was selected because this study used existing records (secondary data) to establish the relevance of conducting this exploratory research (as is outlined throughout this study). However, a Likert-format survey instrument (questionnaires) distributed to a specified group/cohort (within the target population) was ultimately used as the means of determining how the independent variable correlated with the dependent variable.

In this study, the independent variable being examined could not be manipulated, but rather was explored to determine the nature of the relationship between the variables investigated. Knowledge of overdiagnosis was examined in relation to decision-making about whether to participate in screening mammography. Logistic regression was used to explore whether a correlation exists between knowledge of overdiagnosis and screening decision-making. This method of analysis was appropriate because this type of regression analysis is used for predicting a categorical dependent variable—specifically for questions where the dependent variable is binary; that is, the number of available categories is two—based on one or more continuous, independent variables (Black, 2012).

Research Method

Knowledge of overdiagnosis among women aged 50–69 years was assessed with the use of a modified CHBMS (Likert-format) survey. It was also assessed by calculating a total score for this survey, wherein a higher score is indicative of women's thoughts and attitudes being more positive towards breast cancer screening. The study's sample consisted of 41 women aged 50–69 years, who live in the Greater Toronto Area (GTA) in the Province of Ontario, and who can read and write in English. Because current literature did not outline the number of women living in the GTA who were between the ages of 50 to 69 years, the nonprobability strategy was used to determine sample size. As well, there was no single list in the GTA that contained the names or contact information for the sample population. Therefore, finding the accessible population required to have the sample size be generalizable to the target population, was a major challenge. I gained all the necessary preliminary approvals from the Institutional Review Board (IRB) of Walden University prior to commencing the survey and data gathering stage. This was done to ensure that all ethical considerations were appropriately addressed. The study's community partner Tropicana Community Services (TCS) was required to provide a signed letter of cooperation for the data collection process (see Appendix C). Informed consent was implied (see Appendix D) by each participant who returned a completed survey form to me.

The final modified CHBMS (Likert-format) survey used in the study was relatively straight forward to determine as the remaining five scales not selected focused on concerns of (a) susceptibility to breast cancer, (b) perceived seriousness of life style

implications given a positive diagnosed of breast cancer, (c) the benefits of breast self-examinations (BSE), (d) the barriers BSE, and (e) the levels of confidence to conducting BSE. Although all the above are important in the context of understanding an individual's overall knowledge and perception of breast cancer screening, those particular scale items were not directly pertinent to this study. Additionally, although the use of the complete CHBMS would have produced smaller intervals of confidence, the feasibility of getting 41 participants to spend the time required to complete a 53 scale item survey supplemented with another 28-items—that included questions related to their background, knowledge of overdiagnosis, and perceptions of how information on breast cancer screening is presented—could have caused participants to lose interest and/or focus.

As outlined by TCS (2014) a wide variety of programs and services are administered "to provide (GTA) community members with opportunities and alternatives that lead to success and positive life choices" (TCS, 2014, What we do section, para. 1). For these reasons and others I strongly believed a partnership with TCS enhanced the chances of creating and executing on a quality and ethically sound study. With the assistance of TCS, women in the organization's network were contacted via email, the organization's community notice boards, and telephoned to request their participation in the study's survey. Prior to the collection of data, a pilot study was conducted to verify the validity and reliability of the entire survey instrument. More specifically, the pilot test was used to confirm the validity and reliability of the two supplementary scales I created. However, Cronbach's alpha (α) was not calculated given the small number of pilot test

participants (five), but face validity of the survey instrument was confirmed as pilot participants felt the survey covered the concepts it purported to measure.

A similar recruiting and sampling process was used for the pilot test and the actual study survey. In practical terms, this meant that the pilot study included (a) the same letter of invitation; (b) a reminder email outlining the date, time, location, and thank you gifting post survey completion; (c) the same presentation—I presented during the actual survey—about breast cancer screening and its associated benefits and risks, including overdiagnosis; (d) an opportunity for pilot participants to seek clarification, if needed, prior to completing the survey; and (e) distribution of the group administered survey. A copy of the survey instrument that was pilot tested and the informed consent form can be seen in Appendix A and D. Unlike the actual study, the pilot study was (a) not conducted at the TCS facilities, but rather a different location that much like the TCS' facility was at no cost to me and easily accessible for the pilot participants; and (b) conducted on a smaller scale because fewer participants are generally needed for pilot studies. Five participants were used for the pilot test and no revisions were required based on pilot participant feedback. The information collected from these five participants' surveys was not included in the actual study.

Nature of the Study

As mentioned by Geddes (1990), until the research findings indicate the existence of a correlation, one will not be assumed (p. 133). Therefore, because there was no specific research in Ontario indicating the existence of a relationship between the dependent and independent variables, the nature of this research was an exploratory

study. This cross-sectional, correlational (nonexperimental, quantitative) study sought to determine the relationship between two quantitatively represented variables based on data collected using a group administered, close-ended Likert-format survey questionnaire (nonexperimental), among a specified group (cohort–women 50–69 years) (Black, 2012; Creswell, 2009; Frankfort-Nachmias & Nachmias, 2008). Because this study was examining the relationship (correlation) between two quantitatively represented variables, the research method and design were appropriate for the research problem. As indicated by Black (2012), correlational research refers to quantitative approaches that investigate relationships as pairs of variables to see how they vary in relation to each other. This type of research does not offer answers to establish causality (cause-effect), but does provide "a rationale for more structured experimental or quasi-experimental studies when population parameters are known" (p.46), as was the case for this study.

As an exploratory study the results of this research (independent of additional studies using larger sample sizes) has limited usefulness for decision-making by themselves. However, the results of exploratory studies can provide significant insight into a given situation. As well, such studies (like this one) aid in gathering preliminary information that can be used to assist in the definition of problems and the positing of hypotheses (p.51). For Vogt (2007) the levels of measurement for the study's dependent variable, decision to participate in breast cancer screening, were nominal (categorical) because it had two or more categories without having an intrinsic order. It was also dichotomous (binary) because the variable had only two categories or levels: participate or not participate. Vogt (2007) noted that nominal variables "must be exhaustive (not

leaving anything out) and mutually exclusive (each person or things is only categorized in one way)" (p. 9). The study's independent variable, knowledge of overdiagnosis, was an interval level of measurement. It was classified as an interval level variable because there is an increasing score (by units of 1) and a higher score represents women's thoughts and attitudes towards breast cancer screening being more positive (p. 10). The study's target population was limited to women living in Ontario's GTA, particularly those who understand (read and write in) English.

One benefit of this research method and research design—cross-sectional, correlational survey (nonexperimental, quantitative) that included the use of a survey instrument given to a focus group/cohort of female participants—was that a smaller sample population was used based on time and cost constraints. On the other hand, this resulted in a lower probability for more comprehensive generalizations that were reflective of the general Ontario population from which the sample was derived. With a lower probability for comprehensive generalizations, the external validity of the study's findings therefore decreased. However, other value adds to this research method and design were that it facilitated the generation of hypotheses tested post the collection of data, and the testing and reaffirmation of any existing theories about the phenomenon examined. Other benefits to this research method and design were that because of the numerical nature of the data collected, there was a greater opportunity for limited-scope predictions from the information gathered.

Additionally, because this research was examining a correlation relationship, it enabled the establishment of control variables/parameters to better determine what that

correlation was. Consequently, this increased the study's internal validity through the reduction of confounding factors. This research design and method also provided enhanced reliability and validity of the results because the data were largely based on first-hand collected and verified quality data (Lapan & Quartaroli, 2009, p. 60). The research design was ideal for this study as it facilitated the discovery of functional correlations or causal relationships among variables. It was also advantageous because subjects could not be randomly assigned to the level of independent variable—rather, they assigned themselves. As such, this research was better able to focus on the noted effect/phenomenon and, through this, attempted to determine what caused the observed effect (as is the case of this research) (Christensen, 2010).

In discussions of research design strategies Patton (2002) noted that there are critical trade-offs due to limitations of time, resource, and the human ability to understand complex social realities. Hence, "there are no perfect research designs" (p. 223). As the above notion relates to this research, considerations of time constraints, finance, research generalizability, validity and reliability were used to determine what would be the optimal sampling strategy. To this end, purposive sampling (nonprobability sampling, rather than probability sampling) was the more practical and appropriate choice. Patton (2002) also stated that in purposeful (purposive) sampling "cases for study are selected because they are information rich and illuminative, that is, they offer useful manifestations of the phenomenon of interest; Sampling is . . .aimed at insight . . .not empirical generalizations" (pp. 40; 243). Of the various nonprobability sampling options, purposive sampling was implemented as it offered the opportunity to focus on the target

population even though it was not possible to statistically specify this population—as they were not known, and access was difficult.

Probability sampling—stratified random sampling—was initially considered for this research to ensure participants would be randomly selected but targeted to the group of interest, thereby increasing the external reliability. However, as the study was aimed at exploring the phenomenon being investigated (and not focused on making generalization), use of nonprobability purposeful sampling better facilitated the selection of participants—from the list of women contacted by TCS—for this research. This approach allowed the study's specified interest group (all GTA Ontario women aged 50–69 years who are eligible for screening mammography—participants and nonparticipants) a higher probability of being selected (Patton, 2002; Salkind, 2010). Using Cronbach's alpha statistics, the data collected were then assessed for consistency. This then permitted the creation of a total survey score (sum of individual questions) to serve as a single measure representing a women's thoughts and attitudes towards breast cancer screening.

Two sample 2-sided *t* tests were used to compare the mean total survey scores between those who had participated in breast cancer screening and those who did not. Survey scores on subsections (such as mammogram barriers) were similarly compared between the two groups. Using a logistic regression model, the relationship between the outcome (breast cancer screening) and total survey score was assessed. This logistic regression model adjusted for the respondents' education level completed. Results were displayed as odds rations with their associated 95% confidence intervals. Similar logistic regression models were conducted on the total scores for survey subsections.

Given the unique nature of the population, it was uncertain how many females fell into the study criteria inclusion category. Thus, power analysis could not be used to determine sample size. The basis of sample size for this study was as a result of recommendations found in the research of Baumgartner, Strong, and Hensley (2002) who recommended between 8–12 participants and Johnson and Christensen (2004) who contended a group of 6–12 participants was appropriate. Because presentations at TCS generally had 40–60 participants, I opted to incorporate a sample of 41 participants. Using the Statistical Package of the Social Sciences (SPSS software), I analyzed and checked for missing data.

The intent of this study's finding is to assist Ontario public health care policy makers' understand that (a) a balanced presentation of information about screening mammograms (benefits and risks) will facilitate potential participants to make more informed decisions about getting screened; and (b) this balanced presentation of information and the subsequent informed decisions made, will not have adverse/negative consequences to the currently documented rate of participation for screening mammography. Ultimately, the cross-sectional, correlational (quantitative, nonexperimental) survey research design was beneficial as it served the main research purpose. The research purpose was to enable the initial identification of possible associations that need further investigation. The research design also allowed for predication from one variable to the next. The detailed discussions concerning methodologies are discussed in Chapter 3.

Definition of Terms

The relevant concepts related to breast cancer screening and its associated risks which will be encountered throughout this study are as follows:

Benign: "Not cancerous. Benign tumors may grow larger but do not spread to other parts of the body. Also called nonmalignant" (National Cancer Institute [NCI], 2014b, Benign section, para. 1).

Biopsy: "The removal of cells or tissues for examination by a pathologist" (NCI, 2014b, Biopsy section, para. 1).

Breast density: Relates to "the relative amount of different tissues present in the breast" (NCI, 2014a, Breast density section, para. 1).

Breast cancer: Cancer originating in the breast, whether (a) in the line of a breast duct (ductal carcinoma) or (b) in a lobule of the breast (lobular carcinoma) (NCI, 2014e).

Breast lobe: "A section of the breast that contains the lobules (the glands that make milk)" (NCI, 2014b, Breast lobe section, para. 1).

Cancer: A disease caused by changes in normal cells that grow uncontrollably and therefore causes a lump (tumor) to form (NCI, 2014b).

Diagnostic mammogram: "X-ray of the breasts used to check for breast cancer after a lump or other sign or symptom of breast cancer has been found" (NCI, 2014a, Diagnostic mammogram section, para. 1).

Duct: "In medicine, a tube or vessel of the body through which fluid pass" (NCI, 2014b, Duct section, para. 1).

Effective health communication: The strategic dissemination and critical evaluation of—honest, adequate, evidence-based, accessible, unbiased, respectful, relevant, accurate, and understandable—health information that is communicated to and from intended audiences. In effective health communication, adequate consideration must therefore be given to each individual's specific needs, and differences in values and beliefs (Giordano et al., 2006).

False-negative: "A test result that indicates that a person does not have a specific disease or condition when the person actually does have the disease or condition" (NCI, 2014b, False-negative test result section, para. 1).

False-positive: "A test result that indicates that a person has a specific disease or condition when the person actually does not have the disease or condition" (NCI, 2014b, False-positive test result section, para. 1).

Knowledge: "The fact or condition of knowing something with familiarity gained through experience or association; Acquaintance with or understanding of a science, art, or technique; The fact or condition of being aware of something" (Merriam-Webster's Online Dictionary, 2014a, para. 2–3).

Knowledge of overdiagnosis: Refers to indicators that an individual is familiar with (has an association/experience/acquaintance with) or understanding that, by participating in screening mammography, there is the possibility that a nonprogressive cancer and/or slow-growing cancer that is identified correctly would never cause symptoms or death during the lifetime of that diagnosed patient. Using a modified

version of the CHBMS augmented by two research-specific survey scales, this concept of knowledge of overdiagnosis was evaluated (Champion, 1993; 1999).

Lead-time approach: Research that involves a calculation of "the percentage of overdiagnosis by comparing incidence in the current screening group with incidence among women…[x] years older in the historical screening group, accounting for average lead-time" (Kalager, Adami, Bretthauer, & Tamimi, 2012, p.491).

Lifetime risk: "A measure of the risk that a certain event will happen during a person's lifetime; The likelihood that a person . . .free of a certain type of cancer will develop or die from that type of cancer during his or her lifetime" (NCI, 2014b, Lifetime risk section, para. 1).

Lobe: "A portion of an organ, such as the liver, lung, breast, thyroid, or brain" (NCI, 2014b, Lobe section, para. 1).

Malignant: "Cancerous. Malignant cells can invade and destroy nearby tissue and spread to other parts of the body" (NCI, 2014b, Malignant section, para. 1).

Magnetic resonance imaging (MRI): "A strong magnet linked to a computer…used to make detailed pictures of [the] chest, abdomen, or brain. An MRI can show [if a] cancer has spread to these [above-mentioned] areas" (U.S. Department of Health and Human Services, National Cancer Institute, 2012, p. 6).

Mammography: "The use of film or a computer to create a picture [x-ray] of the breast" (NCI, 2014b, Mammography section, para. 1).

Metastasis: The spread of the cancer, as related to time of discovery, diagnosis, progress, and treatment, with some cancers metastasizing at a slower rate than others (NCI, 2014b).

Mortality: The number of deaths caused by cancer over a specific timeframe (NCI, 2014b).

Overdiagnosis: Cancers that may never cause any symptoms or decreased life expectancy or quality of life. In other words, it is the identification of a nonprogressive cancer and/or slow-growing cancer that is identified correctly, but "the disease would never cause symptoms or death during the lifetime [of the diagnosed patient]" (Welch et al., 2011, p. xiv-xv).

Participate: "To take part in or experience something along with others" (Merriam-Webster's Online Dictionary, 2014b, Partake section, para. 1).

Prognosis: "The likely outcome or course of a disease. The chance of recovery or recurrence" (NCI, 2013a, Prognosis section, para. 1).

Randomized clinical trials (RCT): "A study in which the participants are assigned by chance to separate groups that compare different treatments; neither the researchers nor the participants can choose which group. Using chance to assign people to groups means that the groups will be similar and that the treatments they receive can be compared objectively. At the time of the trial, it is not known which treatment is best. It is the patient's choice to be in a randomized trial" (NCI, 2014a, Randomized clinical trial section, para.1).

Risk factors: "Something that increases the chance of developing a disease" (NCI, 2014a, Risk factor section, para. 1).

Schema theory: Describes the cognitive structure of how an individual acquires, processes, and organizes knowledge (Erasmus et al., 2002).

Screening mammography: "X-rays of the breasts taken to check for breast cancer in the absence of signs or symptoms" (NCI, 2014a, Screening mammogram section, para. 1).

Tumor: Abnormal cells that combine to create a lump. Tumors can be either cancerous (malignant) or noncancerous (benign) (NCI, 2014b).

Assumptions, Limitations, Scope, and Delimitations

In the section immediately following, the parameters used to determine the assumptions, scope, limitations, and delimitations of this research are addressed. Each item outlined establishes the rationale for the selected research method and design. Also clearly highlighted are the various considerations entailed in the development and execution of an accurate, reliable, valid and ethically sound study.

Assumptions

In this research, it was critical to identify a community partner that was a credible source and that would facilitate data collection focused on determining (a) the relationships of knowledge of breast cancer, (b) the benefits and risks (including overdiagnosis) of breast cancer screening, (c) decisions related to screening mammography participation, and (d) the perceptions of how information is presented as it relates to breast cancer screening. With these above-noted assumptions in mind, salient

findings were made about the nature of the relationship between the two study variables. Specifically, the study's results assisted in the identification of a potential predictive relationship between the variables examined. The identification of the possibly predictive correlation with the variables establishes the need for further exploration of this research topic. In particular, further study should be conducted to identify guidelines for efficacy in the presentation of (balanced) information about overdiagnosis in breast cancer screening. These identified guidelines would be advantageous in the event future research findings on breast cancer screening suggest there are other seemingly negative outcomes from screening participants.

This study also assumed that the key population of analysis consisted of women aged 50–69 years who (a) can read and write in English, and (b) live in the GTA of Ontario (regardless of whether or not they had previously participated in breast screening). More assumptions were that knowledge of the associated risks and benefits of breast cancer screening, including overdiagnosis correlated well with decisions on whether or not to participate in screening mammography. It was assumed that correlations of benefits, barriers, and health motivations for women (eligible for breast screening) living in the GTA of Ontario were similar to Champion's (1999) findings that established the revised CHMBS. Finally, it was assumed that any missing and/or excluded information in the analysis of the secondary data (during the review of literature) that would have impacted trends and conclusions were clearly indicated. All the above outlined assumptions were relevant for this study because they enabled me to

better understand how to accurately account and adjust for any unexpected findings (anomalies) in the data set collected.

Limitations

This research used a group administered, closed-ended 5-point Likert-format survey questionnaire to collect primary data. Based on this approach one limitation of the study was not being able to provide comprehensive confirmation that all participants had the potentially same/similar level of access to the various communication media (channels) through which screening mammography is promoted and accessed. Because the study's intent laid in determining the correlation between two numerically measured variables—rather than to answer questions concerning cause-effect relationships, best practices, or how to improve breast cancer screening content and/or information presentation—the findings of the study have limited generalizable application. Given survey participants were limited to those contacted by the TCS organization, this geographically specific and small sample restricted the study's ability to draw inferences or conclusions beyond Ontario's GTA. Another limitation of the research related to concerns of participants' available time and their ability to focus over an extended period. Consequently the goal to gain accurate evaluations was balanced with the objective of obtaining larger quantities of participants that would have provided more meaningful and generalizable results. Along the same line of concern for participants' availability and attention span, the number of scales in CHBMS were reduced from eight scales to three. Despite the removal of five of the CHBMS its impact on the study's findings were minimal as the eliminated scales were not directly related to the research topic.

In terms of considerations for reliability, validity, and credibility, other potential limitations specific to this study included (a) the inability to control and/or manipulate the variables being studied, as such attempts would be unrealistic and artificial; (b) concern that this sample population is not a true representation of the general populous; and (c) confounding factors resulting from a variety of biases that may affect the findings. Such biases include selection biases, researcher biases, information misclassification, or information biases as a function of the nature of the research approach (Black, 2012; Lee, 2007; Vogt, 2007). The final limitation was from a sampling perspective. Because purposive sampling (nonprobability strategy) was used—rather than stratified random sampling (probability strategy)—it was not possible to conduct a study that could be considered generalizable to the target population.

Scope

This cross-sectional, correlational (nonexperimental, quantitative) study used a 5-point closed-ended Likert-format survey instrument. This survey instrument was group/cohort administered (see Appendix A) to examine the relationship (correlation) between knowledge of overdiagnosis and decisions to participate in breast cancer screening. This survey instrument was modified from Champion (1999) HBM scale that evaluated the benefits, barriers and health motivations for participations in screening mammography. Validity and reliability for each adopted aspect of Champion's survey instrument—which by extension enabled the exclusion of parts of the survey scale—is further detailed in Chapter 2 and Appendix B. Cronbach's alpha was calculated to assess the reliability of the overall 38 question survey. Cronbach's values of 0.7 or greater are

required for early research (Black, 2012; Nunnally, 1978, p. 245). The Cronbach's alpha value for this survey was 0.79. This showed good consistency and allowed the creation of a summary score for analysis purposes.

Delimitations

This quantitative study used a Likert-format instrument—a group administrated, closed-ended survey questionnaires (Appendix A)—to gather data that examined the relationship between one of each identified independent and dependent variable. As such, there was a potential for confounding factors. This threat to internal validity related to the potential for other unidentified factors being responsible for influencing the dependent variable. Some examples of confounding errors for this type of study include: errors due to history, maturation, instrumentation, selection bias, information biases, and loss to follow-up biases (Salkind, 2010). To address this problem of confounding factors, the study restricted the sample population to English-speaking women aged 50–69 years living in Ontario's GTA who were contacted by TCS. Additionally, a logistic regression analysis was carried out that controlled for the completed educational level of the respondent, thereby adjusting for this potential confounder. Prior to completing this logistic regression analysis, the education level completed variable was made into a binary variable with 2 representing participants who graduated with a bachelor's degree or higher and 1 representing those who graduated with a college diploma/certificate or less.

Relevant to note was that for the internal validity threat of selection bias to have occurred, it meant that the participants retained in the sample population led to results

that were different from what would have been found if the entire target population was used. With regards to information (observation/ misclassification) bias, because the study used primary data, erroneous observations and misclassifications that are inherent in secondary data set was not a major issue. However, to further significantly minimize the small potential for information bias in the primary data, SPSS was used to assess and address such potentials. For loss to follow-up bias to have occurred, it would have meant that this study had initial participants that were not retained for both the independent and dependent variables, thereby increasing the odds that the results were underestimated. This was however not the case for the study given the data were collected via a group administered questionnaire, at the same time, in one setting (cross-sectional research design (Cohort Studies, n.d. “Follow up in cohort,” para. 5).

From the perspective of external validity, because this study did not seek to provide generalizations of the findings across the population of interest (women aged 50–69 years), purposive sampling was used to select participants for the study. This sampling method enabled targeted identification of—Ontario GTA women, who read and write in English, who were contacted by TCS, and who were eligible to participate in screening mammography (participants and nonparticipants)—participants of interest to the study (Patton, 2002). Finally, as it related to issues of content, criterion, and construct (predictive) validity, this study was further able to assess each following the data set collection and analysis, details are outlined in Chapters 3 and 4.

Significance of the Study

This research is significant because it allowed for critical assessment and consideration of how currently aggressive (Favaro, 2012, para. 10) and unbalanced—benefits without much mention of the associated risks—promotion of breast cancer screening have a direct or indirect relationship to the reported increase in rates of breast cancer screening participation. This understanding, in turn, offered some perspective on the efficacy of current breast cancer statistics and the purported successes in cancer treatment as a consequence of screening participation. Another potential benefit was the contribution of this information to objective decision-making on the part of the screening participants. Screening participants would be more informed because they were given a more comprehensive outline of the benefits and risks of the screening process. As such, they can now make informed decisions about screening participation. Finally, it offered an opportunity for the Government of Ontario, in conjunction with the relevant public health policy makers and health care providers, to establish comprehensive criteria of how information related to screening mammography ought to be disseminated to the public and future possible participants.

This research also provides (the Government of Ontario, health care providers, policy makers, and other key stakeholders) a better understanding of the ways that information presented in health care media communication campaigns may or may not positively or negatively impact the rates of participation in publicly-funded breast cancer (and other types of) screening programs. This study was socially significant because it indicates that, in cases where health care media communication campaigns present

balanced and comprehensive (outlining both potential benefits and associated risks) information, there is more efficacy in the rate of participation in public-sector screening services when compared to the current rate of success garnered via the predominant use of the one-sided (and potentially biased) information presentation. As a consequence, this might increase the level of balanced and comprehensive health care media communication campaigns used, and subsequently generate greater rates of success in breast cancer service delivery because participants are presented with all the facts. In addition, this research serves as a (a) litmus test for how participants may react to information presented that clearly outlines risks (such as overdiagnosis), and (b) guide of what communication strategies are to be established and implemented to mitigate against the intuitive reaction of participants to perceived negative information.

Importance for Social Change

From a positive social change perspective, this research identifies and suggests a few more balanced, comprehensive, and effective health care communication guidelines to aid in more transparent present information. This, by extension, creates opportunities for ensuring more accurate reporting (than currently noted) of the rates of success in screening programs. Additionally this study may better equip the Government of Ontario with an understanding and awareness of the concerns and barriers women aged 50–69 years face in accessing a holistic view of the positive and negative potentials of participating in breast cancer screening programs. In turn, this may improve the current rate of success noted. It also may reduce the levels of and potentials for overdiagnosis,

and may help the Ontario government develop awareness campaigns that are ultimately more successful because patients are better informed.

Summary

In this chapter, information necessary for the identification of a gap in knowledge and the justifications of the need for this study were presented in the following sections: introduction; background; problem statement; theoretical framework; purpose of the study; research question; research method; nature of the study; definition of terms; assumptions, limitations, scope, and delimitations; significance of the study; and summary. The chapter specifically presented background information about breast cancer and screening mammography statistics for the Province of Ontario. Also outlined was the need for attention to be paid to females aged 50–69 years who ought to be presented with a balanced overview of the benefits and risks of screening programs, prior to any decision-making about screening participation. Evidence from key researchers in the field of breast cancer and breast cancer screening was provided. The indication was that the issue of overdiagnosis, an associated risk of breast screening, was noted in the U.S. to be one in every three women. The theoretical framework that guided this study was schema theory, along with the support of the effective health communication model. Key definitions of terms were highlighted. A general overview of the rationale for the selected research design—quantitative, nonexperimental study—was outlined. Mention was made of the logistic regression and correlation coefficient statistical tests selected to analyze the data collected.

The coming chapter provides a discussion of the examined literature relevant to the importance of knowledge of overdiagnosis and breast screening decision-making. As well, Chapter 2 gives an overview and background of breast cancer and breast cancer data from the Ontario perspective. Further detail is provided on schema theory and the effective health communication model. In Chapter 3, an overview of the research methodology and its rationale, along with the setting and sample, data collection method, data analysis approach, feasibility and appropriateness of the study, validity and reliability, instrumentation, and other relevant information is discussed. Chapter 4 provides a detailed report of the descriptive and inferential statistical tests conducted. Chapter 5 offers an overview of the study, its findings and conclusions, along with recommendations for future research.

Chapter 2: Literature Review

Introduction

The Public Health Agency of Canada [PHAC] (2013; 2014) noted that cancer is the primary cause of death in Canada, and the Canadian Cancer Society (CCS) specified that of all deaths in Canada, 30% were from cancer (CCS, 2014b). The PHAC also indicated this trend was expected to continue and increase as the population grew and aged (PHAC, 2013; PHAC, 2014). Statistics reported by the PHAC, the CCS, and other Canadian-affiliated organizations show breast cancer is the second leading cause of death amongst all the types of cancers found in Canadian women. Breast cancer is the most prevalent form of cancer in women in Canada (CCS, 2014b; PHAC, 2014). The Government of Ontario and the Ontario Ministry of Health and Long-Term Care (MHLTC) actively promote breast cancer screening and early detection through regular participation in Cancer Care Ontario (CCO)'s publicly available and funded Ontario Breast Screening Program (OBSP), with an objective of reducing the mortality rate of death by breast cancer (CCO, 2011a; CCO, 2012).

In 2011, the MHLTC acknowledged screening mammography as an effective means of lowering the rate of breast cancer mortality (MHLTC, 2011). The MHLTC also noted that approximately 17 cancers are detected annually in every 1,000 women screened via breast MRI and mammography. According to the MHLTC, breast screening facilitated the detection of more cancers at earlier stages, leading to (a) an increased chance of survival, (b) potentially less invasive treatments being used, and (c) ultimately, improved health outcomes for women (MHLTC, 2011). However, the use of breast

screening mammography introduced issues of false-positive, false-negative, mammography-related radiation exposure, and overdiagnosis. This study was established to address the issue of overdiagnosis. It was specifically designed to determine if and what relationship exists between knowledge of overdiagnosis (the study's independent variable) and the decision to participate in breast cancer screening (the study's dependent variable) amongst women aged 50–69 years. The literature review was designed to provide background information, an overview, and a synthesis of existing literature on this topic. In addition, this review established support for the need for continued research concerning the relevance of knowledge of overdiagnosis and its relationship with the level of participation observed in breast cancer screening programs. Although inquiry on this particular topic was documented to have started in Canada as early as 1992, limited prior research extensively or definitively examined the existence of and/or the nature of the relationship between the two variables.

This chapter reviews the existing and relevant literature on (a) breast cancer, (b) screening mammography, (c) the benefits and risks of screening mammography, and (d) the current dissemination approaches used to give information about breast cancer and breast cancer screening. It also presents detailed information and statistics on breast cancer as it relates to Ontario, Canada. In addition, the chapter discusses and critically assesses a variety of research designs implemented by previous researchers whose studies focused on breast cancer. The chapter's main sections are as follows: theoretical foundation, overview of key concepts, statistics on breast cancer in Canada, statistics on

breast screening in Canada, research related to overdiagnosis and breast screening programs, other risks associated with breast cancer screening, and summary.

Strategies for Searching the Literature

The literature search for this dissertation primarily consisted of electronic searches through the online databases of the Walden University Virtual Library and the International School of Management Virtual Library. It also included a search of hardcopy documents at the University of Toronto in Toronto, Ontario. The information for this review was searched and/or obtained from peer-reviewed journals found through the following databases: EBSCOhost databases (Academic Search Complete, Academic Search Premier, MEDLINE with Full Text, SocINDEX with Full Text, CINAHL Plus with Full Text, ebook Collections, and Political Science Complete); ProQuest databases (Dissertations & Theses at Walden University, ebrary® – ebooks, ProQuest Nursing & Allied Health Source, ProQuest Dissertations & Theses Full Text, ProQuest Education Journals, and ProQuest Central); Thoreau: Search Multiple databases; SAGE Full-text Collections (SAGE Encyclopedias and Handbooks, Sage Research Methods Online, and Gale Virtual Reference Library); evidence-based resources (The Cochrane Library, and health-evidence.ca); OvidSP (Nursing Books, and Journal of Public Health Management & Practice); and Google Scholar.

Other relevant information, including current statistics on breast cancer incidences in Canada, was gathered from medical, governmental, and affiliate agencies whose mandate focused on research related to cancer, breast screening, screening participation, and overdiagnosis. These organizations included: PHAC, CCS, Cancer Care Ontario

(CCO), MHLTC, Breast Cancer Society of Canada (BCSC), Canadian Breast Cancer Foundation (CBCF), Cancer Quality Council of Ontario (CQCO), Canadian Task Force on Preventive Health Care (CTFPHC), American Cancer Society (ACS), National Cancer Institute (NCI), and Statistics Canada. The search for salient information was also extended to reference sections of identified publications and web sites referenced in the peer-reviewed articles. From these identified sources, more refined searches were conducted to find information specifically related to breast cancer screening for women living in Ontario, Canada, aged 50–69 years. Relevant references from each of the studies covered in this literature review were also reviewed.

Numerous studies were assessed in searches and the abstracts reviewed. However, several were discarded because they were not directly applicable to this study. The articles selected for this review were predominantly written over the last five years. In instances where literature was more limited and where greater historical context was needed, older studies were included. The preliminary literature search determined that although significant research had been done on various aspects of breast cancer screening, there was limited knowledge and research addressing the issue of overdiagnosis as a factor in determining breast screening participation.

The keyword strings used in the literature search process included: cancer, breast cancer, breast cancer screening, breast screening, mammogram, mammography, screening mammography, diagnostic mammogram, diagnostic mammography, mass screening, false-positives, false-negatives, disease, overdiagnosis, overtreatment, knowledge, social learning theory/social cognitive theory, and health behavior models.

Search terms utilized for the additional variables were: cancer incidence, overdiagnosis in cancer, breast cancer in men, early detection of cancer/methods, gender, age, risk factors, benefits and harm(s), benefits and risks, participation in breast cancer screening programs, randomized clinical trials (RCTs), lead-time approach, focus groups, survey, Likert-type, Likert-format, questionnaires, observational studies, cohort studies, correlation studies, ex post facto research, pilot study, and retrospective studies.

Structure of the Literature Review

The sections that follow in this chapter provide an outline of the theoretical frameworks that acted as a guide for this study, followed by an overview of cancer, breast cancer, and screening mammography. It also provides background information with statistics related to cancer, breast cancer, and screening mammography programs within the Canadian landscape, including descriptions of relevant studies. The chapter concludes with an analysis of the selected methodology outlined in each evaluated study.

Theoretical Foundation

Before identifying the theoretical foundation that was used this study, I considered in general terms the relevance of theory in the development of a quality research paper. As noted by Swanson and Chermack (2013, as cited by the University of Southern California, 2014) "theories are formulated to explain, predict, and understand phenomena . . .and . . .to challenge and extend existing knowledge, within the limits of the critical bounding assumptions. . . .[Therefore] the theoretical framework introduces and describes the theory that explains why the research problem under study exists" (University of Southern California, 2014, Theoretical framework section, para. 1). With

this understanding in mind, outlined below is an overview and critique of the effective health communication model and schema theory. Both the effective health communication model and schema theory are assessed in relation to their respective relevance to the topic under investigation.

Effective Health Communication Model

The extensive promotion of breast-screening programs by the OBSP was justified by the CCO (2011b) in a summative statement that "breast cancer screening saves lives" (CCO, 2011b, para. 1). This health care media communication campaign was paid for by three-year, $15-million Canadian dollar commitment from the Government of Ontario (MHLTC, 2011). This particular focus on and increased media campaigning to improve the public's awareness of breast-screening programs (like OBSP) have been attributed to the increasing reported incidences of breast cancer (MHLTC, 2012a). Despite there being several highly publicized benefits associated with early detection (screening) programs, the information presented had not offered a balanced perspective that outlined not only the benefits but also any associated risks. This lack of emphasis on balanced information presentation to facilitate informed decision-making was also evidenced in the PHAC-funded 50 Over 50 Challenge for increasing breast-screening participation in Ontario.

The 50 Over 50 Challenge was coordinated and operated by South Riverdale Community Health Centre, Mount Sinai Hospital, and Toronto Public Health. Its key implementation steps focused on such things as

- Getting public health care providers' internal buy-in,
- Sourcing media sponsors for free advertising,

- Using radio stations that had a targeted demographic of women aged 50–69 years, and
- Providing shuttle service to transport women to screening sites (South Riverdale Community Health Centre, Mount Sinai Hospital, & Toronto Public Health, 2010).

What was, however, absent in those key implementation steps were considerations that ensured a balanced presentation of information about screening benefits and the associated risks. Bleyer and Welch (2012) highlighted this unbalanced information presentation in a recent study they conducted in the United States of America (U.S.) that found "one in three women had been overdiagnosed" (a risk associated with breast cancer screening) (Results section, para. 1). Hersch et al. (2013) also suggested that, if more information was presented on the risks of overdiagnosis, screening participants would be better-equipped to make informed decisions about whether to participate in screening programs (p. 6).

Other researchers, including Entwistle et al. (1998) and Goyder et al. (2000, as cited in Giordano et al., 2006) provided a detailed and still timely overview and analysis of key considerations necessary for communicating information to enable informed decision-making. The authors noted that, for health communication, specifically in the context of screening, communication was not limited to only information transmitted but rather, for effective communication, it was necessary that "health professionals . . .provide individuals with such information that . . .[would] allow them to 'knowledgeably' decide whether or not to undergo an intervention, taking into

consideration available alternatives, potential risks and foreseeable outcomes" (p. 382). For Entwistle et al. (1998) and Goyder et al. (2000, as cited in Giordano et al., 2006), it was imperative that women knew "the pros and cons of breast screening" to assist in their ability to be informed decision-makers in the screening process (p. 382). Further to this, it was therefore vital to have an established framework tailored to the presentation of health information in an ethical way.

Beauchamp and Childress (1979, as cited in Giordano et al., 2006) listed four principles that underpinned this framework: autonomy, nonmaleficence, beneficence, and justice. The framework's first principle, autonomy was defined as "the obligation to respect the decision-making capacities of autonomous persons," with the authors nothing that patients had a right to refuse interventions (p. 382). Nonmaleficence was defined as "the obligation to avoid causing harm intentionally or directly (the principle [wa]s not necessarily violated if a proper balance of benefits exists; That is, if the harm [wa]s not directly intended, but [wa]s an unintended side effect of attempts to improve a person's health)" (p. 382). Principle three, beneficence, referred to "the obligations to provide benefits, balancing them against risks, [and the final principle] justice [was noted as] the obligation of fairness in the distribution of benefits and risks" (p. 382). Of these four principles, the research observations of Bleyer and Welch (2012), Hersch et al. (2013), and Giordano et al. (2006) indicated that little or no attention was paid to considerations of autonomy and beneficence.

Much like Bleyer and Welch and Hersch et al., Giordano et al. (2006) had noted that there were growing concerns that women being invited to participate in screening

"often [were] told about the positive aspects of screening, ignoring any negative aspects in order to increase the attendance rate and ensure the effectiveness of the screening programme" (pp. 382-383). Giordano et al. also highlighted that usually media communications/campaigns about medical services tended to favor optimistic messaging and so the information distributed often times underlined the benefits, but "gloss[ed] over uncertainties, adverse events and side effects and ignor[ed] legitimate scientific controversies" (p. 383). Screening programs were (and to some extent have continued to be) presented with a 100% accuracy rate. As such, any false-positives or false-negative results noted were attributed to errors on the part of the service providers. "This . . .[led] to the perception that all cancers arising after a normal screening examination [were] 'missed' and that delays in diagnosis [had] prognostic significance" (p. 383). Ultimately, Giordano et al. indicated that any screening information presented "should be honest, adequate, evidence based, accessible, unbiased, respectful, and tailored to individual needs" (p. 383), which then results in an informed screening participant.

Effective health communication was therefore possible only when adequate consideration was given to address each individual's specific needs, and differences in values and beliefs. With an understanding of context, culture, educational status, personality, and other myriad factors, including the influence of "mass media on individuals' perception and understanding of health issues" (Giordano et al., 2006, p. 383), it would then be easier to establish effective health communication. This would be so as the information presented would address specifically the way each individual processed health information. By extension, it would also address how that individual's

processing approach impacted their motivation to participate in screening (Giordano et al., 2006, p. 383). In the context of presenting the risks associated with screening, effective health communication therefore meant that the risk of overdiagnosis ought to be addressed alongside the outlined benefits, in any communication material.

Schema Theory

Schema theory was the theoretical framework for this research. The benefit of using schema theory laid in "its ability to both explain and predict learning. . . .If . . .familiar with the established schemata of learners, we can greatly increase the likelihood that they will understand new information by presenting it in a manner that will be meaningful to them" (Edublogs, 2012, Strengths and Weaknesses section, para. 4). First introduced by Jean Piaget in 1926, then Sir Frederic Bartlett in 1932, schema theory describes the cognitive structure of how an individual acquires, processes, and organizes knowledge. Grounded in Bandura's (1997) social cognitive theory (also called the social learning theory), the key tenet of schema theory states that "every act of comprehension involves one's knowledge of the world," (Carrell & Eisterhold, 1983, p.73). Thus, knowledge is a network of mental frames or cognitive constructs referred to as a schema (Erasmus et al., 2002).

For schema theory, the mind of a human being is organized by a series of schemas that categorize and interpret information to create a general picture of how that individual views a specific topic. This general picture is a consequence of that individual's use of all the various information present, along with their associations, to create a cognitive construct. Therefore, individuals use schemata (scripts) to structure existing knowledge

and establish context for future understanding (Erasmus et al., 2002). So schemata expand and evolve with time as new information is acquired. However, deeply-rooted schemata are slower to change. As schemata develop and evolve, they assist an individual (the learner) to better understand and interpret the world in which they live.

As schema theory relates to this study, I purport that the schemata (script) currently established for identifying how people decide to participate in breast screening programs suggested that, only if benefits of screening mammography were predominantly promoted, then would there be higher rates of screening participation. Consequently, most information presented about screening mammography failed to offer a truly balanced (both positive and negative) outline of the implications of participation. If this purported schemata is correct, then it has limited participants' opportunity to make informed decisions about participating in screening programs. I further believed that, if media campaigns by the Government of Ontario used Giordano et al.'s (2006) framework of ethical principles to guide the development and presentation of health information about screening mammography, including the risk of overdiagnosis, it would be possible that a new schema could be created. Specifically, a new schema that facilitates comprehensive information presentation, while maintaining high levels of screening participation.

It is essential to note that Jean Piaget's theory of cognitive development preceded and laid the foundation for schema theory. However, "schema theory addresses some of the criticisms of its forerunners" (Edublogs, 2012, Strengths and Weaknesses section, para. 2). For example, even though Piaget's theory "was criticized for ignoring the

influence of gender and culture on cognitive development, schema theory suggests that schema are built on individual experience. Thus where gender and culture influence the lived experience of any individual, schemata develops accordingly" (Edublogs, 2012, Strengths and Weaknesses section, para. 2). Schema theory also built on its forerunners' notion of memory. Here, schema theory proposes that "schemata help us to remember, comprehend and problem-solve. At the same time, the encoding of an experience is hindered by selection, gist-extraction, and interpretation" (Edublogs, 2012, Strengths and Weaknesses section, para. 3). Based on this selective understanding and interpretation, in stances where individuals experience the same event, the respective schema developed is not identical.

According to Byrnes (2001, as cited in Edublogs, 2012) one limitation of schema theory is "that it is fairly imprecise on the issue of developmental mechanisms" (Strengths and Weaknesses section, para. 3). According to Holland (1992, as referenced by Edublogs 2012), another limitation of the theory is its "inability to explain human behavior in unprecedented circumstances" (Strengths and Weaknesses section, para. 5). When there is no existing schema to reference "for a situation with which [an individual is] confronted, schema theory is [unable] to explain why we do what we do" (Edublogs, 2012, Strengths and Weaknesses section, para. 5). Further to this point, schema theory is also not able to provide a rationale for acting the way we do.

Overview of Key Concepts

Immediately below is a brief, yet detailed, overview of some key concepts. These concepts include cancer, breast cancer, risk factors associated with breast cancer, and

breast cancer screening (mammography). Also outlined is the purported benefits of breast cancer screening, the screening guidelines for participation in Ontario, and overdiagnosis. This overview is given because each concept mentioned has been and will continue to be encountered during this study. With a review of these concepts, readers have a greater chance of assimilating the information presented and discussed throughout this research.

Cancer

Cancer covers a wide range of diseases that involve irregular cell growth. As highlighted by the CBCF (2014e), cancer is the general classification "of more than 100 diseases that affect the body at a cellular level" ("What is cancer" section, para. 1). Medically referred to as *malignant neoplasm*, cancer results from "extra cells [that] form a mass of tissue called a lump, growth or tumor" (U.S. Department of Health and Human Services, National Cancer Institute, 2012, p. 2), because the cells grow and divide uncontrollably. In normal cell growth, the "body cells grow, divide and die and are replaced by new cells" (CBCF, 2014f, What is cancer section, para. 2). However, in the instance of cancer cell growth, cells that ought to have died instead "continue to grow and form new, abnormal cells" (Mandal, 2013, "Cancer at the molecular," para. 2). In some instances, these tumors are benign (noncancerous) and in other instances they are malignant (cancerous).

Cells become cancerous or malignant as a result of damages (cell mutation) to their DNA (deoxyribonucleic acid). "When DNA is damaged in a normal cell the cell either repairs the damage or the cell dies. . . .[For] cancer cells, the damaged DNA is not repaired, and the cell does not die" (Mandal, 2013, "Cancer at the molecular," para. 3–5),

as it should. Rather than dying, this damaged cell continues to make new abnormal DNA. The "cells from malignant tumors can spread (metastasize) to other parts of the body" (U.S. Department of Health and Human Services, National Cancer Institute, 2012, p. 40). The period of dormancy for cancer is long and as such it may take several years from the first time the cell mutates to when evidence of the disease manifests (CBCF, 2014f).

Breast Cancer

Breast cancer is "cancer that forms in the tissues of the breast" (NCI, 2014b, Breast cancer section, para. 1). As outlined by the BCSC (2014c), the "most common forms of breast cancer begin in the milk ducts, lobules or glands" (noninvasive breast cancers) (Types of breast cancer section, para. 1). Noted by ACS (2014a), CBCF (2014d), and NCI (2014b), the main types of breast cancer include

- *Ductal carcinoma in situ (DCIS)*, where the cancer "cells have not spread (*invaded*) through the walls of the ducts into the surrounding breast tissue [and therefore] cannot spread to lymph nodes or other organs" (ACS, 2014a, Ductal carcinoma in situ section, para. 1). For women with this type of breast cancer, they (the women) can be cured and mammograms generally find many cases of DCIS (NCI, 2014d; Welch, 2004).
- *Lobular carcinoma in situ (LCIS)*, which "is not considered to be a true cancer and is not life-threatening, but it is an indicator that a woman is at increased risk for developing invasive breast cancer in either breast in the future" (CBCF, 2014d, "Noninvasive or in situ," para. 6). "LCIS . . .[begins] in the milk-making glands (lobules), do[es] not go through the wall of the lobules,

and [therefore does not usually] spread to other parts of the body. . . .[It infrequently results in] a lump or changes that can be detected by mammography" (CBCF, 2014d, "Noninvasive or in situ," para. 6–7). "It is [however typically] identified during investigation of other breast changes" (CBCF, 2014d, "Noninvasive or in situ," para. 8). LCIS on its own generally does not need treatment, but both breasts of the patients are closely monitored by trained health care provider (using regularly scheduled clinical breast examinations) (CBCF, 2014d).

- *Invasive (or infiltrating) ductal carcinoma (IDC)*, which represents approximately "80% of invasive breast cancers" (CBCF, 2014d, Invasive breast cancer section, para. 1). IDC "is the most common type of [breast] cancer . . .[and] starts in a milk passage (a duct). [It then] breaks through the wall of the duct and invades the surrounding tissue of the breast" (CBCF, 2014d, Invasive breast cancer section, para. 1). Once the damaged cells have passed through the wall of the duct, it may spread (metastasize) to other body parts (CBCF, 2014d).
- *Invasive (infiltrating) lobular carcinoma (ILC)*, which represents "10% of invasive breast cancers cases. ILC starts in the milk glands (the lobules) of the breast, breaks through the lobules, and invades the surrounding tissue of the breast" (CBCF, 2014d, Invasive breast cancer section, para. 6). Much like IDC, the damaged cells, for ILC, may spread (metastasize) to other body parts. However, the key difference between IDC and ILC is that IDC passes

via the wall of the duct, and ILC passes through the lobules and surrounding breast tissues (CBCF, 2014d).

- *Inflammatory breast cancer (IBC),* an "uncommon type of invasive breast cancer, accounts for [roughly] 1% to 3% of all breast cancers. [In this form of breast cancer] there is no single lump or tumor, [but rather] IBC makes the skin of the breast look red and feel warm" (ACS, 2014a, "Less common types of," para. 1). In addition, it may make the skin have "a pitted, orange peel-like texture (referred to as peau d'orange). The breast may get bigger, hard, tender, or itchy" (CBCF, 2014d, Inflammatory breast cancer section, para. 3). In the "early stages, inflammatory breast cancer, is often mistaken for an infection . . .[and, given there are] no actual lump, it [may be] even harder to find it early" (ACS, 2014a, "Less common types of," para. 2). Meaning that it may be easier to be missed on a mammogram. IBC has a greater probability of metastasizing, and more dire prospects (prognosis) relative to lobular or invasive ductal cancer (ACS, 2014a).
- *Paget's disease of the nipple*, which is also a "less common type of breast cancer [and accounts] for [under] 5% of all breast cancers. [Its] symptoms include: persistent itchiness and scaling of the nipple. [This worsens as] time [passes and leads] to weeping, crusting and nipple pain. The nipple [sometimes] also appear flattened . . .[and is usually] found on . . .one nipple" (CBCF, 2014d, "Paget's disease of the," para. 1–2). It has been noted that many individuals "with Paget's disease . . .may also have another form of

> cancer in the same breast. [Roughly 50%] of the [individuals found] with Paget's disease [exhibit] a lump or mass in the breast that can be felt during physical examination" (CBCF, 2014d, "Paget's disease of the," para. 3). There have been some instances where Paget's disease spread to the areola and throughout the breast (CBCF, 2014d).

Risk Factors Associated with Breast Cancer

Although the exact cause of breast cancer is not known, the explanation for breast cancer development has been attributed to the following risk factors:

> Age, personal history of breast cancer, family history, ancestry, certain breast changes, gene changes, reproductive and menstrual history, race, radiation therapy to the chest, breast density, taking DES (diethylstilbestrol), being overweight or obese after menopause, lack of physical activity, and drinking alcohol. (Bellenir, 2009, p.37)

Other risk factors being studied include considerations of: sex, socio-economic status, sedentary behavior, stress, viruses, bacteria and other infectious agents, weakened immune system, the effect of diet, physical activity, genetics as well as certain substances in the environment that may impact and/or increase possibility of breast cancer (ACS, 2014a; Bellenir, 2009; CBCF, 2014a; Nguyen & Clark, 2014). It is important to note that not all risks are equal. Some risks have a higher degree of association for breast cancer, while others have a moderate or lower degree of association. For this reason, there are a variety of advantages to knowing the various risk factors of breast cancer.

One such advantage to knowing the types of risk factors of breast cancer is that it helps individuals to establish modifications to behaviors that can possibly reduce their chances of having breast cancer. Examples of behavior modifications include (a) an increase in physical activity, (b) exercise to reduce body weight, (c) reduction in alcohol consumption, (d) quitting smoking, and (e) reducing exposure to radiation. Another advantage is that via the establishment of a cognitive construct/schemata that highlights the relevance to actively look for and monitor potential signs of possible cancer, individuals using this schemata will be more likely to make the necessary checks. This active surveillance increases the chances of potentially detecting cancers in their early stages, thus leading to more treatment options. There are however some nonmodifiable risk factors of breast cancer, for example, gender, family history, age, personal history, and breast density. For nonmodifiable risk factors, behavior modifications cannot help in reducing the chances for having breast cancer. But knowledge of these nonmodifiable risk factors may help to reinforce the potential benefits to be gained from developing schemata focused on active surveillance/monitoring of possible signs of cancers (CBCF, 2014a).

Breast Cancer Screening (Mammography)

Screening is the process by which a disease is looked for in persons who have no symptoms (asymptomatic) of the disease for which they are being examined (Welch, 2004). In other words, screening is performed on people who, by appearance, are in good health. In cancer, screening is aimed at reducing mortality and suffering from the disease through regularly scheduled testing as a means of possibly detecting and treating the

disease in the early stages. When screening for breast cancer, the process referred to as mammography involves the use of low-dose x-rays to check for cancer in the breast. Mammograms are used as a means of both screening and diagnosis.

On the one hand, a screening mammogram looks for changes in the human breast, even though there are no signs of breast cancer. "The purpose of screening is to prevent cancer by identifying precancerous changes, or to find early stage cancers when [they] are easier to treat" (CQCO, 2014b, "Cancer screening – breast, cervical," para. 3). On the other hand, "*diagnostic mammogram* . . .[provides a] more detailed image of the breast . . .[and is] used to rule out other breast problems"(U.S. Department of Health and Human Services, National Cancer Institute, 2004, p. 7). As well more x-rays of both breast are taken during diagnostic mammograms so that doctors can conduct a comparison of the scanned breasts (CCS, 2015).

As noted by Welch (2004), the primary assumptions of screening are that (a) "tests can find early cancers, and (b) early treatment works better than late treatment" (p. 19). This, however, has been noted as an inaccurate statement for two reasons: (a) there is a window of opportunity (preclinical phase) for early detection via screening; As such, if a cancer grows rapidly, this preclinical phase is significantly reduced; and (b) cancers develop and grow at different rates; Thus a cancer can be missed simply because the "individual was not screened at the right time" (p. 20). Therefore, if the Government of Ontario, through its various health care providers, hopes to have an enhanced awareness of the OBSP and, by extension, an increased rate of screening participation, it is essential that potential screening participants be provided with health information that employs the

above-mentioned ethical tenets of Giordano et al. (2006). In addition, as explained by schema theory—understanding that each individual's schema (cognitive construct) differs—the information presented "should be honest, adequate, evidence based, accessible, unbiased, respectful, and tailored to [that] individual['s] needs" (p. 383). In so doing, this will facilitate the creation of a schemata that includes information not only of the benefits of screening, but also of overdiagnosis and its other associated risks. Individuals that acquire this new schemata can then potentially establish a cognitive construct that allows for informed decision-making about screening participation.

Purported Benefits of Breast Cancer Screening

According to the CCO's 2010 anniversary report, the World Health Organization's (WHO) International Agency for Research on Cancer (IARC), the United States Preventive Services Task Force (USPSTF), and the CTFPHC maintain that "mammography is [still] the gold standard for [the] early detection of cancer" (CCO, 2010, p. 11). For the NCI (2013a, 2013c), some of the advantages of screening mammography include (a) decreased mortality in breast cancer by up to one third; and (b) an increased five-year survival rate for women screened annually for breast cancer. Another advantage is that for women older than 65 years, screening results may lead to more diagnostic test. This in turn leads to earlier detection, resulting in less invasive treatment options and potentially a better quality of life (NCI, 2013a; NCI, 2013c).

Changes in Ontario Breast Cancer Screening Age Range

As of July 1, 2011, the MHLTC announced that the OBSP started to offer an additional 90,000 mammograms given its (then) new screening parameter. This new

screening parameter include women 30–69 years old who have a greater risk of developing breast cancer. The previous guidelines limited screening to women aged 50–74 years. These additional screening average 30,000 per year over three years. The OBSP guidelines also included (a) annual screening mammography and MRI for persons considered at high risk for breast cancer; (b) biennial screening for women aged 73 years and older; (c) follow-up breast evaluation for those requiring additional tests; and (d) referrals for genetic (DNA) evaluation of women who may have a higher probability for breast cancer (if appropriate) (CCO, 2012).

Overdiagnosis

Overdiagnosis happens when a nonprogressive cancer and/or slow-growing cancer is detected; It occurs in cases where a disease is identified correctly, but that identification is unnecessary (irrelevant). In other words, it is "the systematic evaluation of asymptomatic patients to detect early forms of cancer" (Welch et al., 2011, p. xiv-xv). As such, overdiagnosis is the consequence of testing for the initial stages of disease that potentially turn individuals into unnecessary patients. It also potentially leads to treatments that possibly are of no benefit, but rather may cause harm.

Collectively, nonprogressive cancer and slow-growing cancer are known as *pseudodisease* (meaning false disease), as they do not cause symptoms or death in the affected individual. Pseudodisease is not distinguishable by screening mammography, and therefore the only way overdiagnosis can be confirmed is after an individual is never treated, develops no symptoms of cancer, and ultimately dies of something not cancer-related (Welch, 2004; Welch et al., 2011). As it relates to cancer diagnosis, the

subsequent notion of overdiagnosis gained significant popularity during the increased use of screening for prostate cancer. From the experiences with screening for prostate cancer, the lesson learned was that, while finding the disease has importance, "find[ing] the right cancers, the cancers that matter" (Welch et al., 2011, p. 60), was of greater value (Welch et al., 2011).

An accurate prognosis of a disease can be considered unnecessary because any treatment for that disease was unavailable, not needed, or not wanted. For this reason, those such as Johnson (2012) and Smith, Duffy, and Tabár (2012) contended that the use of the term overdiagnosis was inappropriate, but rather overtreatment was a more representative classification of the phenomenon under examination. This suggestion stemmed from the knowledge that a majority of the individuals diagnosed for cancer were also treated for the disease. It was therefore harder to ascertain when there were instances of overdiagnosis for that specific individual. As such, the inferences about overdiagnosis usually came from studies of populations. One example that strongly indicated possible overdiagnosis was generally observed in the increasing levels of testing and disease diagnosis to establish stable rates for the outcome of the disease (death). Another compelling example of overdiagnosis tended to be evidenced in randomized trials of screening tests that were intended to detect preclinical disease. However, the most definitive examples of overdiagnosis were in any continuous and prolonged excess of identified disease in a group being tested, several years post completion of a trial.

While proponents of screening mammography consistently acknowledged the benefits of early detection through screening, less focus was placed on the associated risks. More specifically, as it relates to overdiagnosis, there has been limited information outlining the additional risks that result from overdiagnosis. The three forms of risk related to overdiagnosis include

- The physical impact of needless diagnosis and treatment—such as, surgery, radiation, and chemotherapy;
- The psychological effects from being identified as a cancer patient—resulting in possible depression, emotional stress, and an enhanced feeling of vulnerability; and
- The financial implication/problem of not only any unnecessary treatment costs but also future premiums for health and life insurance because of preexisting conditions (Welch et al., 2011).

Ultimately, an overdiagnosed patient does not and will not benefit from the identification or treatment of their disease, because the disease (cancer) would never have resulted in any exhibited symptoms, or their death (Welch et al., 2011). As such, considering the information presented above, in conjunction with the statistics that is outlined in the section below, the findings from this research add to the current knowledge about the efficacy of information presented for health-related decision-making. Note importantly that overdiagnosis was selected as the study's topic of focus because it is an area of breast cancer research that is still in its infancy in the Province of Ontario, Canada.

Statistics on Breast Cancer in Canada

Throughout Canada, the incidence rates for breast cancer in women have been generally consistent, do not vary significantly by geography, and have continued to be somewhat stable as of the late 1980s. Although the actual numbers each year have increased, this increase has been proportionate to increases in the country's population (CBCF, 2014b). In 2014, the CCS estimated 191,300 new cases of cancer (not including the roughly 76,100 cases of nonmelanoma skin cancers) and 76,600 deaths. Of the identified cases, 97,700 and 93,600 Canadian men and women respectively would be diagnosed with cancer, of which 40,000 and 36,600 respectively would die. Of all the new cases, more than 52% were estimated to be lung, breast, colorectal, and prostate cancers (CCS, 2014c; CCS et al., 2014, p. 24). Specifically within the Province of Ontario, the CBCF and CCS estimated that, for 2014, for women, breast cancer was the most commonly detected cancer, with 9,500 new cases (see Table 1) and an estimated 1,950 dying from the disease (CCS, 2014c, "Cancer statistics for women," para. 1–4). During 2012 to 2013, the Canadian female population grew by approximately 200,000, whereas the estimated number of diagnosed women with breast cancer increased by 800. The CCS, however, estimated that, for 2014, there would be a slight, yet statistically significant, decrease in the incidence rate for breast cancer. Currently, there are fewer women in Canada who die from breast cancer (CBCF, 2014b).

Table 1

Estimated New Breast Cancer Cases by Province in Canada in 2014

Province	# of New Cases	%
Alberta	2,200	9
British Columbia	3,200	13
Manitoba	850	3
New Brunswick	560	2
Newfoundland and Labrador	330	1
Nova Scotia	760	3
Ontario	9,500	39
Prince Edward Island	110	0.4
Québec	6,000	25
Saskatchewan	700	3
Total	24,000	100

Note. Rates of incidence are comparable throughout all provinces. Provinces that have larger populations have more cases of breast cancer. Data for each Canadian territory (Northwest Territories, Yukon, and Nunavut) are not listed individually as the numbers are small. However, they are included in totals for Canada. Adapted from "Breast cancer in Canada, 2014" by Canadian Breast Cancer Foundation, 2014b. Retrieved from http://www.cbcf.org/central/AboutBreastCancerMain/FactsStats/Pages/Breast-Cancer-Canada.aspx. Copyright 2014 by the CBCF.

Relative to previous years, death by breast cancer was noted to have reduced by 43% (18 deaths per 100,000), since its peak in 1986. CBCF (2014c) projected that in 2014, 5,000 women would have died of breast cancer in Canada (see Table 2), a reduction relative to the roughly 5,100 deaths in 2012 (Breast cancer survival section, para. 1). This noted decreased rate of mortality (increased rate of life expectancy) was attributed to the purported benefits of screening mammograms and is still used as evidence by the Government of Ontario for support of their active and continued advocacy of the OBSP. The CCS (2014d, "Cancer statistics at a," para. 10-18) noted cancer could occur at any age and that roughly two in five Canadians would develop

cancer in their lifetime, of which 25% would die of the disease, and approximately 63% of those diagnosed would survive for at least five years. Of relevance was the CCS's indication that Canadians over the age of 50 years were predominantly affected by cancer. The CBCS (2014b) further stated that, although breast cancer occurred in both females and males, a larger percentage of cases were found in women. Specifically highlighted was that "less than 1% of all breast cancer cases" were found in males (BCSC, 2014b, Male Breast Cancer section, para. 1). In 2014, breast cancer would be identified in 210 men and of that amount 60 would die. For men diagnosed with cancer, there was a five-year, 80% survival rate after being diagnosed, while for women, this five-year survival rate increased by 8% (from 80% to 88%). This increase was partly because the disease was identified at a more advanced stage in men, consequently the diagnosed male had fewer treatment options available (CBCF, 2014b).

The CCO (2011b) supported the CCS's assertion that "breast cancer is the second most common cancer killer among women" when it indicated that 20 per 100,000 women would be killed by cancer ("Overall rate of cancer," para. 6). Other statistics that further supported the notion that breast cancer is the second foremost reason of cancer-related death in Canadian women was presented by the CBCF (2014b) and the CCS (2014c). Both the CBCF (2014b) and the CCS (2014c) indicated that of the estimated 24,400 women diagnosed with some form of cancer (see Table 2), 26% of all first-time cases of cancer in those women would be breast cancer (CBCF, 2014b). Current data as of 2014 suggested approximately 157,000 women in Canada who had been diagnosed with "breast cancer in the last 10 years [were still] living [this] compared to other types of

cancer" (CBCF, 2014b, "Prevalence of breast cancer," para. 1). These statistics pointed to a conclusion that "women with breast cancer [were] surviving for longer periods" (CBCF, 2014b, "Prevalence of breast cancer," para. 1), a result partially attributed to early detection and screening.

PHAC (2009) also highlighted that "breast cancer is rarely diagnosed in people younger than 40 years [and current statistics have shown that] incidence rises steeply…peaking in women aged 75–79 years" (Incidence section, para. 3). Given age is a risk factor for breast cancer, and as an individual ages, this associated risk increases, a collaborative report produced by the CCS, Statistics Canada, PHAC, & Provincial/Territorial Cancer Registries (2014), and further confirmed by the CBCF (2014b) estimated that "women over 50 years of age make up 82% of breast cancers" (CBCF, 2014b, "Breast cancer mortality and," para. 1–5). Specifically, 52% of the cases would be in women aged 50 to 69 years, 30% for women aged 69 years and older, and 19% among women aged 50 years and under (see Table 2) (CBCF, 2014b). "For women 30 to 49 years of age the risk of being diagnosed with any type of cancer [wa]s 1 in 500 (or 0.2%)" (CBCF, 2014b, "Breast cancer incidence and," para. 1–2). Despite this number being considered very low risk, roughly 36% of those women, aged 30–49 years, would be diagnosed with breast cancer (CBCF, 2014b).

Significant to note was that, while 25% (see Table 2) of the first-time cases of breast cancer had been projected to occur in women aged 50 to 69 years, there were more deaths in women aged 80 years and over (CCS et al., 2014). This suggested that those who were diagnosed and treated in their 50s were more likely to live into their 80s.

However, much like the observed decreased rate of mortality noted above, earlier detection via "regular mammography screening, advances in screening technology, and improved treatments" were credited for this overall increase in life expectancy (CBCF, 2014b, "Breast cancer in Canada," para. 2; CCS et al., 2014, pp. 40, 58). Because this research is focused on women aged 50–69 years and their decisions about screening participation, an understanding of the rates of incidence for breast cancer in Ontario helped to create greater context for interpreting (a) the Ontario-specific data presented; (b) screening participation rates documented; and (c) any impact knowledge of overdiagnosis had on participation levels currently observed.

Table 2

Estimated New Breast Cancer Cases Diagnosed and Deaths of Women in Canada, by Age Group

	Estimated new breast cancer cases		Estimated deaths from breast cancer	
Age	Actual number	(%)	Actual number	(%)
80+	3,000	12.3	1,550	31
70-79	4,400	18	1,050	21
60-69	6,500	26.6	1,100	22
50-59	6,100	25	860	17.2
40-49	3,300	13.5	380	7.6
Under 40	1,115	4.6	100	2
Total	24,400	100	5,000	100

Note. Adapted from "Breast cancer in Canada, 2014" by Canadian Breast Cancer Foundation, 2014b. Retrieved from http://www.cbcf.org/central/AboutBreastCancerMain/FactsStats/Pages/Breast-Cancer-Canada.aspx. Copyright 2014 by the CBCF.

As breast cancer is the most commonly identified cancer among Canadian women, the CCS pointed out that it was also the most actively researched/studied area of cancer in Canada. In 2011–2012, the CCS funded more than $46 million Canadian dollars in cancer research, of which $4.1 million dollars was dedicated to breast cancer research (CCS, 2014a). Although not funded by PHAC or the CCS, the studies and their respective methodologies (outlined below) provided appropriate evidence of the importance of overdiagnosis research in the context of participation in screening mammography. The analyzed studies in question addressed the issue of breast screening from varying perspectives, with different objectives in mind. Nevertheless, all in some respect acted as building blocks for this current research.

Statistics on Breast Cancer Screening in Canada

The CTFPHC (2014) reported that, among women aged 50–69 years, 900 die of breast cancer annually, relative to the approximately 470 and 480 that die among women aged 40–49 years and 70–74 years, respectively (Basis of recommendation section, p. 1). CTFPHC further pointed out that, in order to save one life from breast cancer over the span of 11 years, screening would be needed every two to three years. The research findings indicated that, among women aged 40–49 years, for every 1,000 women that would need to be screened, 36 (3.60%) would have an unnecessary breast biopsy, and roughly 329 would have a false-positive mammography (32.90%). Among women aged 50–69 years, out of roughly 1,000 women that would need to be screened, 36 (3.60%) would have an unnecessary breast biopsy, and approximately 283 (28.30%) would have a false-positive mammography. Finally, among women aged 70–74 years, for every 1,000

women that would need to be screened, 24 (24.40%) would have had an unnecessary breast biopsy, and an estimated 213 (21.30%) would have a false-positive mammography. CTFPHC also indicated that, for each identified case of false-positive, the effects on these screened women (overdiagnosed) were "unnecessary anxiety and follow-up testing" ("To save one life," p. 1). For every 1,000 women screened, CTFPHC noted that 5 will undergo unnecessary surgery for breast cancer ("To save one life," p. 1).

In its postanalysis of 2011–2012 statistics, the CQCO (2014a) reported that, in Ontario, roughly 60% (1,138,000) women aged "[50–]74 years were screened for breast cancer with a mammogram" (Key findings section, para. 1). During that period, 1,884,000 were eligible for screening. The CQCO outlined that "although the breast cancer screening participation rate has remained steady at 60%–61% since 2007–2008, more women are being screened within the . . .OBSP which offers important advantages for women and physicians" (Key findings section, para. 1). An estimated 841,000, or more than three-quarters, have been screened via the OBSP (CCS et al., 2014; CQCO, 2014a). However, in spite of increasing levels of eligibility for screening among the population, the rate of participation had remained steady from 2007–2012, as noted in Figure 2.

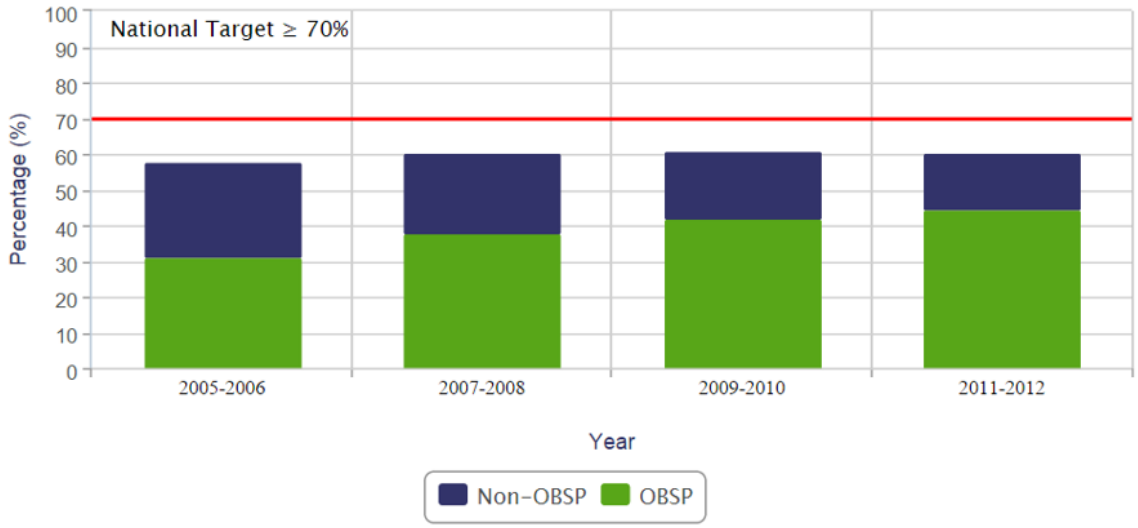

Figure 2. Bar chart of the age-adjusted percentage of women in Ontario, 50–74 years old, who completed one or more mammogram in a 2-year interval. Based on a national target of 70%, the data shown highlights the percentage of mammograms conducted from 2005 to 2012 by OBSP programs = green, and NonOBSP programs = blue. Adapted from "Age-adjusted percentage of Ontario women, 50–74 years old, who completed at least one mammogram within a two-year interval, by OBSP/Non-OBSP, 2005–2012," by Cancer Quality Council of Ontario, 2014a, Retrieved from http://www.csqi.on.ca/cms/one.aspx?portalId=289784&pageId=296132. Copyright 2015 by CQCO c/o Cancer Care Ontario.

During 2010–2011, more than 50% of the screening mammography in each Local Health Integration Network (LHIN) was conducted at OBSP centers, and 55% to 88% of all Ontario women screened came from women who participated in the OBSP. The range observed was attributed to a variety of sociodemographic factors that were influenced by age group, neighborhood income range (highest/lowest income areas), urban/rural residence, and neighborhoods with high percentages of Aboriginal peoples, as shown in Figure 3. The highest amounts of women taking part in organized screening were from LHINs in "North East (89%) and South West (83%) [Ontario]. Toronto Central LHIN had the lowest proportion of screening – 56% of those screened did so through the

OBSP," shown in Figure 4 (CCS et al., 2013, 56-57, 61-63; CCS et al., 2014, pp. 58-59, 61-64; CQCO, 2014a, "What do the results show" para. 3). Further examination of the report indicated that the highest rates of participation were among women aged 60–64 years and 65–69 years old (65%), while the lowest participation rates were found in women aged 70–74 years (53%). In relation to the objective of this study, it was important to note that the currently recorded rates of participation for breast screening would potentially be impacted if it was found that there was a relationship between knowledge of overdiagnosis and the decision to participate in breast screening (the independent and dependent variables). Two of several questions considered during this literature review were (a) whether the high levels of participation documented for Ontario women 60–69 years was the result of the OBSP's targeted media campaigns for this specific demography; and (b) with the July 2011 change in eligible screening age from 50–69 years to 30–69 years for women at high risk of developing breast cancer, would the rates of participation outlined above remain consistent, and, if not, what changes would be observed?

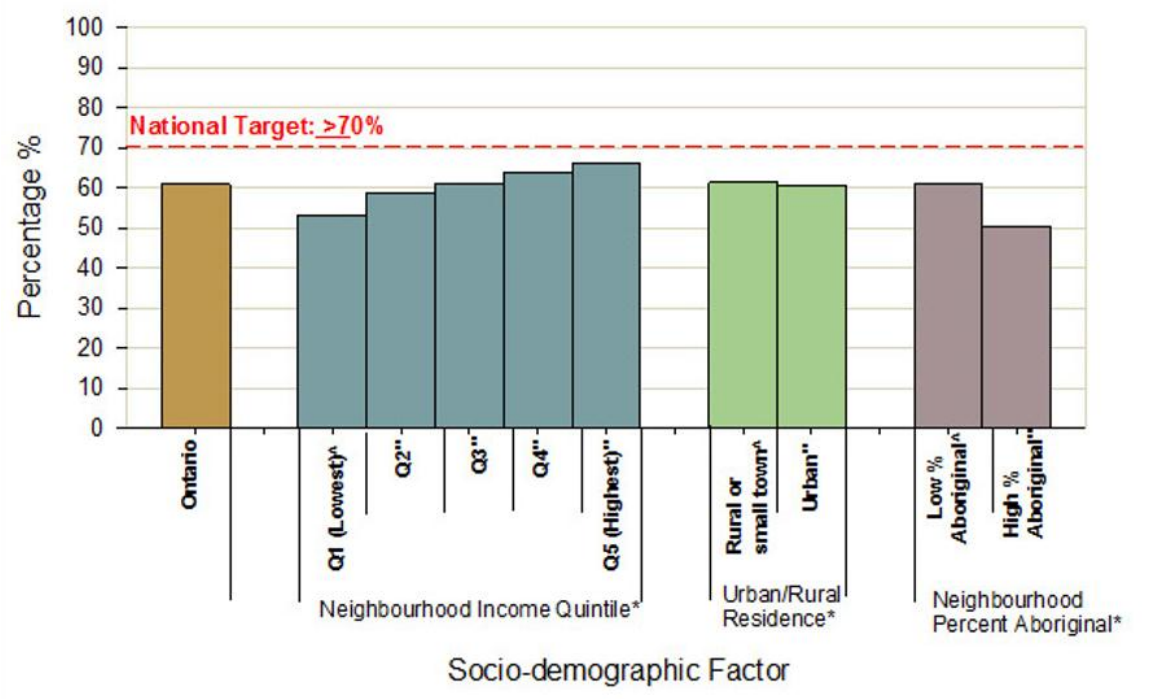

Figure 3. Bar chart of the age-adjusted percentage of women in Ontario aged 50–74 years old who completed one or more mammogram in a 2-year interval. Based on a national target of 70%, the data shown highlights the percentage of mammograms conducted from 2010 to 2011. Data was grouped by sociodemographic factors: the province of Ontario = mustard, neighborhood income quintile = cyan, urban/rural residence = lime green, and Aboriginal neighborhood percentages = dusty pink. Adapted from "Age-adjusted percentage of Ontario women, 50–74 years old, who completed at least one mammogram within a two-year interval, by socio-demographic factor, 2010–2011," by Cancer Quality Council of Ontario, 2013. Retrieved from http://www.csqi.on.ca/cms/One.aspx?portalId=258922&pageId=273161. Copyright 2015 by CQCO c/o Cancer Care Ontario.

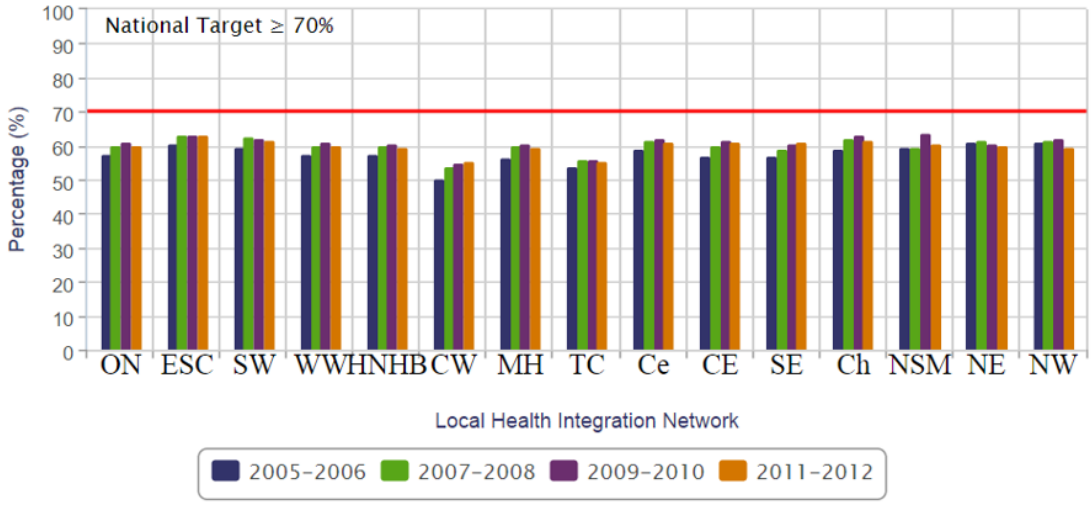

Figure 4. Bar chart of the age-adjusted percentage of women in Ontario aged 50–74 years old who completed one or more mammogram in a 2-year interval. Based on a national target of 70%, the data shown highlights the percentage of mammograms conducted through the Local Health Integration Network from 2005 to 2012. Data was grouped by geographical regions (depicted by acronyms) and years: 2005–2006 = blue, 2007–2008 = green, 2009–2010 = purple, and 2011–2012 = orange. Adapted from "Age-adjusted percentage of Ontario women, 50–74 years old, who completed at least one mammogram within a two-year interval, by Local Health Integration Network, 2011–2012," by Cancer Quality Council of Ontario, 2014a, Retrieved from http://www.csqi.on.ca/cms/one.aspx?portalId=289784&pageId=296132. Copyright 2015 by CQCO c/o Cancer Care Ontario.

On the one hand, despite a greater push and more media communications that highlighted the benefits of screening, over the years (2009–2010 and 2011–20112), a similar pattern, as mentioned above, was noted among the various age groups that did participate in screening. On the other hand, it was interesting to note that, across all age groups, there was only a 2%–6% increase in participation rates, when 2005–2006 and 2011–2012 data were compared, as shown in Figure 5 (CQCO, 2014a). From an international perspective, CQCO (2014b) indicated that participation levels for screening programs in Ontario were notably lower than those observed in such countries as

Australia, Finland, Norway, the Netherlands, and the United Kingdom (England only). Relative to Ontario, Norway was documented as having a 16% higher level of screening participation among women aged 50–69 years (CQCO, 2014b). These reported statistics raised yet another question; For those countries with higher overall participation rates observed, had screening information been presented in a balanced manner—outlining the benefits of screening and the associated risk of overdiagnosis, thereby enabling its participants to be better-equipped to make an informed decision on whether to participate in screening—would their documented rate of screening participation be the same?

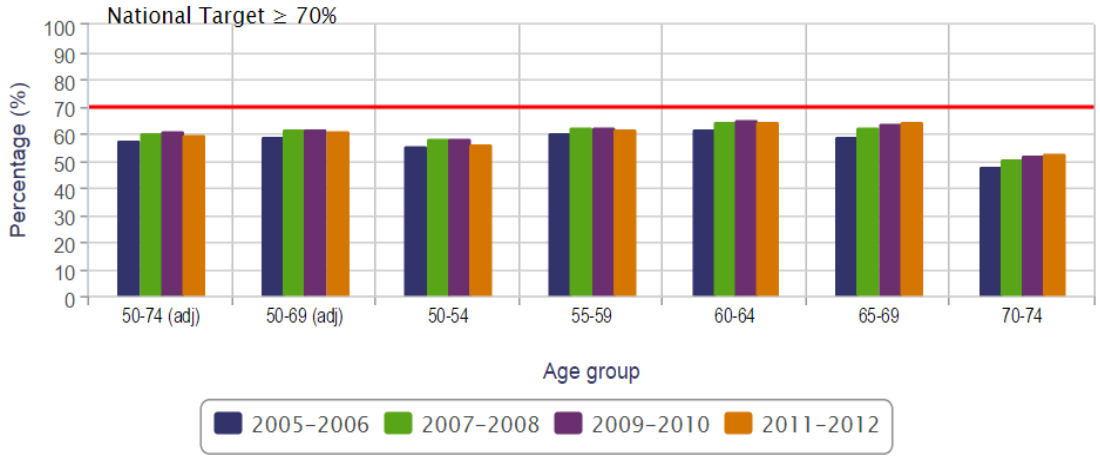

Figure 5. Bar chart of the age-adjusted percentage of Ontario women aged 50–74 years old who completed one or more mammogram in a 2-year interval. Based on a national target of 70%, the data shown highlights the percentage of mammograms conducted from 2005 to 2012. Data was evaluated along the lines of age group and covered the period: 2005–2006 = blue, 2007–2008 = green, 2009–2010 = purple, and 2011–2012 = orange. Adapted from "Age-adjusted percentage of Ontario women, 50–74 years old, who completed at least one mammogram within a two-year interval, by age group, 2005–2012," by Cancer Quality Council of Ontario, 2014a, Retrieved from http://www.csqi.on.ca/cms/one.aspx?portalId=289784&pageId=296132. Copyright 2015 by CQCO c/o Cancer Care Ontario.

As documented by CQCO (2014a), the CTFPHC (2014) in their previously published report outlined evidence that, among women aged 50–69 years, there was a 21% reduction in the rate of breast cancer mortality. The reason for this reduction was stated to be a consequence of screening mammography, and was considered statistically significant. The CTFPHC also indicated that roughly one in every 10 women tested would require more examination because of unclear and/or abnormal mammography (CQCO, 2014a). However, despite unclear and/or abnormal mammograms, according to MHLTC (2013a), since the commencement of the OBSP in 1990, there have been "over 3.6 million screens conducted for more than 1.1 million women, which resulted in more than 19,000 detected cancers," most of which were in the early stages (Quick facts section, para. 2). In the final analyzes, the rate of success for screening participation was noted to be impacted by several factors. Given the observed schemata for an average Ontario participant in the OBSP was based on one-sided (predominantly benefits only) screening information, any knowledge gained from this study (that examined the relationship between knowledge of overdiagnosis and decision-making to participate in screening) would aid in possibly predicting future rates of participation. It would also help in the establishment of a framework for understanding how associated risks (negative outcomes) should be presented, without adversely affecting an individual's decision to get screened.

Research Related to Overdiagnosis and Breast Screening Programs

Cancer Australia (2004) in its report noted that, "for all women, there [was] a chance that mammography [would] either miss a change due to breast cancer (false-

negative) or that further tests [would] be performed to examine a change that [was] not due to breast cancer (false-positive)" (Mammography section, para. 1). They also noted that the possibility of a false-positive or false-negative result was greater for younger women, as the density of a young woman's breast tissue made it harder to identify changes. For older women the breasts becomes generally less dense, particularly after menopause, and this was the justification for mammograms being more effective for women aged 50 years and older (Cancer Australia, 2004). Within the context of the residents of Ontario, this research does support the rationale for screening the selected age group for this current study, given the distinction in breast density that lends greater benefit to women older than 50 years. Gøtzsche et al. (2009) conducted a survey on females who were invited to participate in six countries' publicly-funded screening programs. The survey found that the key risks of screening mammography, including overdiagnosis and subsequently overtreatment, had not been outlined in the 31 invitations distributed. Also noted was that 10 of the 31 invitations purported that the screening resulted in fewer invasive surgeries or simpler treatment. The findings of the survey, however, revealed that there was more surgeries (30%), mastectomies (20%), and radiotherapy, all as a consequence of overdiagnosis (Gøtzsche et al., 2009).

Kalager et al. (2012) sought to roughly determine the proportion of overdiagnosis of breast cancer as a result of screening mammography. The research found that an estimated 15% to 25% of the cases of cancer in the Norwegian female population were overdiagnosed. In numerical terms "six to 10 women for every 2,500 women invited to screen had been overdiagnosed" (p. 495). Another study that underscored the relevance

of researching the relationship between knowledge of overdiagnosis and the decision to participate in breast screening programs was done by Bleyer and Welch (2012). Published in the *New England Journal of Medicine*, the research sought to evaluate the effect of 30 years of screening mammography on breast cancer incidence. Using observation, epidemiology, and the data from end results, trends from 1976 to 2008 were examined in early-stage breast cancer incidence and late-stage breast cancer, among a cohort of women aged 40 years and older. The study found that the U.S. incidences of early-stage breast cancer increased by 122 cases per 100,000 women. Of that amount only eight were expected to progress to the advanced disease. It further found that 1.3 million U.S. women in the preceding 30 years were overdiagnosed; more than 70,000 were noted in 2008 accounting for 31% of all diagnosed breast cancer. The study also found that notwithstanding the significant rise in the instances of early-stage breast cancer identification, mammography screening had only slightly decreased the frequency "at which women presented with advanced cancer. [Additionally,] although it [was] not certain which women [had] been affected, the imbalance [in the diagnosis rates suggested] that there [was] substantial overdiagnosis, accounting for nearly a third of all newly-diagnosed breast cancers" (Holloway, 2015, "Effect of three decades," para. 2). For Bleyer and Welch (2012 as cited in Holloway, 2015) the conclusion was therefore that breast "screening [was] having, at best, only a small effect on the rate of death [mortality] from breast cancer" ("Effect of three decades," para. 2). de Gelder et al. (2011) reviewed research conducted on a sample population from screening mammography participants in the Netherlands from 1990 to 2006. Similar to other

studies assessed in this review of literature, the issue of overdiagnosis was mentioned and supporting statistics were provided, indicating the occurrence of overdiagnosis.

In BC, Canada, as recently as 2013, research related to overdiagnosis as a consequence of breast cancer screening was conducted by researchers Coldman and Phillips (2013). The research design implemented in the study entailed the retrospective study of secondary data collected by the BC Cancer Registry between 1970 and 2009, and was cross referenced with the Vital Statistics Agency of British Columbia records of deaths, to identify deaths and cases of breast cancer. The population of focus was women identified with invasive and ductal carcinoma in situ cancers, aged 40–89 years, during 2005–2009. The (participation and population) methods used to estimate overdiagnosis was based on the collective breast cancer rates among women, and included the estimated difference between (a) women who underwent ongoing screening, and those who did not have screening or stopped screening (the participation method); and (b) observed and projected aggregate population rates in 2005–2009 (the population method) (Coldman & Phillips, 2013, pp. E492–E493). The research found that on the one hand, among women aged 60–79 years, there were significantly increased incidences of invasive breast cancer in 2005–2009, relative to 1970–1979. On the other hand, in women aged 40 to 59 years old, there was no continued rise. This suggested and supported the concept that the consequence of screening on overdiagnosis might dependent on age. It was estimated that there was "a modest association between screening and overdiagnosis after allowing a period of 10 years for a compensatory drop after screening had stopped" (p. E498). The rate of overdiagnosis estimated for breast cancer in women over the age of 60 years was

at 5.4% for invasive diseases and 17.3% for both invasive diseases and ductal carcinoma in situ (p. E492).

The observed limitations of the research included (a) self-selection bias, because the researchers removed the effect of first screens (which tended to yield high detection rates and inflated incidence) after the age of usual screening initiation, (b) over estimations of the populations of overdiagnosis over a 30 year period, and (c) the potential influence of other factors (Coldman & Phillips, 2013, pp. E492, E498). Despite not using the RCT research design, Coldman and Phillips (2013) "reviewed findings from clinical trials, included results on both invasive and in situ [cancers, and outlined that the RCT approach was the] most rigorous method to measure the extent of overdiagnosis" (p. E497). This provided validation for the relevance of the research design, as it was identified in more than 40 years' worth of conducted studies related to breast cancer screening. The results of that research were pertinent to this current study because they provided an examination of the issue of overdiagnosis specific to the Canadian landscape. They also supported and validated the appropriateness of the selected age group under evaluation.

Randomized Clinical Trial (RCT) Research Design Implemented

Conducted between 1963 and 1975 and considered probably to be the first research that implemented the RCT design, the Health Insurance Plan "(HIP) Breast Cancer Screening Project [sought] to [examine] whether periodic screening with clinical examination and mammography [resulted] in reduced breast cancer mortality among women 40–64 years at the start" (Shapiro, 2006, p. 2772). Reevaluated by Sam Shapiro

in 2006, it was noted that the study's sample population consisted of women aged 40–64 years living in the Greater New York area, and included 62,000 participants, of which 50% were placed in a study group, with the remaining 50% placed in a control group. On the one hand, study participants were offered screening examinations, and it was noted that 65% of that group "appeared for initial examinations, and a large majority of [them] had at least one of the three additional screenings at annual intervals" (Shapiro, 2006, p. 2772). On the other hand, the women in the control group were administered their regular medical care (Shapiro, 2006). After nine years' wait from the date of entry, the results revealed "128 breast cancer deaths in the control group compared [to 91] in the study group [a combination of screens and those who refused]" (Shapiro, 2006, p. 2774). Other results noted were that, "over an eight-year period after diagnosis, breast cancer cases that were positive only on mammography when screened, had a case fatality rate of 14%" (Shapiro, 2006, pp. 2777-2778), relative to the "32% for cases positive only in the clinical examination and 41% for cases positive on both modalities" (Shapiro, 2006, p. 2779). The final statistics excluded mammography findings based on the fact that one third of the estimated benefits of screening would have been reduced by such results inclusion (Shapiro, 2006).

Limitations outlined in Shapiro's study related to data collection, and included the following (a) there was no uniformity in the pathology protocol by the hospitals that conducted biopsies, (b) there were strict restrictions to the size and number of nodes, (c) the size of lesions were unknown for roughly "[one] third of the cases, and (d) the number of nodes dissected [per hospital] varied significantly" (Shapiro, 2006, p. 2779).

Despite its limitations, Shapiro's study highlighted the need for more awareness of the effects of radiation for inducing breast cancer (Shapiro, 2006). Some of the recommendations from the research were that (a) consideration be given to whether a new randomized trial was needed, and (b) more critical assessment was necessary to determine the incremental value of mammography in a screening program. The research findings indicated that the impact of the screening program for breast cancer mortality continued to be confined to women aged 50 years and over, and it was strongly suggested that consideration was needed for whether screening and mammography would be beneficial to women under age 50 years. To justify screening under age 50 years, the key recommendation was that new information from other studies was required (Shapiro, 2006). Based on the HIP study findings, the "strong support for periodic screening at ages 50 years and over with clinical examination and mammography [was illustrated]" (Shapiro, 2006, p. 2772). As seen in Cancer Australia's (2004) analysis, the findings again supported the rationale for the selected sample population (aged 50–69 years) for this current research. Even though the HIP study was focused predominantly on the benefits of screening mammography, in its analysis and conclusion, it indirectly addressed the issue of overdiagnosis when mention was made of further risks associated with increases in biopsies as a consequence of false-positive results because of increased screening (Shapiro, 2006; Welch, 2004).

Similar to the HIP study that used the RCT research design, the NCI's "Mayo Lung Project . . .[was aimed at] determin[ing] the effectiveness of intensive screening with chest radiography and sputum cytology in comparison with usual care" (Black,

2000, p. 1280). This project was conducted between 1971 and 1983 on a sample population that included 76,000 person-years of observations in each group (Black, 2000, p. 1280). During the trial, participants had an average three-year follow-up after their last screening. Although this study was focused on overdiagnosis in lung cancer, its findings demonstrated the existence of issues of false-positive and false-negative results. Its results also revealed a marked indication that there was a lack of knowledge about what constituted overdiagnosis, and how this lack of knowledge impacted cancer screening results. The research concluded that it was imperative to establish "some mechanism in the screening process [that would] minimize these side effects" (Black, 2000; p. 1281). Among the recommendations made included was the need for a compulsory surveillance period for small nodules as well as very close monitoring of all mortality causes, in the cases of RCTs, to guarantee accurate accounting of breast screening benefits and risks (Black, 2000).

The final recommendation, which aligned well with this research, was the need to provide "a balanced presentation of the potential benefits and risks (including overdiagnosis) to all prospective [screening participants], to ensure they could make an informed decision about [whether to be] screened or enrolled in a randomized trial of screening" (Black, 2000, p. 1281). The main limitation of the research, as highlighted by Black (2000), was the possibility of contamination, given that several subjects from the control group had radiography during the intervention period. Black, however, noted that the number "of these radiographs obtained for screening, rather than for [the evaluations of] specific symptoms, [was unknown]" (Black, 2000; p. 1280). Additionally noted was

that, because of a markedly higher number of "[five-]year survival and excess cases in the screened group, [it strongly implied] that [the screened] group did undergo more intensive screening than the control group" (Black, 2000; p. 1280). Finally, it was highlighted that there were "no baseline differences in age, smoking habits, or other lung cancer risk factors in the two groups" (Black, 2000; p. 1280). Although the type of the cancer being assessed was lung cancer, several parallels were drawn from the findings highlighted in the research, and these acted as a guide in the examination of the knowledge of overdiagnosis and its relationship with decisions about breast screening participation.

The 1963–1975 HIP project established a good foundation for the 2011 study conducted by Brouwers et al. (2011) that examined (a) what interventions were implemented, and (b) what was the rate of increase for cancer screening. Conducted as a "systematic review of [RCTs] and cluster randomized controlled trials [CRCTs] published between 2004 and 2010, [the final research sample for Brouwers et al. (2011) included] 66 new eligible studies with 74 comparisons" (p.1). The research findings concluded "that client reminders, small media, and provider audit and feedback [seemed] to be [effective interventions] to increase . . .screening for breast, cervical, and [colorectal cancers] CRCs" (p. 13). The study also found that "one-on-one education and reduction of structural barriers appear[ed to be] effective. [However, it was noted that] their [respective] roles with CRC and cervical screening . . .[were] less established" (p. 1). Observed in the study was that no current research had existed that had examined "mass media alone as a means of increasing breast . . .screening" (p. 7). Therefore the study

recommended that more research was "required to assess [interventions of] client incentives, mass media, group education, reduction of out-of pocket costs, and provider incentive" (p. 13), to determine their respective impact on screening uptake (participation).

Some of the limitations of Brouwers et al.'s (2011) study included taxonomy (how concepts were classified across the various studies included in the review), organizational frameworks inherited from the foundational reports used, and potential inaccuracies in the estimates related to the absolute impact of any given intervention. While the research done by Brouwers et al. did not definitively indicate that media campaigns (small media, mass media) presented unbalanced information about the benefits of screening, it did reinforce the notion that further research was needed. In particular, research was needed to assess how media campaigns (mass media) potentially impacted screening participation. This by extension would facilitate considerations about presenting information on the associated risks (such as overdiagnosis) of screening participation (Brouwers et al., 2011).

As this research focused on the examination of whether there exists a relationship between knowledge of overdiagnosis (independent variable) and the decision to participate in breast screening (dependent variable), among women aged 50–69 years (cohort), in Ontario, Canada, the studies conducted and/or assessed by a variety of researchers (e.g., Brouwers et al., 2011; Cancer Australia, 2004; Duffy et al., 2010b; Paci, Warrwick, Falini, & Duffy, 2004; Shapiro, 2006; Zackrisson, Andersson, Janzon, Manjer, & Garne, 2006) formed a part of the foundation for this study. Each provided relevant

evidence and support for the significance of screening research geared towards women aged 50–69 years. If this research confirms a relationship between the independent and dependent variables, then the supposition would be that any new information on overdiagnosis to be introduced should follow Giordano et al.'s (2006) ethical principles for effective health communication. The Government of Ontario also would need to account for the understanding that each individual's cognitive construct (schemata) differs, and therefore information must be tailored to that individual. Once these considerations are addressed, the probability of maintaining and/or enhancing screening rates would improve.

Zackrisson et al. (2006) conducted a study "to evaluate the rate of over-diagnosis of breast cancer 15 years after the end of the Malmö[, Sweden,] mammographic screening trial" (p. 689). The research design was a randomized follow-up study that included a sample population of "42,283 women aged 45–69 years" (p. 689). Divided into two cohorts, one that consisted of 21,088 (invited to be screened) and the other with 21,195 (the control group), the research found that, during the follow-up, 9,279 and 9,514 participants died from the cohort invited to screen and the control group, respectively. Of the deaths in the invited cohort, 32% were from breast cancer when compared to 46% in the control group (p. 691). Zackrisson et al. concluded that there was "a clear difference in the cumulative number of all cases of breast cancer (invasive and in situ) . . .in the invited and control groups" (p. 690). Among women aged 45–54 years and 55–69 years, who were invited to the screened group, respectively, there was a noted 16% and 10%

higher rate of breast cancer relative to the control group, suggesting overdiagnosis had occurred (Zackrisson et al., 2006).

Zackrisson et al. (2006) also pointed to earlier studies in Norway that demonstrated 50% overdiagnosis (although it was indicated there were discrepancies with follow-up). Noted in Sweden was an illustrated "21–54% excess incidence [of overdiagnosis] depending on age. [Again, however, those percentages reported had not accounted for] hormone replacement therapy or changes in childbirth alone or in combination with screening" (p. 691). An interesting finding by Zackrisson et al. (2006) was that the rate of overdiagnosis observed may have been underestimated due to the exclusion of "mammography of asymptomatic women [in] the control [group]" (p.692). In the context of this current research focused on Ontario, Canada, the Zackrisson et al. (2006) study in Malmö, Sweden, much like those conducted in other countries, illustrated the advantage and continued use of the RCT research design in studies related to cancer screening. It also reinforced with evidence that overdiagnosis was a relevant topic necessitating further research.

Jørgensen and Gøtzsche, in their 2009 research, examined the extent to which overdiagnosis occurred in publicly-organized screening programs. The research noted that overdiagnosis and overtreatment were inevitable, because it was "not possible to distinguish between lethal and harmless cancers; all detected cancers [were] treated" (Jørgensen & Gøtzsche, 2009, p. 1). Using linear regression analysis, the data collected during a seven-year period, from both screened and nonscreened age groups in Canada (Manitoba), the United Kingdom (UK), Sweden, Australia, New South Wales, and some

areas in Norway, found that overdiagnosis was estimated at 52%. “One in three breast cancers detected in a population offered organised screening [was] overdiagnosed” (p. 1). The research findings were based on a 95% Cl of 46% to 58%. The research further concluded “that the increase in incidence of breast cancer was closely related to the introduction of screening, [noting] that little of this increase was compensated for by a drop in incidence of breast cancer in previously screened women” (p. 1). Although the article did not outline clearly what recommendations were necessary to address the issue of overdiagnosis, it did strongly support the notion that there was a significant level of overdiagnosis. Within the context of this research, if there was an enhanced understanding of what the current levels of overdiagnosis were in Ontario, Canada, this could help in facilitating the establishment of guidelines that ensured the accurate, balanced, and transparent presentation of information about breast screening programs to potential participants. An added benefit in knowing the level of overdiagnosis would be the potential for creating mechanisms to possibly reduce such noted levels.

Duffy et al. (2010b) sought “to estimate the absolute [number] of breast cancer deaths prevented and [tumors overdiagnosed in] mammography screening for women aged 50–69 years” (p. 25). Based on the RCT research design used in the Swedish Two-County trial, the “quantities for mortality and incidence rates [were estimated] in England between 1974–2004 and 1974–2003[, and using] Poisson regression statistical [inferences were made]” (p. 25). The research concluded that “between 2 and 2.5 lives [were] saved for [each] overdiagnosed case” (Duffy et al., 2010b, p. 29). This was noted to be a significant departure from the results reported by Gøtzsche et al. (2009). These

differences noted in Duffy et al.'s (2010b) study was potentially the result of (a) using estimates straight from empirical data, (b) clearly identifying instances of screening invitation versus being actually screened, and (c) "the time frames in the two sets of estimates" (p. 29), during a 10-year screening period. The suggestion was that Gøtzsche et al. (2009) needed a longer period of follow-up prior to any assessment of overdiagnosis.

Another research reviewed in the literature related to the issue of overdiagnosis in breast cancer screening participation included Moss's (2005) study. This study evaluated eight previously conducted RCTs research designed studies spanning several countries, including: the United States' HIP study; four trials in Sweden (Swedish County, Gothenberg, Stockholm, and Malmö); one study in Edinburgh, Scotland; and two in Canada. Moss (2005) found differences in breast cancer incidence possible, due to randomization biases. It was, however, noted that equality of incidence had been used as evidence of a lack of bias in randomization. Relevant to this current research, Moss's analysis about and conclusion of the assessed Canadian trials (after a 13-year follow-up, post the trial) indicated an 11% to 14% excess of all cancers (especially DCIS). This result implied the existence of overdiagnosis (pp. 233-234).

An independent UK panel that consisted of Altman, Cameron, Dewar, Thompson, and Wilcox (chaired by Marmot) (2012) assessed

> The benefits and harms of breast cancer screening [among] women [aged 50–70 years]. The Panel relied mainly on findings from . . .[11 RCTs designed] breast cancer screening [studies] that compared women invited to screening with

> controls not invited. [In addition, it] reviewed evidence from observational studies. The Panel [observed that, in a meta-analysis,] the relative risk of breast cancer mortality for women invited to screening compared with controls was 0.80 (95% Cl 0·73–0·89), . . .a [20%] relative risk reduction. (Altman, Cameron, Dewar, Thompson, & Wilcox, 2012, pp. 1778, 1780, 1782)

Consideration was given to how long ago the trials were completed and if there were internal biases within the trials. The conclusion was

> That 20% was still a reasonable estimate of . . .risk reduction. The best estimates of overdiagnosis [were] from three trials [where] women in the control group were not invited to be screened at the end of the active trial period. . . .[The] excess incidence [noted was] 11% (95% CI 9–12) when. . .[compared to the 19% noted for those] in the invited group in the long term. . . .Results from the observational studies support[ed] the occurrence of overdiagnosis, [however,] estimate[d that] its magnitude [was] unreliable. (pp. 1778, 1783)

The Panel's final conclusion was "that screening reduce[d] breast cancer mortality but that some overdiagnosis occurre[d]" (Altman et al., 2012, p. 1778). They further noted that "for every 10,000 UK women aged 50 years invited to screening for the next 20 years, . . .[there would be] one breast cancer death prevented for about every three overdiagnosed cases identified and treated" (Altman et al., 2012, pp. 1778, 1784). This observation was also illustrated by Jørgensen and Gøtzsche (2009) in their research. Specifically it was observed that over the next 20 years more than 1% of the

approximately 307,000 women, 50 to 52 years old, invited to be screened annually would be overdiagnosed (Altman et al. 2012).

It was observed that researchers Black (2000), Brouwers et al. (2011), Marcus and Prorok (1999), and Marcus et al. (2000) reviewed a RCT designed research, the Mayo Lung Project, in their analyzes. In addition, Altman et al. (2012), Duffy et al. (2010b), Gøtzsche, Jørgensen, Zahl, and Mæhlen (2012), Kaplan and Malmgren (2011); Kopans et al. (2011), Moss (2005), Narod (2012), Smith et al. (2012), and Verbeek (2011) all used and/or reviewed studies implementing the RCT research design. The use of the RCT research design by the various researchers above as well as others not mentioned in this review of literature, indicates that this research design was one of the most used and potentially appropriate research designs for studies concerned with the topic of breast screening and overdiagnosis.

Research Designs Differing from the RCT Methodology

The 'lead-time' approach. Etzioni, Gulati, Mallinger, and Mandelblatt (2013) focused on the topic of overdiagnosis in prostate and breast cancer screening through an examination of studies conducted on each cancer respectively. As it related to breast cancer, eight studies were selected. The analysis found that conceptual and analytic choices made by study investigators could significantly impact overdiagnosis estimates; Therefore, it was necessary to understand those choices. For studies that used the excess-incidence approach, one limitation was that the observed excess incidence was not an unbiased estimate. As such, ad hoc adjustments would need to be applied to the empirical measures; "Understanding these adjustments [was therefore] key to evaluating these

studies" (p. 837). For those studies that implemented the lead-time approach, it was found that the links among model choices, assumptions, and results were often not transparent, making the evaluation of these studies difficult. However, the prior publication of the model in peer-reviewed statistics or biostatistics literature was a strong positive indicator of the model's validity, and ongoing efforts were aimed at improving and standardizing model reporting for greater transparency (p. 837). Smith et al. (2012) was also noted to have commented on the impact different methodological approaches had on the incidence of overdiagnosis observed, and as such reinforced the need for efficacy in methodology selection (pp. 479–480).

Another research that highlighted the lead-time approach was illustrated by Duffy, Lynge, Jonsson, Ayyaz, and Olsen (2008). Duffy et al. (2008) noted that, because this (lead-time) approach resulted in inflated rates of observed incidence (unless the cohort examined had ceased to be screened), it implied "that cumulative incidence in screened or invited cohorts compared to unscreened or uninvited [groups was the most] desirable source of data for [accurately estimating] overdiagnosis" (p. 1178). However, unlike Johnson (2012), Duffy et al. (2008) purported that in the context of Zahl's (2004) research, overdiagnosis was an epidemiological concept instead of a pathological concept. Therefore restrictions to *in situ* or minimal invasive cancer was not necessary even though instinctively the expectation would be that most of the overdiagnosed cases would be in one of those two categories (Duffy et al. 2008).

Supporting Effective (Balanced) Health Communication

There were earlier studies conducted by Olsen et al. (2003) in Denmark that concluded, in the case of Copenhagen and Fyn, organized mammography screenings were able to operate without the occurrence of overdiagnosis (p. 364). This finding was contested by Zahl (2004), who cited a lack of statistical analysis, reporting of the number of detected cancers, and percentage incidence increase as being vital for the correct estimations of overdiagnosed cases (p. 1686). Although the findings from this study are more than 10 years old, it offered an opportunity to view organized screening programs from the premise that when properly implemented (i.e., being able to illustrate the benefits for early detection, while reducing the consequence of overdiagnosis through the presentation of balanced information), there is a possibility for low levels of overdiagnosis despite potentially increased levels of screening mammography participation. However, one year later in Florence, Italy, Paci et al. (2004) looked at overdiagnosis in approximately 60,000 females aged 50–69 years. The period examined was from 1990 to 1999, and the findings indicated that approximately 5% of the invasive and in situ cases were overdiagnosed. The study further concluded that any "apparent increase[s] in breast cancer incidence [were] inherent to the screening mechanism and [were] mainly [the result of] early detection, rather than overdiagnosis" (p.27). Therefore well-informed women should not be deterred from accepting screening invitations (Olsen, 2013).

Baines (2005) highlighted that Humphrey, Helfand, Benjamin, Chan, and Woolf (2002) noted the USPSTF had indicated that women did not understand that, "even in the

best screening setting, most deaths from breast cancer are not prevented" (Baines, 2005, p. S8; Humphrey et al., 2002). Baines posited that the explanations for why women were poorly informed about breast screening stemmed from "unbalanced media coverage, overselling of mammography, web site falsehoods, falsification of evidence in peer reviewed journals, and population comparisons trumping randomized trials" (p. S8). Welch and Black (2010) in their *Oxford Journal* published review of overdiagnosis in cancer, indicated that "the strongest evidence of overdiagnosis come[s] from long-term follow-up after a randomized trial of screening" (p. 607). For Welch and Black, the expectation was that the control group would "catch up [with] the [screened] group, because cancers [appeared] clinically because of signs and symptoms. [Thus, any excess persistence observed] in the screening group years after the trial [was] completed [constituted] the best evidence [of] overdiagnosis" (p. 607). To address overdiagnosis, Welch and Black (2010) outlined clearly that it was important patients were "adequately informed of the nature and magnitude of the trade-off involved with early detection" (p. 611). While this review noted the difficulty of quantifying overdiagnosis, it did highlight the relevance of effective and balanced information presentation and communication. Welch and Black (2010) and Olsen et al. (2003) maintained that even a best guess estimation of the magnitude of overdiagnosis could play a relevant role in the decision-making process (Olsen et al., 2003; Welch & Black, 2010, p. 611).

The Moller et al. (2010) study resonated with the underlying theme that it was vital for health care practitioners, health care "policy makers, and women attending or considering screening [to be] aware of the potential extent of breast cancer overdiagnosis

and consequent overtreatment" (p. 281). Moller et al. highlighted that "presenting the benefits and harms (including overdiagnosis) of breast cancer screening to women [was] needed . . .to help women make an informed choice about whether to participate in screening" (p. 281). Moller et al. also mentioned the need for greater efforts to minimize overdiagnosis and overtreatment, through the use of "trials of less-aggressive treatment for women with screen-detected cancers, [and through the development of] methods for predicting which screen-detected cancers would be unlikely to progress [in] a woman's lifetime" (p. 281). The need for effective communication was again reinforced by Elmore and Fletcher (2012) and Nelson and Hagedorn (2011) who noted it was vital that breast cancer overdiagnosis be carefully outlined in information related to breast screening. Each also indicated the need for significant assessment of how best to ensure effective communication since informed women deserved no less when making decisions about breast screening participation (Elmore & Fletcher, 2012; Nelson & Hagedorn, 2011).

Narod (2012) discussed overdiagnosis as a problem not identified with clinically - detected (i.e., palpable) cancers or with node-positive cancers. It was noted that the assumption therefore was "that a proportion of nonpalpable mammography detected cancers might disappear. [The question however raised was] . . .how many and which ones" (p. 59)? This question was also highlighted by Kopans et al. (2011) in their article that mentioned the possibility of spontaneous regressions of cancer. Unfortunately, it was stated that there was no definitive evidence to support that notion of spontaneous regression (Kopans et al., 2011, p. 617). Kopans et al. concluded, from their review of various RCT designed studies, that "almost certainly some breast cancers [would] never

be lethal" and that the benefits some treated women gained remained unclear; nevertheless, overtreatment was not confined to only detected cancers. The final recommendation was that for women to make informed decisions about screening participation, they were to be given a balanced presentation (including the potentials for overtreatment, overdiagnosis, and the benefits) of the screening process (p. 619).

The study outlined below further underscored the relevance of researching the relationship between knowledge of overdiagnosis and the decision to participate in breast screening programs. It further cemented Giordano et al.'s (2006) ethical principles of effective health communication and integrated the theoretical framework (schema theory) that guided this literature review. Conducted through the implementation of a qualitative study design (a noted departure from the traditional RCT research design) that used focus groups and incorporated presentations explaining overdiagnosis, Hersch et al. (2013) sought to gain insight into "women's responses to information about the nature and extent of overdiagnosis, [as well as to] explore how an awareness of overdiagnosis might influence [the] attitudes and intentions about screening" (Hersch et al., 2013, p 1). The research found that there was minimal prior awareness of breast cancer overdiagnosis. The research further noted that some women, at the highest estimates – 50%, perceived a need to carefully make personal decisions related to screening. For women in the lower (1–10%) and intermediate (30%) estimates there was minimal effect on their attitudes and intentions; many of these women remained committed to screening (Hersch et al., 2013).

Of significance was that although the level of "information preference varied: many women considered it important to take overdiagnosis into account [to] make

informed choices about whether to have screening" (Hersch et al., 2013, p. 1). The research concluded that the effects on screening intentions may to a large extent depend "on the rate of overdiagnosis[, as] overdiagnosis [was a] new notion and [it was] counterintuitive for many people" (p. 1). Therefore, it had the potential to influence screening and treatment decisions in unintended ways, if particular emphasis was not placed on the need for careful communication that provided "information about overdiagnosis [which] must be balanced with the responsibility to address misconceptions that may lead to problems in clinical practice" (p. 8). Hersch et al.'s conclusion supported the ethical principles of the effective health communication model. Hersch et al. also concluded that there was need for the development of communication strategies about overdiagnosis that applied an understanding of how individuals interact with/react to new information. This conclusion illustrated the underlining concept of schema theory.

However, two limitations of the Hersch et al. research were that (a) to avoid information overload, issues of other important screening consequences (such as false-positives and false-negatives) were not discussed; and (b) because of language barriers for nonEnglish speaking participants, it restricted the researchers' "ability to accurately gather [those participants'] views about overdiagnosis" (Hersch et al., 2013, p. 8). Nevertheless, this research was vital because it demonstrated that, while some participants were willing to accept and make decisions with only partial information, there were others that would rather have all the information (both positive and negative). The Hersch et al. (2013) research provided crucial evidence and rationale for the

framework of this study. Hersch et al.'s study reinforced the relevance of conducting a research that focused on understanding what was the nature of the relationship between knowledge of overdiagnosis? As well as, how this knowledge may or may not impact the decision-making process of the participant.

Overdiagnosis versus Overtreatment

Johnson (2012) supported the belief that overdiagnosis was a misnomer for overtreatment. Johnson further explained that carcinoma in situ (a) were usually found by accident prior to screening, and (b) potentially would not have caused any further problems in that patient's lifetime. As such, reports and discussions that addressed overdiagnosis needed to clearly distinguish in situ and invasive cancer in the represented statistics, as overdiagnosis could not refer to invasive cancers (Johnson, 2013, p. 319). Smith et al. (2012), like Johnson (2012), drew strong parallels between overdiagnosis and overtreatment. Smith et al.'s research also went further and outlined other implications of screening that included (a) patient financial cost and inconvenience, (b) anxiety associated with positive test results, and (c) biopsy for benign lesions. Smith et al. concluded that because screening was inherently imperfect, extra attention was necessary to reduce the adverse effects of false-positive tests (Smith at al., 2012, pp. 475-480).

The final two studies assessed for this review of literature were done by Vigod (2011) and Veerbeek (2011). Vigod (2011) noted that women identified factors such as pain, radiation, and embarrassment as key barriers to participation in screening mammography (p. 11). Whereas Veerbeek (2011) suggested that more research was vital to assess how overdiagnosis, exposure due to radiation, and "the occurrence of interval

cancers [influenced morality rates]" (p. 633). Veerbeek also recommended further research that evaluated how "the physical and psychological effects of further investigation of suspicious mammographic findings in women who ultimately [were] found not to have breast cancer [also influenced mortality rates]" (Veerbeek, 2011, p. 633). By using effective health communication that presents balanced information on both the benefits and risks of breast screening, this approach may mitigate against all the outlined barriers and adverse/negative implications of screening.

In reviewing background information relevant to this research, a variety of other studies were not included. Some examples of those studies that were assessed, but not included were conducted and/or reviewed by such authors as Duffy, Sasieni, Olsen, and Cafferty (2010a), Hellquist et al. (2012), and Willis (2013). These studies were not included in this literature review because they either focused on women outside the age range of 50–69 years, or on women with intellectual disabilities, which were target populations not relevant to this current study.

Other Risks Associated With Breast Cancer Screening

This study is focused on overdiagnosis as a risk associated with breast cancer screening. To ensure one of the limitations noted in Hersch et al.'s (2013) study was not repeated, provided below is a brief overview of the concepts of false-positive and false-negative. Also included is a summary of radiation exposure associated with mammography (all noted related risks in breast screening participation). It is, however, relevant to note that, although there are other risks associated with the screening process, only the ones highlighted above will be further explained below.

False-Positive

The term false-positive refers to a result that indicates a given condition has been fulfilled, when it actually has not (i.e., a positive effect has been assumed erroneously). Generally when abnormal test results are given, they are not necessarily indicative of cancer (Jatoi & Gadgil, 2013). False-positive results commonly are found in younger women being screened. These women usually have a family history of breast cancer, have previously done at least one breast biopsy, and are taking hormones, for example, estrogen and progesterone. In some cases the radiologist's skill may affect the chances of getting a false-positive result (NCI, 2013c). Notwithstanding many viewing a false-positive result as a significant downside to screening mammography, data indicates that if patients are knowledgeable of overdiagnosis, the tendency is to be more worried about overdiagnosis relative to a false-positive result. (Welch, 2004; Welch et al., 2011).

False-Negative

According to the NCI (2013c), false-negative in breast screening refers to cases where a test result indicated a condition failed, despite the fact it was successful; That is, no effect has been assumed erroneously. The screening results in false-negatives are usually in younger women, and appear normal although breast cancer is present. One in five cancers may be missed by mammography, and, in the case of false-negative diagnoses, the diagnosed person may delay seeking medical treatment. False-negative results are affected by the rate of tumor growth, the size of the tumor, and the level of female hormones. Like false-positive results, it is impacted by the skill of the radiologist (NCI, 2013c; Welch, 2004, p. 36).

Radiation Exposure Associated with Mammography

Aside from the above-mentioned risks of false-positive and false-negative results, there is also the consideration of radiation exposure as a result of screening mammography. However, because "modern mammography equipment requires very small doses of radiation, [recent] research confirm[ed] that [any associated] risk of harm from radiation exposure by mammography [wa]s very low, [since the] radiation . . .delivered to the breast tissue [would need to be] 100–1000 times higher than [currently] used for mammography" (CBCF, 2014c, "Radiation by mammography causes," para. 1). As such, in addition to the other previously mentioned benefits, it has been on this premise that support for screening mammography has continued. Several supporters have specifically indicated that the small dose radiation disadvantage of screening mammography is far outweighed by the advantage of early detection/diagnosis and treatment of breast cancer (CBCF, 2014c).

Summary

Canada-wide, the rates of cancer incidence and deaths were varied, and this was "because of differences in the type of population, risk factors (including risk behaviours), early detection practices, . . .cancer screening rates, and the availability and use of treatment [which differed] across the country" (CCS , 2014d, "Trends in cancer rates," para. 1). The CCS indicated that the number of newly diagnosed cases as well as the survival rates, were increasing given the growth in Canadian cancer survivors (CCS, 2014 et al., pp. 37–38; CCS et al., 2013, pp.35–36). This increase has been credited to early detection and screening and is in keeping with the underlining theme of the

communication campaigns that state “early detection saves lives” (CCO, 2011b, para. 1). Subsequently, there was noted active advocacy for population-based screening that uses mammography and MRI because it was rationalized as the “best early detection method available for reducing – deaths from breast cancer” (MHLTC, 2012b, “Can anything be done,” para. 3). Therefore the information presented to the Ontario public predominantly promoted breast cancer screening as advantageous.

As a consequence of this unbalanced presentation of information less attention was given to the disadvantages associated with overdiagnosis, even though researchers in Canada (as early as 1992) were documented to have voiced concerns about the efficacy of mammography. These researchers were heavily criticized and largely ignored (Favaro, 2012). However, in recent years, researchers have become more vocal in highlighting the potential implications of presenting information that is not comprehensive. These implications include (a) misrepresentation of facts; (b) misleading conclusions; and (c) physical, psychological, and economic harm resulting from overdiagnosis. As such a wide range of research findings, positing varying degrees of benefits and risks associated with breast cancer screening, have generated discussions that are now aimed at further determining whether or not breast screening results do less good or more harm. In this increasingly prevalent debate, the fundamental questions include (a) how significant are the benefits of screening (mammography), as measured by reduction in the mortality rates of breast cancer, and (b) how significant is the risk in relation to overdiagnosis (Cassels, n.d., para. 3–4)?

In a follow-up interview with Dr. Welch, one of two researchers of the Bleyer and Welch (2012) study, suggested that it appeared that mammography was over-promoted and was the only test in medicine that had been as aggressively sold (Favaro, 2012, para. 10). Dr. Welch further noted that the communications about breast cancer screening provided "an unbalanced view – we over-state the benefits and understate or ignore [the] harms" (Favaro, 2012, para. 10). In support of Dr. Welch's statement above, commentary made by Danish researcher Dr. Peter Gøtzsche, in the *Canadian Medical Association Journal*, pointed to growing evidence that was now nearly irrefutable that "compelling data from the US, Norway and Sweden show[ed] that most overdiagnosed tumors would have regressed spontaneously without treatment" (Cassels, n.d., para. 8). This above study, the subsequent interview, and Dr. Gotzsche's comment offered insight into the rationale for clear and concise health care media communication campaign guidelines. Particularly, guidelines that promoted transparent and balanced representation of factual information for public sector consumption. For this research, an understanding of what screening participants value as important knowledge, would greater facilitate how the various Canadian cancer affiliate agencies and partnerships organize and utilize information in their media campaigns that promote public awareness of breast screening programs (OBSP).

Aside from outlining the theoretical framework (schema theory) that acted as a guide for this research, this chapter provided a synopsis of existing and salient literature related to the major considerations of this study. This review of literature formed the basis of this study. In particular, it provided an overview, background, and relevant research and data related to breast cancer screening, levels of screening participation, and contemporary understandings of key concepts such as overdiagnosis, false-positive, false-negative, and radiation exposure associated with screening. Throughout most of the studies evaluated in this review, it was noted that there was consistent use of the RCT research design for examining overdiagnosis in breast screening programs, with the exception of two lead-time approached studies, one observational study, one retrospective research, and one qualitative designed approach. Several authors, including Black (2000), Brouwers et al. (2011), Marcus et al. (2000), Marcus & Prorok (1999), and Zackrisson et al. (2006) were noted to have used the RCT study design in their respective researches.

Based on the CTFPHC (2014) report approximately:

- 32.90% (329 divided by 1,000 multiplied by 100) of women aged 40–49 years were noted as overdiagnosed (false-positive);
- 28.30% (283 divided by 1,000 multiplied by 100) were overdiagnosed among women 50–69 years; and
- 21.30% in women aged 70–74 years (213 divided by 1,000 multiplied by 100) were overdiagnosed (CTFPHC, 2014).

Although women aged 40–49 years demonstrated a higher level of overdiagnosis (32.90%), women aged 50–69 years were still the most vulnerable to the effects of breast

cancer because, in real numbers as outlined above (see Table 2), more died from the disease. Based on the above data illustrated in the various researches and statistical reports, there was significant evidence that supported the relevance for conducting this research. This research examined the relationship between knowledge of overdiagnosis and breast cancer screening participation among women aged 50–69 years. Key researches that supported the selected sample population were demonstrated via the data outlined, and through the HIP study and Cancer Australia's (2004) report. All the demonstrated findings served as strong evidence and support for the examination of screening for women aged 50–69 years.

Each highlighted study was focused on different aspects of the topic under examination, but they all indirectly supported and formed the framework of this current research. The literature reviewed in this chapter created an opportunity to critically assess and consider how the currently aggressive (Favaro, 2012, para. 10) and unbalanced promotion of breast cancer screening, as being predominantly beneficial, had a direct or indirect relationship to the reported increases in rates of breast cancer screening participation. This, in turn, offered some perspective on the efficacy of current breast cancer statistics and the purported successes as a result of screening participation. This review also outlined the need for effective health communication that presented balanced information in an ethical manner and therefore allowed for informed decision-making on the part of screening participants.

Chapter 3 provides an in-depth discussion of the methodology of the study, including the design. The chapter also addresses considerations of evidence quality, such

as credibility, reliability, and ethics. In addition, Chapter 3 concludes with an outline of the data collection method, the sample and setting, and the selected approach to analysis the data. Chapters 4 and 5 respectively provide (a) a detailed analysis of the study's survey results, (b) explanations of how the results relate to the underlining theoretical framework, (c) overall conclusions of the study, and (d) recommendations for future research.

Chapter 3: Research Method

Introduction

The purpose of this research was to find out if a relationship exists between individual women's knowledge of breast cancer overdiagnosis and their decision to participate in breast screening mammography. This chapter explores the research design and application relevant to answering the research question. To accomplish this, the chapter discusses the selected research design and the rationale for that selected design, provides a brief summary of the target population, and outlines of the selected sample and sampling strategies that were implemented. Also discussed are the processes established to recruit, collect, operationalize, and analyze the data. This specifically includes (a) the pilot test, (b) the recruitment methods, (c) the planned data collection procedures, (d) operationalization of key constructs, (e) assessments of the instruments and materials used, and (f) the data analysis plan. Also included are an examination of issues of validity, reliability, and credibility; an evaluation of the feasibility and appropriateness of the study; and an outline of considerations for ethics and informed consent.

The combined elements of this chapters promote the notion that if decisions are made based on the information presented, then the current unbalanced information being provided about screening mammography does not afford women the opportunity to be informed decision-makers in the screening process. In order to ensure effective health communication about preventative health care options such as breast cancer screening, the information disseminated in media communiqués need to present balanced, accurate,

evidence-based, and relevant information on both the benefits and associated risks of breast screening programs. This study was accordingly designed to improve the understanding of how knowledge of overdiagnosis correlates with levels of participation for screening mammography. In other words, this research sought to explore the extent that knowledge of overdiagnosis corresponded with whether or not women aged 50–69 years decide to get screened for breast cancer. In accordance with this research question and objective, a quantitative research methodology was selected. The specific research design used was a cross-sectional, correlational (nonexperimental) survey study. The target population for the study was limited to Ontario women aged 50–69 years.

The established research question therefore asked: Is there a relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years? The main objective of this study was only to assess the correlation between the two quantitatively measured variables, without determining causality (cause and effect). The study, however, tested the working hypothesis that the more knowledge a woman has regarding the screening process, the more likely she is to participate in breast cancer screening. It also tested directional hypotheses to determine if there was a potentially predictive relationship between the independent and dependent variables. Schema theory, supplemented by the effective health communication model, provided the theoretical framework that guided this study.

The survey instrument used to gather data for this study was a 5-point closed-ended Likert-format questionnaire with responses that ranged from *strongly disagree* to *strongly agree*, as suggested by Trochim (2006). A pilot test was used to ensure the

reliability of the modified Champion Health Belief Model Scales (CHBMS) 45-item study survey instrument. This pilot test was used to specifically ensure the internal reliability of how the independent variable (knowledge of overdiagnosis) being measured was assessed; This variable was measured using a 21-item questionnaire that included basic background information and asked about knowledge of overdiagnosis and how information is presented regarding breast cancer screening. The reliability of Champion's health belief model (HBM) scale, which was used to evaluate this study's dependent variable, was not tested because this was previously validated by several studies, including Paraska (2012), Taymoori and Berry (2009), and Zelviene and Bogusevicius (2007). The complete study survey is reproduced in Appendix A.

Two sample 2-sided *t* tests and logistic regressions were used to analyze the collected data and answer the research question and hypotheses. The findings of the study are presented below in several tables and figures that are discussed in further detail in the appendices. They collectively indicate a potentially predictive correlation between the study variables, leading to a recommendation for follow-up research to specifically assess this predictive potential.

Research Design and Rationale

A variety of factors needed to be considered in order to determine and justify the study's research methodology and research design. These included but were not limited to (a) what did the study aim to accomplish, (b) how the identified study variables were measured, (c) what types of statistical analyzes were necessary to address the study's objective, and (d) how I conducted the study in an ethical way to ensure internal and

external validity and reliability. One of the first steps to accomplishing clear rationalizations for the selected methodology and research design for this study was to start with a clear understanding of the key variables of the study. These key variables have been outlined in the research question and research hypotheses.

Research Questions and Hypotheses

The research questions and hypotheses were as follows

Primary Research Question. Is there a relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years?

Working hypothesis. The more knowledge a woman has regarding the screening process, the more likely she is to participate in breast cancer screening.

Null Hypothesis. There is no relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years.

Alternate Hypothesis 1^{A}. There is a positive relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years.

Alternate Hypothesis 1^{B}. There is a negative relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years.

Secondary Research Question. Is there a relationship between thoughts and attitudes on subsections of the survey (such as mammogram barriers) and the decision to participate in breast cancer screening among women aged 50–69 years?

Variables for the Study

There were three variables in this study. These variables included one nominal level, categorical (discrete), dichotomous (binary), variable, and one interval level, continuous variables. As well, there was one categorical level variable that was made into a binary variable.

Independent Variables

Knowledge of overdiagnosis was the key independent variable examined in this study. This variable was an interval-level variable that was created from the sum of the 38 individual survey questions. Because this study investigated the correlation between knowing about overdiagnosis and deciding to participate in the breast screening process, this identified variable was appropriate for the study. Education level completed was a categorical-level variable with integer values of 0 to 5 (0 = None of the above, 1 = High School Diploma, 2 = College – Diploma/Certificate, 3 = Bachelor's degree, 4 = Master's Degree, and 5 = Doctoral Degree). This variable (educational level completed) was then transformed into a dichotomous variable, with 2 representing participants who graduated with a bachelor's degree or higher and 1 representing those who graduated with a college diploma/certificate or less.

Dependent Variable

The decision to participate in breast cancer screening was the dependent (outcome) variable. This variable, also defined in Chapters 1 and 2, was a binary variable, where answers were limited to yes/no (participated or did not participate in screening). As stated above, this study was focused on examining the relationship between decisions about screening mammography participation and a participant's knowledge of overdiagnosis. Based on the structure of the research question, whereby the decision to participate in breast cancer screening followed the mention of knowledge of overdiagnosis, the implication of this sentence structure was that decisions about breast screening participation rely (depend) on the introduction of the concept of knowledge of overdiagnosis (the exposure variable) to illustrate any possible outcome. Therefore making it (any such decision about breast screening) the dependent variable.

To answer the research question and test the outlined hypotheses, this study used a cross-sectional, correlational (nonexperimental, quantitative) survey (cohort) research design (Black, 2012; Salkind, 2010). This nonexperimental approach was appropriate because, as stated by Kerlinger (1986) (as cited by Black, 2012), ex post facto and correlative studies entail "systematic empirical inquiry in which the scientist does not have direct control of independent variables because their manifestations have already occurred or because they are inherently not manipulable, [as is the case with the study's independent variable – knowledge of overdiagnosis]" (Black, 2012, p. 70). The selected research design offered the advantage of providing access to the target population being investigated in a time-efficient and cost-effective manner. An additional benefit of this

chosen research design was that it enabled the study's finding to add current and location-specific (Ontario, Greater Toronto Area, GTA) knowledge about the topic being examined. In addition, it also facilitated the examination of the nature of one—information on overdiagnosis—of many real life factors that potentially correlate with screening mammography decision-making. The regression model purported in this study could act as a guide for the assessment of other correlations between other real-life factors that interact with and may influence decision-making about participating in programs that promote preventative health care (screening) for breast cancer.

Operationalization of the Study Variables

Operational definitions of the key variables, as outlined in Chapters 1 and 2, indicated that knowledge is "the fact or condition of knowing something with familiarity gained through experience or association; Acquaintance with or understanding of a science, art, or technique; The fact or condition of being aware of something" (Merriam-Webster's Online Dictionary, 2014a, para. 2–3). Overdiagnosis is the identification of a nonprogressive cancer and/or slow-growing cancer that has been identified correctly, but the disease would have never caused any sign or death during the lifetime of the diagnosed patient (Welch et al., 2011). Therefore, the predictor variable, knowledge of overdiagnosis, referred to indicators that an individual was familiar with (had an association/experience/acquaintance with) or had an understanding that, by participating in screening mammography, there was the possibility that a nonprogressive cancer and/or slow-growing cancer, identified correctly, would never caused any signs or death during the lifetime of that diagnosed patient. The research-specific 5-point Likert-format

questionnaire that was part of the overall survey instrument was used to evaluate this operational term.

The outcome variable, decision to participate in breast cancer screening, related to a participant's individual choice "to take part in or experience something [such as screening mammography", (Merriam-Webster's Online Dictionary, 2014b, Partake section, para. 1), which is an] x-ray of the breasts taken to check for breast cancer in the absence of signs or symptoms" (NCI, 2013a, Screening mammogram section, para. 1). This binary dependent variable was coded as follows: Decision to participate in breast cancer screening, PARTICIPATE, 0 = No, and 1 = Yes. The logistic regression model of these study variables produces coefficients (b_i) which illustrate "change (increase when $b_i>0$, decrease when $b_i<0$) in the predicted logged odds of having the [outcome] of interest for a one-unit change in the [predictor] variables" (MedCalc, 2013, Regression coefficients section, para. 2). In these models, it is more common to take the exponential of the coefficient of the predictor thereby producing an odds ratio (Black, 2012; Long, 1997; Pampel, 2000; Salkind, 2010; Starkweather & Herrington, 2012; Vogt, 2007).

Research Methodology

The section below offers details on the study's target population, survey population, and sample size and power. Also outlined is information on the sampling strategy implemented to select survey participants within the target population. Following this section, information is provided on the pilot study, the recruitment approach, the data collection method, and the instrumentation and materials used to measure participants' response to the survey questionnaire.

Survey Population and Setting

It is important to note that in 2011 changes were made to the age parameter for potential Ontario breast screening participants. Outlined in more detail in Chapter 2, this change by the Ontario Breast Screening Program (OBSP) and the Local Health Integration Network (LHIN) enables Ontario women aged 30–69 years to access breast screening services. Prior to the July 1, 2011, announcement, eligible women for screening participation ranged from ages 50 to 74 years. Despite this expansion facilitating greater sociodemographic information and data collection from a wider spectrum, this study focused on data collected for women aged 50–69 years. This decision was made because the increased age range geared towards women 30–49 years are specific to those who are at higher risks of getting breast cancer due to family history and other preexisting conditions. Therefore any inclusion of this information would have potentially skew noted correlations observed.

To the best of my knowledge there were no data that specifically outlined the percentage of women aged 50–69 years living in Ontario's GTA. However, as this research was focused on the above outlined target population, the study sample was obtained from a population of Tropicana Community Services (TCS)' recruited women aged 50–69 years who (a) lived in Ontario's GTA (at the time of the survey); and (b) could read and write in English. Only participants who met the sampling criteria were included in this study. For this primary data collected a letter of cooperation was gained from TCS, and informed consent was implied from each participant that completed a survey and returned it to me.

Sample Size

Because of the unique nature of the target population it was not possible to identify how many women met the study criteria for inclusion. Therefore any power analysis to determine adequate sample size was also not possible. However, despite this limitation this study had a sample of 41 participants. The selected number of participants exceeded those recommended by researchers Baumgartner et al. (2002) and Johnson and Christensen (2004) who each respectively contended that groups of 8–12 and 6–12 participants were appropriate.

Sampling Method

I considered using stratified random (probability) sampling prior to determining that nonprobability, specifically, purposive (purposeful) sampling was optimal for this study. The stratified random (probability) sampling method would have reduced the chances of sampling error in the study—thus facilitating a greater possibility the sample was representative of the general population (Black, 2012, pp. 120–126). It would have also facilitated an increased reduction in sampling error because it allowed for the sample population to be separated into nonoverlapping groups (strata) along the relevant line of the study (Salkind, 2010). Stratified random sampling was not used as generalizations from sample population to target population were not key priorities of this study.

Purposive sampling. In support of the purposive (purposeful) sampling strategy Patton (2002) noted that this sampling method was appropriate for studies with smaller sample sizes. Patton explained that this technique had the advantage of "selecting information-rich cases . . .[from] which one can learn a great deal about matters of

importance and therefore [making it] worthy of in-depth study" (pp. 242-244). Through the use of purposeful sampling, I was better able to eliminate survey participants who were not appropriate for inclusion in the survey—thus retaining only the most suitable ones. I was also able to reduce time and cost constraints—given the narrower focus on relevant candidates for inclusion. As well, I was able to (a) generate results that were more accurate than those achieved with an alternate form of sampling, and (b) identify members of the study's cohort as there was no known list of Ontario GTA women aged 50–69 years that could have been used to guide/locate appropriate survey participants. One key limitation of purposive sampling was that it was prone to researcher bias, thereby reducing the internal validity of the study.

Recruitment, Data Collection, and Instrumentation

Fundamental to scholarly research paper is the collection and analysis of data. Therefore, if data were inaccurate and/or missing, the results and subsequent analysis, conclusions, and recommendations are inappropriate. As such, it was important for me to create and conduct a study with results that had a high level of confidence.

Pilot Study

Before data were collected for this research, a pilot study of the 5-point closed-ended Likert-format survey instrument was conducted among five participants from the target population. Pilot study participants were not incorporated in the actual study data collection. The questionnaire was piloted following official approvals—01-23-14-0229219—from Walden University Institutional Review Board (IRB). To ensure the pilot recruiting strategy was similar to the method used for the actual study, purposeful

(purposive) sampling was used to recruit each pilot participant. The pilot survey was distributed and group administered to the eligible women who agreed to participate. Their implied consent was assumed based on their willingness to listen to the presentation and return a completed pilot test of the survey instrument (see Appendix D). This approach was decided on as it offered a more comparable approach to the recruitment and data collection procedures for the actual study survey. Note that members of the pilot study served the purpose of confirming whether the data collected from participants in the actual study would result in reliable measurements of the study variables (Thabane et al., 2010; Van Teijlingen, Rennie, Hundley & Graham, 2001). Even though the pilot study was created to be comparable to the actual study there were slight differences in procedure for the pilot study relative to the actual study. These variations included (a) pilot participants were administered the survey at a facility not belonging to TCS; and (b) only five participants were recruited for the pilot survey as opposed to the 41 participants for the actual survey.

Recruitment

Given the study was based on primary data there was recruitment of human participants. To identify potential participants for the study's survey, TCS (the research community partner) was engaged to send a letter of invitation to its network (to enlist participants for the study survey). Once weekly, this invitation was sent via the organization and its elected TCS representative's email (in the capacity as TCS vice president). The letter of invitation was also circulated via the various channels used by the community partner. For example, calls were made to individuals in TSC's network to

request their participation in the study's survey. Also the invitation letter was (a) posted on community notice boards used by TCS, and in some of TCS' partner magazines, newsletters, and electronic notice boards; and (b) distributed through several social media platforms. The invitation letter outlined general details of the purpose of the study and included the date, time, and location for survey completion.

In addition, the invitation letter mentioned the distribution of $5 Canadian dollar gift cards to survey participants as a thank you once the surveys were completed and collected. I tracked all emailed RSVP replies and one day prior to the selected presentation date I informed the elected TCS representative to discontinue weekly recruiting efforts that used email invitations. For convenience and without cost to me, TCS offered use of a room at their GTA facility to accommodate the study presentation and survey completion. This was beneficial as the participants—many of whom were assumed to be associated and familiar with TCS and its' location—found it more convenient to participate in and attend an information and questionnaire session, at a location that was familiar and accessible to them.

As the research design was cross-sectional, the survey was conducted at one specified time. Prior to conducting the actual survey, all confirmed participants were required to read the informed consent form. This form was distributed on the day of the survey before the start of the information presentation and survey completion. All participants that attended the presentation and returned a completed survey instrument were noted as having given implied consent based on their actual participation. After participants were provided the informed consent form I briefly (a) outlined the purpose of

the study, (b) described what was expected of participants, (c) answered any remaining questions participants had, and (d) noted that once participants had completed their individual surveys they were free to return (to me) the completed surveys, collect their $5 Canadian dollar gift card and leave.

Following the above instructions I gave a concise presentation about breast cancer screening, its benefits and risks, including overdiagnosis. After the presentation, I distributed the survey instrument. As participants completed and returned their respective surveys they were free to leave. Note that before the registration, information presentation and survey completion, I was identified to participants as the study's researcher. This approach was aimed at maintaining transparency and increasing the study's internal validity by reducing some of the myriad testing and procedural biases.

Data Collection

The data collected included information about participants' (a) health motivations when deciding whether to participate in screening mammography; and (b) level of knowledge of the benefits and risks of screening mammography (Çam & Gümüs, 2009; CCO, 2012d). This information was augmented by survey questions focused on each participants' (a) background information that highlighted sociodemographic characteristics (such as, family history of cancer, age, educational level, prior knowledge of screening mammography, and so forth); (b) knowledge of overdiagnosis; and (c) feelings on how information regarding breast cancer screening is being presented. When considered from the perspective of the participant, the data gathered offered insights to and validation for the need for this study. As well, it enabled me to identify gaps in what

information was being collected, thus validating the need for further research on this topic.

Instrumentation and Materials

To measure the primary data and to verify the study's construct validity, CHBMS was used. Champion (1993, 1999) initially developed and then later revised this scale. The scale specifically measures the health belief model paradigms associated with breast cancer and screening behaviors. Validity and reliability studies of this scale instrument have been conducted by several researchers across many countries. Some recent studies were conducted by Huaman, Kamimura-Nishimura, Kanamori, Sui, and Lescano (2011), Paraska (2012), Parsa, Kandiah, Mohd Nasir, Hejar, and Nor Afiah (2008), Taymoori and Berry (2009), and Zelviene and Bogusevicius (2007).

Through the use of Cronbach's alpha (α), the reliability and internal consistency of the CHBMS were measured (see Appendix B). According to the findings of Taymoori and Berry's (2009) research, there was a reliability coefficient of 0.74 for general concerns related to mammography and 0.61 for preventive health practices related to mammography (p. 468). The sample population of the study consisted of 606 randomly-selected employed women (aged 20–69 years) in Sanandaj, Iran. Another research that illustrated high reliability of the CHBMS was conducted by Huaman et al. (2011). This cross-sectional, Peru-based study looked at women aged 40 to 65 years who went to an outpatient gynecology public hospital in Lima, Peru. There were roughly 285 participants and Cronbach's alpha confidents were 0.75 (susceptibility), 0.72 (benefits), and 0.86

(barriers) (Results section, para. 3). In Huaman et al.'s (2011) research, for the three dimensions, the test–retest Pearson correlation coefficient was higher than 0.6.

The final study to be highlighted, that provided sufficient evidence that the CHBMS met the criteria for construct validity, was a pilot study developed by Paraska (2012). This research explored the relationship between variables in the expanded HBM and compliance with mammography screening among women with multiple sclerosis (MS) who were homebound. The sample population included approximately 260 women aged 40–74 years in Allegheny County, Pennsylvania, U.S. The reliability coefficient for knowledge of benefits and barriers to mammography screening was 0.79, with test–retest reliability of 0.75–0.88 (p. 144). The test–retest approach used by Huaman et al. (2011) and Paraska (2012) was not applied in this study. As noted by Black (2012) a Cronbach's alpha reliability coefficient of 0.70 or higher is considered acceptable, indicating that it sufficiently measures reliability and internal consistency (see Appendix B). An instrument is considered to have validity if it measures the intended concepts.

Champion's HBM scale was designed based on the original HBM that was developed by researchers at the U.S. Public Health Services. The HBM has been used since the 1950s and provides ways of predicting and explaining health behaviors that are protective in nature (Champion, 1993; Naidoo & Wills, 2010; Stein, 2011). Champion's revised HBM scale was described by Çam and Gümüs (2009) as

> a 53-item self-report measure, representing [eight] scales, namely: *susceptibility to breast cancer* (5 items); *seriousness of breast cancer* (7 items); *benefits-BSE* (6 items); *barriers BSE* (6 items); *confidence* (11 items); *health*

> *motivation* (7 items); *benefits mammography* (6 items); and *barriers mammography* (5 items). All the items have 5 response choices ranging from strongly disagree (scores 1 point) to strongly agree (scores 5 points), which are basically a summation of the responses. Higher scores indicate stronger feelings related to that construct. All scales are positively related to screening behaviors except for barriers, which are negatively associated. (p. 51)

The reliability and construct validity of CHBMS have been confirmed by several studies (Huaman et al., 2011; Paraska, 2012; Taymoori & Berry, 2009). This instrument was considered appropriate for this study because it (a) evaluated screening knowledge and behaviors, (b) highlighted health motivations; and (c) identified some aspects of how information presented related to the likelihood of action (decision-making to participate in screening). Figure 6 and Appendix F outline the general framework for the HBM that formed the basis of the CHBMS.

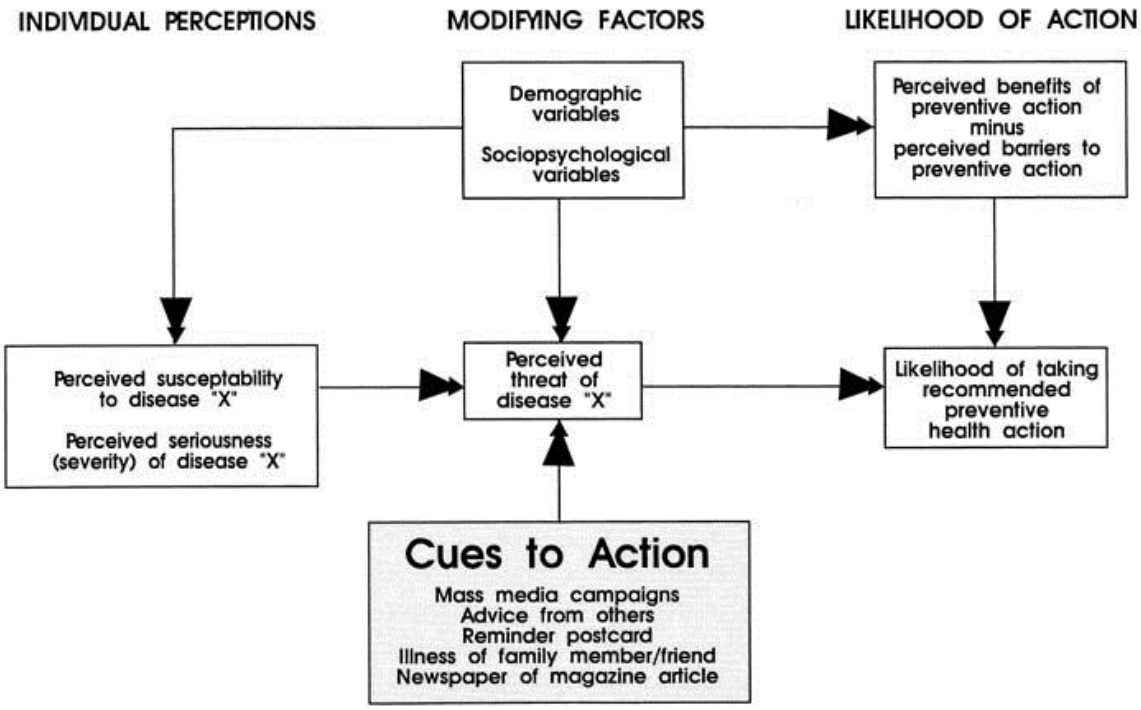

Figure 6. Diagram illustrating the health belief model. The model shows how individuals' perceptions of susceptibility and severity to disease "X" in relation to demographic and sociopsychological considerations, and cues to action inform those individuals' perception of threat levels from disease "X". This in turn informs decisions on how to proceed. Adapted from "Health belief model" by Nursing Information, 2013, Retrieved from http://www.nursing-informatics.com/N4111/HBM.jpg. Copyright 2015 by June Kamnski.

Analysis of the Research Findings

With the assistance of a statistician and the Statistical Package of the Social Sciences (SPSS) software, the data collected were analyzed using two sample 2-sided *t* tests and regression analysis, specifically logistic regression. Logistic regression explains the correlation between the study's dichotomous, dependent (response or outcome) variable and one or more continuous or categorical independent (predictor or explanatory) variables. Logistic regression therefore helped to provide understanding of

the associations and strengths between the study variables. Some of the assumptions of logistic regression include

> [The] functional form of the equation is correct, and hence, the predictors [xi] are linearly and additively related to logit(Y), but variables can be transformed to adjust for nonadditivity and nonlinearity [(for example,] nonlinearly transformed predictors or interaction terms); each case is independent of all the other cases in the sample, or, when cases are not independent, adjustments can be made in either the estimation procedure or the calculation of standard errors (or both) to adjust for the nonindependence; like linear regression, [the variables were] measured without error—all relevant predictors are included in the analysis (otherwise [there might be biases in the logistic regression coefficient)—]and that no irrelevant predictors are included in the analysis [(or else] standard errors of the logistic regression coefficients [might have been] inflated); no predictor may be perfectly collinear with one or more of the other predictors in the model, because perfect collinearity [occurs when] a predictor is completely determined by or predictable from one or more other predictors, and, when perfect collinearity exists, an infinite number of solutions [is available] that maximize the likelihood in ML estimation or minimize errors of prediction more generally; [and the] errors in prediction have a binomial distribution, but when the number of cases is large, the binomial distribution approximates the normal distribution. (Salkind, 2010, "Assumptions of logistic regression," para.1)

As outlined by Salkind (2010)

> The equation for the logistic regression model with a dichotomous outcome is logit (Y) = $\alpha + \beta_1 X_1 + \beta_2 X_2 + \ldots + \beta_K X_K$, where Y is the dichotomous outcome; logit(Y) is the natural logarithm of the odds of Y, a transformation of Y to be discussed in more detail momentarily; and there are $k = 1, 2, \ldots, K$ predictors X_K with associated coefficients β_k, plus a constant or *intercept* α, which represents the value of logit(Y) when all of the X_K are equal to zero. If the two categories of the outcome are coded 1 and 0, respectively, and P_1 is the probability of being in the category coded as 1, and P_0 is the probability of being in the category coded as 0, then the odds of being in category 1 are $P_1/P_0 = P_1/(1- P_1)$ (because the probability of being in one category is one minus the probability of being in the other category). Logit(Y) is the natural logarithm of the odds, $1n[P_1/(1- P_1)]$, where ln represents the natural logarithm transformation. ("Logistic regression, loglinear analysis," para. 2)

In the (logistic regression) model, "the dependent variable [also referred to as Bernoulli variable] take either the value 1 with a probability of success θ, or the value of 0 with the probability of failure 1- θ" (Information Retrieval Blog, 2013, The model section, para. 1). Thus

> Logistic regression generates the coefficients (and its standard errors and significance levels) of a formula to predict a *logit transformation* of the probability of presence of the [dependent variable]
>
> $$logit(p) = b_0 + b_1 X_1 + b_2 X_2 + b_3 X_3 + \ldots + b_k X_k$$

where *p* is the probability of presence of the [dependent variable]. The logit transformation is defined as the logged odds

$$odds = \frac{p}{1-p} = \frac{probability\ of\ presence\ of\ characteristic}{probability\ of\ absence\ of\ characteristic}$$

and

$$logit(p) = \ln\left(\frac{p}{1-p}\right)$$

. (MedCalc, 2013, Description section, para. 1–3)

In this study, the dependent variable, decision to participate in breast cancer screening, (PARTICIPATE) took the value 0 = No, and 1 = Yes. In essence, the research question asked was then answered through logistic regression analysis, because this type of regression analysis provided answers to the question: what was the expected transformation in the outcome variable for a one-unit transformation in X (the independent variable)? Keep in mind that the dependent variable log of odds (not the probability)—the value 1 = Yes—occurred (Vogt, 2007, p. 206). Note carefully that even though a logistic regression model has many similarities to a simple linear regression model, the core distribution is binomial. Also note that the parameters for each model (linear versus logistic) were estimated differently. In ordinary linear regression, the best linear model attempts to minimize the distance measured vertically (the parameter) between the observation point and the model line. While in logistic regression, the opposite is true, the logistic model finds parameters that enhance the conditional probability of detecting the sample values (MedCalc, 2013).

As outlined earlier in the chapter, logistic regression does not make assumptions about the independent variables' distribution. It need not be normally distributed, nor does it have to be linearly related, or of equal variance in each group. The correlation between the predictor and outcome variables is not a direct "function in logistic regression. [Rather] the logistic regression function is used, which is the logit transformation of

$$\theta = \frac{e^{(\propto + \beta_1 X_1 + \beta_2 X_2 + \cdots + \beta_i X_i)}}{1 + e^{(\propto + \beta_1 X_1 + \beta_2 X_2 + \cdots + \beta_i X_i)}}$$

where α = the constant of the equation, and β = the coefficient of the [independent] variables" (Information Retrieval Blog, 2013, The model section, para. 2–3). The significance of the overall logistic regression model is assessed using a maximum likelihood-ratio test. The maximum likelihood-ratio test is a type of chi-squared statistical test used to compare the fit of two models (the null model in which no variables are significantly related to the outcome and the alternative model in which one or more variables are significantly related to the outcome). It assesses how many times more likely the data were present in one model rather than the other. This likelihood-ratio, or equivalently its logarithm, was used to calculate a *p* value, or was compared to a critical value to evaluate whether or not the null model was rejected in favor of the alternative model (Black, 2012; Vogt, 2007).

Maximum likelihood-ratio test (also considered the Likelihood ratio [LR] Chi-square test) was selected because the logistic regression analysis approach was used to examine the data. The likelihood-ratio test (often denoted by *D)* used:

> The ratio of the maximized value of the likelihood function for the full model (L_1) over the maximized value of the likelihood function for the simpler model (L_0). The likelihood-ratio test statistic equals
>
> $$D = -2\ln\left(\frac{\text{likelihood for null model}}{\text{likelihood for alternative model}}\right)$$
> $$= -2\ln(\text{likelihood for null model}) + 2\ln(\text{likelihood for alternative model})$$
>
> This *log* transformation of the likelihood functions [yielded] a chi-squared statistic. (Information Retrieval Blog, 2013, Likelihood-ratio test section, para. 1–2)

It was noted by Agresti (1996) that a Wald test is less reliable than likelihood-ratio tests, particularly as it relates to small sample sizes. SAS Institute Inc. (2013) also indicated that the likelihood-ratio test is preferable—unless computational demands make it impractical to refit the model—to the Wald test, as it provides an asymptotically more powerful and reliable test. Based on these above reasons the maximum likelihood-ratio test was deemed the more appropriate of the two options for this study survey given the limitation of sourcing a large participant sample size. Ultimately, these two statistical tests— two sample 2-sided *t* test and logistic regression,—were conducted, because each helped to explore the different relationships of interest stated in the research hypotheses. The following statistical tests: Point biserial correlation coefficient, Wald test, Pearson's chi-square (X^2) (also referred to as chi-squared), Fisher's exact, *t* tests, Pearson's

correlation coefficient (Pearson's *r*), McNemar's tests, Spearman rho, Kendall tau, Hosmer-Lemshow goodness of fit test, among others, were not selected because they were less desirable tests, given the parameters of the study variables (Black, 2012; Vogt, 2007; Salkind, 2010).

The analyzes in this study follow the standard level of significance, 5% (0.05), and therefore for *p* values lower than or equal to this significance level, the null hypothesis was rejected at that level. Following this rule, the study's *p* value was used to determine that the null hypothesis—there is no relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years—was to be rejected. The nature of correlational studies is that, in their examination of relationships between the independent and dependent variables, the possibility exists for confounding factors, a threat to internal validity. How this study addressed this problem was through logistic regression.

Logistic regression enabled the identification of the relative strength of the predictor variable adjusting for the confounder, educational level completed. Educational level completed was converted to a binary variable with 2 representing those who graduated with a bachelor's degree or higher and 1 representing others who graduated with a college diploma/certificate or less. From an external validity perspective, the study did not attempt to provide generalizations of the findings across the population of interest (women aged 50–69 years). But rather it attempted to find in-depth (information-rich) data to justify the need for further research on this topic. The maximum likelihood-ratio

test was appropriate because the study sample size for this statistical test was small (Agresti, 1996).

Validity, Reliability, and Credibility

Several threats to external and internal validity were addressed above; However, other threats included construct validity. Two such threats were mono-operation bias and mono-method bias. Mono-operation bias, a threat to measurement procedure relative to the independent variable, cause, program or treatment in a research—it does not pertain to measures or outcomes. To address mono-operation bias, relevant studies that assessed the validity and reliability of the CHBMS were examined. Additionally, Appendix B outlines the Cronbach's alpha test for reliability for the individual scales selected from the CHBMS. Mono-method bias, considers the measures or observations, not to programs or causes. Otherwise, it was essentially the same issue as mono-operation bias. Mono-method bias was addressed using a pilot study that was conducted before the main study survey to make sure that the measures established for the study's instrument survey were reliable and operated in practical terms, as suggested by Trochim (2006).

Based on the nature and design of this study there were some threats to internal validity. According to Babbie (2007) such threats include compensatory rivalry and experimental mortality. Because the main point of this study was to measure association/relationship between variables—rather than to compare levels of association between the study target sample and a control group—compensatory rivalry did not exist. Additionally, as the survey instrument was administered and completed at one point in time (cross-sectional research design), experimental mortality also did not exist (Babbie,

2007). However, other threats to internal validity that needed to be addressed in the study were selection bias and instrumentation. Selection bias in some regard was unavoidable, given the (purposeful) sampling strategy. The individuals who agreed to participate in the study survey may not have been representative of the population. Instrumentation issues within the study were predominantly addressed by Champion (1999) and found to be within acceptable limits. To address further concerns of instrumentation bias because of the research-specific 21-item questionnaire that was created, a pilot study was conducted.

The validity, reliability, and credibility of the primary data used in this study were verified through the various statistical tests aimed at assessing (a) *n*—sample size—, 1-β—statistical power—, and α—size effect—; and (b) internal, external, and construct validity, all of which served the purpose of confirming the level of efficacy and accuracy implemented in conducting this study. The credibility of the secondary data sources—that were the foundation of Chapter 2—laid in the fact that they had been used by many experts in the health care field studying the topic of breast cancer and breast cancer screening. The OBSP, in the context of Ontario, Canada, is the foremost expert source for statistical data on cancer in general, and breast cancer specifically. Via the OBSP, information presented by the Cancer Care Ontario (CCO) is based on the same data this research used in the review of literature. The repeated and frequent use of the OBSP as a key source for breast cancer information lends itself to continual scrutiny, resulting in maintained and/or enhanced validity and reliability; secondary data were data easily assessable for replicability (McNabb, 2008).

Notwithstanding all the other threats to validity, reliability, and credibility already outlined, statistical conclusion validity was the key threat for studies of this nature. This was a key threat because there was a possibility that the measured proportions was not sufficiently far apart to allow a conclusion. Therefore this indicated a small bias or a widely spread distribution. Statistical conclusion validity looked at how correct or reasonable statistical conclusions were about the degree to which there actually existed a relationship (correlation) between the study variables. In essence, it looked at whether the study resulted in a Type I—false positive (finding a correlation even though one did not exist)—or Type II error—false negative (finding no correlation even though one did exist). Finally, the last consideration of statistical conclusion validity was whether the results revealed no statistically significant bias in either direction. For any of these above noted statistical outcomes, a study conclusion was still possible. These study conclusions included (a) women aged 50–69 years were highly knowledgeable of overdiagnosis when making decisions to participate in breast cancer screening, (b) women aged 50–69 years had limited knowledge of overdiagnosis when making decisions to participate in breast cancer screening, or (c) women aged 50–69 years had no knowledge of overdiagnosis when making decisions to participate in breast cancer screening.

Feasibility and Appropriateness of the Study

The use of a cross-sectional survey approach, with the assistance of TCS (the community partner) who has a strong presence in the GTA of Ontario, was an effective way to find participants quickly. The research survey was hosted and administered (free of cost) in TCS' GTA facility. Overall costs were minimal because pilot test participants

and actual survey participants were not paid. Participants were however given gifts cards valued at $5 Canadian dollar each as a thank you. I was solely responsible for all costs associated with the completion of this study.

Ethical Considerations and Informed Consent

Any research study that involves human participation requires the approval of the Institutional Review Board (IRB). I did not contact the participants for the study survey until approval (01–23–14-0229219) was given by Walden University's IRB. The IRB's purpose is to help protect all participants in the study, including the researcher, and to ensure no harm, either physical or mental, to any participant. Although direct contact was made with human participants, no adverse effects for any beneficiary, county, or participant occurred from the results of this study. However, as with all studies using primary data, there were participant concerns regarding anonymity and confidentially, therefore no patient identifiers were used in this study.

Anonymity is a strong guarantee of privacy for the individual patients in the collected data, but not for the cancer organizations in this study (Trochim & Donnelly, 2008). This was the case for those cancer organizations identified in Chapter 2 as sources of secondary data. Given the accessed data were publicly available, it was my belief and assumption that each cancer organization understood that studies conducted utilizing that freely accessible information/data would be made public at the time of submission. The primary data gathered were accessible only on my personal computer that was password protected at all times. I was not required to return or destroy any data publicly accessed or collected via the survey instrument as the information gathered was my property and

not that of the community partner. However, the information will be sourced for 5 years following the completion of this study, as is the requirement of Walden University.

There was no conflict of interest in the conducting of this study, as I was in no way affiliated with the community partner whose membership network and facilitates were used to gather the data analyzed. Also there was no conflict of interest regarding the use of TCS' facilities to conduct the survey as the organization's resources are available without cost to anyone requesting its use. Additionally, I did not work in the public sector or any health care sector, including those related to cancer prevention or treatment. Finally, this topic had no personal (sentimental) value that unduly influenced or biased my assessments of the study findings.

Summary and Transition

The purpose of this chapter was to identify the research methodology and research design used for the study. The study's population and setting, sampling strategy, data collection method, data analysis plan, instrumentation, and ethical considerations were outlined. Descriptions of how the research attempted to maintain validity, reliability, and credibility were also provided. As discussed in this chapter, the cross-sectional, correlational (nonexperimental, quantitative) research design was implemented to examine the relationship between overdiagnosis knowledge and decisions to participate in breast screening programs among women aged 50–69 years.

In Chapter 4 the results of the study's survey instrument is outlined along with a detailed report of the descriptive and inferential analyzes conducted. Also included is an interpretation of the working and directional hypotheses discussed in this chapter. As

appropriate, findings are illustrated in the form of tables and figures. Chapter 5 gives an overview of the study's key findings. This chapter also provides the results of the study in relation to the theoretical foundation (the effective health communication model and schema theory). Final recommendations on future research is outlined as well as the implications for positive social change.

Chapter 4: Results

Introduction

This study implemented a cross-sectional, correlational (nonexperimental, quantitative) research design grounded in schema theory and the effective health communication model. The study examined the existence of a relationship between knowledge of overdiagnosis and decisions to participate in breast cancer screening programs, among women aged 50–69 years. To accomplish this analysis, primary data were collected using a 45-item closed-ended Likert-format group administered survey instrument (see Appendix A). The study survey instrument specifically measured each participant's knowledge levels of (a) breast cancer screening and its associated benefits and risks, (b) what motivated their health-related decision-making, and (c) overdiagnosis. In addition, the survey evaluated opinions on how information related to breast cancer screening is presented. Survey data were analyzed using two sample 2-sided *t* tests and logistic regression models.

As outlined in Chapter 2, the Ontario public has predominantly been presented with information about breast cancer screening as being advantageous, while less attention has been given to such disadvantages as false positives, false negatives, mammography-related radiation exposure, and considerations of overdiagnosis. Breast cancer-related overdiagnosis was a focus of this study. Researchers in Canada voiced concerns about the efficacy of mammography as early as 1992, but were strongly criticized and have been largely ignored (Favaro, 2012). This status quo of an unbalanced presentation of information about screening mammography still persists in Canada today.

This chapter presents information on the research question and hypotheses, the pilot test, the recruitment phase and response rates, and the data collection process. In addition, participants' demographic information are outlined. Finally, the findings of the descriptive and inferential statistical analyzes conducted are presented.

Primary Research Question

Is there a relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years?

Working Hypothesis

The more knowledge a woman has regarding the screening process, the more likely she is to participate in breast cancer screening.

Null Hypothesis. There is no relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years.

Alternate Hypothesis 1^{A}. There is a positive relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years.

Alternate Hypothesis 1^{B}. There is a negative relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening among women aged 50–69 years.

Secondary Research Question

Is there a relationship between thoughts and attitudes on subsections of the survey such as mammogram barriers and the decision to participate in breast cancer screening among women aged 50–69 years?

Findings of the Pilot Study

After receiving approval to conduct the study from Walden University's Institutional Review Board (IRB), I first conducted a pilot test to verify the validity and reliability of the entire survey instrument. This pilot study specifically assessed the validity and reliability of the two supplementary scales I created. Cronbach's alpha (α) was not calculated given the small number of pilot test participants (five). However, the face validity of the survey instrument was confirmed by the pilot participants, who indicated that they felt the survey covered the concepts it purported to measure. Based on this face validity, no revisions to the survey instrument were deemed necessary.

Data Collection

The collection of data commenced following the official receipt of Walden University IRB approval (Approval #01-23-14-0229219 on September 17, 2014) that clearly outlined the parameters that the study needed to maintain in order to appropriately address the various ethical considerations. The participant recruitment and data collection process for both the pilot test and actual survey took 18 days from September 17, 2014 to October 4, 2014. A variety of communication platforms were used during this time to post and distribute the electronic and printed letters of invitations. As part of the recruiting process, I tracked all advance RSVPs via my Walden University email. Prior to

conducting the actual study on October 4, 2014, a pilot test was held on September 22, 2014. Overall, 41 women aged 50–69 years participated in the research survey, not including the five women who had participated in the pilot test.

Recruitment Approach in the Greater Toronto Area (GTA)

The data were collected according to the plan outlined in Chapter 3. The research sample was recruited with the assistance of my community partner's elected representative. The research sample consisted entirely of women aged 50–69 years who lived in the GTA and were able to read and write in English. Ontario's GTA covers roughly 2,751 square miles, 24 municipalities, and at the time of the study had a population of more than six million people. The GTA is bordered by the Niagara Escarpment to the west, Kawartha Lakes to the east, Lake Simcoe to the north, and Lake Ontario to the south (Statistics Canada, 2011). From September 17, 2014 to October 3, 2014 the representative elect from Tropicana Community Services (TCS) distributed the study's electronic invitation letters through various social media including Facebook, LinkedIn, Twitter, Instagram, and MailChimp. In addition, I posted printed invites on several community notice boards throughout the GTA, specifically in North York, Scarborough, Etobicoke, East York, and Downtown Toronto. Finally, on October 2, 2014 the research survey was announced in The Caribbean Camera newspaper (see Appendix G).

Descriptive Analysis of the Survey Sample

Background Characteristics of Survey Participants

Thirty-two (78.05%) of the 41 survey participants had no family history of breast cancer (see Figure 7 and Figure 8). Despite having no family history of breast cancer, 33 participants (80.49%) noted that they had previously participated in breast screening programs (see Table 3). A breakdown of the number and percentage of respondents who have previously participated in breast cancer screening (BCS) is shown in Table 3. The statistics outlined below therefore raise the question of why more women aged 50–69 years still opted to get screening regardless of not having a family history of breast cancer. As noted by the Ontario Ministry of Health and Long-Term Care (MHLTC), Cancer Care Ontario (CCO), the Canadian Cancer Society (CCS), the Public Health Agency of Canada (PHAC), the Canadian Breast Cancer Foundation (CBCF), among others, a family history of the disease is associated with a higher risk of breast cancer. As this risk factor is part of the information presented to GTA Ontario women, follow-up questions were posed, asking what other factors are prompting women to still participate in screening mammography, and, of those factors, how significantly not having a balanced presentation of information on breast screening programs' benefits and risks influenced their decisions.

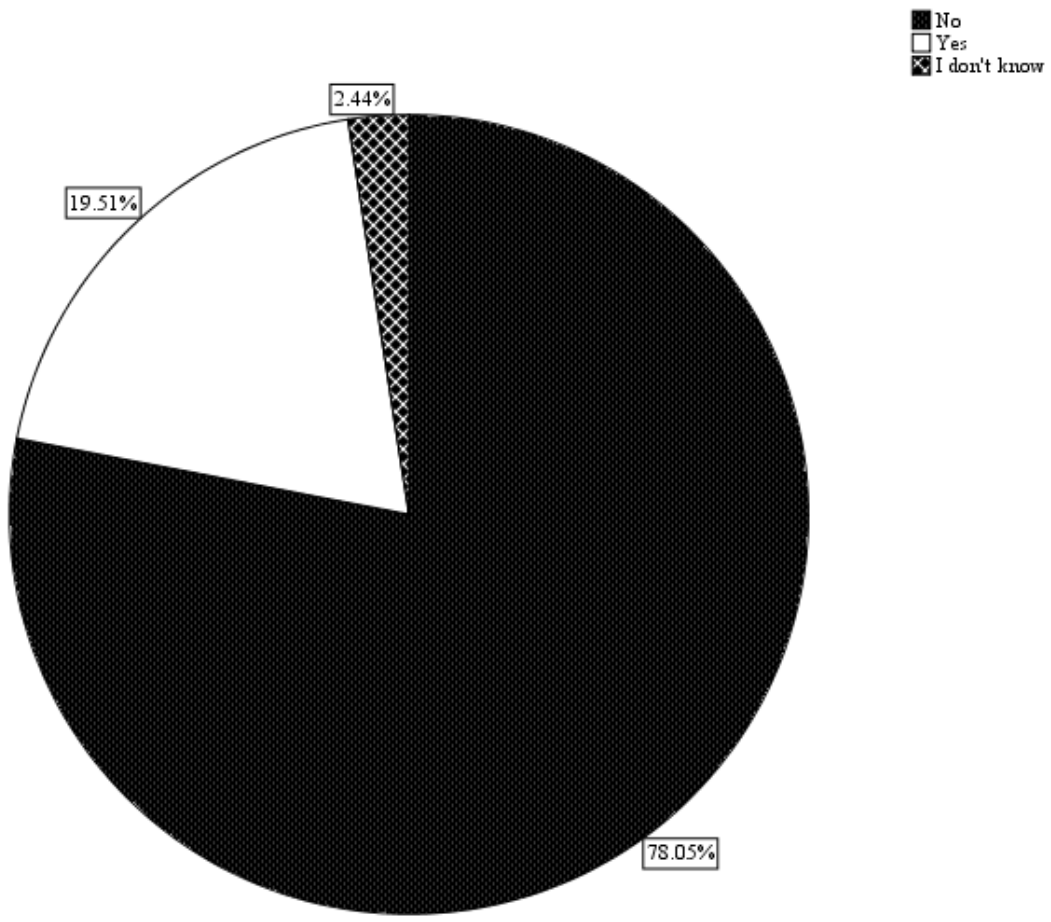

Figure 7. A pie chart showing the participants' family history of breast cancer. Of all the survey participants (*n* = 41), 78.05% had a family history of breast cancer, 19.51% had no family history of the disease, and the remaining 2.44% did not know if there was a family history of breast cancer.

Table 3

Previous Participation in Breast Cancer Screening (BCS) (n = 41)

Previous Participation in BCS	Frequency	Percent
No	8	19.51
Yes	33	80.49
Total	41	100

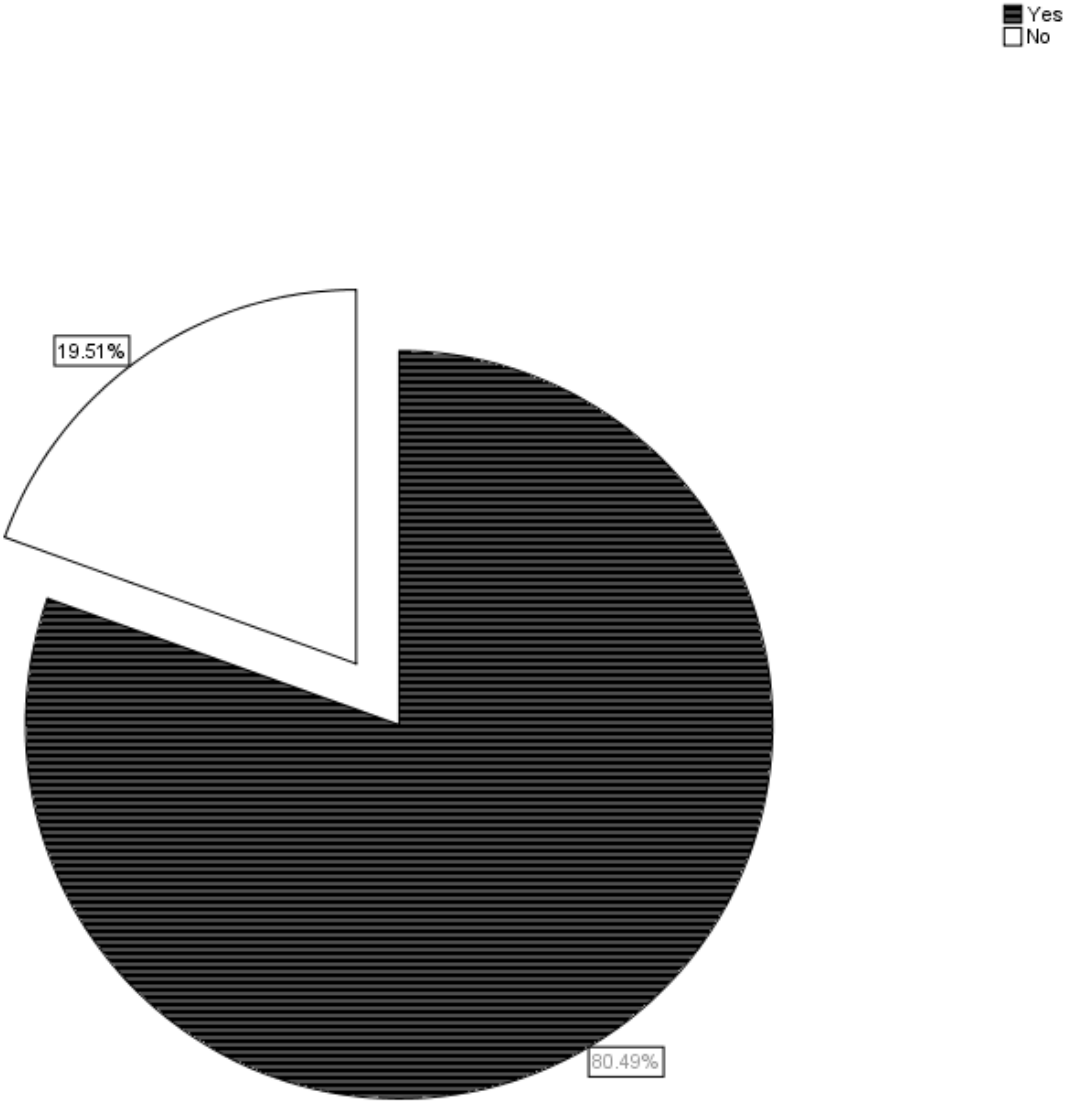

Figure 8. A pie chart of previous participation in breast cancer screening (BCS). This figure illustrates that of the sample size (*n* = 41), 80.49% (33) participants had previously participated in BCS prior to taking part in the research survey. The remaining 19.51% (8) participants had not participated in BCS before the study presentation/survey.

Figure 9 revealed that 58.54% of the survey participants had more than 15 years knowledge of screening mammography, and 26.83% had between 6–10 years of breast cancer screening knowledge. Overall the indication was that on average participants had 11–15 years of knowledge of breast cancer screening even though 75.61% (31 participants) had either no knowledge (*none*) or limited knowledge (*novice level*) of overdiagnosis in breast cancer screening prior to the survey presentation (see Figure 10). Based on the above outlined result, even though 85.37% of the survey sample had more than six years knowledge of screening mammograms (see Figure 9), 75.61% had no/limited knowledge of overdiagnosis (see Figure 10). This result therefore supported the notion that current information presenting breast screening programs to GTA Ontario residents (as the literature in Chapters 1 and 2 suggested) is not balanced. Hence participants in the screening mammography programs are making health-related decisions without being properly informed. As noted by Giordano et al. (2006) this issue needs to be addressed because effective health communication entails the disclosure of both the benefits and risks of an intervention so potential users of that intervention can make decisions based on having all the necessary information pertaining to that intervention.

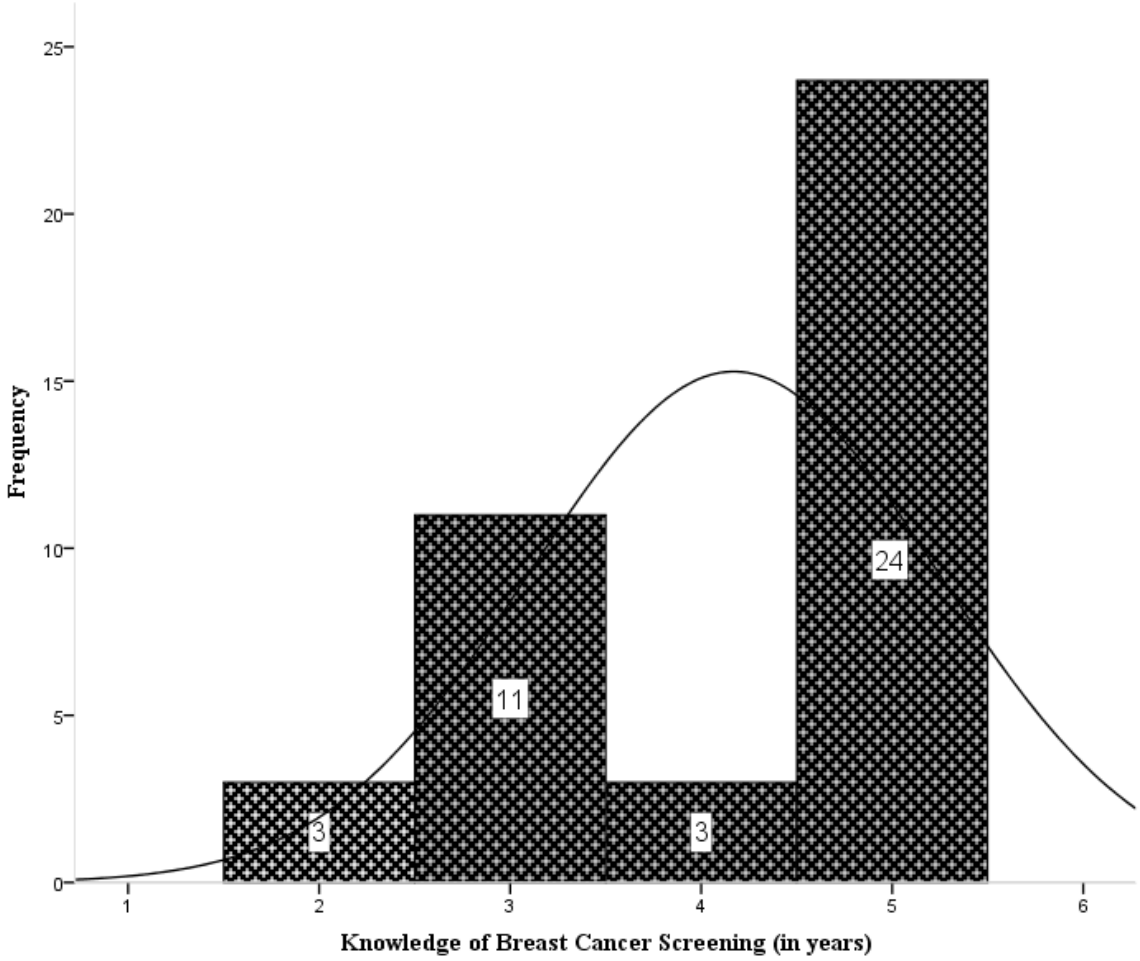

Figure 9. A histogram of each participants' knowledge of breast cancer screening measured in years. The figure shows that 24 of the survey participants had more than 15 years' knowledge of screening mammography, while three had between 6–10 years, another 11 had between 1–5 years, and three had less than 1 year's knowledge of BCS.

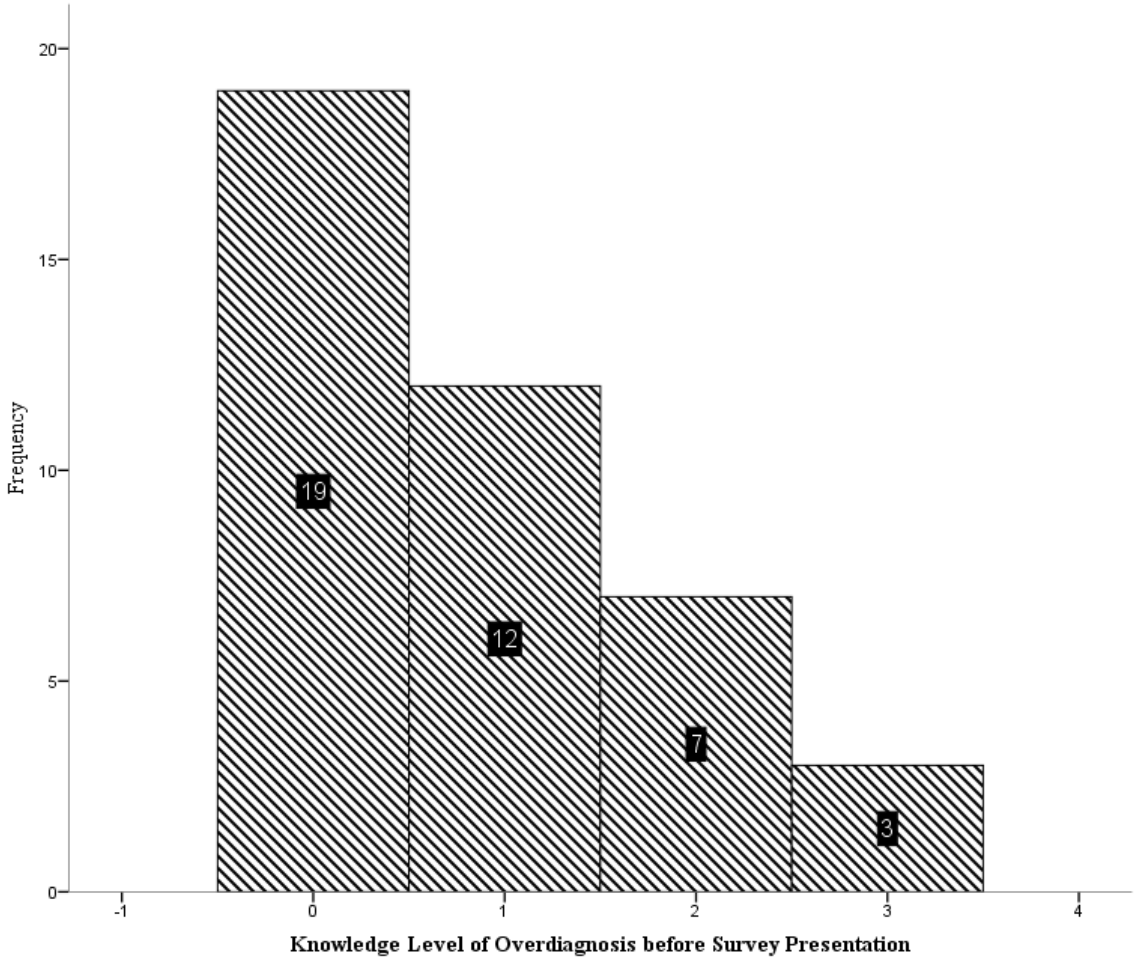

Figure 10. A histogram of each participants' knowledge level of overdiagnosis before the research survey presentation. Prior to the research survey presentation 19 survey participants had no knowledge (*none*) of overdiagnosis in BCS, 12 had limited knowledge (*novice level*), seven had satisfactory knowledge (*intermediate level*), and three had comprehensive knowledge (*advanced level*) of overdiagnosis in BCS.

In Figure 11, 40 (97.56%) of the participants had completed between high school to doctoral level education, and one participant (2.44%) had completed none of the above education levels. The survey sample's result (see Figure 11) indicated that on average survey participants had either college–diploma/certificate or bachelors' level education. The implication of this was that although the major of breast screening participants were

educated, they still have limited and/or no knowledge of overdiagnosis being an associated risk of breast cancer screening. The results showcased that a majority of survey participants still had limited and/or no knowledge of overdiagnosis in the screening process (see Figure 10), despite them having either college–diploma/certificate or bachelors level education (see Figure 11) and more than six years of knowledge of screening mammograms (see Figure 9).

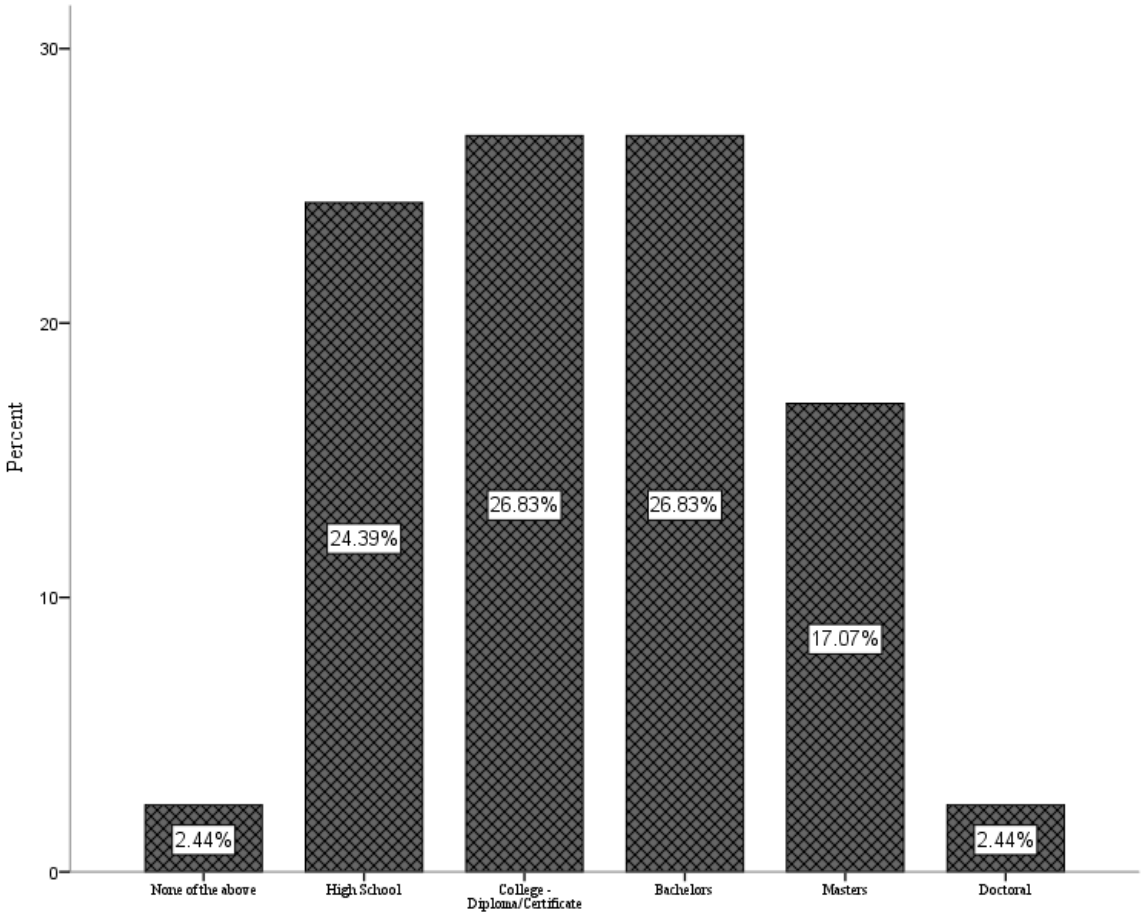

Figure 11. Bar chart showing the participants' highest levels of education completed. Of the sample size (n = 41), 2.44% had completed education at the doctoral level, 17.07% at the master's degree level, 26.83% at the bachelor's degree, another 26.83% had a college diploma/certificate, and the remaining 2.44% had not completed any of the educational levels previously identified.

As outlined in Table 4, seven (13.2%) participants learned about screening through print media. Eight (15.1%) learned about screening via electronic media and 21 (39.6%) using in-person contact. Finally 17 (32.1%) participants used all channels mentioned above as a means of learning of breast screening. These findings show that in 51.2% of the cases participants learned about screening mammograms through in-person contact (via face-to-face, telephone, email with friends, family, health care professionals, etc.). However, 41.5% of the times a combination of print, electronic and in-person contact was used to learn about information related to breast cancer screening.

Table 4

Descriptive Statistics of the Communication Channels Participants Used to Learn About Breast Cancer Screening (BCS)

Communication Channel Used to Learn About BCS		Responses		% of Cases
		n	%	
Media participant learned about Breast Cancer Screening (BCS)[a]	Q.6a - Participant learned about BCS through print media	7	13.2%	17.1%
	Q.6b - Participant learned about BCS through electronic media	8	15.1%	19.5%
	Q.6d - Participant learned about BCS through in-person contact	21	39.6%	51.2%
	Q.6e - Participant learned about BCS through all of the above media	17	32.1%	41.5%
Total		53	100.0%	129.3%

Note. a. Dichotomy group tabulated at value 1.

Inferential Analysis of the Survey Sample

The consistency of the 38 question survey was assessed using a Cronbach's alpha statistic. Values of Cronbach's alpha greater than 0.7 are required for early research work (Black, 2012; Nunnally, 1978, p. 245). The Cronbach's alpha for this survey was 0.79. This shows good consistency and as such allows the creation of summary scores. A total score was created as the sum of the 38 questions. To ensure that all questions were worded such that the highest score represents a positive response, the questions in the *mammogram barriers* section were reverse scored. Three questions in the *knowledge of overdiagnosis* section were also reversed. The total survey sum score can have a theoretical range of 38 (responses are all 1's) to 190 (responses are all 5's). One participant was missing two responses and for this individual their mean score on the section was substituted. A two sample 2-sided *t* test was first run to compare the total survey score between those who participated in BCS to those who did not participate in BCS. This study found that those who previously participated in breast cancer screening had statistically significantly higher total overall survey score (M =149.12, SD =12.07) compared to those who did not (M =134.88, SD =11.06), $t(39) = -3.04$, $p = 0.004$ (see Table 5).

Table 5

*Two Samples t-*Test *Results of Total Overall Survey Score Between Two Groups (n = 41)*

	Previous participation in BCS					
	No	*SD*	Yes	*SD*	*t*	*df*
Total Overall Survey Score	134.88	11.06	149.12	12.06	-3.04**	39

Note. * = $p < .05$, ** = $p < .01$, *** = $p < .001$.

A logistic regression analysis was conducted to predict whether patients had previous breast cancer screening using education level completed and total overall survey score as predictors. The logistic regression model was statistically significant, $\chi^2(2) = 11.08$, $p = .004$. The model explained 37.8% (Nagelkerke R^2) of the variance in previous breast cancer screening. The *p* value demonstrated that only total overall survey score made a significant contribution to prediction ($p = .007$) of past breast cancer screening (see Table 6). The odds ratio (*OR*) indicates that when total overall survey score is increased by one unit (i.e. becomes more positive towards screening), the patient is 1.14 times more likely to have had previous breast cancer screening (95% confidence interval 1.03-1.25). Education level completed was not a significant predictor ($p = 0.14$).

Table 6

Multivariable Analysis Using Logistic Regression To Predict the Previous Breast Cancer Screening Based on Total Overall Survey Score and Education Level Completed (N = 41)

Variable	*OR*	95% CI	B	*SE*	Wald	*df*	*p*
Constant	.00		-17.32	6.83	6.43	1	.011
Education Level Completed (2 vs 1)	4.82	0.61-38.02	1.57	1.05	2.23	1	.14
Total Overall Survey Score	1.14	1.03-1.25	.13	.05	7.08	1	.007

Note. The variable education level completed was made into a binary variable where participants who graduated with a bachelor's degree or higher = 2 and college diploma/certificate or less = 1.

The consistency of the six *mammogram benefit* section questions was assessed using a Cronbach's alpha statistic. Values of Cronbach's alpha greater than 0.7 are required for early research work (Black, 2012; Nunnally, 1978, p. 245). The Cronbach's alpha was 0.74. This shows good consistency and allows the creation of summary scores. A total score was created as the sum of the six questions. This score can have a theoretical range of six (responses are all 1's) to 30 (responses are all 5's). A two sample 2-sided *t* test was first run to compare the total mammogram benefits score between those who participated in BCS to those who did not participate in BCS. This study found that there is no statistically significant difference in total mammogram benefit scores between those who previously participated in breast cancer screening (M = 21.76, SD = 4.75) and those who did not (M = 20.25, SD = 4.46), $t(39) = -0.72$, p = 0.42 (see Table 7).

Table 7

Two Samples t-Test Results of Total Mammogram Benefit Score Between Two Groups (n = 41)

	Previous participation in BCS					
	No	*SD*	Yes	*SD*	*t*	*df*
Total Benefit Score	20.25	4.46	21.76	4.75	-0.82	39

A logistic regression analysis was conducted to predict whether patients had previous breast cancer screening using education level completed and total mammogram benefit score as predictors. The logistic regression model was not statistically significant, $\chi^2(2) = 1.482$, $p = .477$. The model explained only 5.7% (Nagelkerke R^2) of the variance in previous breast cancer screening. The *p* values demonstrated that neither total mammogram benefit score nor education level completed made a significant contribution to prediction ($p = .29$ and $p = .38$ respectively, see Table 9). This is also shown with the odds ratio findings for total mammogram benefit score (*OR* = 1.07, 95% CI = 0.92-1.34) and education level completed (*OR* = 2.19, 95% CI = 0.38-12.79) whose confidence intervals contain the null value of one.

Table 8

Multivariable Analysis Using Logistic Regression To Predict the Previous Breast Cancer Screening Based on Total Mammogram Benefit Score and Education Level Completed (N = 41)

Variable	*OR*	95% CI	B	*SE*	Wald	*df*	*p*
Constant	.371		-1.06	2.20	.23	1	.63
Education Level Completed (2 vs 1)	2.19	0.38-12.79	.78	.90	.76	1	.38
Total Benefit Score	1.07	0.92-1.34	.10	.09	1.11	1	.29

Note. The variable education level completed was made into a binary variable where participants who graduated with a bachelor's degree or higher = 2 and college diploma/certificate or less = 1.

The consistency of the 11 *mammogram barriers* section questions was assessed using a Cronbach's alpha statistic. Values of Cronbach's alpha greater than 0.7 are required for early research work (Black, 2012; Nunnally, 1978, p. 245). The Cronbach's alpha was 0.81 which shows good consistency and allows the creation of summary scores. A total mammogram barrier score was created as the sum of the 11 questions. This score can have a theoretical range of 11 (responses are all 1's) to 55 (responses are all 5's). A two sample 2-sided *t* test was first run to compare the total mammogram barriers score between those who participated in BCS to those who did not participate in BCS. This study found that those who previously participated in breast cancer screening had statistically significantly higher total overall mammogram barrier score (*M* = 47.97,

SD = 5.66) compared to those who did not (*M* = 40.50, *SD* = 3.38), *t*(39) = -3.56, *p* = 0.001 (see Table 9).

Table 9

Two Samples t-Test Results of Total Mammogram Barrier Score Between Two Groups (n = 41)

	Previous participation in BCS					
	No	*SD*	Yes	*SD*	*t*	*df*
Total Barrier Score	40.50	3.38	47.97	5.66	-3.56**	39

Note. * = $p < .05$, ** = $p < .01$, *** = $p < .001$.

A logistic regression analysis was conducted to predict whether patients had previous breast cancer screening using education level completed and total mammogram barrier score as predictors. The logistic regression model was statistically significant, $\chi 2(2) = 11.24$, $p = .004$. The model explained 38.2% (Nagelkerke R^2) of the variance in previous breast cancer screening. The *p* values demonstrated that only total mammogram barrier score made a significant contribution to prediction ($p = .014$, see Table 10). The odds ratio indicates that when total mammogram barrier score is increased by one unit (i.e. becomes more positive), the patient is 1.31 times more likely to have had previous breast cancer screening. Education level completed was not a significant predictor ($p = 0.50$).

Table 10

Multivariable Analysis Using Logistic Regression To Predict the Previous Breast Cancer Screening Based on Total Mammogram Barrier Score and Education Level Completed (N = 41)

Variable	*OR*	95% C.I.	B	*SE*	Wald	*df*	*p*
Constant	.00		-11.01	4.89	5.06	1	.025
Education Level Completed (2 vs 1)	1.91	0.30-12.20	.64	.95	.46	1	.497
Total Barrier Score	1.31	1.06-1.63	.27	.11	6.09	1	.014

Note. The variable education level completed was made into a binary variable where participants who graduated with a bachelor's degree or higher = 2 and college diploma/certificate or less = 1.

The consistency of the eight *information presentation* section questions was assessed using a Cronbach's alpha statistic. Values of Cronbach's alpha greater than 0.7 are required for early research work (Black, 2012; Nunnally, 1978, p. 245). The Cronbach's alpha was 0.72. This shows good consistency and allows the creation of summary scores. A total information presentation score was created as the sum of the 11 questions. This score can have a theoretical range of 8 (responses are all 1's) to 40 (responses are all 5's). A two sample 2-sided *t* test was first run to compare the total information presentation score between those who participated in BCS to those who did not participate in BCS. This study found that there is no statistically significant difference in total information presentation scores between those who previously participated in breast cancer screening ($M = 26.61$, $SD = 4.38$) and those who did not ($M = 27.00$, $SD = 3.34$), $t(39) = 0.24$, $p = 0.81$ (see Table 11).

Table 11

Two Samples t-Test Results of Total Information Presentation Score Between Two Groups (n = 41)

	Previous participation in BCS					
	No	*SD*	Yes	*SD*	*t*	*df*
Total Information Score	27.00	3.34	26.61	4.38	0.24	39

A logistic regression analysis was conducted to predict whether patients had previous breast cancer screening using education level completed and total information presentation score as predictors. The logistic regression model was not statistically significant, $\chi^2(2) = .327$, $p = .849$. The model explained only 1.3% (Nagelkerke R^2) of the variance in previous breast cancer screening. The *p* values demonstrated that neither total information presentation score nor education level completed made a significant contribution to prediction ($p = .917$ and $p = .608$ respectively, see Table 12). This is also shown with the odds ratio findings for total information presentation score (*OR* = 0.99, 95% CI = 0.82-1.20) and education level completed (*OR* = 1.54, 95% CI = 0.30-7.89) whose confidence intervals contain the null value of one.

Table 12

Multivariable Analysis Using Logistic Regression To Predict the Previous Breast Cancer Screening Based on Total Information Presentation Score and Education Level Completed (N = 41)

Variable	*OR*	95% C.I	B	*SE*	Wald	*df*	*p*
Constant			1.51	2.75	0.30	1	.584
Education Level Completed (2 vs 1)	1.54	0.30-7.89	0.43	0.83	0.11	1	.917
Total Information Score	0.99	0.82-1.20	-0.01	0.10	0.01	1	.917

Note. The variable education level completed was made into a binary variable where participants who graduated with a bachelor's degree or higher = 2 and college diploma/certificate or less = 1.

No further analyzes were run for the subset of *health motivation* questions or the subset of *knowledge of overdiagnosis* questions as they were not found to be consistent on their own (Cronbach's alpha values < 0.70). This study's lack of reliability for these particular scales are in part the result of the small study sample size. Note that the sample size limited the running of a multivariable model with more than two predictors. Greater numbers of respondents would allow the inclusion of the variables accessibility (geographic proximity/ease with which participants can access/get screening mammography service). The use of logistic regression analysis would also have been good to explore that variable.

Summary

Chapter 4 served the purpose of examining and describing the data observed during the study survey. The study survey sought to investigate if there exists a relationship between knowledge of overdiagnosis and the decision to participate in breast cancer screening. The 41 participants in the study were women aged 50–69 years who currently reside in Ontario's GTA and read and write (understand) in English. Knowledge of overdiagnosis among participants was measured using a 45-item closed-ended Likert-format group administered survey instrument. Participants were asked to listen to a brief presentation on breast cancer screening, its limitations, benefits, and associated risks, after which they were instructed to complete the survey questions.

Analysis of the study findings showed that the majority of survey participants (75.61%) had limited and/or no knowledge of overdiagnosis prior to the survey presentation. However, the acquisition of knowledge of overdiagnosis during the survey presentation would not negatively impact their decisions about participating in breast screening programs. In total 95.12% of the participants disagreed or strongly disagreed to question 37 that stated 'because overdiagnosis is an associated risk of breast cancer screening, I will no longer/ not participate in breast cancer screening.' The two sample 2-sided *t*-test result showed that those with previous participation in BCS have significantly ($p < 0.01$) higher total survey scores than those with no previous participation in BCS. This meant that these individuals had more positive thoughts and attitudes towards overdiagnosis and the screening process. The logistic regression result showed that, after adjusting for educational level completed, an increasing total survey score is significantly

associated with increased odds of participation in BCS. The working hypothesis for the primary research question was therefore found to be supported by the data. Among the secondary analyzes, two sample 2-sided *t*-test results showed that those with previous participation in BCS have significantly ($p < 0.01$) higher total scores on the *mammogram barriers* subsection than those with no previous participation in BCS. This meant that these individuals had more positive thoughts and attitudes towards mammogram barriers. The logistic regression result showed that, after adjusting for educational level completed, an increasing total mammogram barrier score is significantly associated with increased odds of participation in BCS.

Chapter 5 provides overall conclusions from the key findings of the study. It also offers recommendations for future research and practical applications of the information uncovered during this study. Connections between the theoretical framework (effective health communication model and schema theory) are discussed in relation to the study's findings. Finally, potential positive social change implications are also detailed.

Chapter 5: Summary, Conclusion, and Recommendations

Introduction

This research was focused on determining whether or not knowledge of overdiagnosis correlated with decisions about screening mammography participation. The study's objective was to assess if a relationship exists between these two variables. The study's working hypothesis suggested that the more knowledge a woman has regarding the screening process, the more likely she is to participate in screening mammograms. The purpose of the study was accomplished by assessing 41 women aged 50–69 years who reside in the Greater Toronto Area (GTA), Ontario, and could read and write in English. To answer the research question and hypotheses, a 45-item, closed-ended Likert-format group administered survey instrument was used to measure each participants: knowledge of overdiagnosis; health motivations regarding screening mammograms; perceptions of the limitations, benefits and risks of mammography screening; and how each felt about the information currently presented on breast screening programs.

Findings of the Study

The results of the study revealed that

- Thirty-three participants (80.49%) had previously participated in BCS programs, and eight (19.51%) had not.
- Nineteen participants (46.34%) confirmed that they had no knowledge of overdiagnosis in breast screening mammograms.

- Twelve participants (29.27%) confirmed that they had limited knowledge of overdiagnosis in breast screening mammograms.
- Twenty-eight participants (68.29%) confirmed that they learned about overdiagnosis in breast screening for the first time during this study's survey presentation, an additional two participants (4.88%) were *neutral* in their response to that survey question.
- Twenty-five participants (60.98%) indicated that having knowledge of overdiagnosis would not influence their future decision to participate in screening mammography, and six participants (14.63%) noted that knowing about overdiagnosis in screening mammograms had no impact (i.e., they answered *neutral*) in influencing their future decisions.
- Thirty-nine participants (95.12%) indicated that they would still participate in breast screening programs despite the fact that overdiagnosis was an associated risk of the breast screening process; an additional two participants (4.88%) were *neutral* in their response to that survey question.
- With the exception of one participant who opted not to answer, all remaining 40 participants (100%) felt information promoting breast cancer screening should clearly outline both the benefits and associated risks of screening mammograms.
- With the exception of one participant who opted not to answer, all remaining 40 participants (100%) felt information promoting breast cancer screening

should clearly outline overdiagnosis as an associated risk of screening mammograms.

- The working hypothesis for the primary research question was supported by the survey data. The women with more positive thoughts and attitudes towards overdiagnosis are more likely to undergo BCS. Consequently, the null hypothesis was rejected, confirming that a relationship exists between the two measured study variables.
- Regarding the secondary research question about *mammogram barriers*, women with more positive thoughts and attitudes towards mammogram barriers are more likely to undergo BCS.

Interpretations of the Findings

This study examined the correlation between knowing about overdiagnosis and women's decisions to get breast cancer screening. The results of this study add to the body of knowledge that the Province of Ontario has about breast cancer screening participation rates among women aged 50–69 years who live in the GTA. In the section immediately following, the study's results are interpreted based on the scholarly literature presented in Chapter 2. To a limited extent, this study confirms and extends previous literature addressing overdiagnosis in screening mammography. Specifically, the study confirms that in Ontario overdiagnosis exists and needs to be addressed with special consideration for the Giordano et al.'s (2006) principles of autonomy, beneficence, nonmaleficence, and justice. Additionally, to a limited extent, the study confirms the importance of balanced information presentation. In particular, detailed attention is

needed for not only the quality of the information disseminated, but also the media/channel through which this information is transmitted.

Relating the Study Findings to Previous Studies Discussed

This study's findings support the concerns expressed in studies such as Baines (2005), Brouwers et al. (2011), Elmore and Fletcher (2012), and Nelson and Hagedorn (2011) about overdiagnosis in the breast screening process. Coldman and Phillips (2013) estimated the rate of overdiagnosis for breast cancer in women over the age of 60 years at 5.4% for invasive diseases and 17.3% for both invasive diseases and ductal carcinoma in situ (p. E492). The study results and the literature review collectively showed that even though the terms overdiagnosis and overdiagnosed do not appear in the information that Ontario women aged 50–69 years receive, this does not mean that overdiagnosis has not occurred. As noted by the Canadian Task Force on Preventive Health Care (CTFPHC) (2014), among women in this study's target population, for every 1,000 screening, roughly 283 have false positive results, another 36 will get unnecessary breast biopsy (overdiagnosed), and overall, 5 will undergo unnecessary surgery (overdiagnosed).

This study also support the recommendations from Bleyer and Welch (2012), de Gelder et al. (2011), Duffy et al. (2010b), Hellquist, Duffy, Nyström, and Jonsson (2012), Jørgensen and Gøtzsche (2009), Kopans, Smith, and Duffy (2011), McPherson (2010), and Welch et al. (2011). These previous studies each indicated the need for research that definitively looked at how breast screening programs were impacted by a lack of knowledge of overdiagnosis and mass media. Olsen et al. (2003), Welch and Black (2010), and Moller et al. (2010) highlighted the significance of "practitioners, policy

makers, and women attending or considering screening [being] aware of the potential extent of breast cancer overdiagnosis and consequent overtreatment" (Moller et al. 2010, p. 281). This study's findings supported Moller et al.'s (2010) above statement by way of the data analyzed. The data illustrated that 51.2% of the participants had learned about screening through in-person contact and 41.5% through a combination of print, electronic and in-person contact communication channels (see Table 4). This illustrated result underscored the need for practitioners, policy makers, and women attending screenings to receive balanced information presentations so that issues of overdiagnosis as a risk of breast cancer screening can be properly discussed with potential participants. The need for effective communication was also reinforced by Elmore and Fletcher (2012) and Nelson and Hagedorn (2011) who noted it was vital that breast cancer overdiagnosis be carefully outlined in information related to breast screening. Each further indicated the need for significant assessment of how best to ensure effective communication since informed women deserved no less when making decisions about breast screening participation (Elmore & Fletcher, 2012; Nelson & Hagedorn, 2011).

Approximately three-quarters (75.61%) of the women in the study sample had limited and/or no knowledge of overdiagnosis prior to the survey presentation. However, 80.49% had previously participated in screening mammography (as shown in Figure 7 and Tables 3), and in spite of learning about overdiagnosis being an associated risk of the mammography process, 95.12% agreed or strongly agreed they would still be willing to participate in breast screening programs. These results to a limited extent support the notion that potential issues of overdiagnosis (in the Province of Ontario) could be

reduced if current and future screening mammography participants are given an objective/balanced outline of the benefits and risks of the screening process. This by extension would enable them to make informed decisions about screening participation and possibly reduce currently noted levels of unnecessary breast biopsies, false positives, and surgery (overdiagnosis).

For the NCI's Mayo Lung Project (a study that used the randomized clinical trial, RCT, research design), this study further validated that there is a lack of knowledge in the target population about what constituted overdiagnosis. The applicability of this finding is limited by the sample size; However, the study findings clearly showed that a significant percentage of the survey participants had limited and/or no knowledge of overdiagnosis prior to the survey presentation. This lack of knowledge may have impacted cancer screening results and to a larger extent the noted rates of screening participation. The highlighted studies in Chapter 2 implemented a lead-time and/or RCT approach to evaluating overdiagnosis. However, because Ontario had no research (to the best of my knowledge) outlining an association with levels of documented screening participation and a knowledge of overdiagnosis, prior to examining how breast screening participation was impacted by other factors, including that of overdiagnosis, it was first necessary to determine/confirm an association between those factors (knowledge of overdiagnosis and decisions on whether to get screened).

Relating the Study Findings to the Theoretical Framework

The results of the survey instrument provide strong support for Giordano et al.'s (2006) effective health communication model and schema theory. Both (the effective

health communication model and schema theory) formed the foundation for this research study. As noted in the overall findings a majority of the participants (75.61%) had limited and/or no knowledge of overdiagnosis in the screening process. However, 80.49% would have still opted to participate in screening mammograms despite a knowledge of overdiagnosis. These results illustrated that the more positive women's thoughts and attitudes were towards overdiagnosis the more likely they would undergo breast cancer screening.

Relating the study findings to the effective health communication model. In the effective health communication model Entwistle et al. (1998) and Goyder et al. (2000, as cited in Giordano et al., 2006) noted that effective health communication not only focused on the information transmitted but needed to ensure "health professionals . . .provided individuals with . . .information that would allow them to 'knowledgeably' decide whether or not to undergo an intervention, taking into consideration available alternatives, potential risks and foreseeable outcomes" (p. 382). To this point, the study's findings revealed that 100% of all participants (who opted to answer) agreed or strongly agreed that information promoting breast cancer screening should clearly outline both the benefits and associated risks of screening mammograms. More specifically, they also agreed or strongly agreed that information promoting breast cancer screening should clearly outline overdiagnosis as an associated risk of mammograms. With these results the indication is that consumers of public health programs want health providers to disclose all information related to the (breast screening) program being offered. The indication is also that whether or not that

information could be perceived as negative and/or a risk of the offered health intervention/treatment, consumers still want to know. The overall survey scores further reinforced reliability of Champion's health belief model (HBM) scale that measured health motivation. The survey scores illustrated that persons would still make the best decisions for their health despite receiving information that outlined harms/risks and/or limitations to the intervention/treatment options.

Relating the study findings to schema theory. Schema theory describes the cognitive structure of how an individual acquires, processes, and organizes knowledge. At the start of this study survey I estimated that the schemata (script) currently established for identifying if persons would decide to participate in screening mammograms potentially operated on the belief that, if only the benefits of screening mammography were predominantly promoted, there would be higher rates of participation in screening programs. Conversely, the belief therefore was that if information on screening mammography offered a balanced (both positive and negative) overview of the implications of participation, this would limit participants' willingness to make an informed decisions about whether they should participate in screening programs. However, the results of the study's survey instrument revealed that even though 30 participants (73.17%) agreed, strongly agreed and/or were *neutral* in their answer as it related to learning about overdiagnosis for the first time during the study's survey presentation, 33 participants (80.49%) would have still decided to participate in screening mammograms had they known about overdiagnosis at the time of their decision to participate. Three participants (7.32%) were *neutral* in their response on whether prior

knowledge of overdiagnosis in breast cancer screening programs would have stopped their participating.

As outlined in Table 5, seven (13.2%) participants learned about breast screening through print media, eight (15.1%) via electronic media, 21 (39.6%) using in-person contact, and finally 17 (32.1%) using all channels mentioned above. Given the respective percentages identified for each communication channel the implication is that electronic media (radio, television, cable, internet, etc.) and in-person contact (via face-to-face, telephone, email with friends, family, health care professionals, etc.), which garners more attention, should be priority channels that health care providers and policy makers spend time improving. So that going forward potential participants who access these channels for information on breast screening programs are able to receive a balanced overview of not only the benefits but also the limitations and associated risks of screening mammograms. Of all 41 survey participants, 31 (75.61%) indicated that knowing about overdiagnosis in breast cancer screening would not influence their future decision to participate. Thirty-nine participants (95.12%) also revealed they would still decide to participate in mammograms despite now knowing about overdiagnosis in breast cancer screening. Finally, 100% (40) of the participants stated that they wanted a balanced presentation of information (schemata) about the limitations, benefits and associated risks of mammograms, including the risk of overdiagnosis.

In the context of schema theory these results support the indication that the current schemata being used to promote breast screening programs needs to be adjusted. This adjustment is necessary because a majority of the survey sample participants

preferred to have a balance presentation of the information so they are better able to make informed decisions about whether or not to participate in screening mammography. For schema theory this study's findings also support the indication that if packaged appropriately seemingly negative information can be received in a manner that does not elicit a negative reaction. Answers to the secondary research question of the study—Is there a relationship between thoughts and attitudes on subsections of the survey (such as mammogram barriers) and the decision to participate in breast cancer screening among women aged 50–69 years?—indicated that women with more positive thoughts and attitudes towards mammography barriers were more likely to undergo breast cancer screening.

Potential Bias and Limitations of the Study

As part of the detailed list of limitations mentioned in Chapter 1, specific limitations as they related to sample size and sampling strategic were confirmed during the data collection and analysis. For example, the study was not able to provide comprehensive confirmation that all participants had potentially the same/similar level of access to the various communication media (channels) through which screening mammography is promoted and accessed. Additionally, because of the small sample size it limited generalizability of the findings. Note that the sample size for this study limited the inclusion of more than two variables in the logistic regression model. The inclusion of more variables could allow a model to adjust for more potential confounders. As well, it would have increased the accuracy of the prediction of the outcome (participation in breast cancer screening).

Additional biases and limitations of the study were related to its recruitment strategy. Because the study only recruited participants through Tropicana Community Services' (TCS) network, this approach limited the probability of including participants outside that network. As such, there were concerns that the study's sample population is not a true representation of the general Ontario GTA populous. With respect to this sampling strategy used—purposive sampling—the study's ability to have random and entirely by chance inclusion of participants to the sample population was limited. This by extension raised questions of potential selection bias due to the selection criteria I outlined.

Recommendations for Future Research

The overall results of the survey and particularly the affirmative answers (*agree* or *strongly agree*) for questions 44 and 45—which asked whether information about BCS should include discussions of the benefits, limitations and risks—support the observation that women aged 50–69 years want balanced presentation of information about screening mammograms. Their want for this balanced information presentation was in spite of the noted levels of education, and family history of cancer and/or breast cancer. Based on the specific results as noted in Table 4 the implication is that health care providers have a greater responsibility to ensure they are properly informed. By extension they (health care providers) are then better able to provide potential breast screening participants with a balanced overview of the benefits and risks of the screening process—because more than half of the survey participants (21) look to these health care providers for information and guidance. Additionally, information distributed via electronic

channels/media also ought to be properly vetted to ensure there is consistency, accuracy, and balanced presentation of information. This limited scope survey data collected on both the in-person contact and electronic media supported Giordano et al.'s (2006) statements that highlighted the relevance of paying closer attention to not only what is said but how it is presented. The study findings also support the idea that organizations creating and promoting screening mammograms ought to be held more accountable by the Government of Ontario. An approach to increase accountability would be through the use of more clearly articulated public health policies that reinforce—as a basic requirement that—information be presented in a balanced (benefits and risks) manner regardless of the channel (in-person or electronic) used to disseminate that information.

My recommendation is that this survey be conducted on a larger scale. This will increase the generalizability of the study findings as well as reconfirm that the noted results of this survey is not atypical to the target population (women aged 50–69 years). Another recommendation is that further research be conducted that specifically evaluates how each communication channel (in-person contact, electronic media, social media, and print media) potentially influences decision-making regarding screening mammography participation. Because it was observed in the data analysis that all communication channels (social, electronic, print, and in-person contact), especially in-person contact are the channels mostly used by potential breast screening participants, it would be important and potentially valuable to understand how each media relates to the health decision-making process. As noted by Giordano et al. (2006) the means through which information is transmitted and/or received is just as relevant as the quality of that

information (balanced, accurate, and transparent) presented. Also according to schema theory, the schemata individuals use to process information varies per person, as such each communication channel impacts the interpretation of the information. Therefore close attention and additional research would have the benefit of getting a more detailed understanding of what methods, content presentation, and other underlining factors engage and/or discourage participation in breast screening programs.

Additional recommendations are that the Government of Ontario in conjunction with public health policy makers, health care providers and other key contributors reevaluate existing and/or create guidelines/policies that require all organizations and the health care providers themselves (who are affiliated with breast cancer screening promotion and/or provision) to mandatorily outline the benefits, limitations and risks of any intervention proposed to potential participants. Further to the revamp and/or creation of these guidelines/policies the Government of Ontario should ensure there are strict penalties for failure to comply. Finally, because a portion of the information that is presented to the public on breast cancer screening is controlled and/or provided via news outlets and printing publications, public health care guidelines/policies should outline expectations of quality (balanced, accurate and transparent) information presentation. As well, implications/penalties should be established for any nonhealth-related entity who also fails to comply with the rules.

Implications for Social Change

For key stakeholders to create and implement public health policies and initiatives that will demonstrate the four principles (autonomy, nonmaleficence, beneficence, and justice) of Giordano et al.'s (2006) effective health communication model, it is imperative that these stakeholders understand how the benefactors (the public) of these policies and initiatives feel. Once more thought and understanding is applied to how public health care policies are created and/or implemented, from a positive social change perspective, this potentially increases the level of participation in public health programs. This potential increase in participation levels would be because the end user sees that targeted focus has been placed on not just getting participation levels increased, but that any increase is based on health care provisions tailored for each user. In addition to increased levels of participation, the quality of the public health service being provided would be held to a higher standard and therefore conversely reduce the potential for complains due to lack of transparency and accuracy in information presentation.

Through the identification, revision, and implementation of standards that require a more balanced, comprehensive, and accurate representation of breast cancer screening facts, this has the potential to ensure future health care media communication campaigns deliver more balanced information in a transparent manner. This, by extension, creates the potential for ensuring more accurate reporting (than currently noted) of the rates of success in screening programs. Additionally, the results of this study (along with any future larger scaled study on this topic) may better equip the Government of Ontario with an understanding and awareness of the concerns and barriers women aged 50–69 years

face in accessing a holistic view of the positive and negative potentials of participating in breast cancer screening programs. In turn, this may improve the current rate of success noted. It also may reduce the levels of and potentials for overdiagnosis, and may help the Ontario government develop awareness campaigns that are ultimately more successful because patients are better informed.

Conclusion

The study showed a statistically significant relationship between thoughts and attitudes towards overdiagnosis and participation in breast cancer screening. The logistic regression model showed that those with more positive thoughts and attitudes towards overdiagnosis are more likely to participate in BCS. This model was able to adjust for the completed educational level of the respondents and therefore this conclusion can be made after accounting for the educational background of each individual that took the survey. The study also found a statistically significant relationship between thoughts and attitudes towards mammogram barriers and participation in BCS. The logistic regression model showed that those with more positive thoughts and attitudes towards mammogram barriers are more likely to participate in BCS. This model also adjusted for the completed educational level of the respondents and therefore this conclusion can be made after accounting for the educational background of the individual taking the survey.

With the understanding that women (people) usually make the best health decisions based on their respective circumstances, regardless of the perceived negative consequences, it is therefore imperative that those persons be equipped with accurate and balanced information. Specifically, accurate and balanced information that maintains a

high level of transparency. To this end the Government of Ontario and entities affiliated with breast cancer screening promotion and provision have a responsibility to potential participants to ensure information presented demonstrates the four principles (autonomy, nonmaleficence, beneficence, and justice) of Giordano et al.'s (2006) effective health communication model. They (the Government of Ontario and its affiliates) should also take into account the fact that each individual's schemata (how they organize current knowledge and provide a framework for future understanding) differs (Erasmus et al., 2002). As such, it is necessary to identify and use appropriate communication channels (print, electronic, social, and in-person contact) relative those individual's schemata.

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Appendix A: Survey Instrument

Instructions

- All answers provided in this survey will remain **private and confidential**.
- Following a brief presentation on breast cancer screening (mammogram), please answer the following questions about yourself and your knowledge of breast cancer screening.
- Answers in Part 1 will **ONLY** be used for background and contextual purposes.
- Answers in Part 2 will be used to evaluate what motivates decisions about participating in breast cancer screening, knowledge of breast cancer screening (its associated benefits and risks, including overdiagnosis), and how information is being presented.

PART ONE

General Background Information

Please put an X in front of your answer.

1. What is the highest level of education you have completed?

   ☐ High school
   ☐ College -diploma/certificate
   ☐ Bachelor degree
   ☐ Masters degree
   ☐ Doctoral degree
   ☐ None of the above

2. Do you have a family history of cancer?

   ☐ Yes
   ☐ No
   ☐ I don't know
   ☐ I prefer not to answer

3. Do you have a family history of breast cancer, specifically?

   ☐ Yes
   ☐ No
   ☐ I don't know
   ☐ I prefer not to answer

4. Have you ever participated in breast cancer screening?

   ☐ Yes
   ☐ No
   ☐ I prefer not to answer

5. How long have you known about of breast cancer screening?

- ☐ Less than 1 year
- ☐ 1-5 years
- ☐ 6-10 years
- ☐ 11-15 years
- ☐ Over 15 years

6. Through which communication media did you learn about breast cancer screening?

- ☐ Print media: newspapers, books, pamphlets, articles, journals, magazines, etc.
- ☐ Electronic media: radio, television, cable, internet, etc.
- ☐ Social media: Facebook, Instagram, Twitter, LinkedIn, YouTube, other blogs, etc.
- ☐ In-person contact (via face-to-face, telephone, email) with friends, family, healthcare professionals, etc.
- ☐ All of the above
- ☐ Other, please specify_____

7. Prior to this presentation, which level best describes your knowledge of overdiagnosis?

- ☐ None (I have no knowledge)
- ☐ Novice level (I have limited knowledge)
- ☐ Intermediate level (I have satisfactory knowledge)
- ☐ Advanced level (I have a comprehensive knowledge)

PART TWO

Information and Presentation of Breast Cancer Screening and its associated benefits and risks

Please answer the following questions about your health motivations in deciding whether or not to participate in breast cancer screening.

		Health Motivations					
Please mark (X) to indicate the extent to which you agree or disagree with each of the following statements.		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
		1	2	3	4	5	0
1.	I want to discover health problems early.	☐	☐	☐	☐	☐	☐
2.	Maintaining good health is extremely important to me.	☐	☐	☐	☐	☐	☐
3.	I search for new information to improve my health.	☐	☐	☐	☐	☐	☐
4.	I feel it is important to carry out activities which will improve my health.	☐	☐	☐	☐	☐	☐
5.	I eat well-balanced meals.	☐	☐	☐	☐	☐	☐
6.	I exercise at least 3 times a week.	☐	☐	☐	☐	☐	☐
7.	I have regular health check-ups, even when I am not sick.	☐	☐	☐	☐	☐	☐
8.	Someone I know was diagnosed.	☐	☐	☐	☐	☐	☐

Please answer the following questions about your knowledge of the benefits of breast cancer screening.

		Mammogram Benefits					
Please mark (X) to indicate the extent to which you agree or disagree with each of the following statements.		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
		1	2	3	4	5	0
1.	When I get a mammogram, I don't worry as much about breast cancer.	☐	☐	☐	☐	☐	☐
2.	Having a mammogram will help me find lumps early.	☐	☐	☐	☐	☐	☐
3.	Having a mammogram is the best way for me to find a very small lump.	☐	☐	☐	☐	☐	☐
4.	Having a mammogram will decrease my chances of dying from breast cancer.	☐	☐	☐	☐	☐	☐
5.	Having a mammogram will decrease my chances of requiring radical or disfiguring surgery if breast cancer occurs.	☐	☐	☐	☐	☐	☐
6.	Having a mammogram will help me find a lump before it can be felt by myself or a health professional.	☐	☐	☐	☐	☐	☐

Please answer the following questions about your knowledge of breast cancer screening risks.

		Mammogram Barriers					
Please mark (X) to indicate the extent to which you agree or disagree with each of the following statements.		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
		1	2	3	4	5	0
1.	I am afraid to have a mammogram because I might find out something is wrong.	☐	☐	☐	☐	☐	☐
2.	I am afraid to have a mammogram because I don't understand what will be done.	☐	☐	☐	☐	☐	☐
3.	I don't know how to go about getting a mammogram.	☐	☐	☐	☐	☐	☐
4.	Having a mammogram would be embarrassing.	☐	☐	☐	☐	☐	☐
5.	Having a mammogram would take too much time.	☐	☐	☐	☐	☐	☐
6.	Having a mammogram would be painful.	☐	☐	☐	☐	☐	☐
7.	People doing mammograms are rude to women.	☐	☐	☐	☐	☐	☐
8.	Having a mammogram exposes me to unnecessary radiation.	☐	☐	☐	☐	☐	☐
9.	Having a mammogram would cost too much money.	☐	☐	☐	☐	☐	☐
10.	I have other problems more important than getting a mammogram.	☐	☐	☐	☐	☐	☐
11.	I am too old to need a routine mammogram.	☐	☐	☐	☐	☐	☐

Please answer the following questions about your knowledge of overdiagnosis in breast cancer screening.

		Knowledge of Overdiagnosis					
Please mark (X) to indicate the extent to which you agree or disagree with each of the following statements.		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
		1	2	3	4	5	0
1.	I had knowledge of overdiagnosis in breast cancer screening before this presentation.	☐	☐	☐	☐	☐	☐
2.	I learned about overdiagnosis in breast cancer screening for the first time during the presentation.	☐	☐	☐	☐	☐	☐
3.	I would have decided not to participate in breast cancer screening if I had known about overdiagnosis in the screening process.	☐	☐	☐	☐	☐	☐
4.	Having knowledge of overdiagnosis will influence my future decision to participate in breast cancer screening.	☐	☐	☐	☐	☐	☐
5.	Because overdiagnosis is an associated risk of breast cancer screening, I will no longer/ not participate in breast cancer screening.	☐	☐	☐	☐	☐	☐

Please answer the following questions about your feelings on how information regarding breast cancer screening is presented.

		Information Presentation					
Please mark (X) to indicate the extent to which you agree or disagree with each of the following statements.		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
		1	2	3	4	5	0
1.	I feel that the information outlining the benefits of breast cancer screening is comprehensive.	☐	☐	☐	☐	☐	☐
2.	I feel that the information outlining the benefits of breast cancer screening is readily accessible.	☐	☐	☐	☐	☐	☐
3.	I feel that the information outlining the risks of breast cancer screening is comprehensive.	☐	☐	☐	☐	☐	☐
4.	I feel that the information outlining the risks of breast cancer screening is readily accessible.	☐	☐	☐	☐	☐	☐
5.	I feel that the information outlining overdiagnosis in breast cancer screening is comprehensive.	☐	☐	☐	☐	☐	☐
6.	I feel that the information outlining overdiagnosis in breast cancer screening is readily accessible.	☐	☐	☐	☐	☐	☐
7.	I feel that information promoting breast cancer screening should clearly outline both the benefits and associated risks of screening mammograms.	☐	☐	☐	☐	☐	☐
8.	I feel that information promoting breast cancer screening should clearly outline overdiagnosis as an associated risk of mammograms.	☐	☐	☐	☐	☐	☐

Appendix B: Cronbach's alpha (α) - Reliability Test for Survey Instrument

HEALTH BELIEF MODEL SCALES FOR MEASURING
BELIEFS RELATED TO BREAST CANCER

Introduction: Scales were assessed for content validity by a panel of 3 nationally known judges familiar with the Health Belief modal and breast cancer screening. Scales were revised based upon analysis for content validity and administered to a probability sample of 581 women who were participants in a large intervention study. All scale items were measured on a 5 point Likert scale with the following coding: Strongly disagree (1); disagree (2); neutral (3); agree (4); and strongly agree (5). Scales were summated for analyses. The first table gives information on internal consistency and test retest reliability. The second table gives scale items. Results of criterion and construct validity for BSE related scales are reported in Nursing Research, Champion (1993) Instrument refinement for breast cancer screening behaviors.

	Alpha	Test/Retest	M	SD	# of Items
Susceptibility	.93	.70	2.54	.81	5
Seriousness	.80	.45	3.25	.68	7
Benefits (BSE)	.80	.45	3.88	.52	6
Barriers (BSE)	.88	.65	2.02	.60	6
Confidence	.88	.65	3.31	.57	11
Health Motivation	.83	.67	3.78	.59	7
Benefits (Mammography)	.79	.45	23.86	3.17	6
Barriers (Mammography)	.75	.65	11.02	3.26	5

Appendix C: Community Partner Letter of Cooperation

TROPICANA COMMUNITY SERVICES

Centre of Excellence:

1385 Huntingwood Drive
Scarborough, ON
M1S 3J1

Tel: 416.439.9009

Fax: 416.439.2414

www.tropicanacommunity.org

AYCE Employment Centre:
505 Consumers Road, Suite 102
North York, ON
M2J 4V8
Tel: 416.491.7000
Fax: 416.491.4669

Scarborough Youth Resource Centre:
300 Borough Drive
Scarborough, ON
M1P 4P5
Tel: 416.296.7154
Fax: 416.296.9408

Children of Tomorrow Preschool/School-age Centre:
1325 Danforth Road
Scarborough, ON
M1J 1G5
Tel: 416.261.9893
Fax: 416.261.6236

Children of Tomorrow Infant/Toddler Centre:
400 McCowan Road
Scarborough, ON
M1J 1J5
Tel: 416.269.7093
Fax: 416.269.4874

ProTech Media Centre:
Kennedy & Eglinton Branch - Toronto Public Library
2380 Eglinton Ave. East
Toronto, ON
M1K 2P3
Tel: 647.345.1448

September 8, 2014

Kimberly Nembhard, Doctoral Student
Walden University
100 Washington Avenue South, Suite 900
Minneapolis, MN 55401

Dear Ms. Nembhard:

Re: Letter of Cooperation

Based on my review of your research proposal, I give permission for you to conduct the study entitled ***Knowledge of Overdiagnosis and Decision to Participate in Breast Cancer Screening*** within Tropicana Community Services (TCS). As part of this study, I authorize you to:

- send letters of invitation through our organization's network (email, community notice board, newsletter) – for the purpose of recruiting potential survey participants;
- directly track participants' confirmations and refusals;
- conduct the survey in one of our facility's room at no cost to you – for data collection
- send letters of reminder to participants outlining the date, time and location of the survey;
- distribute gift cards valued at $5 Canadian dollar each to the survey participants; and
- provide a copy of the final research findings for our records.

We are cognizant that individuals' participation will be voluntary and at their own discretion and remind you to abide by TCS' privacy policy (see website).

We also understand that our organization's responsibilities include providing:

i. one TCS representative (Ms. Paula A. Morrison, Vice President) to assist with the distribution/email of invitation letters to potential participants, and;
ii. a room to conduct the survey. This room will be at no cost.

We reserve the right to withdraw from the study at any time if our circumstances change.

Working together to help each other!

United Way Toronto

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of your supervising faculty/staff without permission from the Walden University IRB and TCS.

Sincerely,

Sharon Shelton
Executive Director

Cc Paula Morrison, VP Board of Directors

Appendix D: Informed Consent Form

CONSENT FORM

You are invited to take part in a research study that is trying to examine if a relationship exists between knowledge of overdiagnosis and decision to participate in breast cancer screening. The researcher is inviting women between the age of 50 to 69 who currently live in the Greater Toronto Area (GTA), and understand (write and read in) English to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Kimberly Nembhard, who is a doctoral student at Walden University. This is in partial fulfillment of the requirements to obtain a Doctor of Philosopy degree in public policy and administration. The study's survey procedure is approved by Walden University's Institutional Review Board.

Background Information: The purpose of this study is to investigate if there is a relationship between knowing about overdiagnosis and deciding whether or not to participate in breast cancer screening among women aged 50–69. In Canada, breast cancer is the second leading cause of death among Canadian women. In Ontario, it has been noted that 80% of the identified cases of breast cancers are found in women over age 50. To deal with this issue of breast cancer, screening mammography programs were introduced. Since the introduction of breast screening programs, other studies reveal that some of risks of breast cancer screening are false-positive, false-negative, radiation exposure, and overdiagnosis. In Ontario, there is very limited information or research conducted on the issue of overdiagnosis. This study would like to investigate this phenomenon.

Procedures: If you agree to be in this study, you will be asked to:

□ **NOT** write your name, sign or place any identifying marks on the questionnaire. This is to protect your privacy and maintain confidentiality.

□ Be available for a one-time presentation and group administered survey in a room at the Tropicana Community Services' facility, between 1:00 P.M. to 3:00 P.M. (EST), on a Saturday, October 4, 2014.The presentation and survey will last approximately 45-60 minutes. Prior to the presentation, there will be registration for participants where this consent form will be distributed by this researcher. After the registration a brief presentation by this researcher will be given on breast cancer screening and its associated benefits and risks, including overdiagnosis. Participations will be given a chance to ask for clarification if any part of the presentation is not clear. The survey will then be distributed. The survey will include 45 statements, which will require answers ranging from "strongly disagree to strongly agree" (a Likert scale) to evaluate your responses. At the end of the survey, once each completed survey is returned/collected the survey participant will be issued a $5 Canadian dollar gift cards and will be free to leave.

Here are some sample statements:

Having a mammogram will decrease my chances of dying from breast cancer.

Someone I know was diagnosed.

I am afraid to have a mammogram because I don't understand what will be done.

Voluntary Nature of the Study: Your participation in this study is voluntary. Everyone will respect your decision to participate or decline participation in this study. No one at Tropicana Community Services will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study: Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as encountering another participant you may recognize. Being in this study would not pose risk to your safety or wellbeing because the information collected here is kept confidential.

The direct benefit for individual participants is that you may learn new/more information about the benefits and risks of breast cancer screening, so you can make more informed decisions about whether or not to participate in breast cancer screening. Another benefit is that the Ontario Government, healthcare providers, and policy makers may gain a better understanding of how information is being presented by the media and how this may or may not positively or negatively impact the level of participation in breast cancer screening programs.

Payment: Payment will not be provided to participants in this study. However, as a 'thank you', gift cards valued at $5 Canadian dollar each will be distributed at the end of the survey.

Privacy and Confidentiality: Any information you provide will be kept confidential. The researcher will not use your personal information for any purpose outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure on the researcher's computer and will be password protected. The subsequent USB drive will be locked in a file cabinet which only the researcher has a key. Data will be kept for a period of at least 5 years, as required by the university.

Additional Breast Cancer & Breast Cancer Screening Information: For more information on breast cancer and breast cancer screening in Ontario, please contact either the Canadian Breast Cancer Foundation (CBCF) at breastcancer@cbcf.org or call 1-866-373-6313 **OR** the Ontario Breast Screening Program (OBSP) at breastscreen@cancercare.on.ca or call 1-866-662-9233.

Contacts and Questions: You may ask any questions you have now. Or if you have questions later, you may contact the researcher via kimberly.nembhard@waldenu.edu and/or cell 647-888-7872. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 001-612-312-1210. Walden University's approval number for this study is **01-23-14-0229219** and it expires on **January 22, 2015.**

The researcher will give you a copy of this form to keep.

Statement of Consent

I have read the above information and I feel I understand the study well enough to make a decision about my involvement.

By attending this presentation and returning a completed survey it indicates that:

- I have read the above information,
- I voluntarily agree to participate,
- I am 50 to 69 years of age,
- I read and write in English,
- I have given implied consent, and
- I understand and am agreeing to the terms described above.

Appendix E: Permission to Use Survey Instrument

INDIANA UNIVERSITY
SCHOOL OF NURSING
Center for Research and Scholarship

January 27, 2013

Ms. Kimberly Nembhard
Walden University

Dear Ms. Nembhard,

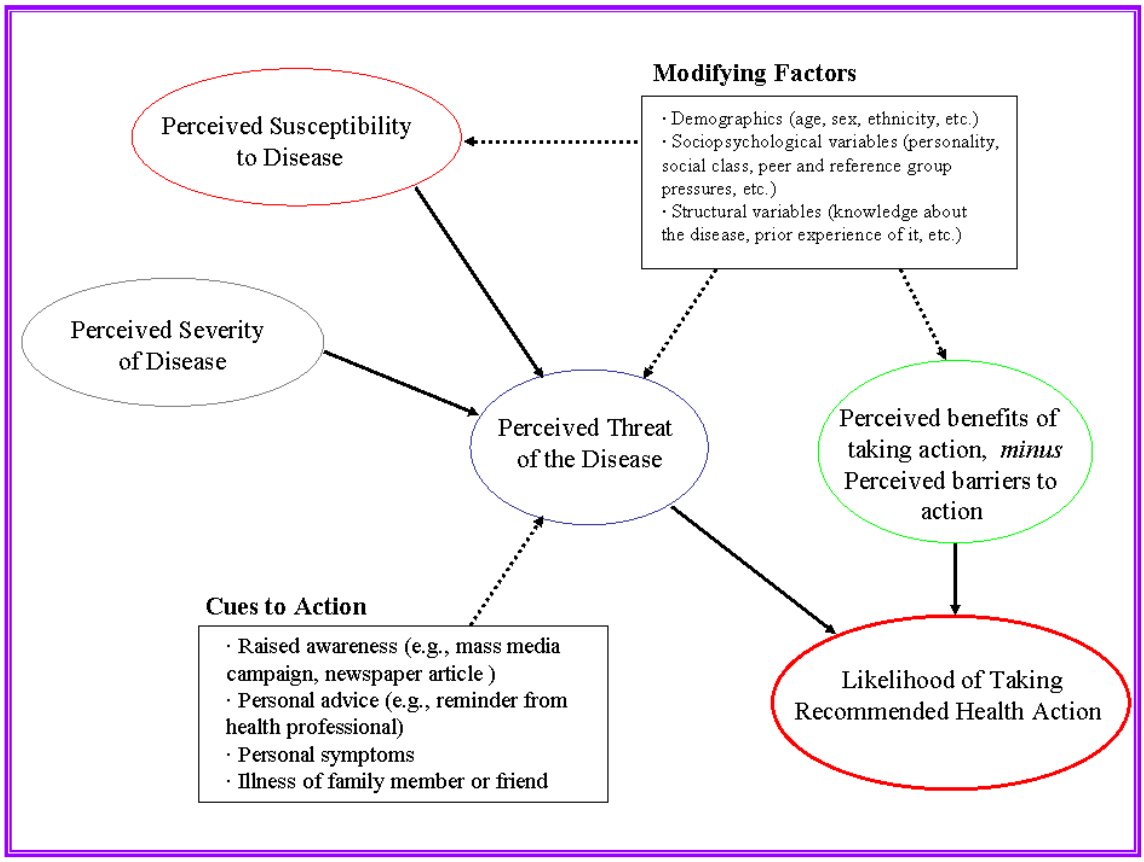
Thank you for your interest in my work. You have permission to modify and use my instrument as long as you cite my work and send me an abstract of your completed project.

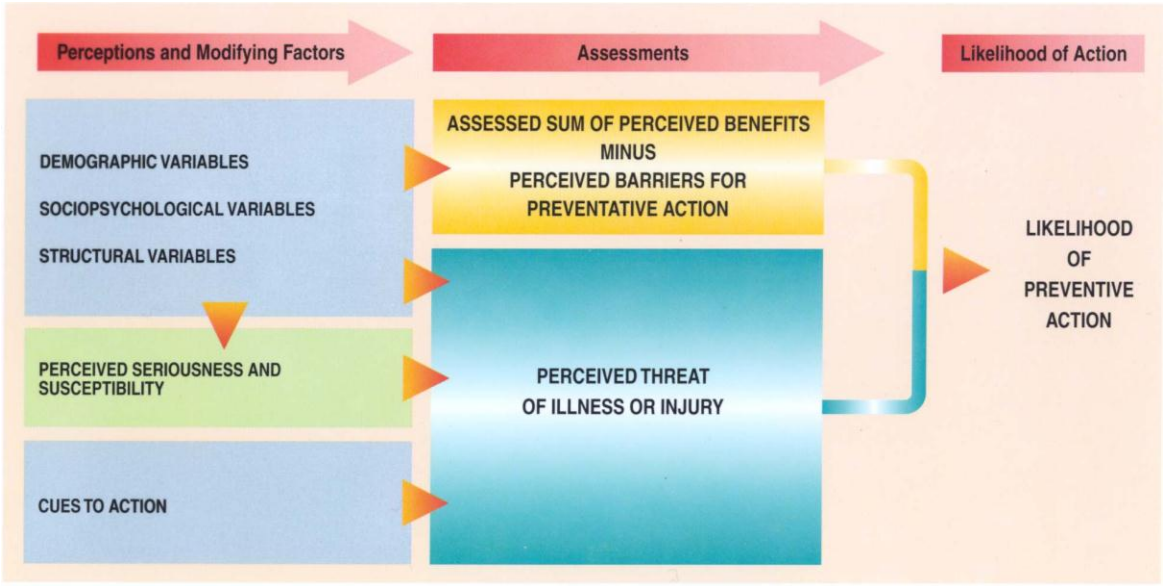
Sincerely,

Victoria Champion, Ph.D., R.N., F.A.A.N.
Distinguished Professor
Edward W. and Sarah Stam Cullipher Endowed Chair
Associate Director Cancer Prevention and Control/Population Sciences
Indiana University Simon Cancer Center

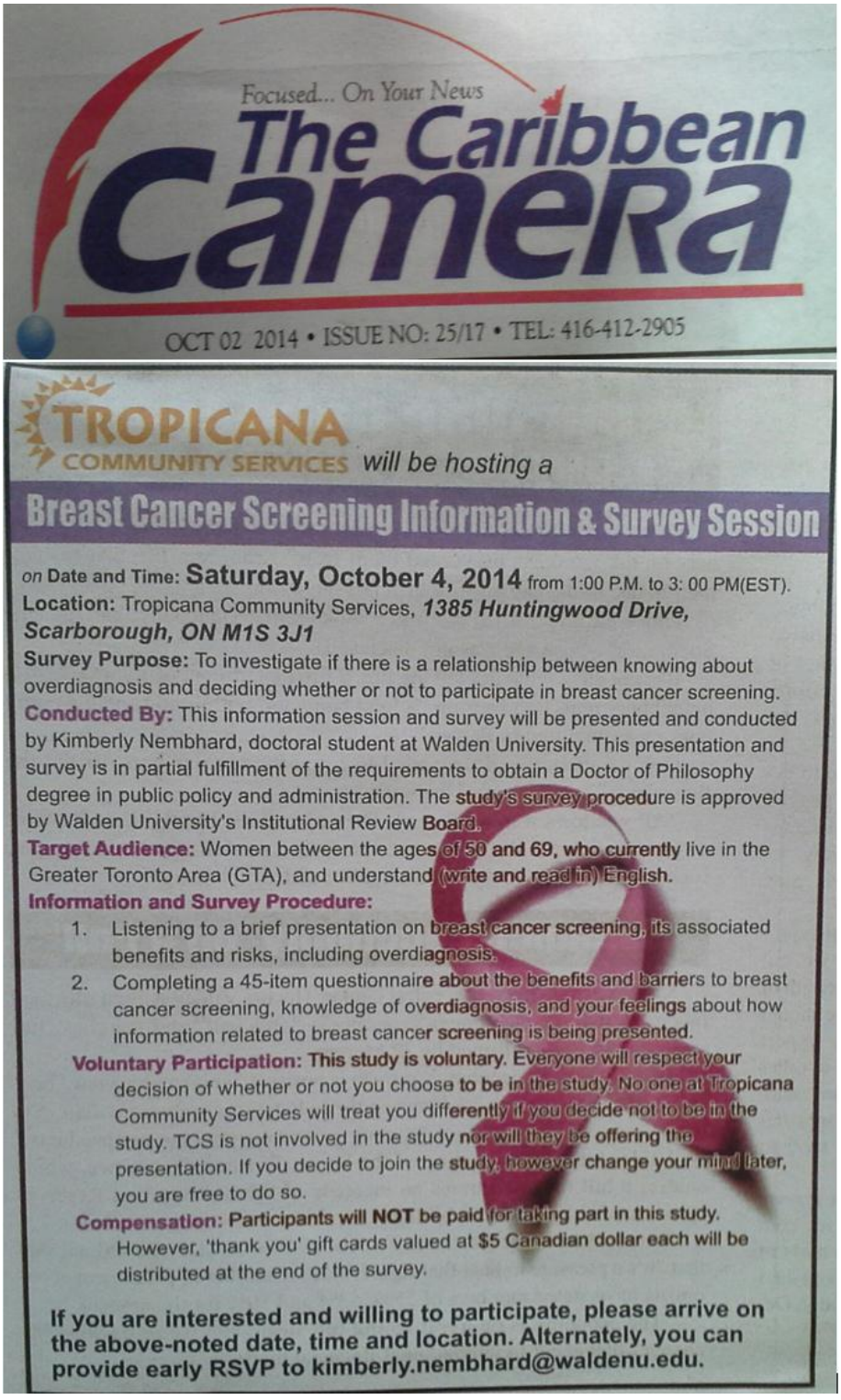
VC:dg

Appendix F: Two Versions of the Health Belief Model





Appendix G: Caribbean Camera Announcement of Research Survey



Focused... On Your News

The Caribbean Camera

OCT 02 2014 • ISSUE NO: 25/17 • TEL: 416-412-2905

TROPICANA COMMUNITY SERVICES will be hosting a

Breast Cancer Screening Information & Survey Session

on **Date and Time:** **Saturday, October 4, 2014** from 1:00 P.M. to 3: 00 PM(EST).
Location: Tropicana Community Services, ***1385 Huntingwood Drive, Scarborough, ON M1S 3J1***
Survey Purpose: To investigate if there is a relationship between knowing about overdiagnosis and deciding whether or not to participate in breast cancer screening.
Conducted By: This information session and survey will be presented and conducted by Kimberly Nembhard, doctoral student at Walden University. This presentation and survey is in partial fulfillment of the requirements to obtain a Doctor of Philosophy degree in public policy and administration. The study's survey procedure is approved by Walden University's Institutional Review Board.
Target Audience: Women between the ages of 50 and 69, who currently live in the Greater Toronto Area (GTA), and understand (write and read in) English.
Information and Survey Procedure:

1. Listening to a brief presentation on breast cancer screening, its associated benefits and risks, including overdiagnosis.
2. Completing a 45-item questionnaire about the benefits and barriers to breast cancer screening, knowledge of overdiagnosis, and your feelings about how information related to breast cancer screening is being presented.

Voluntary Participation: This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at Tropicana Community Services will treat you differently if you decide not to be in the study. TCS is not involved in the study nor will they be offering the presentation. If you decide to join the study, however change your mind later, you are free to do so.
Compensation: Participants will **NOT** be paid for taking part in this study. However, 'thank you' gift cards valued at $5 Canadian dollar each will be distributed at the end of the survey.

If you are interested and willing to participate, please arrive on the above-noted date, time and location. Alternately, you can provide early RSVP to kimberly.nembhard@waldenu.edu.

Appendix H: List of Key Acronyms used in the Study

American Cancer Society . ..... ACS

Breast Cancer Screening. ..... BCS

Breast Cancer Society of Canada. ..... BCSC

Breast Self- Examinations ..... BSE

Canadian Breast Cancer Foundation ..... CBCF

Canadian Cancer Society . ..... CCS

Canadian Task Force on Preventive Health Care. ..... CTFPHC

Cancer Care Ontario . ..... CCO

Cancer Quality Council of Ontario . ..... CQCO

Champion's Health Belief Model Scale. ..... CHBMS

Greater Toronto Area ..... GTA

Health Belief Model ..... HBM

Local Health Integration Network . ..... LHIN

National Cancer Institute . ..... NCI

Ontario Breast Screening Program . ..... OBSP

Ontario Ministry of Health and Long-Term Care ..... MHLTC

Public Health Agency of Canada . ..... PHAC

Statistical Package of the Social Sciences ..... SPSS

Tropicana Community Services ..... TCS

United States of America ..... U.S.

U.S. Preventive Services Task Force ..... USPSTF

Curriculum Vitae

KIMBERLY T NEMBHARD

kim.nembhard@gmail.com

EDUCATION

2015	**Ph.D.**, College of Social and Behavioral Sciences, Walden University Dissertation Title: *Knowledge of Overdiagnosis and the Decision to Participate in Breast Cancer Screening.*
2009	**M.Sc.,** Public Policy and Management**,** Centre for Financial & Management Studies (SOAS), University of London
2006	**B.Sc. (Hons),** International Relations and Criminology, Department of Government, The University of the West Indies

SCHOLARSHIPS, AWARDS AND HONOURS

2010–2015	Walden University (Entrance) Scholarship for Ph.D. in Public Policy and Administration
2014	Pi Alpha Alpha National Honor Society for Public Affairs and Administration
2013	Golden Key International Honour Society

TEACHING AND RESEARCH INTERESTS

Public Policy and Administration, Public Health, Decision Making, Public Management, Leadership, Health Policy, Governance, Ethics, Strategic Planning, Social Justice, Policy Analysis, Research Methodology, and Quantitative Research.

TEACHING EXPERIENCE

Trainer, developed and delivered training seminars and workshops on proposal and grant writing for lawyers. Also worked with lawyers to improve interviewing skills for enhanced individual reputational recognition and firm brand awareness.
Tutor (Math and English), identified learning styles of each K1-12 student and helped them thoroughly understand math and English concepts in order to excel in school.
Team leader and **Mentor**, worked with undergraduate students, via the BBPA National Scholarship Fund program, to enhance their research and analytic skills to produce well written and quality academic papers.
Mediator for Roundtable discussions and workshops for the Ontario Black History Society International Conference.

RESEARCH EXPERIENCE

Writing research proposals; critiquing peer and non-peer reviewed articles; primary data collection; analysis of secondary data; using statistical software (SPSS and NVIVO) to code/recode data, identify missing data, calculate statistics, and interpret and present findings in the form of quantitative, qualitative, and mixed methods research plans.

PROFESSIONAL EXPERIENCE

2013–present	**McCarthy Tétrault LLP** **Marketing & Communications Specialist,** managing and developing persuasive written content for firm and lawyer brand positioning and promotions. Preparation (research, write and edit) of: legal directory submissions, awards, news announcements, presentations, internal communications, and other marketing materials to support the firm's information distribution and business development initiatives. In addition, integrating social media into the firm's public relations and marketing efforts.
2012–2013	**Stikeman Elliott LLP** **Marketing Content & Proposal Specialist,** developed compelling written proposal content and legal directory submissions, presentations, and other marketing materials to support the firm's marketing and business development initiatives.
2011–2012	**Ontario Black History Society** **Events & Project Manager and Office Manager,** focused on building and expanding relationships with government, corporate partners and membership for an Ontario-based national non-profit organization.
2008–2011	**Black Business Professional Association** Progressive roles including **Project Manager** (BBPA National Scholarship Fund and Harry Jerome Awards), **Office Manager** and **Senior Office Administrator** responsible for business development, driving relationship growth, resource development and visibility among sponsors, community and local media.
2003–2009	**Meuze** **Marketing Project Manager** focused on business developing and implementing comprehensive marketing strategy for a privately-owned fashion design and fashion marketing/PR business.

PROFESSIONAL MEMBERSHIPS/AFFILIATIONS

2011–present Member, Ontario Black History Society
2011–2013 Member, Urban Financial Services Coalition
2008–2011 Member, Black Business and Professional Association

COMMUNITY INVOLVEMENT/OUTREACH

2011–present Volunteer, Ontario Black History Society
2011–2013 Volunteer, Urban Financial Services Coalition
2010–2012 Volunteer, Reel World Film Festival
2009–2010 Volunteer, The Applause Institute
2008–2011 Volunteer, Black Business and Professional Association
2008–2010 Volunteer, Caribbean Tales

References available upon request