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An Analysis of the Factors Affecting Willingness to Decrease Mammogram Frequency Among Women at Low Risk for Hereditary Breast Cancer

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B.S.
Georgia Institute of Technology
2016

Committee Chair: Dr. Colleen McBride, Committee Member: Dr. Eric Nehl

An abstract of
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A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

Background In 2009, The US Preventative Services Task Force changed mammography screening recommendations, recommending that women start having mammograms later in life and that women have less frequent mammograms, based on their risk of breast cancer. These changes were meant to maximize the positive aspects of mammography while minimizing the negative aspects, which can often be sizeable. However, mammography recommendation changes have not resulted in a decrease in mammography. Hereditary breast cancer tends to be early onset and aggressive. Women at high risk of hereditary breast cancer benefit from early and frequent mammography, whereas women at low risk of hereditary breast cancer do not. Family history can be used to determine whether a woman has a high genetic risk of hereditary breast cancer, however convincing low risk women to forgo frequent mammography will likely prove challenging. This study seeks to understand the factors that influence willingness to decrease mammogram frequency among women at low risk of hereditary breast cancer.

Methods 157 participants were recruited from Emory clinic breast imaging centers. Women who completed a breast cancer genetics referral screening tool (B-RST) and received a negative result were sent a survey which included items evaluating women's risk understanding, recall of B-RST result, demographics, past mammogram frequency, healthcare trust, perceived risk of breast cancer, breast cancer worry, acceptance of B-RST result, and willingness to decrease their mammogram frequency based on their low risk. Analysis was conducted by calculating descriptive statistics for survey items and significant differences between questionnaire responses between those who were willing, unsure, and unwilling to decrease their mammogram frequency using ANOVAs and Chi-Square tests. Binomial logistic regressions were conducted to assess the association between study variables and willingness to decrease mammogram

frequency, as well as to assess the association between study variables and being undecided of willingness.

Results Overall, 57.3% of the women included were either willing to decrease their mammogram frequency based on their genetic risk or uncertain of their willingness. Chi square analysis showed a significant differences in past mammogram frequency between willingness variables, with 94.0% of women who had had yearly mammograms or more unwilling to decrease their mammogram frequency ($p<0.00$). Differences were also found in breast cancer worry frequency, with the majority of those who were unwilling, 65.7%, reporting having experienced breast cancer worry ($p=0.02$). Those who were willing to decrease their mammogram frequency were less likely to report experiencing a high perceived risk of breast cancer ($p=0.01$). Binomial logistic regression showed significant associations between being willing to decrease mammogram frequency and both past mammogram frequency ($p<0.00$) and perceived risk of breast cancer ($p=0.07$).

Conclusion The majority of the study population were either willing to decrease their mammogram frequency based on their genetic risk or were uncertain of their willingness and could potentially be swayed. Past mammogram frequency, breast cancer worry, and perceived risk were all found to be associated with willingness to decrease mammogram frequency. This knowledge can be used to create future guidelines and education efforts, improving patient understanding of breast cancer genetic risk and providing patients to tools necessary to make informed decisions.

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I.

Introduction

Statement of Problem

The aim of this thesis research was to examine the factors associated with willingness to alter mammogram frequency based on communication that a woman is at lowered risk for a BRCA1/BRCA2 mutation, and therefore at a lowered risk for hereditary breast cancer. Mammography is a population screening tool used to detect breast cancer before the onset of symptoms. Although use of mammography can reduce morbidity and mortality from breast cancer (Kandlikar et al., 2017; Warner, 2011; Welch & Passow, 2014), there are substantial negative side effects that can come with mammography screening (Brenner et al., 2002; Kandlikar et al., 2017; A. B. Miller et al., 2014). In 2009, The US Preventative Task Force changed mammogram screening guidelines, recommending that women at average risk start having mammograms at age 50 instead of the previously recommended age of 40 (U.S. Preventative Services Task Force, 2009). These recommendation changes aimed to maximize the positive aspects of mammography while minimizing the negative possible side effects (Siu & Force, 2016). However, these changes were met with distrust and disagreement from women who felt left out of the decision and who were suspicious that the changes were driven by insurance company financial incentives instead of interests in their wellbeing (Allen et al., 2013). As medical knowledge of genetic and environmental interactions increases, breast cancer risk stratification can become more precise, resulting in tools that can be used to better tailor preventative measures. It is possible that further advancements could result in future changes to mammogram recommendations. As past recommendation changes have been received negatively, it is important to understand the factors that may contribute to a willingness or

unwillingness to alter personal breast cancer preventative care based on knowledge of genetic risk. A theoretical framework by Waters et al. was used to guide the selection of constructs for this study, which included health communication messages, demographics, health history, institutional trust, and cognitive and emotional processes (Waters, Wheeler, & Hamilton, 2016).

This study was designed to answer the following questions:

1. Do healthcare trust and acceptance of B-RST predict willingness to decrease mammogram frequency among women at low risk for hereditary breast cancer?
2. Are variables suggested by the Waters et al model associated with willingness to decrease mammogram frequency based on lowered genetic risk?

Population Screening

Mammography is a form of population screening. Population screening is relied on heavily by the medical field. Screening frequently begins in utero and continues throughout a person's lifetime as a means to detect disorders, such as genetic abnormalities, dyslipidemia, hypertension, mental health disorders, and various types of cancers, when the negative health effects can be minimized (Rose, 1992). Screening of everyone in a population, known as population screening, is necessary if risk for a certain disease is evenly distributed across a population (Rose, 1992). Utilized as a tool to uncover medical conditions before the onset of symptoms, population screening becomes an important tool of preventative medicine (Russel, 1994). In order for a screening test to be an effective method of early disease detection, a treatment or intervention must exist for the condition being screened for. Additionally, the treatment must be more effective if it is administered early, before the onset of symptoms (Russel, 1994). Knowledge of risk is not useful in the reduction of morbidity and mortality if

there is no way to reduce this risk. However, if preventative options do exist, early risk identification could enable lifestyle changes or prophylactic treatment.

High-risk screening strategies focus efforts on those most likely to develop a condition (Rose, 1992). Selective screening based on such risk stratification can prove more cost effective and efficient than population screening, for both physician and patient. Selective screening can be based on a number of factors such as lifestyle and environmental exposures, family history, and biomarkers. For cancer, advances in genomic discovery have led to new genetic biomarkers of risk. Genetic biomarkers have been found that increase the risk of prostate cancer (Dhanasekaran et al., 2001), colorectal cancer (Bellido et al., 2015), and melanoma (Mangas et al., 2016), as well as pancreatic cancer syndromes (Bruno et al., 2017) and breast cancer syndromes (Szabo & King, 1995).

However, these genetic variants are relatively rare at the population level. Thus, only patients with a suggestive family history of the cancer should undergo genetic testing to determine whether they carry the mutation linked with that type of cancer (Robson et al., 2015). For breast cancer, ethnic background and degree of kinship to relatives with breast cancer can be used to estimate the risk that a woman carries a genetic mutation that greatly increases her risk of breast cancer.

Women of Ashkenazi Jewish ancestry are particularly at risk of carrying a BRCA1 or BRCA2 mutation. Estimates of BRCA1/2 mutations among Ashkenazi Jewish women vary from about 1 in 33 to 1 in 56, and between 7% and 12% of breast cancer cases among these women can be attributed to such a mutation (McClain, Nathanson, Palomaki, & Haddow, 2005). Additionally, women who have a first degree relative who has had bilateral breast cancer or both breast and ovarian cancer are at increased risk of familial breast cancer, as are women with a first

degree relative who had breast cancer before the age of 40, women with a first degree male relative diagnosed with breast cancer, women with two first or second degree relatives on the same side of the family diagnosed under the age of 60 or diagnosed with ovarian cancer, and women with three first or second relatives on the same side of the family diagnosed with breast or ovarian cancer (McPherson, Steel, & Dixon, 2000).

Mutations in BRCA1/2 have now been well studied and are shown to significantly increase lifetime risk for breast cancer (Mehrgou & Akouchekian, 2016; Szabo & King, 1995). Moreover, there are lifesaving strategies that can be used to reduce mortality in this high-risk population (Cuzick et al., 2015; Ludwig, Neuner, Butler, Geurts, & Kong, 2016; Rebbeck et al., 2004). However, as those at low risk would not benefit, and could even be harmed by some of the options, risk stratification becomes important in reducing harm. Using risk stratification to identify women who would most benefit from these strategies could result in reduced morbidity and mortality among high risk women without exposing low risk women to the negative side effects breast cancer intervention options.

Available Interventions to Reduce Breast Cancer Mortality for Those at Highest Risk

Proactive breast cancer screening of those at high risk could result in early detection of cancer and reduce mortality. For breast cancer, like most types of cancer, the stage of the disease at detection is the most important determinant of outcome, as metastatic disease has a poorer outcome (Kandlikar et al., 2017). The chance of a positive prognosis is much higher if the breast cancer is detected before the lump is palpable. To lessen mortality and morbidity of breast cancer, early detection becomes imperative.

Inherited breast cancer has a higher likelihood of early onset and can be more aggressive (Mehrgou & Akouchekian, 2016). As a result, morbidity and mortality caused by hereditary breast cancer has a higher social cost in years of life lost. Identifying women at risk for hereditary breast cancer and providing them with prophylactic treatment options could reduce the amount of life lost to breast cancer.

There are a number of ways that women can choose to lessen their risk. Tamoxifen can be taken orally by those at higher risk. Tamoxifen is a treatment for oestrogen receptor positive breast cancer (Cuzick & Baum, 1985) and has been shown to reduce breast cancer occurrence in high risk women. A study by Cuzick et al. showed that women at high risk who took tamoxifen for five years had a reduced risk of breast cancer when compared to the placebo group even after ten years of follow up (Cuzick et al., 2015). Bilateral prophylactic mastectomy is also an option for women with a BRCA1 or BRCA2 mutation. Studies have found a 90% to 95% decrease in risk of breast cancer among women with a BRCA mutation (Ludwig et al., 2016; Rebbeck et al., 2004). Women with a BRCA1 or BRCA2 mutation are also at an increased risk of ovarian, fallopian tube, and peritoneal cancer. Prophylactic oophorectomy can reduce the risk of these cancers by approximately 80% (Finch et al., 2006).

Women at high risk can also choose to begin breast cancer screening earlier in life, and to be screened more frequently than the general population. Mammography is the primary method of screening for breast cancer. X-rays are used to generate pictures of breast tissue. Each breast is flattened between two plastic plates during the x-rays to ensure a clear picture, once from the top and bottom and once from side to side. Abnormalities can be detected on the images by a radiologist and can lead to further tests including more precise imaging or tissue biopsy.

Abnormalities can be detected by mammogram much sooner than lumps are palpable and before symptoms are present.

Breast cancer screening guidelines vary in their recommendations but generally suggest starting yearly mammography somewhere between the ages of 40 and 50 and reducing frequency to every other year as women age. However, there have been some considerations to change these recommendations based on various risk factors. Adjusting the starting age and frequency of mammograms based on inherited risk could further inform guidelines for screening intervals for women. Those at high risk may require more frequent mammograms earlier in life, while those at low risk may require less frequent screening. Adjusting the screening regimen of those at low risk will require de-implementation of long standing medical policies.

De-Implementation of Mammography

From to 1983 until October of 2015, the American Cancer Society recommended that women between the ages of 40 and 50 get an annual mammogram ("History of ACS recommendations for the early detection of cancer in people without symptoms," 2018). Even now, the American Cancer recommends yearly mammograms for women between 45 and 50. Many physicians use these guidelines to refer their patients to mammography. However, the United States Preventative Task Force has recommended that low risk women begin mammogram screening at age 50 (U.S. Preventative Services Task Force, 2009). De-implementation of mammogram screening for women between the ages of 40 and 50 could protect this age group from negative side effects of mammography and can prevent unnecessary medical spending (U.S. Preventative Services Task Force, 2009).

Mammograms are not benign procedures and can yield false negative results. False positives are relatively common, reporting a specificity of 82.3% (Jacobsen et al., 2015). These false positives often induce breast cancer anxiety (Tosteson et al., 2014). Additionally, mammography can result in the detection of breast lumps that likely would never become symptomatic (Welch & Passow, 2014), sparking unnecessary treatment, side effects, and healthcare costs. In 2010, the United States spent a substantial $7.8 billion on mammography screening (O'Donoghue, Eklund, Ozanne, & Esserman, 2014). De-implementation of mammography among low risk women could help them avoid these risks and could low healthcare costs, improving the efficiency of population mammography screening.

Challenges of Using Risk Stratification in Guiding Health Service Delivery

While early and frequent mammograms can be lifesaving for women at high risk for hereditary breast cancer, the majority of women screened for BRCA mutations will get a low or moderate result, indicating that they are not at high risk for carrying a BRCA1 or BRCA 2 mutations. This puts most women at low risk for early onset, aggressive hereditary breast and ovarian cancer and at the same risk for nonhereditary breast cancer as the average population. This majority may be less likely to benefit from early, annual mammography. Increased mammogram frequency for those at low risk of hereditary breast cancer would serve only to put these women at a higher risk of experiencing the negative side effects that can come with mammography (Brenner et al., 2002; L. Y. Miller & Hailey, 1994; Tosteson et al., 2014; Welch & Passow, 2014). However, convincing women at low risk of hereditary breast cancer that it is not necessary for them to get mammograms at the same frequency as women at high risk of hereditary breast cancer may prove to be difficult. One of the main challenges with using risk

stratification to guide health service delivery will likely be talking those who are at average risk out of unnecessary screening procedures.

Effectively changing mammogram screening recommendations might be challenging due to current recommendations having been being deeply ingrained into the public perceptions of appropriate medical care. Past changes in mammogram recommendations have been met with anxiety and mistrust (Allen et al., 2013), making it likely that future changes would be met with similar responses. Recommendations to decrease the frequency of breast cancer screening for low risk women may be met with apprehension and resistance for various reasons. The Waters et al theoretical framework was used to look into some of these potential reasons. This framework was used to guide selection of variables included in analysis and is described below.

Theoretical Framework

Waters et al. created a theoretical framework based on research in psychology, public health, and genomic medicine in order to understand how a person's causal beliefs about a disease are influenced by external factors and how such beliefs influence health behaviors (Waters, Muff, & Hamilton, 2014). This relatively new theoretical framework seeks to guide research into understanding how genetic testing and genetic information will affect health behavior changes. The framework is based on the idea that complex information, such as that learned from genetic testing, may be difficult to understand for people with a limited understanding of health (Waters et al., 2014). The framework was adapted and used in a 2016 study to understand how cancer information seeking, scanning and processing affect the development of multifactorial beliefs about cancer (Waters et al., 2016).

In their 2016 study, Waters et al. sought to determine how development of multifactorial beliefs influence engagement in healthy behaviors, including cancer screening, and ultimately found that individuals who had multifactorial beliefs regarding cancer risk were more likely to engage in screening behaviors (Waters et al., 2016). Based on literature review, Waters et al included health communication methods, demographics, health history, causal beliefs, and cognitive and emotional processes as predictors of health behavior.

Waters et al. have used their theoretical model to examine the relationship between causal beliefs and mammography and found that multifactorial beliefs about cancer were significantly associated with adherence to mammography guidelines (Waters et al., 2016). However, the framework has not been used to evaluate how genetic risk communication effectiveness, demographics, health history, and cognitive and emotional processes are associated with adherence to mammography recommendations among women who are told they are at low risk for hereditary breast cancer. Based on a review of current literature, this framework has been better adapted to fit to mammogram screening behavior, as shown in Figure 1.

Institutional trust has been added as a predictor of mammography screening and likely influences message acceptance. Although previous research studies have shown that many of the factors included in this framework are correlated with mammogram screening behavior, little is known about the effects these correlates may have on hypothetical mammography guideline adherence among women told they are at low risk for hereditary breast and ovarian cancer. In order to significantly impact health, genetic risk communication must prompt a behavior change. Better understanding of the factors that may influence behavior change could lead to multipronged interventions and could increase likelihood that communication of genetic risk leads to health improvements.

Figure 1 shows the pathways included in the Waters et al theoretical framework. Based on the framework, health communication messages, health history, and demographics can influence causal beliefs, which affect cognitive and emotional processes. Cognitive and emotional processes in turn affect health behaviors. Literature review shows that demographics can affect institutional trust (Q. T. Edwards et al., 2009; Harmon et al., 2014), which also affects health behavior (O'Malley, Sheppard, Schwartz, & Mandelblatt, 2004; Taber, Leyva, & Persoskie, 2015).

Health communication messages include mass media, public health campaigns, and health-care provider communication. To properly use information about their hereditary breast cancer risk level when making healthcare decisions, women must correctly understand how their genes influence their risk, which in turn affects causal beliefs. Effectively communicating risk information may prove to be a challenge when using risk stratification to guide screening recommendations. A 2006 study showed that 36% of participants only had basic or lower healthcare literacy (Cutilli & Bennett, 2009; Me, Greenberg, Jin, & Paulsen, 2006). Women with basic or lower healthcare literacy may have a more difficult time understanding their genetic risk. As method of risk communication can affect risk perception (Ahmed, Naik, Willoughby, & Edwards, 2012), it is important that the appropriate presentation is used when informing women of their risk of hereditary breast cancer.

Health history can include family history, personal history, body mass index, health status, and awareness of direct to consumer genetic testing. Waters et al. found a significant association between some aspects of health history, most notably family history of cancer, and multifactorial cancer causal beliefs (Waters et al., 2014). Multifactorial cancer causal beliefs can be made up of perceived effect of genetic, behavioral and environmental risk factors and have

been shown to affect perceived risk of cancer, as well as cancer worry (Hamilton & Waters, 2018). Waters et al. also found that multifactorial causal beliefs were significantly associated with mammogram adherence (Waters et al., 2014).

It is also important to consider demographics when considering willingness to alter medical care. Waters et al found that race was significantly associated with causal beliefs (Waters et al., 2014). Age and race may influence medical decision making among women. Older women are more likely to have more frequent mammograms (Moser, McCaul, Peters, Nelson, & Marcus, 2007), making it likely that older age can predict hesitation to alter mammogram frequency. Given the current racial disparities in mammogram utilization (Sassi, Luft, & Guadagnoli, 2006; Swan, Breen, Coates, Rimer, & Lee, 2003), it is possible that race could be a predictor of willingness to change mammogram frequency. Such an association could be explained by variation in trust in medical institutions. African American women are less likely to trust their healthcare providers than white women (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003). Trust, defined as "the optimistic acceptance of a vulnerable situation in which the truster believes the trustee will care for the truster's interests" (Hall, Dugan, Zheng, & Mishra, 2001; Hay, McCaul, & Magnan, 2006), has been found to be associated with adherence to treatment recommendations (Hall et al., 2001; Schoenthaler et al., 2014). Differences in trust may affect adherence to medical advice and influence mammogram frequency.

Cognitive and emotional process consist of perceived risk, perceived control, worry, and message acceptance. Perceived risk of breast cancer, breast cancer worry, and acceptance of risk information may influence how patients react to changes in recommendations. Perceived risk is defined as how likely a person believes it is that he or she will develop a certain disease (Moser et al., 2007). Perceived risk is a cognitive conceptualization of illness threat and can be

distinguished from worry, which is an affective conceptualization of illness threat. Both perceived risk and worry have been shown to facilitate screening behaviors and are independent predictors of increase in frequency of mammography screening (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; McCaul, Branstetter, O'Donnell, Jacobson, & Quinlan, 1998; Moser et al., 2007).

Application of this theoretical framework will allow for a guided analysis of how these factors affect each other and ultimately willingness to alter screening behaviors, among a population of women told they are at low risk for hereditary breast cancer.

Purpose of Study

This analysis explores willingness to decrease mammogram frequency based on low risk of hereditary breast cancer and examines the associated correlates among women getting a mammogram. An understanding of willingness to decrease mammogram frequency among women utilizing mammogram services can be used to inform future mammogram recommendations and can guide risk communication efforts. Understanding the factors affecting willingness to decrease mammogram frequency based on genetic risk can also inform health education efforts, increasing willingness to base mammogram screening routines on risk stratification, making de-implementation efforts more successful, preventing unnecessary healthcare spending, and ensuring that early mammography efforts were targeted towards women who would benefit from them the most.

Significance of Study

The efficacy of mammography has recently been called into question. Some studies have found that mammography does not reduce breast cancer mortality in the general population when compared to breast exams (A. B. Miller et al., 2014; Nelson, Pappas, et al., 2016). There has been increasing evidence that routine mammography can lead to over-diagnosis and over-treatment (A. B. Miller et al., 2014; Nelson, Pappas, et al., 2016; Welch, Prorok, O'Malley, & Kramer, 2016). Over-diagnosis and treatment can place an undue burden, both emotionally and financially, on women who would otherwise not have to deal with the treatment. Additionally, mammography is expensive and excessive screening could put an undue burden onto the healthcare system. Tailoring medical care and screening practices based on risk can increase the success of screening programs, prevent overtreatment, and ensure that financial efforts and time spent on medical care are optimized to improve individual health.

To date, a study examining the factors that affect how willing women are to reduce their mammogram frequency based on their hereditary breast cancer risk level, particularly their genetic risk level, has not been conducted. Studies have been conducted examining how worry (Andrykowski et al., 2001; Consedine et al., 2004; Hay et al., 2006), perceived risk (Gross, Filardo, Singh, Freedman, & Farrell, 2006; Katapodi, Lee, Facione, & Dodd, 2004), institutional trust (O'Malley et al., 2004), and demographics (Q. T. Edwards et al., 2009; Harmon et al., 2014; Smith-Bindman et al., 2006) can effect mammogram frequency. However, no study has looked into how these correlates influence willingness to alter mammogram frequency. Understanding the factors that may influence patient willingness to change their medical care based on their genetic risk is a vital part of ensuring tailored screening programs work. Programs and campaigns aimed at addressing patient concerns could make such programs more successful.

Limitations

This study was limited by the following factors:

1. This study was based in the Metro Atlanta area, a large metropolitan city with an estimated population of 5.7 million residents, located in the Southeast. Study results may not be representative of women living in other areas, including but not limited to rural areas, cities with smaller populations, and areas outside the Southeast.
2. This study was a secondary data analysis. This did not allow for alterations of the questionnaire.
3. The sample size for this study was relatively small. This limited the statistical power of the study.

Definition of Terms

Population Screening: Population screening is used to identify the presence of disease before symptoms appear. Mammography is a type of population screening, using x-ray imaging to identify abnormal lumps in the breast that could be cancerous.

Population Strategy: The population strategy is a type of screening practice where entire populations are screened, regardless of potential risk. This strategy is the most useful in cases where the factor causing onset of disease is evenly distributed throughout the population and there is no effective way of determining who is affected by said risk factor. Current U.S. Preventative Service Task Force mammogram recommendations for women above the age of 50 use the population strategy.

High-Risk Strategy: The high-risk strategy is a type of screening practice that targets people who are known to be at higher risk for a particular disease due to environment, lifestyle factors (diet, exercise, etc.), and genetics. Current U.S. Preventative Services Task Force mammogram recommendations for women between the ages of 40 and 49 use the high-risk strategy, only screening women who are known to be at increased risk.

Risk Stratification: Risk stratification is a method of predicting which patients are at higher risk for certain conditions using environmental, lifestyle, and genetic factors and altering medical care based on these predictions.

Perceived risk of breast cancer: Perceived risk is an individual's assessment of their risk of developing a given disease, in this case their risk of developing breast cancer. Perceived risk is a cognitive conceptualization of disease threat.

Breast cancer worry: Worry is an affective conceptualization of threat. Breast cancer worry or fear can be described as a state of anxiety regarding the thought of developing the disease.

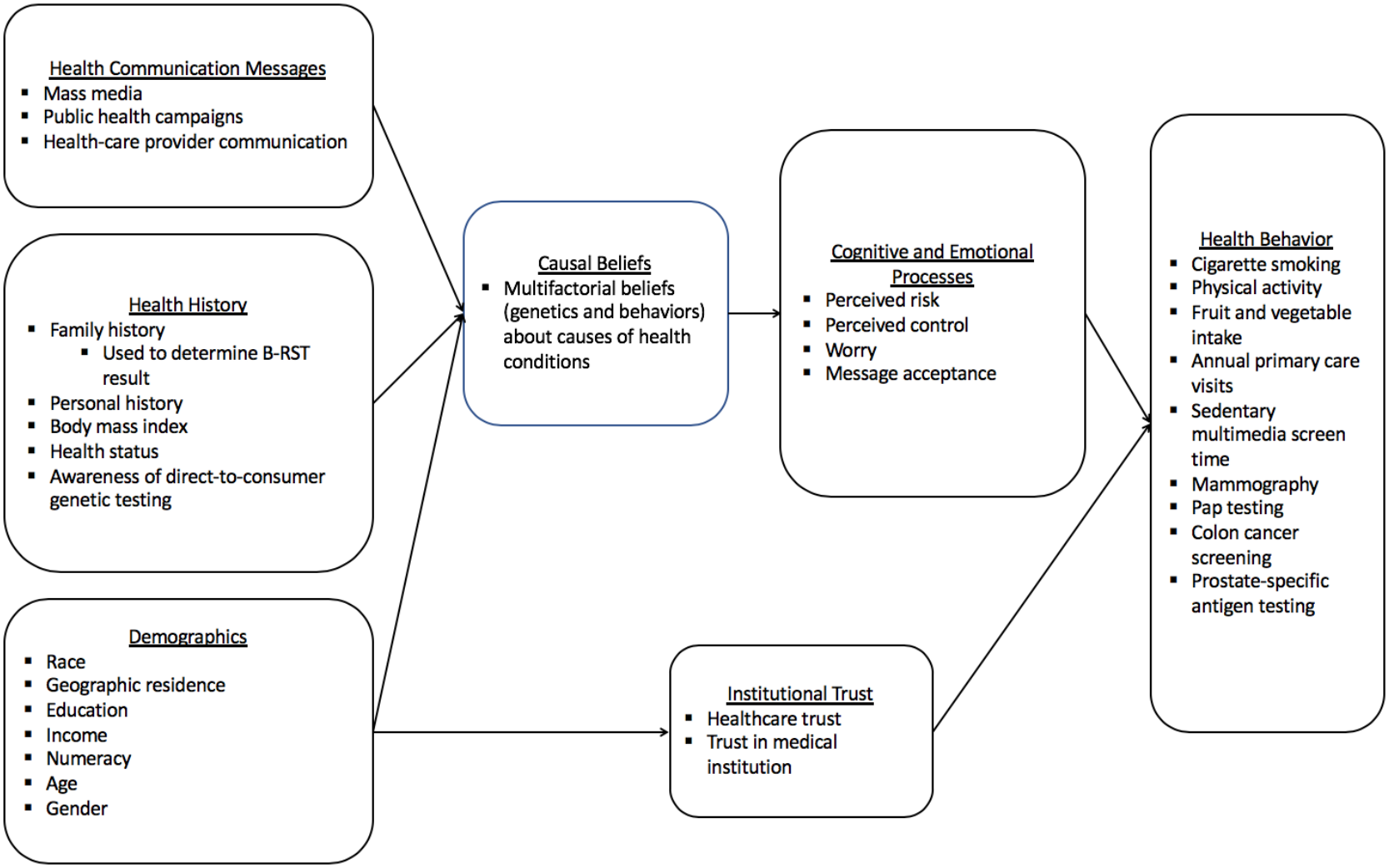
Institutional Trust: Institutional trust is the relationship between an individual and an institution. The trust between patients and the physicians/healthcare institutions that manage their care requires the belief that the person and entity they seek healthcare from has their best interests in mind, given that patients can be in a vulnerable position.

Demographics: Demographics describe the make-up of a population. This study will focus on race and age as demographics, as well as reason for screening on day of B-RST

Number Needed to Screen: The number needed to screen refers to the number of people who need to be screened to prevent one mortality caused by the disease being screened for. For mammography, for women between the ages of 40 and 84, 84 women need to be screened to prevent one breast cancer death (Hendrick & Helvie, 2012).

Evidence Based Public Health: Evidence Based Public Health is the development and implementation of programs based on scientific evidence. A focus on Evidence Based Public Health can ensure that healthcare resources are going into programs that will make the most significant impact on the public's health.

Figure 1 Adaptation of Waters et al theoretical framework



II.

Literature Review

Public Health Burden of Breast Cancer

Breast cancer is the second most commonly diagnosed cancer among women in the United States and the second leading cause of cancer death, second only to lung cancer (Ma & Jemal, 2013). Women in the United States have a 1 in 8 chance of developing breast cancer (Warner, 2011), resulting in a lifetime risk of about 12%. It is estimated that 246,660 women were diagnosed with breast cancer in 2016 (Kandlikar et al., 2017). Among these diagnosis, 5-10% are thought to have had hereditary causes, with BRCA1 and BRCA2 genes making up 30% of these cases (Economopoulou, Dimitriadis, & Psyrri, 2015).

The lifetime risk that a woman with a BRCA1 mutation develops breast cancer is 45%-90%. This risk for women with a BRCA2 mutation is 36%-75%. BRCA1 and BRCA 2 genes are known as anti-oncogenes and are responsible for the production of tumor suppressor gene (TSG) proteins. TSG proteins suppress cell growth and help repair cell damage. By repairing cell DNA damage, TSG proteins ensure that genetic material is preserved (Mehrgou & Akouchekian, 2016). Mutations in BRCA1 and BRCA2 can prevent TSG from working correctly, allowing cell DNA damage to build up and making cancer more likely.

Women with a BRCA1 or BRCA2 gene are at a greater risk, not only for developing breast cancer, but also for developing it at a younger age (Mehrgou & Akouchekian, 2016). These women are more likely to have tumors with a higher nuclear grade, which describes the size and growth rate of the tumor (Hadden, 2007). The majority of breast cancer associated with BRCA1 is triple negative, meaning that cancer cells do not have progesterone receptors, estrogen receptors, or HER-2 cell surface receptors (Mehrgou & Akouchekian, 2016). Triple negative

breast cancer is more aggressive, more likely to be bilateral, and has a poorer prognosis compared to other types of breast cancer (Mehrgou & Akouchekian, 2016). Given the early onset and aggressive nature of BRCA1/BRCA2 related breast cancer, early detection of the cancer is vital in reducing morbidity and mortality among women with BRCA1/BRCA2 mutations (Kandlikar et al., 2017).

Breast Cancer Screening: Unclear Mammography Recommendations

The two main forms of breast cancer screening are breast examination, both clinical and self-administered, and mammography. While women are still encouraged to routinely perform self-examinations of their breasts and check for changes in size, shape, or feeling, breast examination catches cancer in later phases, when it is likely to be harder to treat. In order to catch breast cancer earlier, breast imaging is used. Mammograms are the main type of breast imaging, reducing mortality among women ages 40 to 74 by 31% (Kandlikar et al., 2017). It is estimated that among 1000 US women aged 50, 0.3-3.2 will avoid death because of screening mammography (Welch & Passow, 2014). Breast cancer mortality has decreased by 2.2% every year since 1990, a reduction partly due to the increased use of mammography (Warner, 2011).

Differing recommendations about mammography make it hard for women to know when and how often to get a mammogram. Recommendations from the Society of Breast Imaging tell women with an average risk to start getting yearly mammograms at age 40 (Lee et al., 2010) while the American Cancer Society tells women 40-44 to decide with their doctor whether to get screened and women 45-54 to have yearly mammograms (Oeffinger et al., 2015). They recommend that those at higher risk, including those with genetic risk and those with more than a 20% lifetime risk, get a yearly mammogram starting at age 30.

In 2009, the U.S. Preventative Services Task Force changed their guidelines for mammography from recommending women start getting mammograms at 40 to recommending they start at 50 (Siu & Force, 2016; U.S. Preventative Services Task Force, 2009). Many other societies, including the American Cancer Society, have not changed their recommendations to match. Figure 2 outlines the differences in screening recommendations between the American Cancer Society, the Society of Breast Imaging, and the USPSTF.

Figure 2 Differing Breast Cancer Mammography Screening Recommendations

	SOCIETY OF BREAST IMAGING	AMERICAN CANCER SOCIETY	USPSTF
BEFORE 40	No recommendation	Based on risk	No recommendation
40-44	Yearly	Based on risk	Based on risk
45-49	Yearly	Yearly	Based on risk
50-54	Yearly	Yearly	Biennial
55 AND OLDER	Yearly	Biennial	Biennial
STOP GETTING MAMMOGRAMS	Life expectancy less than 5-7 years	Life expectancy less than 10 years	74

(Lee et al., 2010; Oeffinger et al., 2015; Siu & Force, 2016)

Limited Access to Mammography

Further complicating the issue of mammography frequency, the availability of mammography decreased from 2000 to 2010 among 3141 varying United States counties. In 2000, 13,100 mammography machines were available at 9434 locations. Median country level capacity showed 1.77 machines per 10,000 women over the age of 40. By 2010, that number had dropped to 11,762 machines in only 8469 facilities, leaving only 1.42 machines per 10,000

women over the age of 40 (Elkin, Atoria, Leoce, Bach, & Schrag, 2013). Vulnerable populations were affected by this decrease the most, with counties in which residents were less educated, had increased poverty rates, and had an increasing percentage of elderly residents more likely to have experienced a reduction in mammography access. Counties with a higher percentage of uninsured residents were also more likely to have seen a decrease in mammogram capacity from 2000 to 2010 (Elkin et al., 2013). As accessibility of mammography declines, it becomes more and more pertinent to ensure that mammography efforts target those who will benefit the most from breast cancer screening. Paring down the number of women to whom mammograms are recommended could alleviate access issues, insuring those who would benefit from mammograms can get them.

Improved risk stratification could potentially clarify who should get a mammogram and when. Given the increased risk for women with BRCA1/BRCA2 mutations to develop early onset and/or aggressive breast cancer, targeting these women for earlier, more frequent mammography could reduce cancer mortality for those at high risk. However, the entire population would likely not benefit from earlier screening and could actually experience negative side effects. There is an inflated perception of breast cancer risk in the United States (de Jonge, Vlasselaer, Van de Putte, & Schobbens, 2009), likely making convincing women to forgo early, frequent mammograms difficult. For example, mammography rates did not decrease following the release of the 2009 U.S. Preventative Service Task Force guidelines (Pace, He, & Keating, 2013). Moreover among women 40-49 years old, the age group specifically told they did not have to start getting mammograms, rates have actually slightly increased, although this increase was not significant (Pace et al., 2013).

Drawbacks of Mammography Screening

Although the importance of routine mammograms is generally accepted, the efficacy of mammography has recently been called into question. A study by Miller et al. found that annual mammography does not decrease mortality from breast cancer among Canadian women (A. B. Miller et al., 2014). Meanwhile, routine mammography can come with risks. Some studies have shown that repeated exposure to low radiation, such as the level used in mammography, can increase the chances of cancerous mutations, potentially increasing a woman's risk of developing cancer (Brenner et al., 2002). Beginning mammography later in life can decrease this risk. False positives are common with 490-670 among a group of 1000 women aged 50 years experiencing at least one false alarm, given routine screening (Welch & Passow, 2014). The likelihood of a false positive over ten years, assuming a yearly mammogram is 49.1% (Kandlikar et al., 2017). False positives can result in unnecessary biopsy procedures, with 15% of women with a false positive undergoing a biopsy compared to only 1% of those with negative mammograms (Tosteson et al., 2014). These false positives can significantly increase anxiety among women (Tosteson et al., 2014), anxiety that has been shown to persist even after the result was proven incorrect (Barton et al., 2004). Tosteson et al. found that 51% of women with a false positive exam experiences moderate or higher anxiety, and that 5% experienced extreme anxiety (Tosteson et al., 2014). Women seem to be willing to go to great lengths to avoid having to experience the anxiety that can come with a false positive, with the majority of women studied reporting that they would be willing to travel up to 4 hours to avoid a false-positive mammogram, and that they would prefer a mammogram technology with less false positives over a technology where they could avoid breast compression (Tosteson et al., 2014).

Over-diagnoses results in many women who undergo radiation or chemotherapy needlessly. According to one study, between 3 and 14 women out of 50 will be over diagnosed and needlessly treated (Welch & Passow, 2014). Miller et al. found that 22% of invasive breast cancer detected in Canadian women by mammography is likely to have not grown aggressively enough to cause a problem, resulting in over-treatment (A. B. Miller et al., 2014). Mammograms can also result in false negatives, with 1.0 to 1.5 women in 1000 experiencing a false negative (Nelson, O'Meara, Kerlikowske, Balch, & Miglioretti, 2016). This can give women a false sense of reassurance, making them more likely to dismiss other potential symptoms.

Women grossly overestimate mammogram success. Among a cohort of 4140 women surveyed, more than 50% believed that mammography could lower their chances of dying from breast cancer by at least 50% (Domenighetti et al., 2003; Løberg, Lousdal, Bretthauer, & Kalager, 2015). While mammograms can prevent breast cancer deaths, mammography is far less successful than most women believe.

Studies have shown that the vast majority of women being screened through mammography do not directly benefit from the procedure. The number needed to screen (NNS) represents the number of women who have to get a mammogram in order for one breast cancer death to be prevented. For women 40-49, 746 women need to be screened to prevent one death. The NNS for women 50-59 is 351, for women 60-69 is 233, for women 70-79 is 377, and for women 80-84 is 1316 (Hendrick & Helvie, 2012). Mammograms can be painful and stressful. Studies have found that pain of mammography can be a deterrent to screening (D. Miller, Livingstone, & Herbison, 2008), and that this pain is worse for women with smaller breasts (de Groot, Broeders, & den Heeten, 2015). Women with previous breast cancer and those who perceive their physician as disengaged were more likely to experience stress related to

mammography (Gurevich et al., 2004). This means that many women must risk experiencing negative side effects, as well as radiation exposure, for only a few to ultimately benefit.

Lastly, the United States spends billions on mammography screening every year. In 2010, $7.8 billion was spent on mammography screening. However, if U.S. Preventative Services Task Force guidelines were to be followed, screening 85% of women would cost $3.5 billion (O'Donoghue et al., 2014). Given continually rising healthcare costs, determining who in the population would benefit from earlier, more frequent mammography and who would not, has the potential to lower costs. Thus, high risk screening to identify those who could benefit most from earlier, more frequency mammography screening could reduce the amount of people likely to experience negative consequences as a result of mammography, reducing the cost burden of mammography, and potentially increasing screening sensitivity.

Risk Stratification

Genetic testing can be used to determine whether or not family history is likely to have an effect on an individual by showing whether the individual has the gene likely causing their family's breast cancer history. As more and more gene mutations are linked to breast cancer, risk stratification through genetic testing will become more precise, allowing for better tailored medical care.

BRCA1/BRCA2 increase in risk. As previously mentioned, having a BRCA1 mutation increases a woman's risk of developing breast cancer to 45%-90% and having a BRCA2 mutation increases this risk to 36%-75% (Mehrgou & Akouchekian, 2016). BRCA1 and BRCA2 mutations are the best studied of the genes that have been found to be associated with breast cancer. As these genes are relatively well understood, BRCA1 and BRCA2 mutations are a good

starting point for risk stratification based on genetic testing. Screening methods based on these and other associated genetic mutations have been developed, putting in place the tools needed to better understand individual breast cancer risk.

B-RST. One such method is based on a referral screening tool (RST) designed to determine whether or not women are at high risk for hereditary breast/ovarian cancer (Bellcross, Lemke, Pape, Tess, & Meisner, 2009). The screening tool asks individuals questions related to well-studied indicators associated with carrying BRCA1/BRCA2 mutations. Hereditary breast cancer indicators include relatives who had breast or ovarian cancer before the age of 50, two or more relatives with breast cancer after 50 on the same side of the family, or a male relative who developed breast cancer at any age. A simple algorithm was used to determine which women were likely to have a BRCA1, BRCA2, or other breast cancer associated mutation and should be referred to a genetic counselor. Those with two or more indicators were considered high risk, those with one were considered at intermediate risk and those with no check marks, at low risk.

The accuracy of this screening tool has been measured within a private Midwestern Health Care System. Among a study population of 2464 women undergoing mammogram screening, 6.2% were found to be at high risk. When compared to pedigree analysis, the RST showed a sensitivity of 81.2% and a specificity of 91.9% (Bellcross et al., 2009).

While this referral screening tool was a good start towards simplifying risk assessment, the tool was updated in 2010. An interactive, web-based version of the tool (breast cancer genetics referral screening tool [B-RST]) was created in 2010 (Bellcross, 2010). The web version of this tool was more available, increasing its accessibility. The updated version distinguished between maternal and paternal lineages, included nieces and nephews in the list of second-degree relatives and had parameters of bilateral breast cancer, as well as both breast and ovarian cancer

in the same individual added to the algorithm. Evaluation of the updated tool increased sensitivity to 89.4% when compared to detection of high risk individuals by other models (Bellcross, 2010). Use of B-RST can successfully identify patients at higher or lower risk for carrying a genetic mutation likely to cause breast cancer.

De-implementation

De-implementation is the abandonment of ineffective medical practices and interventions and can protect patients from risks of the interventions while minimizing healthcare costs and improving patient outcomes (Prasad & Ioannidis, 2014). Given limited health resources, adoption of evidence based public health (EBPH) and evidence based medicine has been proposed as a way to limit health care expenditures and ensure that time and money are being spent on the implementation of the most effective programs and policies (Brownson, Fielding, & Maylahn, 2009). De-implementation of programs that may not be effective or where the harms outweigh the benefits goes hand in hand with EBPH, alleviating the rise in healthcare costs and improving patient outcomes. For mammography screening, de-implementation would mean reducing mammogram screening frequency among women who are at low risk of developing breast cancer.

However, other factors must also be considered when de-implementing programs. Conflicts, both financial and professional, and cultural and societal values play a role in the endurance of certain programs (Prasad & Ioannidis, 2014). Companies who benefit from the continuation of a program are likely to fight it's abandonment through the presentation of counter evidence from less thorough studies (Prasad & Ioannidis, 2014). Such conflicts can

obstruct de-implementation or can cause programs already abandoned to be brought back (Prasad & Ioannidis, 2014).

The influence of societal values is evident in cancer screening. Cancer screening has become engrained into American culture, with public health organizations, physicians, and advocacy groups pushing screening through advertisements, media campaigns, and public service announcements. Such messages are difficult, if not impossible, to avoid and are present in newspapers, in television programming, and as ads on public transportation (Schwartz, Woloshin, Fowler, & Welch, 2004). These messages have had an effect on people's healthcare perceptions and decision making. A 2004 study showed that the majority of people surveyed were committed to getting regularly screened for cancer, and that they would ignore their physician if they believed they needed a screening test the doctor did not recommend. The study showed that people preferred getting a total body CT scan, a test with no proven benefits, over receiving $1000 in cash (Schwartz et al., 2004). The people surveyed felt like it was an obligation to get screened for cancer and that they both owed it to their families and that it "would be selfish" to not get screened (Schwartz et al., 2004).

For breast cancer, corporate interests influenced media campaigns. Starting in the 1990s, multinational corporations have seen partnerships with breast cancer charities as a pathway to marketing success (Patton, 2017). These marketing campaigns, known collectively as the pink ribbon campaign, changed the way breast cancer was thought of worldwide, making women with breast cancer out to be heroic survivors instead of women with an embarrassing disease (Patton, 2017). Although the pink ribbon logo raised awareness, many of the messages included with these campaigns were misleading. Pink ribbon campaign messages simply told women to get mammograms, without disclosing the benefits and risks that can come with mammography

screening (Gigerenzer, 2014). These messages skewed public perceptions of mammography and contributed to the screening fervor that exists today.

Celebrity accounts also affect awareness and perceptions of cancer screening options. In 2013, Angelina Jolie published the story of her double mastectomy after finding out she carried a mutation in the BRCA1 gene. Her story increased awareness of the options surrounding breast cancer risk but did not increase understanding (Borzekowski, Guan, Smith, Erby, & Roter, 2014; Lebo, Quehenberger, Kamolz, & Lumenta, 2015). Following the publishing of her editorial, referral rates for breast cancer associated treatments increased (Lebo et al., 2015), exemplifying the effects that celebrity influence can have on healthcare decisions. Angelina Jolie's story further contributed to an overall trend of fervor for cancer screening. A group of 407 women between the ages of 40 and 59 were surveyed regarding their perceptions of mammography (Yu, Nagler, Fowler, Kerlikowske, & Gollust, 2017). Results of this survey reflected the screening fervor detected by previous studies, with most of the women concluding that the benefits of mammography were very important (Yu et al., 2017). However, awareness of harm was not as common, with only 26.5% aware of overdiagnoses as a result of mammography, and only 39.7% aware of overtreatment as a result of mammography (Yu et al., 2017).

With screening being so ingrained as the way to prevent getting cancer, de-implementation in the form of changing recommendations may be met with a certain amount of backlash. This is likely especially true for breast cancer screening, as there has been an abundance of breast cancer campaigns encouraging regular mammogram screening.

Previous Reactions to Changes in Guidelines

Following the change in US Preventative Task Force guidelines regarding breast cancer screening, researchers sought to determine how women viewed this change and whether or not they were planning on following the recommendations by using focus groups to determine themes in these opinions. Overall, women did not view these changes favorably, and reacted to reductions in mammography frequency with feelings of distrust (Allen et al., 2013). Women suspected that the guideline changes were driven by insurance companies' cost cutting measures. African American women especially viewed the change as a reduction in their access to "life-saving" care (Allen et al., 2013). Although many women had stories of anxiety and discomfort related to mammograms, most stated that they intended to continue with yearly screenings, with some wanting screenings more than once a year from an earlier age (Allen et al., 2013). Women felt left out of the decision to alter screening recommendations and since they believed in the importance of early detection, were not comfortable leaving the decision up to other people (Allen et al., 2013). Many primary care providers did not implement these guidelines with their patients, with 98% of gynecologists included in one study recommending that their patients continue to receive annual screening (Corbelli et al., 2014). As a result, in the three years following the change in guidelines, there was no perceptible change in mammography trends among women in the United States (Dehkordy et al., 2015).

Much of this trust in mammography is likely the result of the decades of efforts from public health officials, physicians, and advocacy groups to convince individuals of the importance of cancer screenings. Given how pervasive stressing the importance of mammography has been, it will likely be difficult to deviate from in the future.

Study Correlates within Waters et al Theoretical Framework

No previous study has considered the many factors that may affect how willing patients may be to tailor their care based on their genetic risk factors, especially if that would mean cutting back on methods of preventative care that they consider part of their medical routine. Personal factors would likely play a major role in patients' willingness to alter their medical routine based on their genetic risk. The Waters et al. conceptual framework describes how a number of factors interact to influence health related behaviors. The current study used this framework as a guide, mapping factors that have been previously shown to affect mammogram screening behavior to the constructs included in the model. Understanding of risk, demographics, past mammogram habits, institutional trust, perceived risk, and worry have all been shown to affect medical care decisions in various ways and address many of the various constructs included the theoretical framework. These factors may be linked to how likely women would be to listen to recommendations that they reduce their screening service utilization.

Various studies have found that health communication messages, health history and demographics affect causal beliefs, which affect cognitive and emotional processes, and ultimately, health behavior (A. Edwards & Elwyn, 2001; Haber, Ahmed, & Pekovic, 2012; Harmon et al., 2014; Ishikawa & Kiuchi, 2010; Katapodi et al., 2004; Lechner, de Vries, & Offermans, 1997; O'Malley et al., 2004; US Department of Health and Human Services, 2000). Waters et al. found that women who had multifactorial causal beliefs were more likely to adhere to mammogram recommendations (Waters et al., 2014). Although this study did not include causal belief variables in analysis, variables representing health communication messages, health history, demographics, and cognitive and emotional processes were included. Institutional trust was added to the model based on literature review. Studies have shown that demographics, in

particular race, can affect institutional healthcare trust (Q. T. Edwards et al., 2009; Harmon et al., 2014; Moser et al., 2007; Peek & Han, 2004; Smith-Bindman et al., 2006), and that healthcare trust ultimately influences health behaviors and adherence to recommendations (O'Malley et al., 2004; Taber, Leyva, et al., 2015). These variables have been linked to mammography screening behaviors and are outlined below and in Figure 3.

Health Communication Messages. Health messages are communicated through mass media, through public health campaigns, and through healthcare providers. According to Health People 2010, health communication can positively contribute to healthcare professional-patient relationships, increase individuals' exposure and use of health information, improve adherence to clinical recommendations, and can improve consumer knowledge of how to access public health and health care (Ishikawa & Kiuchi, 2010; US Department of Health and Human Services, 2000). However, patients cannot garner all of the benefits of health messages if they are incapable of understanding the message.

Ensuring that patients understand the risk information provided to them can be vital in convincing them to tailor their healthcare to their personal needs. Patients who understand their risk can better participate in decision making regarding their healthcare (Ahmed et al., 2012). The way that risk information is presented can have a significant effect on patient comprehension (Ahmed et al., 2012; A. Edwards & Elwyn, 2001). Studies have also shown that method of presentation can influence the degree to which the risk information will have an effect on behavior change (Ahmed et al., 2012; Lipkus, 2007). Health communication method can be assessed through evaluation of patient understanding following communication of genetic risk. According to the Waters et al theoretical framework, health communication messages influence

causal beliefs and institutional trust, changing cognitive and emotional processes regarding health information, and ultimately changing health behavior.

Perceived risk of breast cancer has been shown to be associated with mammogram frequency (Gross et al., 2006; Katapodi et al., 2004). However, many people do not possess the level of health literacy necessary to process and understand health information, including risk communication, and may have a difficult time making informed decisions about their healthcare (Peters, Hibbard, Slovic, & Dieckmann, 2007). People with a lower health literacy are also less likely to correctly recall information about a genetic test (McBride, Koehly, Sanderson, & Kaphingst, 2010). Understanding if a population correctly understands their risk could indicate if the health message is being effectively communicated. Understanding of population level risk, understanding of what B-RST results means in terms of risk of carrying a BRCA mutation, and correct recall of risk result can all influence decision making when it comes to mammography. It is likely that those with an improved understanding of their risk would be more likely to tailor their mammogram frequency to their risk.

Health care messages are also linked with institutional trust. Gurmankin, Baron, and Armstrong found that use of a numeric statement of risk increased acceptance of risk information (Gurmankin, Baron, & Armstrong, 2004). By influencing message acceptance, healthcare messages can further impact willingness to decrease mammogram frequency.

Demographics. Many studies have found significant differences in screening utilization based on racial and ethnic differences (Q. T. Edwards et al., 2009; Harmon et al., 2014; Smith-Bindman et al., 2006). Significant differences in mammogram utilization exist between white women and minority women, with African American, Hispanic/Latina, Asian, and Native American women less likely to have regular mammograms (Smith-Bindman et al., 2006).

Differences in mammogram utilization also exist by age, with older women more likely to have regular mammograms than younger women (Moser et al., 2007). Age may also affect how ingrained the habit of mammography is in women. Women who have been having mammograms for longer may find it more difficult to alter their routines than women who have just started having mammograms. Income and education can also predict mammogram frequency, with low income women less likely to utilize mammography (Peek & Han, 2004) and women with higher education more likely to get mammograms (Smith et al., 2016).

The Waters et al theoretical framework predicts that demographics can influence cognitive and emotional processes, such as perceived risk and worry, by influencing causal beliefs and institutional trust. Researchers have suggested that African American and Caucasian women may have cultural differences in how they experience and process emotions, in particular in relation to care-seeking behavior (Consedine, Magai, Cohen, & Gillespie, 2002; Consedine et al., 2004).

This study will examine the effects of race, age at time of B-RST, income, and education level on mammogram frequency. Age will be included as a demographic because of previously mentioned variations in mammogram frequency by age. Age stratification may also be important because mammogram recommendations currently vary by age. This may change how important women consider mammogram screening.

Health History. Health history, like demographics and health communication messages**,** impacts behavior by altering causal beliefs according to the Waters et al framework. Past mammogram frequency and reason for mammogram at the time of B-RST are aspects of health history that may affect patient willingness to alter their mammogram frequency. Past mammogram has been shown to be a significant predictor of future mammogram screenings

(Lechner et al., 1997). Intent to pursue mammogram screening in the future has also been found to be positively correlated with past mammogram frequency (Mayne & Earp, 2003). Women who have placed a high importance on getting a mammogram in the past may be less likely to forgo future mammograms based on learning more about their breast cancer risk and may be less likely to trust their doctor's recommendation to decrease their frequency. In this way, past mammogram frequency may be a predictor of willingness to alter future mammogram frequency.

The reason that women came to the mammography clinic, which is part of women's health history and can also indicate their health status, may affect how important they think getting a regular mammogram is. Those who are at the clinic because it was recommended by their doctor may be less invested in mammography than those who chose to come get a mammogram on their own. It is possible that those who chose to have a mammogram on their own decided to do so because they believe they are at higher risk. Those who had previously received an abnormal breast screening likely are experiencing anxiety regarding breast cancer and may be less likely to reduce their mammogram frequency.

Most importantly, family history is used to assess whether women are at high risk or at low risk for hereditary breast and ovarian cancer and determines whether women would benefit from reduced mammogram frequency. Family history of breast cancer has been shown to affect breast cancer risk perception, with women who have a family history much more likely to have a high perception of risk than those without family history (Haber et al., 2012). Health history may influence willingness to decrease mammogram frequency by impacting institutional trust and cognitive and emotional processing.

Institutional Trust. Institutional trust was added to the Waters et al theoretical framework based on literature review showing trust was associated with many of the constructs

already present in the model. Institutional trust can include trust in physicians, trust in medical guidelines, and trust in the overall medical system.

Demographics have been shown to be a predictor of trust. Trust in physicians and in the medical institution has been shown to vary by race. Among low income African American women, increased trust has been linked to an increase in the use of preventative services such as mammography (O'Malley et al., 2004). African Americans have been shown to be more likely to distrust their physicians than white patients (Boulware et al., 2003). African Americans were also more likely to be concerned about harmful experiments in hospitals (Boulware et al., 2003). An increased concern regarding being experimented upon make may African Americans less likely to trust in a relatively new medical technology such as genetic testing and may make them wary of tailoring their medical care in response to such results. African Americans may be more skeptical of the medical system due to a greater awareness of the history of racial discrimination within the health care system. This awareness has been associated with a decrease in trust (Boulware et al., 2003; Shavers, Lynch, & Burmeister, 2002). As previously mentioned, effective physician communication, or health care message, has been linked to increased trust in patients (Thom, 2001).

Studies have shown that patients who had more trust in their physicians were more likely to adhere to medical recommendations (Schoenthaler et al., 2014), indicating that trust may correlate to decisions to follow medical guidelines. Shared decision making and communication have also been shown to influence adherence (Bauer et al., 2014). Decreased trust in the medical system and in physicians has been shown to predict avoidance of medical care (Taber, Leyva, et al., 2015). This association between trust and both utilization of medical services and recommendation adherence could be seen in patient willingness to base their preventative care

on their genetics and should be considered as the use of genetics as a risk predictor is further integrated into healthcare. Women who trust their physicians and trust medical guidelines are likely to be more willing to decrease their mammogram frequency based on communication of risk.

Cognitive and Emotional Processes Cognitive and emotional processes can include perceived risk, perceived control, worry, and message acceptance. Perceived risk, worry, and message acceptance have all been shown to be associated with mammography screening behavior. According to the Waters et al theoretical framework, these processes can directly affect mammogram screening behavior and would likely affect willingness to reduce mammogram frequency based on genetic risk.

Studies have shown an association between perceived risk and mammography screening (Gross et al., 2006; Katapodi et al., 2004). Women who perceived their breast cancer risk to be higher were more likely to have had routine mammograms. Women with a family history of breast cancer were more likely to view themselves as high risk, as were younger women, those who were obese, and those who were smokers. Having had a previous abnormal mammogram was also linked with a higher perceived risk (Gross et al., 2006). White women were more likely to view themselves as having a high risk for developing breast cancer when compared to Black or Hispanic women (Gross et al., 2006), which could partly explain why white women are more likely to get regular mammograms. Women also tend to overestimate their lifetime risk of developing breast cancer (Bunker, Houghton, & Baum, 1998; de Jonge et al., 2009; McCaul et al., 1998), making it likely that some women base their mammogram frequency on an over estimation of their risk of ever developing breast cancer. Women who estimate their breast

cancer risk to be high would likely be hesitant to change the frequency of their mammograms based on their hereditary risk.

Women also tend to worry most about breast cancer, even if risk of other diseases may be higher (Wang et al., 2009). The effect of breast cancer worry on screening behavior has been unclear, with some studies indicating that worry facilitates screening (Hay et al., 2006) and some indicating that worry hinders screening behavior (Andrykowski et al., 2001; Consedine et al., 2004). While the majority of studies indicate that an increase in breast cancer worry is linked to an increase in screening behaviors (Hay et al., 2006), breast cancer worry has been linked to screening avoidance among certain populations, in particular among African American women (Consedine et al., 2004; L. Y. Miller & Hailey, 1994). The fear of "finding something wrong" has been a commonly cited fear among both African American and Hispanic women (Austin, Ahmad, McNally, & Stewart, 2002; Consedine et al., 2004; Friedman et al., 1995). Given that worry has been linked to screening behavior, it is likely that breast cancer worry is also linked to willingness to alter mammogram frequency.

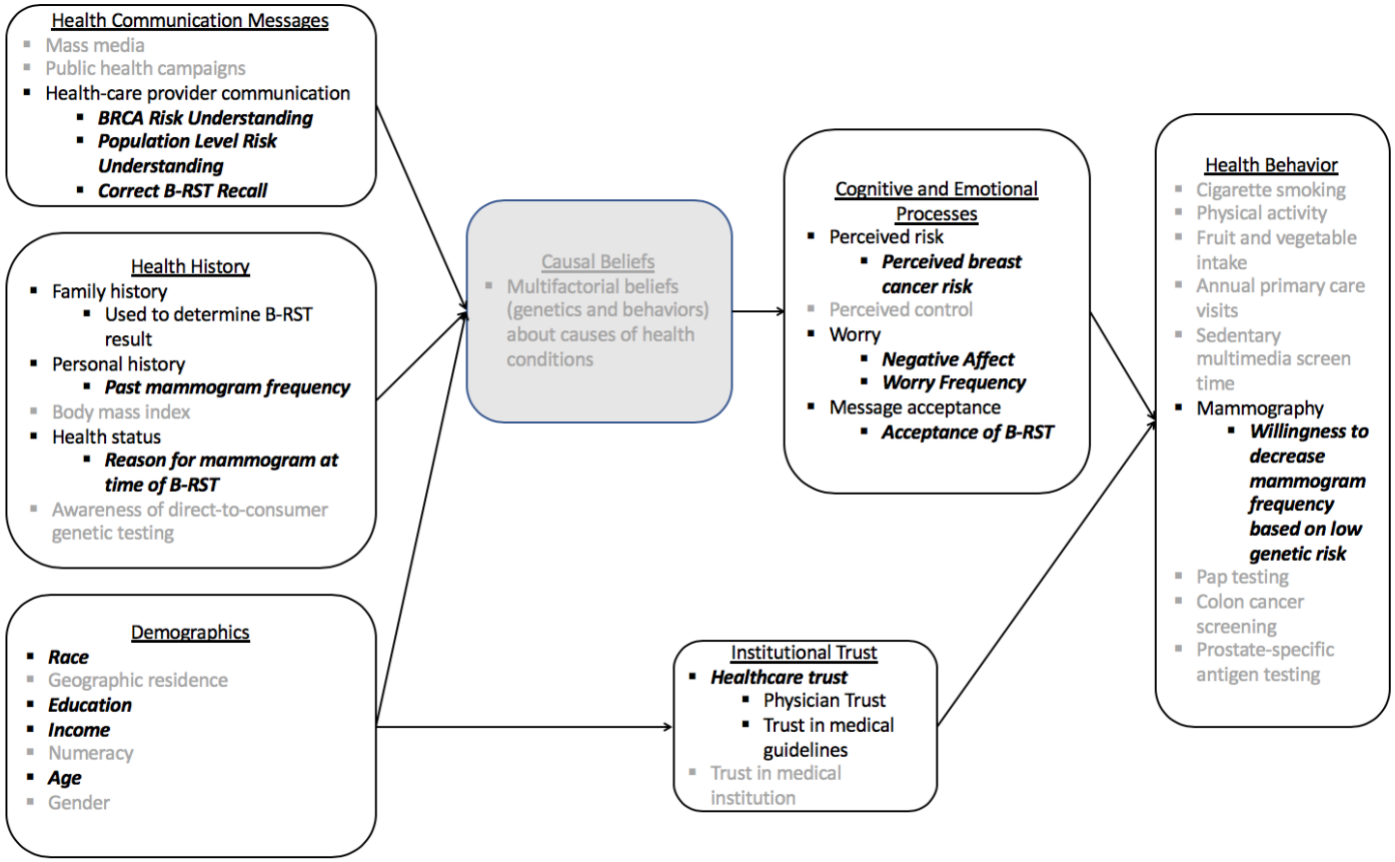
In order to accept a message, patients must be willing to experience the emotions and sensations that may come with the information (Bond, Hayes, & Barnes-Holmes, 2006; Zhang et al., 2017). It has been shown that health communication message, in the form of physician feedback, can influence how women rate their risk and whether or not they accept risk information. This interaction seems to be moderated by trust (Gramling, Anthony, Simmons, & Bowen, 2006). As mammogram frequency can be predicted from risk perception, it is likely that women who do not accept their B-RST result telling them they are at low risk will be less likely to be willing to reduce their mammogram frequency, due to misinterpretation of their breast cancer risk.

Summary

Given the negative side effects and high cost of mammography screening, the population strategy of screening does not seem like the most effective policy to implement. Instead, using the high-risk strategy could protect women from needlessly exposing themselves to increased anxiety, radiation exposure, and potential pain, in addition to the risk of unnecessary treatment. Genetic testing has provided an additional tool for risk stratification, more accurately detecting women at risk for early onset and aggressive hereditary breast cancer. Basing mammogram frequency on risk stratification by using genetic information as well as information about other risk factors can improve the benefit to cost ratio for mammography, save money, and lower the number of women experiencing the negative effects of mammography. However, implementing this type of screening strategy would likely result in a change in screening recommendations, and as recommendation changes have been met with distrust in the past, would likely make many women uncomfortable.

While many studies have examined the factors that affect mammography screening frequency, there has been no assessment of the variables that affect willingness to alter mammogram frequency. This study can provide insight into whether or not risk communication influences screening practices and can examine the causes of unwillingness to adjust personal healthcare routines based on changing recommendations. Based on women's reactions to previous changes in recommendations, it is likely that many women will be unwilling to alter care based on genetic risk communication. Constructs included in the Waters et al theoretical framework will likely play a role in determining willingness to alter screening frequency, based on research into the factors that facilitate mammography.

Figure 3 Study measures stratified within Waters et al. theoretical framework



III.
Data Collection and Procedures

Aim of Study

Willingness to decrease mammogram frequency was examined among a group of women who had been told they were unlikely to be at risk for hereditary breast cancer. The factors associated with breast cancer screening behaviors were analyzed among this population. This study was designed to determine goodness of fit between study data and the Waters et al. theoretical framework model while answering the following two questions:

1. Do healthcare trust and acceptance of B-RST predict willingness to decrease mammogram frequency among women at low risk for hereditary breast cancer?
2. Are variables suggested by the Waters et al model associated with willingness to decrease mammogram frequency based on lowered genetic risk?

Participant Recruitment Methods

This thesis study was a secondary data analysis of a larger B-RST Negative Results Interpretation Study. The B-RST Negative Results study was part of a cross sectional parent study aimed at increasing identification and referral to genetic counseling for women at risk for hereditary breast/ovarian cancer. Throughout the duration of the parent study, 3883 women were approached in the waiting rooms of the Emory clinic breast imaging centers including the Winship Cancer Institute (N=2991), Emory University Hospital Midtown (N=452), Emory John's Creek (N=75) and Emory Saint Joseph's Hospital (N=355). Recruitment location for the remaining participants (N=10) was missing data. Participants were recruited from April 2016 through June 2017. Prospective participants were approached by trained recruiters and were

given a study overview and a detailed recruitment packet. The B-RST Negative Results study began midway through the parent study and ran from June 2016 through January 2017.

Consent Methods

All participants of the parent study were recruited voluntarily while they waited to be called for their mammogram appointments. Participants were given a pamphlet with information about hereditary breast and ovarian cancer, a combined informed consent/HIPAA form, a one-page handout summarizing study procedures, and a short form where they could indicate their interest in completing the B-RST screening while in the clinic and could provide their email if they wished to be contacted about future related studies. Patients were asked to review material while in the waiting room and to return the short form to reception staff. Those who did not consent on the form were not included in the study. All participants had to provide authorization for study use of protected health information before any data could be collected from them. Those who indicated interest in B-RST screening while they were in the clinic were included in the study resulting in a total 2429 women screened as part of the parent study. 1078 were screened during the B-RST Negative Results study.

All hard copy patient data collected was stored in a locked cabinet in a locked office on the Emory University campus. Electronic data was stored on Emory Box, a secure, HIPAA compliant file sharing website accessible only to study staff. Survey information was de-identified and data was linked to a study ID number. A file containing participant emails addresses and corresponding study ID numbers was stored on an Emory Box project folder and was password protected.

Completion of B-RST

Women were given a computer tablet on which they could complete the web version of the screener tool (B-RST 3.0). Computer tablets were connected to the internet through a secure internet connection and were open to a second consent/HIPAA authorization page that participants had to complete before they could proceed to the B-RST. Upon patient initiation of the B-RST, recruiters placed a sticker listing the patient's medical record number, name, date of birth, appointment number, referring provider, and date of appointment onto the short form containing consent, email address, and permission to contact in the future. Completion of the B-RST tool took between 2 and 5 minutes, depending on complexity of family history. There was no incentive for completion of the B-RST, however, women benefited from learning more about their risk for hereditary breast and ovarian cancer.

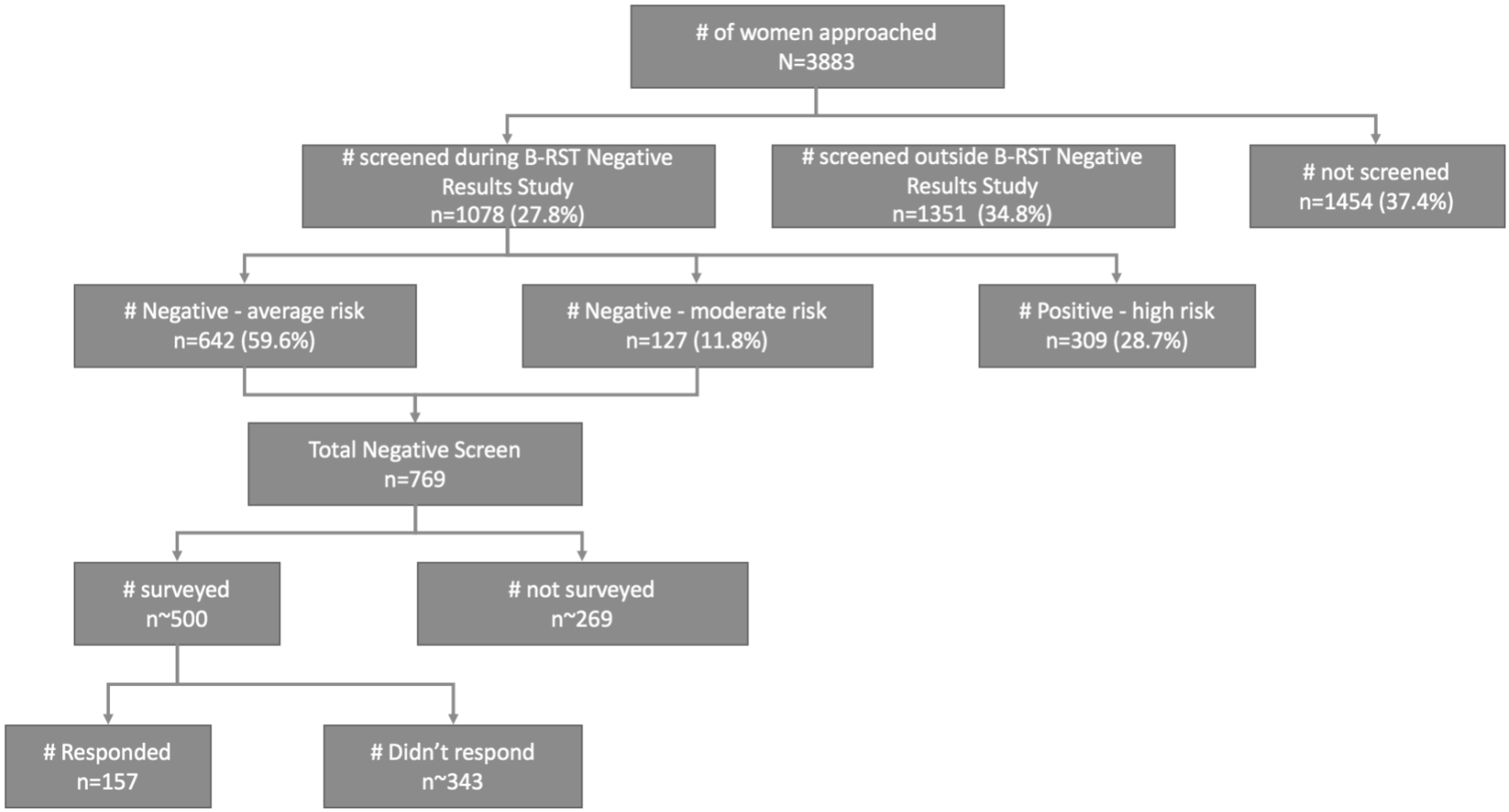
Of the women screened during the B-RST Negative Results Study, 642 were found to be at average risk for breast cancer and 127 were found to be at moderate risk for breast cancer. Both of these categories (n=769) were considered negative screens. The remaining 309 women were considered at increased risk for hereditary breast cancer and were not eligible for participation in the B-RST Negative Results Study. Patients who screened negative on the B-RST and who consented to being contacted in the future were considered for inclusion in the B-RST Negative Results Interpretation Study.

Data Collection Procedures

Target enrollment for the B-RST Negative Results Interpretation Study research study was 250. 500 women were sent emails with an invitation to participate in an online survey approximately 2-6 weeks after completion of the B-RST. The expected response rate was 40%-

50%. The survey was conducted using REDCap survey software. REDCap is a web-based tool for capturing research data and is secure, HIPAA compliant, and provides encryption of data storage. Winship Institute Research Staff members were contracted to program the survey into REDCap and to provide technical support. Potential participants were asked to provide consent to the survey via a separate consent website before they could begin. The full survey consisted of 74 questions and took 20-30 minutes to complete. Participants were sent a $25 Amazon electronic gift card via email upon completion of the survey. Survey files were exported to Excel from REDCap and were stored on Emory Box. 157 surveys were ultimately collected and analyzed as part of this study. The participant recruitment cascade is outlined in figure 4.

Figure 4 Participant recruitment cascade, stratified by those screened during B-RST Negative Results Study, hereditary breast cancer risk result, number of negative screens surveyed, and survey responses.



Survey Measures Development

Health Communication Messages. Health communication messages were evaluated by measuring how well the messages were understood by the study population. Women were asked the following questions to assess how well they understood their breast cancer risk.

Understanding of BRCA Risk. Women were asked to select a statement describing the meaning of their B-RST results in terms of their risk of having a genetic change in BRCA1 or BRCA2 genes associated with hereditary breast and ovarian cancer. Women could choose from 'You are unlikely to have a genetic change in one of your BRCA genes,' 'You have a low (less than 5%) chance,' 'You have an average chance,' 'You have a moderate to high chance,' or 'I don't know what my chance is.'

Understanding of Population Level Breast Cancer Risk. Women were asked to choose a statement describing the meaning of their B-RST result in terms of their risk of developing breast cancer based on their family history. Choices included 'Your risk is expected to be lower than the average population risk,' 'Your risk is expected to be greater than the average population risk,' 'Your risk is the same as the average population risk,' or 'I don't know my risk.' This question determined whether or not women understood that their B-RST result meant that they were not at increased risk of developing breast cancer but had the same risk as the average population.

Recall of Correct B-RST Result. Women were asked to recall the type of negative screen result they received. Answer choices included 'Low risk,' 'Moderate risk,' and 'Don't know.'

Demographics.

Race and Age. Participants were asked to report their race and could choose 'Black or African American,' 'Asian,' 'White,' 'Native Hawaiian or Other Pacific Islander,' 'American

Indian or Alaska Native,' 'Other,' and 'Prefer not to answer.' Women were also asked to report their age at the time of their B-RST.

Income and Education. Participants were asked to choose an income bracket that best described their income. Choices included '$15,000 or less,' '$15,001 to 25,000,' '$25,001 to 50,000,' '$50,001 to 75,000,' '$75,001 or more,' and 'I do not wish to answer.' Participants were also asked to report their education level and could choose from 'Less than high school,' 'Grade 12 or GED,' 'Some college,' 'College graduate (4 years or more),' 'Graduate or professional degree,' or 'I do not wish to answer.'

Health History. Participant health history was evaluated through the following two variables.

Reason for Current Mammogram. Participants were asked to indicate the reason for their mammogram at the time of their B-RST. Response options included 'personal choice for routine screening,' 'doctor recommendation for routine screening,' 'family/friend recommendations for routine screening,' and 'referred due to breast abnormality.'

Past Mammogram Frequency. Women were asked to report how frequently they had had a mammogram in the past two years with answers including 'More than once a year,' 'Once a year,' 'Once every two years,' Less than every two years,' 'Other,' and 'Prefer not to answer.'

Institutional Trust. Institutional trust was measured through the evaluation of trust in the healthcare system.

Healthcare Trust. Trust in the healthcare system was measured using 10 items from the multidimensional trust in health care systems scale (Egede & Ellis, 2008). Participants were asked to respond to statements including 'My health care provider will do whatever it takes to give me the medical care that I need,' 'All things considered, I completely trust my healthcare

provider,' and 'The recommendations for breast cancer screening I have heard are trustworthy.' Options included 'strongly disagree,' 'disagree,' 'neither agree nor disagree,' 'agree,' and 'strongly agree.' Results were coded so that a higher score reflected increased trust. Cronbach's alpha for the multidimensional trust in health care systems scale was found to be good (Cronbach's Alpha=.89). Answers were added together for an overall trust in the healthcare system score.

Cognitive and Emotional Processes. Cognitive and emotional processes were evaluated using the following variables.

Perceived Risk of Breast Cancer. In order to evaluate perceived risk of breast cancer, women were asked 'How likely do you think it is that you will develop breast cancer in your lifetime? Would you say your chance of getting breast cancer is:' with answers varying from 'very low' to 'very high.' Participants could also choose not to answer. This question was adapted from previous research studies on how genetic information and family history can affect acceptance of recommendations and screening behaviors (Haas et al., 2005; Taber, Aspinwall, et al., 2015).

Breast Cancer Worry Frequency. Participants were asked how often they worried about getting breast cancer with answer options varying from 'rarely or never' to 'all the time' on a 4-point Likert scale. Women could also choose 'prefer not to answer.' This question was based on background research reflecting the importance of frequency of worry on breast cancer screening behaviors (Karliner et al., 2007; Lerman, Track, et al., 1991; Lerman, Trock, et al., 1991).

Breast Cancer Negative Affect. As part of breast cancer worry, women were asked to evaluate a series of five statements from the Positive and Negative Affect Schedule (PANAS) scale (Thompson, 2007; Watson, Clark, & Tellegen, 1988) to assess their negative affect.

Women read the phrase 'When I think about breast cancer…' and were asked respond to statements including 'I feel anxious,' 'I feel calm,' "I feel confident,' 'I feel upset,' and 'I feel uneasy. Women could select 'strongly disagree,' 'disagree,' 'neither agree nor disagree,' 'agree,' or 'strongly agree.' Answers for 'I feel calm' and 'I feel confident' were reverse coded so that a higher score reflected more negative affect. Cronbach's alpha for the PANAS scale was found to be acceptable (Cronbach's Alpha=.89). Answers were added together to create an overall negative affect score.

Acceptance of B-RST. Acceptance of B-RST result was assessed using 6 statements based on a survey by Taber et al (Taber, Aspinwall, et al., 2015). Statements included 'The information I received from the B-RST result about my risk for hereditary breast and ovarian cancer seems accurate,' 'The information I received from the B-RST result about my risk for hereditary breast and ovarian cancer was missing some important information about me and my family,' 'The information I received from the B-RST result about my risk for hereditary breast and ovarian cancer doesn't seem right to me,' 'The information I received from the B-RST result about my risk for hereditary breast and ovarian cancer applied to me,' and 'The information I received from the B-RST result about my risk for hereditary breast and ovarian cancer applied to my family.' Response options included 'strongly disagree,' 'disagree,' 'neither agree nor disagree,' 'agree,' and 'strongly agree.' Responses were coded so that a higher score reflected a higher acceptance of the B-RST. Cronbach's alpha for acceptance of B-RST scale was found to be acceptable (Cronbach's Alpha=.72). Coded responses were added together to create an overall acceptance of B-RST score.

Health Behavior: Willingness to Decrease Mammogram Frequency. Willingness to decrease mammogram frequency based on low genetic risk was assessed with the question 'How

willing would you be to have mammography screening less often if you were found to be at lower genetic risk of breast cancer based on the B-RST result?' to which women could respond 'Very unwilling,' 'Unwilling,' 'Not Sure,' 'Willing,' or 'Very willing.'

Measures within Theoretical Framework. Study measures were mapped to the Waters et al theoretical framework model as shown in figure 2.

Treatment of Data

Data entry was completed using the Statistical Package for Social Science (SPSS) version 25. After data collection, survey responses were analyzed.

Preliminary Analysis

Frequency distributions were calculated for each measure in the sample, including age, race, reason for recent mammogram, mammogram frequency in the last 2 years, worry frequency, perceived risk, multidimensional trust in health care systems score, acceptance of B-RST score, and negative affect score. Distributions were analyzed and guided recoding of variables. Variables were recoded as described below.

Variable Development

Health Communication Messages

Understanding of BRCA Risk. Understanding of B-RST result responses for risk of genetic mutation were grouped so that women who correctly understood their risk ('You are unlikely to have a genetic mutation in one of your BRCA genes') were in one group and those

who had an incorrect understanding of their risk, everyone else, were combined into a second group.

Understanding of Population Level Breast Cancer Risk. Understanding of population level risk based on B-RST result responses were grouped so correct answers made up one group and incorrect answers made up the other group. The correct answer was 'Your risk is the same as the average population risk.'

Recall of Correct B-RST Result. Women's recall or B-RST result responses were compared with their actual B-RST result on file. If the answers matched, women were placed into a 'correct' category. Women whose answers did not match their actual result or who did not remember their result were placed into a second 'incorrect' category.

Demographics

Race. Participants were grouped into three race categories, 'White,' 'African American,' and 'Other' due to the demographic makeup of the population and based on background research. 'Prefer not to answer' responses were treated as missing data. Participants were not dropped due to missing demographic data.

Age. Age categories were based on mammogram guideline categories for mammogram screening from the United States Preventative Services Task Force (Siu & Force, 2016). Categories included women younger than 50 who are recommended to speak with their doctor regarding whether or not to have a mammogram and women 50 and older who should have mammograms every other year.

Income and Education. Income brackets were grouped into three categories representing income of $50,000 or less, between $50,001 and $75,000, and $75,001 or more. Education options were regrouped so that categories reflected women who reported having completed some

college or less, women who had a college degree, and women who had graduate or professional degrees.

Health History

***Reason for Current Mammogram, Past Mammogram Frequency*.** Answers for reason for current mammogram and past mammogram frequency were not recoded. Original answer categories were used for analysis.

Institutional Trust

Healthcare Trust. Multidimensional trust in health care systems score was not recoded during preliminary analysis.

Cognitive and Emotional Processes

Perceived Risk of Breast Cancer. Perceived risk responses were grouped so that women who thought their risk was very low or low were in one category and women who thought their risk was medium to high were in a second category.

Breast Cancer Worry Frequency. Based on population distribution, answers were grouped into two categories, women who had no breast cancer worry and women who worried about breast cancer at all. Choose not to answer responses were coded as missing data but participants were not dropped from analysis.

Trust in B-RST, Negative Affect. Acceptance of B-RST score and negative affect score were used as continuous variables and were not recoded during preliminary analysis.

Health Behavior: Willingness to Alter Care. Willingness to alter care based on low genetic risk responses were grouped into three categories to reflect those unwilling, those unsure, and those willing to decrease their mammogram frequency.

Descriptive Statistics

Descriptive statistics of the sample were conducted for all participants using recoded variables. Demographic and health history variables consisted of age category, race category, reason for recent mammogram, and mammogram frequency in the last two years. Willingness to alter mammogram frequency was also stratified by population descriptives. The percent and number of women willing to reduce their mammogram frequency was calculated for each age category, race category, income category, education level, and reason for recent mammogram response. The percent and number of women unsure of their willingness in each of the previously mentioned categories was determined as well as were the percent and number of women unwilling to alter their mammogram frequency in each of the categories. Chi-Square analysis was conducted to test for significant demographics differences between willingness categories.

Variable Correlations

The percent and number of participants in each past mammogram frequency category, each perceived risk category, each breast cancer worry frequency category, each BRCA risk understanding category, each population level risk understanding category, and each correct recall of B-RST result category were calculated for the overall study population. Willingness to alter mammogram frequency was also stratified by these correlate categories and the percent and number of participants in each subcategory was determined. Chi-Square analysis was conducted to test for significant differences in these variables between those willing to decrease their mammogram frequency, those unsure of their willingness, and those unwilling.

Mean and standard deviation of multidimensional trust in health care systems score, acceptance of B-RST score, and negative affect score were calculated for the total study population, as well as for those willing to alter mammogram frequency, those unsure of their willingness, and those unwilling. ANOVA analysis was used to determine whether there were significant differences in mean trust in health care systems, mean acceptance of B-RST score, or mean negative affect score between willingness categories.

Variable Selection for Final Model

Responses for willingness to decrease mammogram frequency were regrouped into two dichotomous new dependent variables. Likelihood of willingness compared those willing to decrease their mammogram frequency with those uncertain and those unwilling put into one category. Likelihood of uncertainty compared those uncertain of their willingness with those who had made a decision one way or the other combined into one category. Likelihood of willingness was used to analyze if study variables could be used to predict feeling willing to decrease mammogram frequency. Likelihood of uncertainty was used to analyze associations between study variables and feeling uncertain of willingness to decrease mammogram frequency. Chi square analysis was repeated for categorical correlates and ANOVA analysis was repeated for continuous correlates. Correlates were considered for inclusion in the final regression based on significant associations with willingness category at the p=.20 level as well as based on inclusion in the Waters et al. theoretical framework (Waters et al., 2014; Waters et al., 2016).

Multicollinearity Analysis

Variables being considered for inclusion in regression analysis were analyzed for multicollinearity. A Phi coefficient was calculated to test for multicollinearity between categorical variables. Multicollinearity between continuous variables and categorical variables was calculated using Spearman Rho analysis.

Specific Analysis by Study Question

Question 1. Do healthcare trust and acceptance of B-RST predict willingness to decrease mammogram frequency among women at low risk for hereditary breast cancer?

Bivariate variable analysis previously described was used to determine whether or not healthcare trust and trust in B-RST were significant predictors of willingness to decrease mammogram frequency. Chi-square bivariate analysis was used to determine whether healthcare trust and acceptance of B-RST significantly predicted women's willingness to decrease their mammogram frequency based on being at low genetic risk for hereditary breast and ovarian cancer.

Question 2. Are variables suggested by the Waters et al model associated with willingness to decrease mammogram frequency based on lowered genetic risk?

A binomial logistic regression was conducted using the dependent variable likelihood of willingness. The adjusted odds ratio, 95% confidence interval, and p-value were calculated for each association. The Nagelkerke R^2 value was also calculated for the model analysis. A second binomial logistic regression was conducted using the dependent variable likelihood of uncertainty. The adjusted odds ratio, 95% confidence interval, and p-value were calculated for each association. The Nagelkerke R^2 value was also calculated for the second model analysis.

IV.
Results

Demographic Descriptive Statistics

A total of 157 women were enrolled in this study. The average age of these women was 57.38±10.62 years. The majority of women included were in the higher age category, with 69.4% (n=109) 50 years or older. The youngest woman included was 34 years old and the oldest 81 years old. Four women did not report their age. The majority of women in the study were white, with white women making up 55.4% (n=87) of the study population. 42.0% (n=66) of the study population reported that they were African American, with the rest of the study population identifying as Asian, mixed, or other. Four women chose not to report their race. Women were asked to report their education and income levels. The largest proportion of women in the study population (35.0%, n=55) reported having a graduate or professional degree, 27.4% (n=43) reported having a college degree, and 17.8% (n= 28) reported having completed some college or less. 19.7% (n=31) chose not to report their education level. The largest proportion of the study population (38.2%, n=60) reported an income of $75,001 or more, 14.6% (n=23) reported a salary between $50,001 and $75,000, and 21.0% (n=33) reported a salary of $50,000 or less. 26.1% (n=41) did not report an income level. As age category (p=0.74), race category (p=0.71), education (p=0.07), and income (p=0.84) were not significantly associated with willingness to decrease mammogram frequency, demographic variables were used only as population descriptors, and not included in analysis.

Mammography Correlates Descriptives

Differences in study variables by willingness to decrease mammogram frequency were analyzed using Chi-Square analysis and ANOVA. Results are shown in Table 1 and are summarized below.

Health Communication Messages Women were asked to describe their risk of a BRCA mutation, their breast cancer risk when compared to the average population and were asked to recall the results of their B-RST. The accuracy of their answers was used to evaluate how well the health message had been communicated to them.

***B-RST Result Regarding Chances of BRCA Mutation*.** Women were asked to describe what their B-RST results meant in terms of the likelihood that they carried a BRCA mutation. Women were grouped based on whether their responses were correct or incorrect. The majority answered correctly with 54.0% (n=81) of women knowing that they had a low chance of carrying a mutation. A Chi square analysis did not show significant differences in correct response between those willing to decrease mammogram frequency, those unsure of their willingness, and those unwilling to decrease their mammogram frequency (p=0.49).

***Understanding of Population Level Risk*.** Women were asked to describe their risk of breast cancer compared to the average population. Those who responded that they were at average risk were put into the correct group, with everyone else placed into the incorrect group. The majority of women were incorrect regarding their breast cancer risk with 60.4% (n=90) underestimating or overestimating their risk. A Chi square analysis did not show a difference in population risk accuracy between willingness categories (p=0.31).

***Recall of B-RST Results*.** Women were asked to recall the results of their B-RST. Those whose answer matched their B-RST result on record were counted as correct and grouped

together. The majority, 56.5% (n=78) of women in the study were incorrect, which included both women who did not recall their result and those who recalled a wrong result. Chi square analysis did not show a significant difference in accuracy between willingness category (p=0.69).

Health History Women were asked about their past mammogram frequency and were asked to report the reason for their mammogram at the time of their B-RST.

Past Mammogram Frequency. The majority of the women included reported having had a mammogram once a year or more within the past two years making up 83.4% (n=131) of the study population. 16.6% (n=26) reported having had a mammogram once in the past two years or less. There was a negative association between more frequent mammogram history and willingness to decrease mammogram frequency according to risk, with those who had had less frequent mammograms more likely to be willing to decrease their mammogram frequency. Fisher exact analysis showed significant differences in past mammogram frequency between those willing to alter their mammogram frequency, those unsure of their willingness, and those unwilling to decrease their mammogram frequency (χ^2=15.82, p<0.00). Of those who were unwilling to decrease their mammogram frequency 94.0% (n=63) reported having had a mammogram once a year or more during the past two years. Of those who reported being unsure of their willingness to decrease mammogram frequency, 87.5% (n=35) said they had had a mammogram once a year or more during the past two years. 66.0% (n=33) of those willing to decrease their mammogram frequency reported having had a mammogram once a year or more. Although only 34% (n=17) of those willing to decrease their mammogram frequency reported having had only one mammogram or less in the past two years, this percentage was significantly higher than the percent of those unwilling to decrease frequency who had less frequent

mammograms (6.0%, n=4) and higher than the percent of those unsure of their willingness (12.5%, n=5).

Reason for Current Mammogram. Women were asked to report the reason for their mammogram at the time of their B-RST. The majority, 60.5% (n=95) reported that the reason for their current mammogram was that their doctor recommended it. 36.3% (n=57) of the women were having a mammogram due to personal choice, and 3.2% (n=5) were having a mammogram because of a breast abnormality. Reason for current mammogram was not found to be significantly associated with willingness to decrease mammogram frequency (p=0.88). Given the small number of participants in the breast abnormality category, reason for current mammogram was not included in the analysis and was used only as a population descriptor.

Institutional Trust Institutional trust was evaluated using the trust healthcare trust scale.

***Trust in Healthcare System*.** Participants were asked a series of questions regarding their trust in their physician, their trust in the healthcare system, and their trust in healthcare guidelines. Answers were scored and added together, resulting in a healthcare trust scale. The average healthcare trust score for the study population was 39.33±6.05 with possible scores between 10 and 50, indicating that there was relatively high trust in the healthcare system among the study population. An ANOVA did not show significant differences in healthcare trust by willingness category (p=0.88).

Cognitive and Emotional Processes Women's cognitive and emotional process were evaluated through perceived risk of breast cancer, breast cancer worry frequency, and negative affect when thinking about breast cancer. They were also asked to rate how accurate and how applicable they found their B-RST result to evaluate how much the study population accepted the results of their B-RST.

Perceived Risk of Breast Cancer. Women were asked how they perceived their risk of breast cancer and were placed into two groups, one with those who thought their risk was not high and one with those who thought their risk was medium or high. The majority of the study population (61.3%, n=95) perceived themselves to be at low risk of breast cancer. Chi square analysis did not show a significant difference perceived risk between the willingness to decrease mammogram frequency groups (χ^2=4.49, p=0.11).

Breast Cancer Worry Frequency. Women were asked to describe their breast cancer worry frequency and were grouped by those reporting no worry compared to those reporting any worry. Chi square analysis showed significant differences in breast cancer worry between those willing to decrease mammogram frequency, those unsure, and those unwilling to decrease their mammogram frequency (χ^2=7.73, p=0.02). Increased breast cancer worry was negatively associated with willingness to decrease mammogram frequency. The majority of those unwilling to decrease their mammogram frequency reported having experienced breast cancer worry (65.7%, n=44). Among those unsure of their willingness to decrease their mammogram frequency, 57.5% (n=23) reported having experienced breast cancer worry. The majority of those willing to decrease their mammogram frequency reported experiencing no breast cancer worry (60.0%, n=30).

Negative Affect. Women were asked a series of question to measure the negative emotions they experienced when they thought about breast cancer. Answers were scored and added together for a total negative affect score. The average score for the study population was 14.44±4.75 with a possible range of 5 to 25 indicating that the women in the study population experienced a moderate amount of negative emotions regarding breast cancer. An ANOVA did not show any significant differences in average negative affect score between those willing to

decrease mammogram frequency, those unsure of their willingness, and those unwilling to decrease their mammogram frequency (p=0.80).

Acceptance of B-RST. Women were asked a series of questions to determine how much they accepted their B-RST results. Answers were added together to create a B-RST acceptance score. Participants had an average B-RST acceptance score a 22.03±3.33 on a possible scale from 6 to 30, indicating that there was high acceptance of B-RST results overall. An ANOVA did not show significant differences in acceptance of B-RST by willingness category (p=0.67).

Health Behavior: Willingness to Decrease Mammogram Frequency Women were asked whether they would be willing to decrease their mammogram frequency, based on the fact that they were at low risk of carrying a BRCA gene. 31.8% (n=50) of women enrolled would be willing to decrease their mammogram frequency, 25.5% (n=40) were unsure of whether or not they would be willing to decrease their mammogram frequency, and 42.7% (n=67) reported that they would be unwilling to decrease their mammogram frequency.

Table 1 Willingness to decrease mammogram frequency stratified by predictor variables

Variable	Total N=157	Unwilling N=67 (42.7%)	Not Sure N=40 (25.5%)	Willing N=50 (31.8%)	χ^2 (df), p-value[a]
	% (n)	% (n)	% (n)	% (n)	
Past Mammogram Frequency					χ^2 (2)=16.92, p<0.00
Annually or more	83.4 (131)	94.0 (63)	87.5 (35)	66.0 (33)	
Biannually or less	16.6 (26)	6.0 (4)	12.5 (5)	34.0 (17)	
Perceived Risk of Breast Cancer					χ^2 (2)=4.49, p=0.11
Medium to High	38.7 (60)	43.9 (29)	45.0 (18)	26.5 (13)	
Not High	61.3 (95)	56.1 (37)	55.0 (22)	73.5 (36)	
Breast Cancer Worry Frequency					χ^2 (2)=7.73, p=0.02
No Worry	44.6 (70)	34.3 (23)	42.5 (17)	60.0 (30)	
Any Worry	55.4 (87)	65.7 (44)	57.5 (23)	40.0 (20)	
BRCA Risk Understanding					χ^2 (2)=1.42, p=0.49
Correct	54.0 (81)	59.1 (39)	52.6 (20)	47.8 (22)	
Incorrect	46.0 (69)	40.9 (27)	47.4 (18)	52.2 (24)	
Population Level Risk Understanding					χ^2 (2)=2.36, p=0.31
Correct	39.6 (59)	43.1 (28)	44.7 (17)	30.4 (14)	
Incorrect	60.4 (90)	56.9 (37)	55.3 (21)	69.6 (32)	
Correct Result Recall					χ^2 (2)=0.73, p=0.69
Correct	43.5 (60)	46.7 (28)	37.8 (14)	43.9 (18)	
Incorrect	56.5 (78)	53.3 (32)	62.2 (23)	56.1 (23)	
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	F (df), p-value[b]
Negative Affect (possible range: 5-25)	14.44 (4.75)	14.65 (5.03)	14.55 (4.59)	14.06 (4.57)	F(2)=0.23, p=0.80
Healthcare Trust (possible range: 10-50)	39.33 (6.05)	39.21 (6.69)	39.75 (6.09)	39.14 (5.15)	F(2)=0.13, p=0.88
B-RST Acceptance (possible range: 6-30)	22.03 (3.33)	22.23 (3.73)	21.62 (2.44)	22.07 (3.39)	F(2)=0.40, p=0.67

Notes. N less than number enrolled due to missing data, a. P-value calculated by chi-square analysis, b. P-value calculated by ANOVA analysis

Bivariate Associations with Willingness

Willingness to decrease mammogram frequency was recoded into two new variables. This allowed one analysis to focus on the factors that made women willing to decrease their mammogram frequency based on their genetic risk for hereditary breast cancer and a second analysis to focus on the factors that made women undecided about their willingness.

Those willing to decrease mammogram frequency compared to those unsure and unwilling. The dependent variable, willingness to decrease mammogram frequency, was recoded into a new variable so that women who were willing to reduce their mammogram frequency could be compared to women unsure of their willingness and unwilling to reduce their frequency. The 31.8% (n=50) of women who were willing to decrease their mammogram frequency were compared to the 68.2% (n=107) of women who were either unsure or unwilling. After regrouping of dependent variables, Chi Square analysis and ANOVA testing were repeated. Results are shown in Table 2 and are summarized below.

Health Communication Messages. There were no significant differences in BRCA risk understanding (p=0.31), population level risk understanding (p=0.13), correct result recall (p=0.95) between those unwilling or unsure and those willing to decrease their mammogram frequency.

Health History When using the likelihood of willingness variable to compare those willing to decrease mammogram frequency with those unwilling and unsure grouped together, Fisher exact analysis showed a negative association between mammogram frequency and willingness to decrease mammogram frequency. Among those willing to decrease their mammogram frequency, 34.0% had had a mammogram biannually or less, compared to only 8.4% of those unwilling or unsure (χ^2=16.15, p<0.00).

Institutional Trust ANOVA testing did not show significant differences in average health care trust (p=0.79) between those willing to decrease mammogram frequency and those unwilling and unsure.

Cognitive and Emotional Processes Both increased perceived risk of breast cancer and increased breast cancer worry were negatively associated with willingness to decrease mammogram frequency. 44.3% of women who were unsure or unwilling reported having a medium or high perceived risk of breast cancer, compared to only 26.5% of women who were willing to decrease their mammogram frequency (χ^2=4.48, p=0.03). Among women who were unwilling or unsure of their willingness to decrease mammogram frequency, 62.6% reported having experienced breast cancer worry, compared to only 40.0% of women willing to decrease their mammogram frequency (χ^2=7.06, p=0.01). ANOVA testing did not show significant differences in average negative affect (p=0.50) or average B-RST acceptance (p=0.92) between those willing to decrease mammogram frequency and those unwilling and unsure.

Table 2 Willingness to Decrease Mammogram Compared to Unwillingness and Uncertainty Frequencies Stratified by Predictor Variables

Variable	Total	Unwilling or Unsure	Willing	χ^2 (df), p-value [a]
	N=157	N=107 (68.2%)	N=50 (31.8%)	
	% (n)	% (n)	% (n)	
Past Mammogram Frequency				16.15
Annually or more	83.4 (131)	91.6 (98)	66.0 (33)	(p<0.00)
Biannually or less	16.6 (26)	8.4 (9)	34.0 (17)	
Perceived Risk of Breast Cancer				4.48
Medium to High	38.7 (60)	44.3 (47)	26.5 (13)	(p=0.03)
Not High	61.3 (95)	55.7 (59)	73.5 (36)	
Breast Cancer Worry Frequency				7.06
No Worry	44.6 (70)	37.4 (40)	60.0 (30)	(p=0.01)
Any Worry	55.4 (87)	62.6 (67)	40.0 (20)	
BRCA Risk Understanding				1.02
Correct	54.0 (81)	56.7 (59)	47.8 (22)	(p=0.31)
Incorrect	46.0 (69)	43.3 (45)	52.2 (24)	
Population Level Risk Understanding				2.34 (p=0.13)
Correct	39.6 (59)	43.7 (45)	30.4 (14)	
Incorrect	60.4 (90)	56.3 (58)	69.6 (32)	
Correct Result Recall				0.00
Correct	43.5 (60)	43.3 (42)	43.9 (18)	(p=0.95)
Incorrect	56.5 (78)	56.7 (55)	56.1 (23)	
	Mean (SD)	Mean (SD)	Mean (SD)	F (df), p-value)[b]
Negative Affect (possible range: 5-25)	14.44 (4.75)	14.61 (4.85)	14.06 (4.57)	0.45 (p=0.50)
Healthcare Trust (possible range: 10-50)	39.33 (6.05)	39.42 (6.44)	39.14 (5.15)	0.07 (p=0.79)
B-RST Acceptance (possible range: 6-30)	22.03 (3.33)	22.01 (3.32)	22.07 (3.39)	0.01 (p=0.92)

Notes. N less than number enrolled due to missing data, a. P-value calculated by chi-square analysis, b. P-value calculated by ANOVA analysis

Those undecided of their willingness to decrease mammogram frequency compared to those who have decided.

The dependent variable, willingness to decrease mammogram frequency, was recoded into a new variable to compare Water's model variables association with decidedness. Those 25.5% (n=40) of women who were undecided were compared to the 74.5% (n=117) of women who were decided, that is, who were either willing to decrease their mammogram frequency or unwilling to decrease their mammogram frequency. Chi Square analysis and ANOVA testing were repeated. Results are shown in Table 3 and are summarized below.

Health Communication Messages There were no significant differences between BRCA risk understanding (p=0.85), population level risk understanding (p=0.45) or correct recall of B-RST (p=0.42) between those who were unsure of their willingness to decrease their mammogram frequency and those who had made a decision.

Health History Chi Square analysis did not show significant differences in mammogram frequency (p=0.62) between women unsure of their willingness to decrease their mammogram frequency and those who had made a decision.

Institutional Trust ANOVA testing did not show differences in average healthcare trust (p=0.61) between women unsure of their willingness to decrease their mammogram frequency and those who had made a decision.

Cognitive and Emotional Processes Chi square testing did not show significant differences in perceived risk of breast cancer (p=0.34) and breast cancer worry frequency (p=0.76) between women who were unsure and women who had made a decision. ANOVA testing did not show differences in average negative affect (p=0.86), or average B-RST acceptance (p=0.39).

Table 3 Uncertainty of willingness to decrease mammogram frequency compared to unwillingness and willingness stratified by Predictor Variables

Variable	Total	Unwilling or Willing	Unsure	χ^2 (df) p-value [a]
	N=157	N=117 (74.5%)	N=40 (25.5%)	
	% (n)	% (n)	% (n)	
Past Mammogram Frequency				0.64
Annually or more	83.4 (131)	82.1 (96)	87.5 (35)	(p=0.62)
Biannually or less	16.6 (26)	17.9 (21)	12.5 (5)	
Perceived Risk of Breast Cancer				0.90
Medium to High	38.7 (60)	36.5 (42)	45.0 (18)	(p=0.34)
Not High	61.3 (95)	63.5 (73)	55.0 (22)	
Breast Cancer Worry Frequency				0.10
No Worry	44.6 (70)	45.3 (53)	42.5 (17)	(p=0.76)
Any Worry	55.4 (87)	54.7 (64)	57.5 (23)	
BRCA Risk Understanding			(N=46)	0.04
Correct	54.0 (81)	54.5 (61)	52.6 (20)	(p=0.85)
Incorrect	46.0 (69)	45.5 (51)	47.4 (18)	
Population Level Risk Understanding				0.56
Correct	39.6 (59)	37.8 (42)	44.7 (17)	(p=0.45)
Incorrect	60.4 (90)	62.2 (69)	55.3 (21)	
Correct Result Recall				0.65
Correct	43.5 (60)	45.5 (46)	37.8 (14)	(p=0.42)
Incorrect	56.5 (78)	54.5 (55)	62.2 (23)	
	Mean (SD)	Mean (SD)	Mean (SD)	F (df) p-value [b]
Negative Affect (possible range: 5-25)	14.44 (4.75)	14.40 (4.83)	14.55 (4.59)	0.03 (p=0.86)
Healthcare Trust (possible range: 10-50)	39.33 (6.05)	39.18 (6.05)	39.75 (6.09)	0.26 (p=0.61)
B-RST Acceptance (possible range: 6-30)	22.03 (3.33)	22.16 (3.58)	21.62 (2.44)	0.73 (p=0.39)

Notes. N less than number enrolled due to missing data, a. P-value calculated by chi-square analysis, b. P-value calculated by ANOVA analysis

Variables included in final analysis Mammogram frequency, perceived risk of breast cancer, breast cancer worry, and population level risk understanding were all shown to be significantly associated with being willing to decrease mammogram frequency at the p=0.20 level and so were considered for inclusion in both regression analysis. Race, age, income, education and reason for mammogram at the time of B-RST were not included in the analysis because of poor data distribution and lack of significant association with willingness to decrease mammogram frequency. Although BRCA risk understanding, correct recall of B-RST result, negative affect, healthcare trust, and B-RST acceptance were not shown to be associated with either being willing or uncertain, these variables were also considered for the regression analysis based on inclusion in the Waters et al. theoretical framework (Waters et al., 2016).

Multicollinearity Analysis

Variables considered for final regression analysis were included in a bivariate analysis to check for multicollinearity. Results are shown in Table 4. A Spearman Rho correlation test between negative affect and breast cancer worry frequency showed significant multicollinearity ($r=-0.59$, $p<0.00$). Preliminary multivariate associations were run using each variable. Although Chi Square analysis showed that breast cancer worry frequency was significantly associated with the dependent variable, negative affect was chosen instead of breast cancer worry frequency because including negative affect improved the overall model. The remainder of the variables considered did not show multicollinearity and so were all included in the final regression models.

Table 4

Multicollinearity of variables considered for logistic regression

	Perceived Risk of Breast Cancer	Breast Cancer Worry Frequency	BRCA Risk Understanding	Population Level Risk Understanding	Correct B-RST Recall	Negative Affect	Healthcare Trust	B-RST Acceptance
Past Mammogram Frequency	0.00 (p=1.00)	0.12 (p=0.20)	0.00 (p=1.00)	0.02 (p=1.00)	0.02 (p=1.00)	-0.01 (p=0.88)	-0.11 (p=0.16)	0.09 (p=0.28)
Perceived Risk of Breast Cancer	-	0.40 (p<0.00)	0.11 (p=0.24)	-0.16 (p=0.06)	0.11 (p=0.22)	-0.28 (p<0.00)	0.07 (p=0.40)	0.21 (p=0.01)
Breast Cancer Worry Frequency	-	-	0.04 (p=0.74)	-0.13 (p=0.13)	-0.03 (p=0.73)	-0.59 (p<0.00)	0.10 (p=0.20)	0.26 (p<0.00)
BRCA Risk Understanding	-	-	-	-0.09 (p=0.32)	0.19 (p=0.04)	-0.07 (p=0.37)	0.00 (p=0.98)	0.30 (p<0.00)
Population Level Risk Understanding	-	-	-	-	0.25 (p=0.01)	0.18 (p=0.03)	-0.02 (p=0.81)	0.02 (p=0.81)
Correct B-RST Recall	-	-	-	-	-	0.03 (p=0.71)	-0.04 (p=0.68)	0.07 (p=0.45)
Negative Affect	-	-	-	-	-	-	-0.18 (p=0.03)	-0.27 (p<0.00)
Healthcare Trust	-	-	-	-	-	-	-	0.33 (p<0.00)

Note. Correlation coefficients appropriate for level of data were used

Multivariate Associations by Study Questions

Question 1. Do healthcare trust and acceptance of B-RST predict willingness to decrease mammogram frequency among women at low risk for hereditary breast cancer?

As shown in Table 1, Chi square analysis did not show a significant association between healthcare trust and willingness to decrease mammogram frequency (p=0.88). There was not a significant association between acceptance of B-RST and willingness to decrease mammogram frequency either (p=0.67). Trust variables were not significant predictors of willingness to decrease mammogram frequency among this population.

Question 2. Are variables suggested by Waters et al model associated with willingness to decrease mammogram frequency based on lowered genetic risk?

Those willing to decrease mammogram frequency compared to those unsure and unwilling. A binomial logistic regression was conducted using the likelihood of willingness as a dependent variable. Results are summarized in Table 5. Results showed a negative association between population level risk understanding and willingness to decrease mammogram frequency. Those who have a correct understanding of their population level risk are 0.36 times less likely to be willing to decrease their mammogram frequency based on their low genetic risk than those who misunderstand their population level risk (AOR=0.36 95% CI=0.14, 0.94, p=0.04). There was a negative association between past mammogram frequency and willingness to decrease mammogram frequency. Those who had had a mammogram annually or more often were 0.13 times less likely to be willing to decrease their mammogram frequency compared to those who had had a mammogram biannually or less often (AOR=0.13, 95%CI= 0.04, 0.38, p<0.00). Perceived risk (p=0.07), BRCA understanding (p=0.22), B-RST recall (p=0.62), negative affect (p=0.98), healthcare trust (p=0.68), and B-RST acceptance (p=0.68) were not

significant predictors of being willing to reduce mammogram frequency. The total regression model accounted for 23% of the variance in likelihood that women were willing to decrease their mammogram frequency.

Table 5 Results from binomial logistic regression predicting being willing to decrease mammogram frequency versus being unsure of decision and unwilling to decrease mammogram frequency

Variable	OR	95% Confidence Interval	Significance
Past Mammogram Frequency			
Annually or more	0.13	(0.04, 0.38)	0.00
Biannually or less (referent)	-	-	-
Perceived Risk			
Medium-High Risk	0.41	(0.15, 1.08)	0.07
Low Risk (referent)	-	-	-
BRCA Risk Understanding			
Correct	0.56	(0.22, 1.41)	0.22
Incorrect (referent)	-	-	-
Population Level Risk Understanding			
Correct	0.36	(0.14, 0.94)	0.04
Incorrect (referent)	-	-	-
B-RST Recall			
Correct	1.26	(0.51, 3.11)	0.62
Incorrect (referent)	-	-	-
Negative Affect	1.00	(0.91, 1.10)	0.98
Healthcare Trust	1.02	(0.94, 1.10)	0.68
B-RST Acceptance	0.97	(0.83, 1.13)	0.68

Note. Dependent variable represents willingness to alter mammogram frequency according to lower genetic risk→ Those willing to decrease mammogram frequency are compared to those unsure or unwilling

Those undecided of their willingness to decrease mammogram frequency compared to those who have decided. A second binomial regression was conducted using likelihood of uncertainty as the dependent variable. Results are summarized in Table 6. The results did not show any significant associations. Perceived risk (p=0.44), BRCA understanding (p=0.89), population level risk (p=0.40), B-RST recall (p=0.48), past mammogram frequency (p=0.64), negative affect (p=0.44), healthcare trust (p=0.74), and B-RST acceptance (p=0.46) were not significant predictors of being unsure of willingness to reduce mammogram frequency. The total regression model accounted for 4% of the variance in uncertainty.

Table 6 Results from binomial logistic regression predicting likelihood that women will be unsure of their willingness to decrease their mammogram frequency versus having made a decision regarding their willingness

Variable	OR	95% Confidence Interval	Significance
Past Mammogram Frequency			
Annually or more	1.30	(0.43, 3.96)	0.64
Biannually or less (referent)	-	-	-
Perceived Risk			
Medium-High Risk	1.39	(0.60, 3.23)	0.44
Low Risk (referent)	-	-	-
BRCA Risk Understanding			
Correct	1.06	(0.46, 2.48)	0.89
Incorrect (referent)	-	-	-
Population Level Risk Understanding			
Correct	1.44	(0.62, 3.33)	0.40
Incorrect (referent)	-	-	-
B-RST Recall			
Correct	0.73	(0.32, 1.71)	0.48
Incorrect (referent)	-	-	-
Negative Affect	0.97	(0.88, 1.06)	0.44
Healthcare Trust	1.01	(0.95, 1.08)	0.74
B-RST Acceptance	0.95	(0.83, 1.09)	0.46

Note. Dependent variable represents willingness to alter mammogram frequency according to lower genetic risk→ Those willing to decrease mammogram frequency are compared to those unsure or unwilling

V. Discussion

Findings

Willingness to Decrease Mammogram Frequency Analysis of willingness to decrease mammogram frequency based on genetic risk among this population showed promising results. 57.3% of the study population were either unsure of their willingness or willing to decrease their mammogram frequency. This is important as women who are unsure of their willingness could be more easily convinced to be willing to decrease their mammogram frequency than those who are unwilling. Education efforts on the part of their physician and public health workers could sway these women towards being willing. Results of this study indicate that the majority of the population are either already willing or could be convinced to tailor their mammogram frequency according to their genetic risk. These results are encouraging for future applications of risk stratification based on genetic risk.

Demographics Age breakdown for the study population was similar to the age breakdown of women in the United States (*Current population survey*, 2016). 35.12% of women in the United States are between the ages of 35 and 49, compared to 30.6% of the study population. 64.9% of women in the United States are 50 or older, compared to 69.4% of the study population. Given the small study sample, 30.6% of the sample was not comprised of many participants and so age was not included in analysis.

Study race breakdown was similar to the race breakdown in the state of Georgia with 55.4% of the study population made up of white women, compared to 62.6% of the state of Georgia and 36.9% were African American, compared to 32.6% of the state of Georgia (*Current population survey*, 2016). The sample study sample resulted in few African American women included in the study and as a result, race was not included in the analysis.

Study income and educational make-up was not equivalent to the make-up of women in the United States. Women included in the study tended to have higher income and more education when compared to the general female population. 38.2% had an income of $75,001 or more, compared to 13.4% of the general population. 14.6% reported an income between $50,001 and $75,000 and 21.0% reported a salary of less than $50,000, compared to 16.5% and 70.1% respectively, in the generally population. 35.0% of the study population had a graduate or professional degree, compared to just 12.6% of the general female population. 27.4% had a college degree, compared to 32.0% in the general population, and 17.8% reported having completed some college or less, compared to 55.4% of the general population (*Current population survey*, 2016).

However, while this population may not have been completely representative of the population of Georgia, the study population demographics represented women more likely to have frequent mammograms. White women, older women, more educated women, and women with a higher income have been shown to get mammograms more frequently. This study population was made up of the women most likely to get frequent mammograms, and more likely to have to be talked out of frequent mammography. The demographic makeup of women included in this study indicated that this population was a good target for understanding how to convince those who are in favor of mammography to decrease their mammogram frequency based on their genetic risk.

Question 1. Do healthcare trust and acceptance of B-RST predict willingness to decrease mammogram frequency among women at low risk for hereditary breast cancer?

Trust in the healthcare system was moderately high among the study population, with women having an average institutional trust scale of 39.33 out of a possible score from 10 to 50.

However, institutional trust was not significantly associated with willingness to decrease mammogram frequency based on Chi-Square analysis. Although results of this study did not link institutional trust and willingness to decrease mammography as indicated by the literature, the high institutional trust results among this population are in line with previous studies linking increased mammography with increased trust (Waters et al., 2014). As women were recruited in a mammography waiting room, it made sense that healthcare trust among this population was high. Women with low trust in healthcare may not get frequent mammograms and would be less likely to be in the waiting rooms were recruitment took place. Including more women who do not trust the healthcare system in future analyses may lead to different results.

Question 2. Are variables suggested by Waters et al model associated with willingness to decrease mammogram frequency based on lowered genetic risk?

Health communication messages and health history, namely population level risk understanding and past mammogram frequency respectively, were found to be significantly associated with being willing to decrease mammogram frequency when controlling for all other variables. No variables suggested by the Waters et al model were found to be associated with being undecided regarding willingness when controlling for other variables. Although binomial logistic regression results did not show any other associations between variables, breast cancer worry frequency was found to be significantly associated with willingness to decrease mammogram frequency. These associations are described in more detail in the following sections.

Health communication messages Overall understanding was low among the study population. Women had the best understanding of their risk of having a BRCA1 or BRCA2 mutation based on their B-RST result, however, only 54% correctly understood that their result

meant it was unlikely that they would have a BRCA1 or BRCA 2 mutation. The majority of the population did not understand that their risk was equal to that of the general population, with only 39.6% correctly understanding population level risk. Less than half of the study population, 43.5%, correctly recalled their B-RST result. The lack of understanding among women who participated may reflect ineffective health communication messages.

Among the health communication messages variables, only understanding of population level risk was significantly associated with willingness when comparing those willing to decrease their mammogram frequency based on their genetic risk to those unwilling or unsure of their willingness. Women who understood that their risk of developing breast cancer was equivalent to the general population were less likely to be willing to decrease their mammogram frequency according to their low genetic risk. While literature suggests that better understanding of health communication can improve adherence to clinical recommendations (Ishikawa & Kiuchi, 2010), this did not appear to be the case among this population. Understanding and recall of results were either not significantly associated with willingness to change behavior or were associated with decreased willingness.

However, while some women could identify that their risk was equivalent to the general population, their understanding of breast cancer risk among the general population was not evaluated. Studies show that women tend to overestimate breast cancer risk (Domenighetti et al., 2003) and may overestimate breast cancer risk among the general population. Women could understand that they are at the same risk for breast cancer as the average population, but could have an inflated perception of average risk, making them less likely to be willing to decrease their mammogram frequency.

Health history Participants health history indicated that the study population was largely in favor of frequent mammography, with 83.4% of women having had a mammogram annually or more in the past two years. Past mammogram frequency was significantly associated with willingness to decrease mammogram frequency, with those who had had regular mammograms less likely to be willing. Study results were in line with previous study results, indicating that past behavior is a significant predictor of future behavior and future intention of behavior (Lechner et al., 1997; Mayne & Earp, 2003).

The majority of the study population, 60.4%, were getting a mammogram at the time of their B-RST because their doctor had recommended it. This could indicate a high level of trust in their healthcare provider among this study population, given that many of the women were following through on a recommendation from their physician.

Institutional Trust Institutional trust was not found to be significantly associated with willingness to decrease mammogram frequency based on genetic risk, when controlling for other included variables. As previously mentioned, this population had high overall institutional trust.

Cognitive and Emotional Processes Some cognitive and emotional processes were found to be significantly associated with willingness to decrease mammogram frequency based on low genetic risk. Perceived risk of breast cancer and breast cancer worry frequency were both shown to be associated with being willing to decrease mammogram frequency. Increases in both perceived risk and worry frequency were positively associated with willingness to decrease mammogram frequency. However, when controlling for other variables, only perceived risk was associated with being willing to decrease mammogram frequency when controlling for other variables. These results agree with previous studies (Gross et al., 2006; Hay et al., 2006). Overall, women had a moderately high acceptance of their B-RST results. This may be due to the

high overall institutional trust among the population. Acceptance of B-RST result may be more significantly associated with willingness to decrease mammogram frequency among women less trusting of the healthcare system. Negative affect was average among the study population and was not associated to willingness to decrease mammogram frequency, contrary to previous study results (Andrykowski et al., 2001; Consedine et al., 2004; Hay et al., 2006).

Conclusion

This study aimed to determine whether institutional trust and B-RST acceptance were associated with willingness to decrease mammogram frequency, as well as to determine whether conceptual constructs contributed to willingness to decrease mammogram frequency when controlling for other model-associated study variables. A large portion of the study sample was either willing to decrease their mammogram frequency or was uncertain of their willingness and could possibly be swayed towards willing. These results indicate that using genetic information for risk stratification has the potential for success. Institutional trust and B-RST acceptance were not associated with willingness to decrease mammogram frequency. Logistic regression analysis showed that past mammogram frequency and population level risk understanding could both be used to predict the likelihood that women were willing to decrease their mammogram frequency when controlling for other variables. No variables were shown to predict the likelihood that women were uncertain of their willingness to decrease their mammogram frequency when controlling for other variables, but breast cancer worry frequency and perceived risk of breast cancer were shown to be individually associated with willingness to decrease mammogram frequency. These variables merit further study and could be used to develop patient education materials.

Study Strengths and Limitations

A significant strength of this study was the recruitment location. As women were recruited in a mammography clinic, the study population was made up of women who were likely to be in favor of mammography and more likely to be hesitant about decreasing their mammogram frequency. By focusing on this population, this study provided insight into the factors affecting willingness to decrease mammogram frequency among a population who is likely to be more difficult to convince to adhere to changing guidelines. Recruiting in a mammography clinic resulted in a cost-efficient data collection method, allowing researchers to easily contact potential participants and making it easy to scale the study up in the future.

As this study was based in the Metro Atlanta area, application of results may be limited to similar areas, and may not apply to rural areas or areas outside of the Southeast. Limitations of this study also included analysis of secondary data, preventing alterations of questions included in the questionnaire. The response rate for this study was relatively low, with only 31.4% of women responding to the survey, despite an incentive. This could be due to the length of the survey. The small sample size limited the statistical power of the analysis.

Implications

Research techniques and improved, public databases have led to the rapid expansion of genetic information resulting in a plethora of data finding associations between genes and disease. Genome wide association studies (GWAS) attempt to detect genetic variants associated with certain traits within a population (Visscher et al., 2017). The combined efforts of the SNP Research Center in Tokyo, Japan and The International HapMap Project led to the creation of a

public, genome wide database of common sequence variations, together with the Human Genome Project, laying the foundation for the first GWAS in 2002 (Ikegawa, 2012; Visscher et al., 2017). The completion of the HapMap greatly simplified GWAS, resulting in a boom in these types of studies (Ikegawa, 2012). The increase in sharing of genetic data among researchers in the field of gene mapping led to larger experimental sample sizes, increasing the statistical power of such studies and leading to the success of many of these studies (Visscher et al., 2017). DisGENet is a database containing information from GWAS catalogues as well as animal models, literature, and expert curated repository (Piñero et al., 2017). The DisGENet database currently contains 561,119 gene-disease associations between, 17,074 genes and 17,074 diseases, and 135,588 variant disease associations, between 83,002 single nucleotide polymorphisms and 9,169 phenotypes (Piñero et al., 2017).

In 2015, President Barack Obama announced the launching of the Precision Medicine Initiative, a government funded research effort aimed at understanding how a person's genetics and environment interact to affect their health (Ashley, 2015). As part of the Precision Medicine Initiative, the National Institutes of Health has launched the All of Us Research Campaign, aimed at recruiting one million or more volunteer research subjects to expand the scale of potential research ("National Institutes of Health All of Us Research Program," 2017). The All of Us Research Project hopes to enable researchers to find new ways to measure risk based on interactions between environment exposures and genetic factors ("National Institutes of Health All of Us Research Program," 2017).

Having such a large cohort would increase the statistical power of any studies done using the data, allowing researchers to find many more associations between genes, exposure, and disease. With the government funding a project on such a large scale, it is likely that many more

associations between genes and disease will be discovered in the near future, ushering in precision medicine and individualized treatment into routine clinical care. There are many applications of precision medicine already being used, making it more and more vital to fully understand the effects the integration of precision medicine into primary care will have.

Although researchers and physicians are gaining a better understanding of how genes can affect disease risk, some studies indicate that knowledge of genetic risk does not prompt a behavior change (Hollands et al., 2016). Unless knowledge leads to behavior change, increased use of genetic risk assessment will not result in improved health. A better understanding of the factors that may influence likelihood of behavior change could inform efforts to support patient behavior change, including targeted patient education and improved communication methods. Results of this study indicate that even among a highly educated population likely to have high health literacy, understanding and recall of genetic risk are weak. Genetic risk communication methods must be adjusted so that those with all levels of health literacy can understand. Studies such as this one are vital to ensuring that genetic information is integrated into healthcare in a way that is effective and makes a significant impact on patient and population health.

Future Directions and Recommendations

Future attempts to understand the effects or risk communication should include more detailed questions evaluating understanding of risk, including an evaluation of numeracy regarding breast cancer risk. While this study was a good first step in understanding the beliefs and factors affecting the likelihood that hereditary breast cancer genetic risk communication will affect behavior change, this study only sampled 157 women. Future studies should include more

participants, as a larger sample size could result in higher statistical power. A larger sample size could allow for a more in-depth analysis of mammogram screening behaviors among various demographic groups, such as minority women. As minority women have been shown to be more likely to have reduced trust in the healthcare system, using a larger study population to analyze factors affecting willingness to decrease mammogram frequency among minority women may result in different outcomes.

It is important for both women and their physicians to be cognizant of the low levels of understanding prevalent among women eligible for mammography. Emphasizing the importance of such information could result in better recall of genetic risk communication, and as a result, behavior changes based on this information. The low level of understanding among this population indicates that women should talk to their doctors about their risk for breast cancer and should place more importance on risk messages being communicated to them. Women who put forth the effort to research and understand their breast cancer risk are more likely to have improved health as higher health literacy has been linked to better health outcomes and utilization of health services (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011).

Mammography screening has been strongly pushed in American culture. While understanding willingness to change mammogram frequency based on genetic risk may provide insight into the effects of genetic risk communication on behavior change, other factors may be involved when communicating risk using genetic biomarkers linked to different disease. Studies analyzing preventative behaviors following communication of melanoma risk, prostate cancer risk, and pancreatic cancer risk could shed light on the various factors that need to be considered when creating healthcare messages. As perceived risk has been shown time and again to predict screening behaviors, ensuring that patients have an accurate perception of their risk could be

vital in encouraging them to follow screening recommendations. Results from this study and future studies like it can be used to evaluate and improve patient understanding of genetic risk, allowing patients to make better informed decisions regarding their healthcare.

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