Assessing Geography as a Barrier in Choosing to Undergo Genetic Testing in a Cohort of Young Women with Breast Cancer

THESIS

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By

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Abstract

BACKGROUND:
Breast cancer is the most common cancer diagnosis for women under 40 years of age. Since 1999, the National Comprehensive Cancer Network (NCCN) has recommended that anyone who is diagnosed with breast cancer under the age of 40 meet with a genetic counselor and be offered genetic testing. In our cohort of women with breast cancer diagnosed at or before age 40, 555 of 2,223 (24.9%) reported that they had not had genetic testing for Hereditary Breast and Ovarian Cancer syndrome (HBOC) at the time of enrollment. Our study aimed to assess whether geographic barriers had an effect on whether high-risk women underwent genetic testing.

METHODS:
We surveyed 1,673 women who were still living and had valid email addresses to assess geography as a barrier. Using the Health Belief Model, questions were designed to assess barriers believed to have an impact on women in rural areas getting genetic testing. We expected to observe that women from rural areas who had longer distances to travel for care, had a stronger relationship with their healthcare provider, and reported less of an understanding of cancer genetics were less likely to have undergone genetic testing for HBOC regardless of their high-risk status.
RESULTS:
We received 865 returned surveys giving a response rate of 51.6%. Of these, 825 were able to be analyzed. Nearly an equal proportion of women from both urban and rural areas reported having had genetic testing prior to the study. As expected, our study showed that women from rural areas did have a longer travel time required in order to receive care. Unexpectedly, our study showed that women from urban areas were more likely to have a stronger relationship with their physician and results were mixed in regards to which group of women had more of an understanding of cancer genetics.

CONCLUSION:
We did not receive enough responses from women in rural areas to make our data statistically significant and therefore did not have statistical power. Trends we were able to observe were that women from rural areas report an increased travel time to receive care, women from urban areas were more likely to report a closer relationship with their treating physician, and that both groups were likely to select answers indicating a potential lack of understanding of genetics. Other trends unique to smaller populations were likely lost when we combined the three distinct rural populations (small urban, large rural, small rural). There is a need to address health disparities observed in rural areas and this study emphasized that more focus should be put on recruiting participants from rural areas.
Dedication

This document is dedicated to my parents whose unconditional support throughout the years made it possible for me to chase my dreams, wherever that has and will continue to take me.
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Chapter 1: Background

One in 8 women in the United States will be diagnosed with breast cancer in their lifetime. For women under 40 years of age, breast cancer is the most common cancer diagnosis (Rosenberg et al., 2016). When diagnosed early, breast cancer can be a survivable condition. Hereditary breast cancer accounts for approximately 5% to 10% of breast cancers (Glenn et al., 2012), and women who are diagnosed at a young age are more likely to harbor a germline mutation in genes known to cause breast cancer such as \textit{BRCA1} and \textit{BRCA2} (Anders et al., 2009). Lifetime breast cancer risk for women who carry a \textit{BRCA1} or \textit{BRCA2} mutation can be anywhere from 50% to 85% and their risk for ovarian cancer is about 14% to 40%, both of which are significant increases over the general population risks of 12% and 1.5%, respectively (Glenn et al., 2012).

Genetic testing can be extremely useful to those at risk of carrying a mutation in genes such as \textit{BRCA1} and \textit{BRCA2}, but only if patients choose to undergo genetic testing. Receiving negative test results can reduce breast cancer risk for an individual. Positive test results would also clarify risk and allow for a surveillance/management plan to be established. Each year the National Comprehensive Cancer Network (NCCN) updates guidelines regarding management for individuals who test positive for mutations in known cancer susceptibility genes. These management guidelines can reduce the overall
mortality of breast cancer through proper surveillance of women who have already had breast cancer to detect a second primary and screening/preventive surgery/chemoprevention for women who have not yet developed cancer (Berry, 2013; Mandelblatt et al., 2016). There are benefits of receiving both positive and negative test results. A positive test result can lead to cascade testing which entails testing for the known mutation for at-risk, first degree relatives and further throughout the family as appropriate. Cascade testing can potentially warrant earlier and more effective cancer screening for asymptomatic relatives who test positive. A negative test result may result in feelings of relief in that the chances of a genetically-linked second primary cancer is unlikely and aggressive prophylactic management is less likely to be recommended.

Included in the aforementioned NCCN guidelines are a set of criteria to help distinguish individuals and families that may be at risk for carrying a mutation in a cancer susceptibility gene. These criteria take into account age of diagnoses, related cancers (e.g. male breast, ovarian, prostate, melanoma, pancreatic, etc.), number of affected family members, and their degree of relatedness to the proband. While these are nationally recommended guidelines, meeting criteria for testing does not guarantee that a patient will be made aware of and/or choose to undergo genetic testing. Indeed, a number of studies suggest that only a minority of eligible women undergo counseling and/or testing. Bellcross (2015) analyzed characteristics associated with choosing to undergo genetic testing for BRCA1 and BRCA2 and showed that although 90% of their high-risk patients discussed their family history with their healthcare professional only 20% chose to have
genetic testing. Kinney et al. (2014) reported that although there are guidelines recommending that women diagnosed with breast cancer under age 50 have a genetic risk assessment, less than half of them ever get counseling. A study done in New South Wales showed that 50% of breast cancer patients enrolled in their study qualified for genetic testing based on national guidelines, but only 12% underwent testing (Butel-Simoes and Spigelman, 2014).

A study assessing utilization of \textit{BRCA} testing identified characteristics of those electing to undergo genetic testing and showed that most individuals were non-Hispanic Caucasian race, college educated, married, and earned higher incomes (Armstrong et al., 2015). In another study discussing genetic testing for Long QT syndrome, the most common socioeconomic traits among those who elected to undergo testing were Caucasian, had degree from a university, and had a high household income (Burns et al., 2016).

A common approach used to assess decision-making regarding individual healthcare is the long-established Health Belief Model. The health belief model (HBM) was originally developed by Hochbaum, Rosenstock, and Kegels in the 1950’s in order to assess the failure of individuals to participate in preventive and detective measures for disease (Cyr et al. 2010). The health belief model takes into account four major components of decision-making regarding personal healthcare: 1) perceived susceptibility of contracting the illness, 2) perceived severity of both medical and social consequences of contracting
the illness, 3) perceived benefits of taking clinical action, and 4) perceived barriers to taking clinical action or an unconscious cost-benefit analysis. These four core concepts are also influenced by age, gender, ethnicity, personality, socioeconomic status, and education level and how they alter the perception of an illness. Analyzed together, these factors help predict the kind of decision an individual will make regarding his or her health. We used this model to develop probing, relevant questions to ask our study participants as well as to guide interpretation of participant responses to these questions.

Perceived susceptibility defines an individual’s thoughts regarding how likely they think they are to contract a specific illness. The degree of perceived susceptibility can be a factor in whether or not a person acts in a proactive manner to help ward off sickness. If someone perceives that the likelihood of becoming ill is high, it is more likely they will take preventative measures. One study found that higher perceived susceptibility to breast cancer was associated with an increased likelihood to comply with screening (Speedy et al., 2000). The same is true for the reverse in that if the perceived susceptibility is low, the individual is less likely to take action.

Perceived severity is an individual’s perception of how contracting this illness would affect their health along with the social consequences of it. For example, contracting an illness might require a significant hospital stay for required treatment (severity) along with the difficulty of being away from home and family for an extended period of time (social consequences). Perceived severity and risk of occurrence (perceived
susceptibility) relative to actual risk can be correlated to the degree of preventative action a person takes to promote a positive outcome. An individual’s perception of susceptibility and severity together define the threat a particular illness poses for the individual. This perceived threat can provide motivation to act which can be either inhibited or facilitated by perceived barriers or perceived benefits, respectively. It is believed that perceived benefits and barriers are the strongest predictors of behavioral change when the perceived threat is high (Taylor et al., 2013).

**Perceived benefits** are the potential gains an individual believes can result from taking action. Awareness of the timing and intervals of appropriate screening can be a facilitator in taking action in personal healthcare as individuals tended to react more favorably if they understood the reasoning and potential benefits (Honein-AbouHaidar et al., 2016). When perceived genetic risk is high, greater perceived benefit tends to motivate individuals to perform personal self-checks for the illness for which they are concerned and to discuss their health with their primary physician (Boeldt et al., 2015). A study done by Honein-Abouhaidar et al. (2016) provides insight into the complexity of the relationship between perceived benefits and barriers. They demonstrated that being proactive about health screening can be perceived as a benefit for people who have a relative affected by a condition which was detected through early screening. However, having an affected relative can also be a barrier to being proactive if the relative whose condition was detected early subsequently died from the condition and the individual
therefore views screening as useless or ineffective in altering a disease course (Honein-Abouhaidar et al., 2016).

Perceived barriers can be socioeconomic, demographic, or internal factors that prevent an individual from taking action regarding their health. Examples of socioeconomic barriers include: lower income/inability to afford testing, no health insurance/worries about health insurance discrimination, or inability to speak the regional language (Glenn et al., 2012). Certain demographic barriers can have an indirect effect on health behaviors by altering a patient’s perception of their health behaviors and choices. For example, African American individuals undergo genetic testing less frequently than any other ethnic group although it is unknown why this occurs within this demographic (Taylor et al., 2013). Internal barriers can also take several forms. One type can be described as an unconscious cost-benefit analysis of going forward with a particular health-related action. Another one, which is a common theme among barriers to getting routine health screens and/or genetic testing, is a lack of patient knowledge regarding the purpose and benefit of routine screening and genetic testing (Carroll et al., 2003; Taylor et al., 2013). Wouters (2014) found that women undergoing endocrine therapy following a breast cancer diagnosis who did not believe the anti-estrogen drug Tamoxifen was useful were more likely to discontinue using it. This same study reported that approximately 20% (n = 49) of their cohort did not know how endocrine therapy works and did not have information about it. Approximately 32% (n = 77) did not know to what extent this therapy reduced the risk of cancer recurrence while 30% (n = 72) were not convinced that endocrine
therapy was effective in reducing cancer risk at all. In another study, women who are more knowledgeable about breast cancer screening and its benefits were more likely to keep their appointment for a mammogram (Speedy et al., 2000). Taylor et al. (2013) reports that knowledge of breast cancer genetics has a significant impact on whether or not women choose to undergo genetic testing. Therefore, not understanding the utility of a particular screening, treatment, or test can be a potential barrier to taking action. It has been demonstrated using the HBM that the perception of fewer barriers predicts higher compliance (VanDyke and Shell, 2016).

Cues to action and self-efficacy are also contributory to the main four concepts of the Health Belief Model in predicting and assessing patient decision-making. A cue to action is a stimulus that motivates an individual to take action to promote their health. For example, losing a close relative to colon cancer might lead to initiation of routine colon cancer screening. Self-efficacy can be interchanged with perceived control or an individual’s sense of their ability to positively affect his or her outcome from choices the individual makes. For example, one of the most significant concerns for breast cancer survivors is the fear of recurrence (Freeman-Gibb et al., 2016). If perceived self-efficacy is high in these individuals, they believe that they can potentially prevent a negative outcome based on their own actions. One study demonstrated that women with a greater feeling of control tended to adhere to their endocrine therapy to better treat their breast cancer (Wouters et al., 2014).
**Geography as a Barrier**

A review of recent literature suggests that geography may act as a barrier to individuals in rural areas getting genetic testing. One component of geography acting as a barrier is the distance an individual must travel to receive an appropriate diagnosis and follow-up care. An additional component is the difference seen in the type and intensity of relationship between patients and their physician in rural versus urban locations, and the impact this has on patient decision-making. Finally, the third component is rural vs urban differences in the depth of understanding cancer patients have of cancer and cancer genetics. The following is a review of the literature highlighting these three components of geography acting as a barrier.

**Rural Location as a Barrier**

**Increased Travel Time for Care**

Smaller population size has been shown to be linked to having fewer medical specialists in the area and an increased distance required to travel in order to receive specialty, specifically oncologic, care (Purnell et al., 2016). Many studies have indicated that greater travel time to receive care has an impact on where individuals choose to receive care and what type of care they receive (Baldwin et al., 2008). Studies have also demonstrated the different trends in healthcare decisions made by individuals living in rural areas as compared to urban areas. Baldwin (2008) found that patients coming from isolated rural communities travel on average 47.8 to 67.0 miles to get cancer care in an
urban location whereas those living in a large urban area traveled on average under 10 miles. Another study reports an average travel time of 51 minutes in order for patients living in rural areas to receive specialized oncology care (Charlton et al., 2015). In a study aimed at understanding the breast cancer experience from women living in rural areas, traveling long distances to obtain treatment was viewed as an additional stressor (Bettencourt et al., 2007). The location of the treatment facilities often required significant travel on the part of the patients to get the treatment they needed. In this study of 433 rural breast cancer survivors, 50% reported over 1 hour of travel time to get to their surgery and 25% reported over 3 hours of travel time. It is not surprising that this study also reveals differences in treatment choices between rural and urban women. Rural women were more likely to undergo either a unilateral or bilateral mastectomy (versus lumpectomy) and chemotherapy and less likely to have reconstructive surgery, which generally requires additional visits to the clinic or hospital. Their urban counterparts were more likely to elect breast-conserving treatment and radiation and more likely to have reconstructive surgery if a mastectomy was the surgery of choice. This same trend was also observed by Schroen et al. (2005). A different study demonstrated that increased travel time to obtain oncologic care has been associated with decreased utilization of breast conserving therapy (Onega et al., 2008).

This parallels a common theme in the literature: additional travel that is required for many individuals in rural areas to receive care can lead to a difference between rural and urban-dwelling individuals in the type of treatment that is chosen. Individuals living in
rural or remote settings tend to elect a treatment option that will require less follow-up
with their care provider who is located some distance away from their home. This
recurrent finding is not just specific to individuals with breast cancer. A study comparing
treatment for early stage prostate cancer in rural and urban settings revealed that men
with early-stage prostate cancer who resided in a rural area were less likely to receive the
most appropriate treatment but rather chose the most convenient therapy as compared to
men in urban locations (Baldwin et al., 2013). Galandiuk (2010) demonstrated that
residents of urban areas were more likely to receive perioperative radiation and
chemotherapy than their rural counterparts, which could be attributed to a shorter travel
time to receive ongoing follow up care. Baldwin (2012) concluded that patients residing
in rural areas tend to fail to obtain recommended radiation therapy treatment which may
be in part due to distance to care acting as a barrier. This study showed that having a
radiation oncologist located within a rural county increased the uptake of radiation
therapy by patients who also lived in that county. Of note, this trend was only observed in
low-employment counties, which suggests local services may be more important with
inhabitants of lower socioeconomic status. An underlying theme regarding treatment
choice is minimizing the need for constant travel for continued care.

**Physician Shortage in Rural Areas**

An additional hurdle for individuals residing in rural areas in getting specialized health
care is the overall physician shortage that is linked to rural locations. It is well
documented that rural residents have poorer access to care than their urban counterparts
(Purnell et al., 2016). Individuals living in rural areas also have a higher overall death rate from all causes than those living in urban settings, with the highest level of mortality rates occurring in the regions with the highest poverty rates which may be associated with limited access to healthcare (Singh and Siahpush, 2013). People who live in rural areas, defined by the U.S. Department of Agriculture Economic Research Service as open countryside, rural towns (population less than 2,500 people), and smaller urban areas (population ranging from 2,500 to 49,999 people) not included as part of larger metropolitan areas, account for approximately 20% of the population of the United States (Bhattacharya, 2013, Caldwell et al., 2016). Residents of rural areas reported half as many physician visits as their urban counterparts and were less likely to receive home care due to the burden of significant travel and scarcity of available resources (Goodridge et al., 2010, Caldwell et al, 2016). Only 9% of physicians in the United States practice in rural areas leading to a shortage of qualified health care professionals in those areas (Bhattacharya, 2013). Caldwell et al. (2016) found that for every 10,000 inhabitants, urban areas averaged about eight physicians while rural areas averaged about five. In addition to limited access to general physicians, the affinity of specialists to cities with larger populations means that individuals in rural areas are less likely to have access to specialist care, which includes state-of-the-art cancer care (Baldwin et al., 2008, Bush et al., 2015) Onega (2008) demonstrated that individuals with increased travel time, such as those living in remote locations, were not receiving the most appropriate cancer care. This likely has implications for genetic testing as well. Although it is now considered standard of care to either offer genetic testing to those individuals who are at an increased
risk for hereditary cancers or to refer them to a genetic counselor, it is not a reality for individuals without easy access to specialized care (Buchanan et al., 2009).

**Lack of Educational Resources for Rural Physicians**

A major reason specialists tend to practice in urban areas is because this is where there are usually more resources and educational opportunities (Charlton et al., 2015). Physicians practicing in a rural setting face the added difficulty of accessing and obtaining the most up to date educational information for best practice (Bush et al., 2015). Harris et al. (2016) reported that rural health departments have less access to technology and electronically available information including, but not limited to, educational materials and national practice guidelines and updates. The barriers physicians in rural areas have in staying abreast of the latest standards of care may be an underlying reason why many rural patients do not receive or even know about the most appropriate screening protocols. Rural healthcare providers are less likely to report use of evidence-based decision making, provide fewer types of services to their patients, and report lower compliance rates among patients (Harris et al., 2016). In a study addressing the differences in colorectal screening between urban and rural communities in individuals 50 years of age and older, individuals in rural areas were less likely than individuals from urban areas to have had standard of care colon cancer screening (Davis et al., 2013). Another study revealed that rural physicians had a greater difficulty than urban physicians in accessing resources to provide care, especially when it was in a specialty they felt less comfortable discussing (Khoong et al., 2014). Both of these
studies report findings that could affect the rate of genetic testing due to the underutilization of evidence-based care and lack of familiarity with counseling patients about genetics and genetic testing.

In a study regarding genetic testing for long QT syndrome, a hereditary form of heart disease, it was observed that appropriate referral by doctors is necessary in facilitating genetic testing for those who want it (Burns et al., 2016). This study highlighted the need for continuing education for these referring physicians in order to ensure that high-risk patients are getting the care they need. It also highlighted the need for future studies to address physician education in rural settings and to gain a better understanding of why some physicians practicing in both urban and rural areas are not referring high-risk patients to genetics when guidelines to assist with such are readily available. In a study by Khoong et al. (2014), all 10 rural physicians included in the study reported that a greater availability of educational resources encouraged guideline adherence while less availability of these resources discouraged guideline adherence. Other factors were put forth by Kelly et al. (2009) suggesting why rural physicians are not prepared to assess individuals with hereditary cancers. This study reports that rural physicians may not only be limited by lack of continuing education resources but also by PCP shortages, competing demands, less patient accessibility to health services, inability of patients to pay for said services, and lower education levels of patients.
Rural Physicians Under-Refer High-Risk Patients

Lack of opportunities for continuing education and access to updated practice guidelines could be reasons why rural physicians do not identify and either refer or test high-risk patients. The literature suggests that this is especially evident in high-risk minority groups, which includes individuals living in rural areas (Lynce et al., 2015). If physicians have a lower confidence level in identifying high-risk families, believe identifying genetic cancers is not important, or believe it is not their role, then they are less likely to do a proper genetic assessment and subsequently refer to genetics counseling (Kelly et al., 2009). Studies have shown that many providers lack appropriate knowledge of who to refer for genetic counseling/testing even with the availability of clear guidelines that delineate who is at an increased risk (Trepanier et al., 2016). Approximately one in ten women in Michigan has a significant family history of breast and/or ovarian cancer; however, only 10% of these women have had genetic counseling (Trepanier et al., 2016).

Rural physicians report seeing value in education about cancer screening, diagnosis, and treatment, but often fail to stay abreast of new guidelines, technology, and therapies for their patients (Rayman and Edwards, 2010). In one study directed at understanding physician adherence to appropriate referral guidelines for genetic counseling/testing, 71.3% of physicians surveyed adhered and did not offer genetic testing/counseling to those at a low risk (n=46,370) for hereditary breast and ovarian cancer syndrome (HBOC) (Trivers et al., 2011). Conversely, in the same study only 41.1% reported adherence to guidelines by actively referring high-risk women (n=43,073) to genetics. Although less likely to refer a high-risk patient than not refer a low-risk patient, it should
be noted that most referrals either to a genetic counselor or for genetic testing came from specialists in obstetrics and gynecology. When broken down by urban and rural referrals, rural physicians were more likely than urban physicians to not refer low-risk patients (80.5% vs. 69.3%) and were less likely to refer high-risk patients (24.8% vs. 44.1%) indicating decreased referrals in general by rural physicians. This study also reported higher physician adherence to referral guidelines when the appropriate risk was estimated for the patient. This suggests that physician risk assessment is important for both high and low-risk women.

Meeting with a genetic counselor has been shown to both increase a patient’s understanding of BRCA testing and leave them more satisfied with their care and level of understanding of the testing, making referrals to a genetics specialist an impactful part of complete patient care (Armstrong et al., 2015). According to Armstrong (2015), obstetricians/gynecologists were the least likely to refer patients to a genetic counselor and are placing the highest volume of genetic testing orders for their patients. Of the 50 participating physicians in a study by Teng and Spigelman (2013), only 60% (n=30) felt it was their duty to facilitate genetic testing or a genetics referral. The physicians surveyed were general practitioners, oncologists, obstetricians and gynecologists, and internal medicine specialists. This is an interesting finding when considered in the context of other literature which reports one of the main reasons why physicians do not want to broach the topic of genetic testing is because they do not want to inflict undue distress upon their patients (Teng and Spigelman, 2013, Biesecker et al., 2000,
Bettencourt et al., 2007, Van Riel et al., 2010). It could be argued that ordering *BRCA* testing without some form of genetic counseling may itself cause undue stress to patients. Studies by Armstrong (2015) and Trivers (2011) highlight that obstetricians/gynecologists in particular are more likely to order genetic testing and more likely to not involve a genetic counselor. These discrepancies lend themselves to the idea that some physicians are not aware of the details of the genetic testing process nor how the benefit of testing could outweigh the harm from initial distress.

According to Bettencourt (2007), it can be dangerous for women living in rural areas to put so much stock in their physician’s knowledge as there is more limited availability for providers in rural settings to engage in continuing education opportunities which would enable them to be up to date with the most recent screening guidelines. For example, Van Riel (2010) found that less than half (49%, n=14) of the physicians surveyed would refer for genetic counseling/testing a breast cancer patient who had a close relative with ovarian cancer, which is standard practice. In a survey assessing physicians’ attitudes towards genetic testing, over 84% of oncologists who participated felt comfortable recommending genetic testing compared to only 40% of primary care physicians (Freedman et al., 2003). This study as a whole indicated there is a significant amount of uncertainty among physicians in the U.S. regarding genetic testing services and its utility. This study reveals the danger in patients relying heavily on physician knowledge of genetic testing alone especially in a rural setting.
Individuals find it extremely important that their care provider who is discussing cancer genetics with them have specialty training in the area of cancer genetics (McDonald et al., 2014). However, a study performed in Utah demonstrated that on average, individuals from rural cities in Utah who participated in telephone genetic counseling had a higher uptake of genetic counseling and genetic testing than individuals in the urban cities in Utah suggesting a lack of referrals and genetic counseling/testing offerings in rural areas (Kinney et al., 2014). These two studies suggest that individuals would like to be referred to a genetics specialist if appropriate, but those who would most benefit are not being offered a referral as often as is recommended.

**Strong Patient-Physician Relationship in Rural Communities**

Another component to geography acting as a barrier is the strength of the relationship and level of dependency patients have with their treating physicians. Rural communities have been noted to have increased levels of group familiarity than those living in urban areas and are often characterized by these close social networks, which include their physicians (D’Agincourt-Canning, 2004). Providers in rural areas believe that women turn to them for aid in decision-making because they see them as their trusted expert and have established a long-standing relationship with them (Rayman and Edwards, 2010). Bettencourt (2007) introduces the idea that the relationship between doctors and their patients in rural settings can have an impact on their surgical and treatment decision-making. Esplen (2001) noted that 50% of their subjects reported that a genetic testing referral from their primary physician was a significant motivator in getting genetic testing
which stresses the significance of this relationship. Women who have been diagnosed with breast cancer often go to their primary care physician or medical specialist for referral for genetic counseling and/or genetic testing (Van Riel et al., 2010). Kelly et al. (2007) found that most cancer patients look to their physician for assistance in decision-making regarding treatment.

Having a high level of dependency on a physician who may be under-referring high-risk women for genetic counseling/testing could result in high-risk patients not receiving the proper risk assessment and counseling, with potential implications for appropriate screening and care. Farmer (2006) examined the intensity of the relationship between doctors and patients in rural areas. This study reports that the relationships appeared strongest when their doctor uses their first name, both doctor and patient are involved in local activities, and the patient felt they knew the doctor well based on personal circumstances and shared experiences (Farmer et al., 2006). The intensity of the relationship was inversely related to the size of the practice, with a greater intensity of relationship reported with smaller rural practices. Campbell et al. (2006) also note the strong relationship often observed between rural patients and their rural primary care physician. Patients in a rural setting often see their primary care physician as their friend or neighbor rather than their healthcare provider (Douthit et al., 2015). Closeness of rural communities has also been observed as a barrier to engaging in medical care for fear of loss of confidentiality and privacy with the physician who is also a member of this small, tight-knit community (Thorndyke, 2005). For those who do seek out medical care, this
same strong relationship that facilitates patient decision-making could result in patients not getting genetic testing if their doctor does not have the most up to date information and is not referring as recommended (Thorndyke, 2005). Patients in rural areas also have limited options when it comes to their primary care provider due to the lack of providers in rural areas. Additionally, strong interpersonal relationships may make them feel compelled to do as their physician recommends which could impact genetic testing for high-risk woman as well (D’Agincourt-Canning, 2004). In one study, it was reported that 48% of women who were considered high-risk and did not have genetic testing indicated that it was because either the individual or her physician did not feel it was likely they would test positive for a mutation in \textit{BRCA1} or \textit{BRCA2} (Blazer et al., 2016). Thus culturally conservative rural physicians whose patients rely on their expertise and recommendations could be a significant barrier in getting genetic testing. Notably, physician recommendation has been revealed as one of the most important factors to a patient when considering surgery type as part of their breast cancer care (Blazer et al., 2016). Similarly, it has been observed that differences in physician recommendations regarding genetic testing are associated with disparities in testing (McCarthy et al., 2016). Both studies underline that physician recommendation has a significant impact on the type of care a patient receives.
**Decreased Understanding of Cancer/Cancer Genetics and Its Value in Individuals from Rural Areas**

Cancer patients may rely heavily on family doctors in rural settings because of the general lack of understanding of cancer and the value of genetic counseling and testing they possess (Riesgraf et al., 2015). A study conducted by Ulloa et al. (2015) indicated that among their cohort of breast cancer survivors, there was a significant lack of understanding of basic cancer biology. In another study of 124 breast cancer survivors conducted by Taioli et al. (2014), about 50% of patients reported having limited understanding of their breast cancer diagnosis. In Appalachian populations, it has been demonstrated that there is a general underestimation of susceptibility to colorectal cancer even when these study participants are aware of the age when screening should begin. This underestimation of cancer risk may be due to lack of personal understanding of cancer (Llanos et al., 2014). It also may not be general knowledge amongst patients and perhaps their physicians that genetic testing can lead to improved healthcare and screening for relatives who test positive and are asymptomatic (Burns et al., 2015).

Meisel et al. (2015) demonstrated that higher perceived risk in women at an increased risk for ovarian cancer was not associated with an increased uptake in genetic testing. One reason for this may be the lack of familiarity with the genetic nature of ovarian cancer.
**Discrepancies in Geographic Categorization**

Our research into defining the proper parameters for rural/urban city classification based on population highlights the difficulties of classifying populations by geographic size. Population density as a defining parameter is skewed by the amount of space designated within the boundaries of small rural cities making the population seem much smaller than it actually is (Hall et al., 2006). This also does not take into account proximity to major urban cities where patients from smaller towns may have sought treatment. Dichotomous structure of analysis has been shown to misrepresent more remote rural areas by grouping them in with larger rural towns (Hall et al., 2016). Goodridge (2010) classified their respondents into rural (population <9,999), small urban (population 10,000-100,000) and urban (population >100,000). Galandiuk (2006) does not report how their study classified rural and urban hospitals. Cyr (2010) classified a frontier city by population density using 6 or less individuals per square mile, a rural city as more than 6 but less than 50 people per square mile, and urban as greater than 50 people per square mile. Curran (2012) designated rural cities as having a population less than 100,000 people. Any city with a population above 100,000 people was considered urban for their study. Henry (2011) categorizes an urban city as having greater than 50,000 people, a small town as having 10,000-49,999 people, and a small rural town as less than 10,000 people. The 2010 U.S. Census defines an urbanized area as containing a population of 50,000 or more and an urban cluster as an area containing a population of 2,500-49,999 people. Below 2,500 is considered a rural area.
In summary, the literature revealed many trends in regards to rural location and increased travel time to receive care as barriers to individuals in rural areas undergoing genetic testing. Individuals living in rural areas reportedly had a longer travel time in order to receive care as compared to those living in urban areas. It is well-documented that rural areas have a physician shortage and what few physicians practice in rural areas have more limited access to ongoing and updated educational resources. As a result, it is believed that the scarcity of both physicians and educational resources for them is partly responsible for people in rural areas not being referred to genetics when it is appropriate. Published literature also indicates that individuals in rural areas have a stronger relationship with their primary care physician and rely heavily on their recommendations on how best to manage their personal health care. Lastly, it was shown that individuals oftentimes demonstrated lack of understanding of cancer and cancer genetics. These findings are further complicated by discrepancies in how different studies categorize rural vs urban populations.

There is large potential gain from this study involving young women diagnosed with breast cancer in that it could identify geographic and other potential barriers to their getting genetic testing. This study aimed to expose these barriers and give insight to the medical community. Oliver et al. (2011) pointed out the idea that barriers such as health literacy, patient-provider communication, and overall health beliefs in combination with geographical location have a significant contribution to health disparities. This study
could help improve the completeness of care, the rate of testing, and quality of care for
this unique set of patients by identifying and addressing barriers for these patients.

**Hypothesis and Specific Aims**

We hypothesize that women in rural areas are less likely than their urban counterparts to
undergo genetic testing for a number of reasons. Therefore, we aim to:

(1) determine if women in rural areas have an increased travel times to receive
treatment compared to women living in urban areas.

(2) assess whether women living in rural areas are more likely to report a
closer/longer relationship with their physician than women living in urban areas
and if women in rural areas rely more heavily on their physician’s
recommendation than women in urban areas.

(3) determine if there are differences in understanding of cancer genetics and its value
for women living in rural and urban settings.

We expected that in our cohort, the same relationships between socioeconomic features
reported in the literature as associated with undergoing genetic testing for high-risk
cancer susceptibility genes would exist. We expected to see a majority of the women in
our cohort who had undergone genetic testing were Caucasian women with higher education, higher annual income, and had a family.
Chapter 2: Methods

We used the Health Belief Model in designing questions to assess our cohort’s perceptions of susceptibility, severity, benefits, and barriers. In this study we were mainly focused on the barriers to getting genetic testing for women who were young at diagnosis and therefore are at high risk, but all four components (perceived susceptibility, severity, benefits, and barriers) were necessary to understand why the women in our cohort made the decisions they did.

Research Subjects

The cohort of women who participated in this study were all diagnosed with breast cancer at age 40 or younger and were recruited over the 2004 to 2016 period to the Young Women’s Breast Cancer Research Study. Recruitment took place both locally and at the national level. A majority of the subjects (1,167 individuals 52.5%), were recruited through an online posting by the Army of Women breast cancer advocacy group (https://www.armyofwomen.org/). The Young Women’s Breast Cancer Research Study was initiated at Barnes-Jewish Hospital and Washington University in St. Louis and 717 subjects (32% of the cohort) were enrolled locally or were informed about the study through physician referral, the news, a clinical research information website, from a friend, or similar sources. Another 339 women (15.2%) were recruited nationally while
attending the Young Survival Coalition annual conference for women with early-onset breast cancer.

Of the 2,223 women enrolled in the Young Women’s Breast Cancer Research Study, 1,844 gave permission to be contacted in the future regarding additional research studies and became the base for our cohort. We then cross-checked our cohort against the Social Security Death Index (SSDI) and identified 18 deceased individuals. Approximately 50-60 women in our cohort of 1,844 women were diagnosed with breast cancer for the first time before genetic testing for $BRCA1$ and $BRCA2$ was clinically available, accounting for about 5-7% from both rural and urban groups. We elected to not remove these participants’ surveys as it would not affect data in a meaningful way and genetic testing was available to them for at least 6 years by the time they had enrolled in the study.

**Questionnaire Development**

We developed a survey consisting of 32 multiple choice questions (Appendix A) with some questions permitting more than one selection. This survey was developed using the four core components of the Health Belief Model (perceived susceptibility, severity, benefits, and barriers) as a guide. This survey was broken down into four categories: Demographic Information, Motivation, Your Diagnosis, and Cancer Genetics. All questions and responses were coded to fall into one of the four main categories of the Health Belief Model or to address demographics.
Distribution of Web-Based Questionnaire

We obtained approval for this study from The Ohio State University Institutional Review Board (IRB) and the Clinical Scientific Review Committee (CSRC). Using the REDCap system, a secure, encrypted web application approved by our institution for building and managing online research surveys and databases, we sent a separate invitation email that contained the necessary components of informed consent to each woman (Harris et al., 2009). At the bottom of each email contact information for study personnel was listed along with a unique link to a secure survey. Each entry was received anonymously so the study coordinators could not link the survey to the individual. Two follow-up emails were subsequently sent out at two week intervals reminding those who had not opened/completed their surveys that it was still active and available to them should they wish to participate.

Geographical Classification Based on County Size

For the purpose of our research, it was necessary to delineate which respondents were to be categorized as urban or rural based on the city in which they reported living at the time of their first breast cancer diagnosis and where they reported being diagnosed or treated. Given the critique by Hall (2006) of the problems with rural/urban population classification for comparative research and the lack of consensus seen in various studies, we used a combination of population definitions provided by the U.S. Census Bureau and the classification system used in the study by Henry (2011). For the 2010 U.S. Census, an urbanized area was defined as containing a population of 50,000 or more. An urban
cluster was defined as containing a population of 2,500-49,999 people. Henry (2011) categorized an urban city as having greater than 50,000 people, a small town as having 10,000-49,999 people, and a small rural town as less than 10,000 people. In an effort to identify characteristics unique to smaller rural towns, we used the definitions from the U.S. Census Bureau along with further delineation of populations, similar to Henry. We elected to classify by county because census data dating for the 1970’s and 1980’s is archived by county not city. A few of our participants were diagnosed during that time, so to keep analysis comparable, we chose to classify each location by county size. As a result, we define urban counties as “large urban” when the population is greater than 50,000 people and “small urban” as counties with a population between 10,000 and 49,999 people. We also categorized rural counties to be “large rural” (counties with a population between 2,500 and 9,999 people) and “small rural” (less than 2,500 people). The primary analysis compared the odds of genetic testing between women from urban and rural areas.

Descriptive statistics (means and standard deviations for continuous variables and counts and relative percentages for categorical variables) were calculated comparing urban (large urban area) to rural (all others) and those with prior genetic testing to those without. Chi squared tests and logistic regression were used to test the primary hypothesis of an association between genetic testing status and urban/rural status.
Chapter 3: Results

Response Rate and Geographical Classification

A total of 1,844 individuals were eligible for the study. Review of the SSDI (August 8th, 2016) revealed 18 deaths since the late update of vital status for the Young Women’s Breast Cancer Research Program database leaving 1,826 subjects who could be contacted by email. One hundred and fifty-three email addresses were no longer valid for a total of 1,673 potential contacts. A total of 865 surveys were completed giving a response rate of 51.6%. We subsequently removed 19 additional participant surveys because they listed an international location for residence or treatment. An additional 21 respondents could not be classified as urban or rural, giving a final total of 825 usable responses.

Of the 825 usable responses, 742 (90%) reported living in a large urban area (population greater than 50,000 people) at the time of diagnosis, 75 (9%) reported living in a small urban area (population of 10,000 – 49,999 people), 7 (1%) reported living in a large rural area (population of 2,500 – 9,999 people), and 1 (0.1%) reported living in a small rural area (population less than 2,499 people). Due to the limited number of responses received from individuals in large rural or small rural areas, we combined data on subjects reporting residence of small urban, large rural, and small rural at the time of diagnosis (now labeled “rural” for all comparisons). As defined by the U.S. Department of
Agriculture Economic Research Service, approximately 20% of the population of the United States resides in areas with a population of less than 49,999 people. As such, with small rural, large rural, and small urban combined, we expected to see about 20% of our responses belong to individuals living in rural areas at diagnosis. Only about 10% of individuals who responded reported living in a rural area at that time thereby limiting the power of our study.

**Demographic Make Up of Respondents**

Below, Table 1 displays the self-reported demographic makeup of individuals who participated in our study. Participants most often reported being White, non-Hispanic married women with a Bachelor’s degree.
<table>
<thead>
<tr>
<th></th>
<th>Small Urban and below (n=83)</th>
<th>Large Urban (n=742)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>79 (95%)</td>
<td>686 (93%)</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>0 (0%)</td>
<td>12 (2%)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (1%)</td>
<td>10 (1%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0 (0%)</td>
<td>23 (3%)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (4%)</td>
<td>6 (1%)</td>
</tr>
<tr>
<td><strong>Income at diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;25K</td>
<td>6 (8%)</td>
<td>39 (5%)</td>
</tr>
<tr>
<td>25-49</td>
<td>31 (39%)</td>
<td>121 (17%)</td>
</tr>
<tr>
<td>50-74</td>
<td>15 (19%)</td>
<td>183 (25%)</td>
</tr>
<tr>
<td>75-99</td>
<td>15 (19%)</td>
<td>137 (19%)</td>
</tr>
<tr>
<td>&gt;100</td>
<td>13 (16%)</td>
<td>244 (34%)</td>
</tr>
<tr>
<td><strong>Education at diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS (or less)</td>
<td>15 (19%)</td>
<td>71 (10%)</td>
</tr>
<tr>
<td>Associate’s Degree</td>
<td>15 (19%)</td>
<td>85 (12%)</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>39 (48%)</td>
<td>331 (45%)</td>
</tr>
<tr>
<td>Master’s Degree (or higher)</td>
<td>12 (15%)</td>
<td>248 (35%)</td>
</tr>
<tr>
<td><strong>Marital Status at diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>16 (20%)</td>
<td>148 (20%)</td>
</tr>
<tr>
<td>Married</td>
<td>61 (75%)</td>
<td>544 (74%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>4 (5%)</td>
<td>41 (6%)</td>
</tr>
<tr>
<td>Widow</td>
<td>0 (0%)</td>
<td>1 (0%)</td>
</tr>
<tr>
<td><strong>Number of Children at diagnosis:</strong></td>
<td>2.6 (1.3)</td>
<td>2.2 (1.2)</td>
</tr>
</tbody>
</table>

Data are not statistically significant (p>0.05) unless otherwise noted

Table 1. Respondent Demographics

Odds ratios (Table 2) were calculated to delineate the association between urban and rural demographics and the likelihood of having had genetic testing prior to the study.
In contrast to the literature and our main hypothesis, Table 2 demonstrates that individuals from rural areas were about as likely as women from urban areas to have had genetic testing prior to enrolling in this study (OR=1.04, CI=0.61,1.78). As expected, as annual salary increased for both rural and urban dwelling individuals, so did the

<table>
<thead>
<tr>
<th>Location</th>
<th>Entire Sample n=825</th>
<th>Urban only n=742</th>
<th>Rural only n=83</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural</td>
<td>(reference)</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Urban</td>
<td>1.04 (0.61, 1.78)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Income</th>
<th>Entire Sample</th>
<th>Urban only</th>
<th>Rural only</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;25K</td>
<td>(reference)</td>
<td>(reference)</td>
<td>(reference)</td>
</tr>
<tr>
<td>25-49</td>
<td>2.01 (0.99, 4.11)</td>
<td>1.78 (0.81, 3.86)</td>
<td>17.1 (1.1, 258)</td>
</tr>
<tr>
<td>50-74</td>
<td>2.32 (1.13, 4.80)</td>
<td>1.76 (0.81, 3.78)</td>
<td>79.5 (3.3, 1912)</td>
</tr>
<tr>
<td>75-99</td>
<td>3.53 (1.61, 7.74)</td>
<td>2.79 (1.21, 6.40)</td>
<td>58.7 (2.7, 1290)</td>
</tr>
<tr>
<td>&gt;100</td>
<td>6.43 (2.92, 14.1)</td>
<td>5.23 (2.29, 12.0)</td>
<td>131 (3.8, 4582)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>Entire Sample</th>
<th>Urban only</th>
<th>Rural only</th>
</tr>
</thead>
<tbody>
<tr>
<td>HS (or less)</td>
<td>(reference)</td>
<td>(reference)</td>
<td>(reference)</td>
</tr>
<tr>
<td>Associate’s Degree</td>
<td>0.68 (0.37, 1.26)</td>
<td>0.61 (0.31, 1.21)</td>
<td>1.04 (0.19, 5.70)</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>1.66 (0.97, 2.84)</td>
<td>1.61 (0.90, 2.90)</td>
<td>1.70 (0.39, 7.44)</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>1.72 (0.95, 3.1)</td>
<td>1.70 (0.90, 3.22)</td>
<td>1.97 (0.26, 14.7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Entire Sample</th>
<th>Urban only</th>
<th>Rural only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not married</td>
<td>(reference)</td>
<td>(reference)</td>
<td>(reference)</td>
</tr>
<tr>
<td>Married</td>
<td>0.59 (0.38, 0.92)</td>
<td>0.67 (0.42, 1.06)</td>
<td>0.11 (0.01, 1.06)</td>
</tr>
</tbody>
</table>

Data are represented as odds ratio (95% confidence interval)
Data are not statistically significant (p>0.05) unless otherwise noted

Table 2. Odds Ratio of the Likelihood of Having Genetic Testing
likelihood of having genetic testing. This same trend was observed in both groups regarding education level. The more education participants reported, the more likely they were to have had genetic testing. Again in contrast to expectations, being married was associated with a lower likelihood of having had genetic testing prior to enrollment in the study.

**Survey Results**

Our hypothesis was that geography acted as a barrier keeping the high-risk women in our cohort who were from rural areas from getting genetic testing. The urban-rural split between individuals who, prior to enrolling in this study, did or did not get genetic testing was almost equal in our cohort. Below in is a table (Table 3) displaying results from the survey.

<table>
<thead>
<tr>
<th>Category</th>
<th>No (%)</th>
<th>Yes (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small Urban and below</td>
<td>20 (24%)</td>
<td>63 (76%)</td>
</tr>
<tr>
<td>Large Urban</td>
<td>173 (23%)</td>
<td>569 (77%)</td>
</tr>
</tbody>
</table>

Data are not statistically significant (p>0.05) unless otherwise noted

Table 3. Genetic Testing Status of Participants
We then assessed the three specific aims addressing aspects of rural life that may act as barriers and support the main hypothesis: (1) Women living in rural areas, as defined above, have to travel a longer distance to receive care. (2) Women in rural areas had a greater intensity of relationship with their treating physician. (3) Women in rural areas had less cancer/cancer genetics knowledge.

(1) **Aim**: determine if women from rural areas have increased travel times to receive treatment compared to women living in rural areas.

In order to receive a diagnosis of breast cancer, 45% (n=37) of rural women had to travel 30 minutes or greater with 22% (n=18) having reported greater than one-hour travel time. In comparison, only 18% (n=131) of urban women reported greater than 30 minutes and only 3% (n=23) reported greater than one-hour travel time. The same trends were observed in travel time to receive treatment and/or genetic counseling. Table 4 summarizes these results.
<table>
<thead>
<tr>
<th></th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel Time for Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greater than 30 min</td>
<td>131 (18%)</td>
<td>37 (45%)</td>
</tr>
<tr>
<td>Greater than 1 hour</td>
<td>23 (3%)</td>
<td>18 (22%)</td>
</tr>
<tr>
<td>Travel Time for Treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greater than 30 min</td>
<td>206 (28%)</td>
<td>56 (71%)</td>
</tr>
<tr>
<td>Greater than 1 hour</td>
<td>53 (7%)</td>
<td>33 (42%)</td>
</tr>
<tr>
<td>Travel Time for Genetic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counseling*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greater than 30 min</td>
<td>114 (37%)</td>
<td>21 (75%)</td>
</tr>
<tr>
<td>Greater than 1 hour</td>
<td>36 (12%)</td>
<td>13 (47%)</td>
</tr>
</tbody>
</table>

*308 (42%) of urban women met with a genetic counselor compared to 28 (35%) rural.
Data are not statistically significant (p>0.05) unless otherwise stated.

Table 4. Travel Time Reported to Receive Care

(2) Aim: assess whether women living in rural areas are more likely to report a closer/stronger relationship with their physician than women living in urban areas.

Women in urban areas were somewhat more likely to have a more familiar relationship with their physician. Almost all women in rural areas reported having just met and hardly knew the physician treating them (98%; n=78). This was true for most women in urban areas as well (90%; n=651); however, women in urban areas were more likely than their rural counterparts to have also answered they had known their doctor for around or longer than one year (urban: 7%; n=56 compared to rural: 3%; n=2). Of note, these observations were not statistically significant. In the group of women who reported having had genetic
testing prior to enrollment in the study, the urban group was more likely to report the reason they had genetic testing was because their doctor suggested it (37%, n=213) than the rural group (23%, n=15) and this difference was shown to be statistically significant (p=0.033).

(3) **Aim:** determine if there are differences in the understanding of cancer genetics and its value for women living in urban and rural settings.

In the subset of women who had not had genetic testing prior to enrolling in the parent study (rural: n=20, urban: n=173), we asked why they had not had genetic testing in order to assess whether there was a lack of understanding of genetics and its value held by the participant (Table 5). Women in urban areas were more likely to select answers that revealed a possible lack of understanding.
<table>
<thead>
<tr>
<th>Answer choices provided on survey*</th>
<th>Rural (n=20)</th>
<th>Urban (n=173)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would lose insurance coverage</td>
<td>1 (5%)</td>
<td>15 (9%)</td>
</tr>
<tr>
<td>Genetic testing is not useful</td>
<td>1 (5%)</td>
<td>12 (7%)</td>
</tr>
<tr>
<td>Do not know what genetic testing is</td>
<td>0</td>
<td>7 (4%)</td>
</tr>
<tr>
<td>My cancer risk is not serious enough</td>
<td>0</td>
<td>8 (5%)</td>
</tr>
</tbody>
</table>

*These answer choices represent 4 of 14 answer choices provided on the survey. Multiple selections were permitted. Most participants did not select the above four answer choices. Data are not statistically significant (p>0.05) unless otherwise noted.

Table 5. Responses Selected When Asked Why Participants Had Not Had Genetic Testing

The same approach was used when providing responses participants could select in order to help us understand why they did not meet with a genetic counselor (Table 6).
**Table 6.** Responses Selected When Asked Why Participants Did Not Meet with a Genetic Counselor

<table>
<thead>
<tr>
<th>Answer choices provided on survey*</th>
<th>Rural (n=49)</th>
<th>Urban (n=402)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Didn’t see how this could help</td>
<td>5 (10%)</td>
<td>27 (7%)</td>
</tr>
<tr>
<td>Do not know what a genetic counselor is/does</td>
<td>0</td>
<td>14 (3%)</td>
</tr>
<tr>
<td>My cancer risk is not serious enough</td>
<td>1 (2%)</td>
<td>4 (1%)</td>
</tr>
</tbody>
</table>

*These answer choices represent 4 of 11 answer choices provided on the survey. Multiple selections were permitted. Most participants did not select the above four answer choices. Data are not statistically significant (p>0.05) unless otherwise noted.

As demonstrated above in Tables 5 and 6, responses were mixed in that women from urban areas and rural areas both selected responses indicating a lack of understanding of cancer/cancer genetics and its value.

Finally, one last question directly asked of each participant to assess their own level of understanding of cancer genetics. The following is a table (Table 7) summarizing the responses obtained from our survey.
Table 7. Participant Self-Reported Understanding of Genetics

As shown by Table 7, urban women were about as likely as their rural counterparts to self-report at least moderately understanding the topic (rural: 59; 74%, urban: 555; 76%).

The Health Belief Model

Participants were asked a fixed response question on why they had not had genetic testing prior to entering the study, with each answer choice correlated to one of the four parts of the Health Belief Model.
As shown in Table 8, women from both rural and urban groups usually only selected one response. Women from rural areas were more likely than women from urban areas to primarily cite barriers (rural: mean=0.9, SD=0.45; urban: mean=0.73, SD=0.62) as reasons why they had not had genetic testing prior to enrollment. Women from urban areas tended to be more diverse in their answer choices and were more likely to select susceptibility, severity, and benefit choices than women from rural areas, although the differences were not statistically significant. The two most common answer choices were barriers and were the same for both groups: their doctor never offered testing (rural: n=10, 50%; urban: n=73, 42%) and that they did not having insurance or that it would not cover testing (rural: n=8, 40%; urban: n=42, 24%).
Below (Table 9) are the data reflecting the responses selected by participants who had not had testing at the time of initial study enrollment explaining why they still had not had genetic testing as of the time they took our survey (rural: n=12; 14%, urban n=85; 11%).

<table>
<thead>
<tr>
<th></th>
<th>Rural (n=12)</th>
<th>Urban (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total # of listed reasons selected</strong></td>
<td>1.08 (0.51)</td>
<td>0.92 (0.53)</td>
</tr>
<tr>
<td># of barriers reasons selected</td>
<td>1.0 (0.43)</td>
<td>0.69 (0.55)</td>
</tr>
<tr>
<td># of susceptibility reasons selected</td>
<td>0.0 (0)</td>
<td>0.03 (0.17)</td>
</tr>
<tr>
<td># of severity reasons selected</td>
<td>0.0 (0)</td>
<td>0.09 (0.29)</td>
</tr>
<tr>
<td># of benefit reasons selected</td>
<td>0.08 (0.29)</td>
<td>0.11 (0.31)</td>
</tr>
</tbody>
</table>

Data are represented as mean (standard deviation)
Data are not statistically significant (p>0.05) unless otherwise noted

Table 9. Categorical Responses Selected as Reasons Why Participants Still Did Not Have Genetic Testing at the Time They Took the Survey

Table 8 demonstrates a similar trend to that depicted in Table 9 in that women from rural areas were more likely than women from urban areas to choose barriers (rural: mean=1.0, SD=0.43; urban: mean=0.69, SD=0.55) as reasons to why they still had not had genetic testing. Again we observed that women from urban areas were more likely to be diverse in their responses by selecting choices correlated to susceptibility, severity, and benefits more often than their rural counterparts. The most common answer choice selected by
both rural and urban women was a barrier and was that their physician never offered testing (rural: n=8, 67%; urban: n=33, 38%). The second most common answer choice selected by women from urban areas was a barrier and was that they did not have insurance or it would not cover testing (n=17, 20%).

Table 10 shows the data reflecting the responses selected by participants explaining why they did have genetic testing prior to enrolling in the study (rural: n=63; 76%, urban n=569; 77%).

<table>
<thead>
<tr>
<th></th>
<th>Rural (n=63)</th>
<th>Urban (n=569)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total # of listed reasons selected</td>
<td>2.7 (1.5)</td>
<td>2.9 (1.8)</td>
</tr>
<tr>
<td># of cues to action selected</td>
<td>1.8 (1.1)</td>
<td>2.0 (1.3)</td>
</tr>
<tr>
<td># of susceptibility reasons selected</td>
<td>0.3 (0.5)</td>
<td>0.2 (0.4)</td>
</tr>
<tr>
<td># of severity reasons selected</td>
<td>0.1 (0.2)</td>
<td>0.1 (0.3)</td>
</tr>
<tr>
<td># of benefit reasons selected</td>
<td>0.5 (0.5)</td>
<td>0.6 (0.5)</td>
</tr>
</tbody>
</table>

Data are represented as mean (standard deviation)
Data are not statistically significant (p>0.05) unless otherwise noted.

Table 10. Categorical Responses Selected as Reasons Why Participants Did Have Genetic Testing

Individuals who had genetic testing before enrolling in this study typically selected 2-3 reasons why they made this choice. The three most common answer choices selected by
rural and urban women were cues to action and were the same. They were that their
doctor recommended it (rural: n=40, 63%; urban: n=337, 59%; p=0.51), testing would be
useful in their case (rural: n=34, 54%; urban: n=320, 56%); p=0.73), and their insurance
covered the testing (rural: n=29, 46%; urban: n=273, 48%; p=0.77).

Below (Table 11) is a table demonstrating question and answer choices from the survey
that were aimed to discover the rationale for why some women in our study chose to have
 genetic testing prior to enrollment and why others did not.
Participants with genetic testing | Participants without genetic testing
---|---
Rural | Urban
n=63 (76%) | n=569 (77%)
n=20 (24%) | n=173 (23%)

Cues to Action

- My doctor suggested it*
- My doctor recommended it*
- The emotional burden was minimal
- My insurance covered the testing*

Barriers

- My doctor never offered it*
- My doctor advised against it*
- The emotional burden would be too great
- No insurance/insurance would not cover testing*
- Would lose insurance coverage*
- Testing/result is not useful in my case

Testing/result would be extremely useful in my case (ex. Surgery, family planning, etc.)

- I just wanted to know*

Religious reasons

- Did not want to know*
- Do not know what it is*

Cancer risk was very serious

- Religious reasons
- My cancer risk was not serious enough

I had the time*

- Didn’t have time*

My doctor’s office is not far from me*

- My doctor’s office is too far away*
- I did have testing since then

Other: __________

Data are not statistically significant (p>0.05) unless otherwise noted.

* denotes answer choices that correlated with barriers

Table 11. Cues to Action and Barriers Offered as Answer Selections on Survey

Answer choices were written in an attempt to address the three barriers we aimed to assess in our cohort of women. Other answer choices assessed different parts of the Health Belief Model (severity, susceptibility, and benefits).
Chapter 4: Discussion

We were unable to reach statistical significance because of the small sample size for rural women. Consequently, our results were unable to be cross-referenced because the small number of rural participants could make the data appear misleading. However, we did notice a number of interesting trends.

Participants were mostly White, non-Hispanic married women with a Bachelor’s degree. It was not surprising to see that having more education and a higher annual salary was associated with a higher likelihood of having had genetic testing in both groups. However, it is unclear why being married is correlated with a decreased uptake in genetic testing. A large majority of our participants were White thereby we cannot comment on trends observed between different races due to the underrepresentation of other ethnic groups. Again, these results should be considered in the context that we did not have enough participants from rural areas to make our data statistically significant.

Considering our cohort consists of women who were diagnosed with breast cancer at or before age 40, everyone in our cohort should have been at least offered genetic counseling and/or genetic testing. Our hypothesis was that fewer women from rural areas would report having genetic testing as compared to women from urban areas.
Surprisingly, we did not find a significant difference. One reason for this may be that by combining the smallest three groups (small urban, large rural, small rural) we may have masked some differences in specific rural subgroups. As mentioned earlier, Hall discusses that making a dichotomous comparison in urban versus rural studies leads to the loss of trends seen in the smaller groups (Hall et al., 2016).

We discovered that women residing in rural areas do have a longer distance to travel in order to receive care. Whether it was to receive a diagnosis, begin care for their cancer, or meet with a genetic counselor, women in rural areas reported a greater amount of time spent traveling than women in urban areas. While this seems like an obvious statement, this was not necessarily a given as women from rural areas could have elected to receive care near their home, if it was available.

One of our aims was to see if more women in rural areas reported a stronger relationship with their treating physician, which may indicate a heavier reliance on this physician. Heavy reliance coupled with under referral by rural physicians may explain why these women were not getting genetic testing. Our data actually hints at less familiarity between doctors and patients in a rural setting. One reason to explain this may be that women in rural areas reported having to travel further to receive care meaning they would see a brand new doctor whom they had likely never met before to manage their oncologic care. Considering this, it is not shocking to see that women from rural areas then reported unfamiliarity with their physician compared to urban women who were reportedly closer
to their physician had a stronger relationship with them. Interestingly, our data show that urban women who did have genetic testing prior to enrollment were more likely than rural women to indicate it was because their doctor had suggested it in the first place. This could suggest either that women in urban areas have a stronger relationship with their physician, or that urban physicians are more likely to identify and refer high risk women.

To address Specific Aim 3, we designed answer selections on our survey that would reveal a lack of understanding of genetics and its value. Results were inconclusive as women from both urban and rural groups selected answers that could indicate lack of understanding. One challenge in interpreting this finding is that very few women selected any of these answers. Interestingly, women from both groups were equally as likely to self-report at least a moderate understanding of genetics and its value.

Using the Health Belief Model as a framework to understand the rationale for choices these women made regarding genetic testing, we noted interesting trends. Women from rural areas who did not have genetic testing until after enrollment in the study and those who still had not had genetic testing when completing this survey were both more likely than women from urban areas to cite a barrier as a reason for this choice. Given that we listed answer choices correlated to susceptibility, severity, benefits, and barriers from which to choose and the barriers listed were all impacts of geography, this supports our hypothesis that geography is a barrier for rural women, however our data was statistically
insignificant. Additionally, selections from the “barriers” category were most often chosen out of all four categories of the Health Belief Model by both those who did have testing and those who did not have testing. Answers that were barriers for women who did not have testing acted as cues to action for those who did. We wrote the answer choices (Table 11) to be equal but opposite for the two groups of women with the option of writing in an answer that was not listed.

Our results indicate that for many participants who did not have genetic testing the potential barriers we offered as answer choices did in fact act as barriers and kept them from getting testing. Table 8 and Table 9 demonstrate that women from rural areas who did not have testing most often chose barriers (the other three parts of the Health Belief Model were selected but in a much smaller proportion) as did their urban counterparts with the most common selection for both groups being that their doctor never offered testing. However, women from rural areas almost exclusively picked barriers while women from urban areas tended to select other answers relating to the other three parts of the health belief model. Additionally, and to the opposite point, for many of our participants who did have genetic testing cited cues to action (phrased as the opposing counterpart to barrier answer choices) as motivation and justification for getting genetic testing (Table 10).
Chapter 5: Limitations

There were several limitations to this study with the main limitation being the small number of rural participants which precluded statistically significant comparisons between groups. Only 10% of respondents reported smaller than “large urban” residence, compared to the 20% expected based on data provided by the U.S. Department of Agriculture Economic Research Service. This may indicate an ascertainment bias due to the fact that the majority of subjects were recruited from the Army of Women website and those in rural areas without access to the internet or an email address would not have been able to join. In 2014, 39% of people in rural areas did not have internet access as compared to only 4% in urban areas (Kruger and Gilroy, 2014). The discrepancy in the earlier years of study enrollment was likely even greater. Additional participants were recruited at the annual Young Survivor Coalition conference which would restrict those who could not travel to the annual summit from enrolling in this study. Due to the limited number of responses received from women in rural areas, we combined responses from small urban, large rural, and small rural into one group to compare against large urban. This combination may have hidden some trends that might have been observed within each of the smaller groups that were combined.
Underrepresentation of individuals from rural areas made most of our results statistically insignificant and allowed us to only comment on interesting trends. This is especially true when analyzing the demographic trends regarding prior genetic testing. The number of rural participants was small to begin with, and when that number was divided into two groups of those who did and those who did not report having had genetic testing prior to enrolling in this study, the sample sizes became extremely small. While the demographic trends noted are interesting, they should be viewed with caution and not considered representative of larger populations.

Direction for Future Research

We believe our study highlights the need to focus future studies on recruitment strategies aimed towards individuals from rural areas. We suggest considering the following:

1) Involve and incentivize rural physicians to participate in study recruitment and provide a group webinar to ask questions directly to study personnel.

2) Engage genetic counselors who participate in telephone counseling to identify patients who might qualify for rural studies.

Additionally, when assessing patient knowledge, we recommend using a validated knowledge-assessment tool.
Chapter 6: Conclusion

It is well-documented that individuals in rural areas have poorer access to proper health care and specialty services. This study was aimed to prove that this lack of access to specialized care can be extended to genetic testing. We expected to see that women from rural areas had a decreased uptake in genetic testing due to a longer distance to travel in order to receive care, a stronger relationship with the physician, and a general lack of understanding of cancer genetics and its value. Unfortunately, there were not enough participants from rural areas to make our study results significant. Although we began by comparing four different groups categorized by population size, we were limited by the small number of completed surveys by women from small urban, large rural, and small rural areas. As a result, we were not able to assess data trends that may have been unique to the smaller population groups. The Health Belief Model was useful as we intended it to be when it came to interpreting why women made the choices they did regarding genetic testing. It is important to understand why many high-risk women are not getting genetic testing for cancer susceptibility genes such as BRCA1 and BRCA2. This study emphasized the importance of understanding this from a rural perspective and the need to increase participation by individuals in rural areas to achieve this.
References


LeMasters, T., Madhavan, S., Atkins, E., Vyas, A., Remick, S., & Vona-Davis, L. (2014). Don't know; and accuracy of breast cancer risk perceptions among Appalachian women attending a mobile mammography program.


Appendix A: Sample Survey
# Assessing Geography as a Barrier in Choosing to Undergo Genetic Testing in a Cohort of Young Women with Breast Cancer

Please select the most appropriate answer for each question.

Note: some questions may allow more than one answer selection.

## Demographic Information

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Race/Ethnicity</td>
</tr>
<tr>
<td></td>
<td>□ Caucasian/White</td>
</tr>
<tr>
<td></td>
<td>□ African American</td>
</tr>
<tr>
<td></td>
<td>□ Asian</td>
</tr>
<tr>
<td></td>
<td>□ Hispanic</td>
</tr>
<tr>
<td></td>
<td>□ Other</td>
</tr>
<tr>
<td>1a</td>
<td>Other</td>
</tr>
<tr>
<td>2</td>
<td>At the time of diagnosis, what was your estimated yearly household income?</td>
</tr>
<tr>
<td></td>
<td>□ Under $25,000</td>
</tr>
<tr>
<td></td>
<td>□ $25,000-$49,999</td>
</tr>
<tr>
<td></td>
<td>□ $50,000-$74,999</td>
</tr>
<tr>
<td></td>
<td>□ $75,000-$99,999</td>
</tr>
<tr>
<td></td>
<td>□ Over $100,000</td>
</tr>
<tr>
<td>3</td>
<td>At the time of diagnosis, what was your highest education level?</td>
</tr>
<tr>
<td></td>
<td>□ High School Diploma or less</td>
</tr>
<tr>
<td></td>
<td>□ Associate's Degree</td>
</tr>
<tr>
<td></td>
<td>□ Bachelor's Degree</td>
</tr>
<tr>
<td></td>
<td>□ Master's Degree or higher</td>
</tr>
<tr>
<td>4</td>
<td>At the time of diagnosis, how many children did you have?</td>
</tr>
<tr>
<td></td>
<td>□ None</td>
</tr>
<tr>
<td></td>
<td>□ 1</td>
</tr>
<tr>
<td></td>
<td>□ 2</td>
</tr>
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<td></td>
<td>□ 3</td>
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<td>□ 4</td>
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<td>□ 5</td>
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<td>□ 7</td>
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<td>□ 8</td>
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<tr>
<td></td>
<td>□ 9</td>
</tr>
<tr>
<td></td>
<td>□ 10</td>
</tr>
<tr>
<td>5</td>
<td>At the time of diagnosis, what was your marital status?</td>
</tr>
<tr>
<td></td>
<td>□ Single</td>
</tr>
<tr>
<td></td>
<td>□ Married</td>
</tr>
<tr>
<td></td>
<td>□ Divorced</td>
</tr>
<tr>
<td></td>
<td>□ Widow</td>
</tr>
<tr>
<td>6</td>
<td>What is your CURRENT estimated yearly household income?</td>
</tr>
<tr>
<td></td>
<td>□ Under $25,000</td>
</tr>
<tr>
<td></td>
<td>□ $25,000-$49,999</td>
</tr>
<tr>
<td></td>
<td>□ $50,000-$74,999</td>
</tr>
<tr>
<td></td>
<td>□ $75,000-$99,999</td>
</tr>
<tr>
<td></td>
<td>□ Over $100,000</td>
</tr>
</tbody>
</table>
7. What is CURRENTLY your highest level of education?
   - High School Diploma or less
   - Associate’s Degree
   - Bachelor’s Degree
   - Master’s Degree or higher

8. How many children do you CURRENTLY have?
   - None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10

9. What is your CURRENT marital status?
   - Single
   - Married
   - Divorced
   - Widow
**Motivation**

10. Why did you initially choose to enroll in The Young Women’s Breast Cancer Research Program? (check all that apply)
- Help the medical community learn more about breast cancer
- Potentially lower my own risk of getting another cancer
- Learn more information about breast cancer
- It would benefit my family
- It was convenient for me to enroll
- I had no reason not to enroll

11. Did you have genetic testing done before enrolling in The Young Women’s Breast Cancer Research Program?
- Yes
- No

11a. Why didn’t you have genetic testing prior to or at the time of your enrollment in this study? (select all that apply)
- My doctor never offered it
- My doctor advised against it
- The emotional burden would be too great
- No insurance/Insurance would not cover testing
- Would lose insurance coverage
- Testing/result is not useful in my case
- Did not want to know
- Do not know what it is
- Religious reasons
- My cancer risk is/was not serious enough
- Did not have time
- My doctor’s office is too far away
- I had an appointment to get genetic testing at the time I enrolled, but had not yet been tested
- Other

---

**Other reason**

---

11b. Have you had clinical genetic testing since the time of enrollment? Why or why not? (select all that apply)
- Yes, I had an appointment to get it done scheduled after I enrolled
- No, it was never offered
- No, my doctor advised against it
- No, the emotional burden would be too great
- No, I had no insurance/my insurance would not cover the cost of testing
- No, I would lose my insurance
- No, testing/result is not useful in my case
- No, I do not know what it is
- No, religious reasons
- No, my cancer risk was not serious enough
- No, I did not have time
- No, my doctor’s office is too far away
- Other

---

**Other reason**

---
11a Why did you have genetic testing prior to your enrolment into this study? (select all that apply)

☐ My doctor suggested it
☐ My doctor recommended it
☐ The emotional burden was minimal
☐ My insurance covered the testing
☐ Testing/result would be extremely useful in my case (surgery, family planning, etc.)
☐ I just wanted to know
☐ Religious reasons
☐ My cancer risk was very serious
☐ I had the time to get it done
☐ My doctor's office is not far from me
☐ Other

Other reason

_________________________________________
Your Diagnosis

12 In what year were you diagnosed with breast cancer?

13 In what CITY were you diagnosed?

13a In what STATE were you diagnosed?

13b In what COUNTY were you diagnosed?

13b Why did you go to this location for your diagnosis?
   (select all that apply)
   □ This is my primary care physician
   □ This place specializes in identifying/treating cancer
   □ It was close to my home

13c How far is this from your home?
   □ 15 to 30 minutes travel time
   □ 30 minutes to 1 hour travel time
   □ 1 to 2 hours travel time
   □ Over 2 hours travel time

14 At the time you were diagnosed, in what CITY did you live?

14a At the time you were diagnosed, in what STATE did you live?

14b At the time you were diagnosed, in what COUNTY did you live?

15 In what CITY were you treated?

15a In what STATE were you treated?

15b In what COUNTY were you treated?

16 Why did you choose this location for your treatment?
   (select all that apply)
   □ This is my primary care physician
   □ This place specializes in identifying/treating cancer
   □ It was close to my home

17 While actively undergoing treatment, in what CITY did you live?

17a While actively undergoing treatment, in what STATE did you live?

17b While actively undergoing treatment, in what COUNTY did you live?

18 How far was your center for treatment from your home?
   □ 15 to 30 minutes travel time
   □ 30 minutes to 1 hour travel time
   □ 1 to 2 hours travel time
   □ Over 2 hours travel time
## Cancer Genetics

19. Was cancer genetics and/or genetic testing discussed at the time of diagnosis or shortly after?  
   - Yes
   - No
   - I don’t know

20. At the time of your diagnosis, were you referred to a genetic counselor?  
   - Yes
   - No
   - I don’t know

21. At the time of your diagnosis, did you meet with a genetic counselor?  
   - Yes
   - No
   - I don’t know

21a. How long was the travel time to see the genetic counselor?  
   - 15 to 30 minutes travel time
   - 30 minutes to 1 hour travel time
   - 1 to 2 hours travel time
   - Over 2 hours travel time

21a. Why didn’t you meet with a genetic counselor?  
   - I was not offered a chance to meet with one
   - My doctor said I didn’t need to meet with one
   - It was too far away
   - I didn’t see how it could help me
   - The emotional burden was too great
   - Insurance would not cover it
   - I did not want to know what they had to tell me
   - I do not know what a genetic counselor is/does
   - Religious reasons
   - My cancer risk isn’t serious enough
   - I did not have time

22. At the time of your diagnosis, were you offered genetic testing?  
   - Yes
   - No
   - I don’t know

23. Have you been offered genetic testing since then?  
   - Yes
   - No
   - I don’t know

23a. How many times were you offered genetic testing?  
   - Once, at diagnosis
   - Once, months after diagnosis
   - Once, years after diagnosis
   - More than once

24. What kind of doctor was PRIMARILY responsible for your breast cancer care?  
   - Oncologist
   - Breast surgeon
   - Gynecologist
   - Primary care physician (PCP)
   - Other

---

**Other**

25. Why did you choose this physician to manage your treatment? (select all that apply)  
   - This is my primary care physician (PCP)
   - This physician specializes in identifying/treating cancer
   - This physician was located in a practice close to my home
   - My PCP referred me to this physician
   - Other

---

Other
26. At the time of your diagnosis, how long had you seen this doctor for your care?
   - This was when I first met him/her
   - Less than 1 year
   - 1-5 years
   - 6 years or more

27. At the time of your diagnosis, how would you describe your relationship with this doctor?
   - We hardly knew each other
   - We had gotten to know each other over the years
   - We talked frequently, not always about my health

28. Has anyone else in your family been diagnosed with breast cancer?
   - Yes
   - No
   - I don't know

29. Has anyone in your family had genetic testing?
   - Yes
   - No
   - I don't know

30. Did you ever discuss your family history of cancer with your doctor?
   - Yes
   - No
   - I don't know

30a. Who started the conversation about your family history?
   - Me, I brought it up
   - My doctor asked me about it

31. Did anyone on your father's side of the family have breast or ovarian cancer?
   - Yes
   - No
   - I don't know

32. How would you describe your knowledge of inherited aspects of cancer?
   - Minimal
   - I am moderately well-versed
   - I am an expert