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UNDERSTANDING DELAYS IN DIAGNOSIS AND TREATMENT OF BREAST CANCER
IN APPALACHIA

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ABSTRACT

Previous research has revealed that 10.4% of breast cancer deaths in white women in the United States occurred in Appalachia (Yao et. al, 2012). Rates of unstaged breast cancer, cancer for which there is not enough medical evidence to classify the disease progression (National Cancer Institute, 2013), are higher in the rural regions compared to the urban regions of Appalachia (Lengerich et. al, 2005). In the United States, the rates of adherence to adjuvant hormone therapy, a standard therapy prescribed for estrogen receptor positive breast cancer cases, are between 70-80%, while the rate of discontinuation of this treatment is 20%. However, in Appalachia, there is a 69% adherence rate and a 30% discontinuation rate to the same adjuvant hormone therapy.

A disparity in breast cancer diagnosis and care exists not only between Appalachia and the rest of the United States but also between urban and rural areas of Appalachia (Lengerich et. al, 2005). While biological or environmental differences may contribute to the increased rates in rural Appalachia, there may be psycho-social-cultural barriers that prevent women with breast cancer in Appalachia from receiving equitable diagnosis or care for their cancer. Women in the United States are benefiting from advances in medical treatment for breast cancer (Elkin & Hudis, 2015); however, women in rural Appalachia still seem to suffer from the burden of this disease (Lengerich et. al, 2005; Yao et. al, 2012). They are more likely to be diagnosed with unstaged cancer, more likely to discontinue using critical therapies, and more likely to die of breast cancer than their urban counterparts. To develop effective interventions to increase optimal care in Appalachia, we need to understand why some women receive diagnosis and care for their breast cancer, while some do not.

This thesis explores a facet of this complex issue by considering: of women in Appalachia with breast cancer who did receive care, what positively influenced their pursuit of care and treatment? Using the theory of reasoned action (Ajzen & Fishbein, 1980) as a framework, I sought to understand the experiences of women in Appalachia who pursued care for their breast cancer, and how these experiences influenced their entrance and continuation of care.

The results of this study revealed consistencies and inconsistencies with the theory of reasoned action, as well as the need for consideration of factors not address by the theory. These findings have practical implications for how cancer centers support and educate patients, and how physicians present treatment plans.

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Chapter 1

An Introduction to Cancer and the Theory of Reasoned Action

Despite multiple decades of funding and research, cancer remains a significant public health issue. In 2012 (the last year for which data is available), fourteen million people around the world were diagnosed with cancer (CDC, 2015). Eight million people die of cancer each year (WHO Globocan, 2012). In the United States alone, an estimated 1.69 million new cases will occur in 2016, while nearly six hundred thousand people will die of the disease (American Cancer Society, 2016). Closely following heart disease, cancer is the second most common cause of death in the US (CDC, 2016). According to the Agency for Healthcare Research and Quality, the direct medical costs for cancer in the US in 2011 were estimated at \$88.7 billion (Soni, 2011).

Chapter 1.1: Breast Cancer and Current Treatments

“Cancer” is the term for a group of diseases characterized by uncontrolled cell division and spread. Mutations in the cellular DNA- the code that controls all functions of a cell- disrupt the normal mechanisms that maintain growth and homeostasis (Kumar, Abbas & Aster, 2014). A number of extrinsic and intrinsic factors are responsible for these mutations; tobacco use, infectious disease and diet are outside influences, while inherited and random mutations, hormones and immune conditions also play a role in overriding the cellular growth controls

(Kumar, Abbas & Aster, 2014). Cells with these mutations divide, forming a mass of cells called a “tumor”.

The term “breast cancer” refers to a cancer arising in the breast, which can arise from epithelial linings (called *carcinomas*) or another tissue such as supportive or connective tissues (called *sarcomas*) (Kumar, Abbas & Aster, 2014). The vast majority (greater than 95%) of malignant cancers originating in the breast are breast carcinomas that arise from the ductal secretory tissue (Kumar, Abbas & Aster, 2014).

There are two types of breast cancer carcinoma- ductal carcinoma *in situ* (DCIS) and invasive ductal carcinoma- that differ in prognosis and treatment. Cancer cells of DCIS have not yet infiltrated tissues proximal to the ducts, so DCIS is considered a pre-invasive breast cancer. Because there is a chance these cells may become invasive, DCIS is often treated with surgery to remove the cancerous mass. Radiation therapy and hormone therapy can be used in combination with surgery depending on their appropriateness for the patient’s DCIS case. The more aggressive type of breast cancer is invasive ductal carcinoma, in which the cells of the tumor have invaded nearby tissues. These cells can also break off and migrate through the blood or lymphatic systems, often first to lymph nodes in the underarm and then on to other parts of the body (Kumar, Abbas & Aster, 2014). Cases of invasive breast cancer can be treated through surgical excision of the primary lump, radiation and chemotherapy, often in addition to hormone therapy. (Kumar, Abbas & Aster, 2014). Radiation therapy uses high-energy waves of various types targeted at a cancerous mass to destroy the cancerous cells (Zellers, George & Myers, 2011). Conversely, chemotherapy is any medicine that diffuses throughout the body (as opposed to the targeted action of radiation) that damages or destroys cancerous cells. There are numerous types and classes of chemotherapy, and they can often be used in combination or with radiation

(Briest & Stearns, 2011). Like chemotherapy, hormone therapy is systemic, but it is used to prevent breast cancer from reoccurring. If estrogen receptors are present on the surface of breast cancer cells, hormone therapy blocks these receptors and prevents estrogen from triggering growth and division of the cancer cells (Tamoxifen, 2013). Treatment is often based on the cellular and genetic markers of tumor cells, the stage and the grade.

Chapter 1.2: Breast Cancer Staging

When diagnosed, the particular cancer is classified by its respective size (called the *stage*) and its histologic features as a measure of aggressiveness (called the *grade*) (Kumar, Abbas & Aster, 2014). This system of classification denotes how far the cancer has spread throughout the body and how likely it is to spread further. Breast cancer is further classified by the presence of certain receptors, like the estrogen receptor, on the surface of the cancer cells; this information has important implications for optimal treatment and prognosis (Kumar, Abbas & Aster, 2014).

Chapter 1.3: Cancer in Appalachia

The rate of unstaged and distantly spread breast cancer in rural Appalachia is higher than the national rate (Lengerich et. al, 2005). Women in Northern Appalachia (including most of Pennsylvania) have the highest rates of breast cancer compared to the other areas of Appalachia (Wingo et. al, 2008). Between 2003 and 2007, the rate of deaths due to breast cancer in Appalachian counties was significantly higher than that in counties outside of Appalachia (Yao et. al, 2012). These findings indicate that there is a population of Northern Appalachian women suffering and dying from late-stage or unstaged cancer because early diagnosis and treatment is

not made. It suggests the existence of environmental, biological and/or psycho- social- cultural factors contributing to these increased rates of cancer, and potentially creating a barrier to seeking or receiving care in Appalachia.

This thesis explores the psycho- social- cultural predictors of seeking care. A relevant theory for understanding such predictors is the theory of reasoned action (TRA; Ajzen & Fishbein, 1980). Thousands of studies have empirically validated the theory of reasoned action as a model for predicting behaviors (Sheppard et. al, 1988). The rationale of the theory is explained next.

Chapter 1.4: The Theory of Reasoned Action

According to the theory of reasoned action, the best predictor of a person's behavior is their intention to do it. An intention is defined as the cognition to work towards a goal or outcome (Encyclopedia Britannica, 2016). In this study, the primary intention investigated was the patient's plan to receive (or not receive) care in the future for their breast cancer (Madden, Ellen, & Ajzen, 1992).

The theory states that intentions, in turn, are determined by the person's attitudes, subjective norms, and perceived behavioral control. Attitudes are beliefs about the outcomes of the behavior and perceptions of those outcomes. In the context of this study, attitudes were represented in part by women's beliefs in severity (the likelihood cancer will lead to death) and their susceptibility (their chance of developing cancer based on genetics) (Montano & Taplin, 1991; Witte, 1992). Subjective norms are a person's evaluation of social pressure to behave in a certain way. Routine mammograms were one example of a subjective norm in this population;

many women believed in receiving mammograms regularly (Doll & Ajzen, 1992; Montano & Taplin, 1991). Finally, perceived behavioral control is a person's ability to control the behavior (Doll & Ajzen, 1992; Bandura, 1997); in this case, the patient's ability to choose therapy was a representation of perceived control. As a precursor to TRA, previous experience with the behavior (for example, witnessing a loved one's care for cancer) was also investigated for its effects on the current behaviors of women (Doll & Ajzen, 1992).

Chapter 1.5: Exploring Emotions

While the theory of reasoned action is a strong model of behavior, it focuses exclusively on cognitions. Emotions are likely to be involved in the experiences of diagnosis and treatment of cancer, both on the part of patients and their friends and family. Previous research has also argued that cognition and emotions are interrelated and influential of the other (Storebeck & Clore, 2007). For these reasons, emotions were also explored to understand their effect on behavior.

Chapter 1.6: Research Questions

One general question informed this thesis: what attitudes, norms and behavioral control do women in northern Appalachia report about their pursuit of care for their breast cancer, and their intentions to pursue care in the future?

More specifically, I asked a series of questions related to the theory of reasoned action, emotions and the experiences women had in pursuing care for breast cancer.

RQ 1: What attitudes do patients have about their prompt to care and diagnosis?

RQ 2: What emotions do women experience during their prompt to care and diagnosis?

RQ 2.1: Are patients' feelings related to patients' prompt?

RQ 3: How much control do patients feel they have over their care and treatment?

RQ 3.1: Are the supporters' feelings about the patient's cancer diagnosis and their opinions about where the patient should receive care related?

RQ 4: What subjective norms do patients experience with regard to diagnosis and treatment?

Chapter 2

Methods

Chapter 2.1: Participants

Women ($N = 25$) recruited from three cancer centers in Pennsylvania Appalachia participated in this study. The participants ($M = 62.24$ years, $SD = 9.26$ years, $Minimum = 46$ years, $Maximum = 78$ years) were from seven counties in Pennsylvania (Tioga, Lycoming, Clinton, Sullivan, Union, Cambria and Crawford). The lowest level of education reported was 10th grade, and the highest was a graduate degree. Twenty-two participants reported having some form of health care coverage.

Chapter 2.2: Procedures

The protocol (ID: STUDY00000906) was approved by the Pennsylvania State University's Institutional Review Board before recruitment began. Five cancer centers associated with the Northern Appalachia Cancer Network (NACN) were initially approached to recruit participants (the NACN is a network of clinical and community partners at the Penn State College of Medicine, aimed at improving quality of life and cancer survival in Pennsylvania and New York Appalachia). These centers included Mount Nittany Cancer Center, Susquehanna Health Cancer Center, the Yolanda G. Barco Oncology Institute at the Meadville Medical Center, the Herbert L. Hanna Center for Oncology Care at the Indiana Regional Medical Center,

and Allegheny Health System's Forbes Regional Hospital Breast Care Center. Ultimately, two centers, Mount Nittany Cancer Center and the Forbes Breast Care Center, were unable to participate.

At the three remaining centers, staff identified patients fitting the eligibility criteria by reviewing the patient's medical records. Eligibility criteria included a) receiving care for breast cancer at the center, b) being diagnosed with Stage 1-3 estrogen receptor- positive breast cancer within the past 12 months, c) aged 40 and older, d) being menopausal or post-menopausal, and e) having filled at least one prescription for the hormone therapy drugs tamoxifen or an aromatase inhibitor (including anastrozole, letrozole or exemestane) within the previous 12 months of the interview. Additionally, each participant had to reside in a Pennsylvania county classified as part of Appalachia (Counties in Appalachia, 2016). Finally, the participant had to be able to speak, read and communicate well in English.

The study investigators provided a one- page description of cancer center hospitals, a memorandum of agreement, a copy of the IRB approval letter and recruitment materials for patients (which included a flyer, a one-page description of the study, a summary explanation of research and the interview questions). Centers were also provided with a schedule of available times for telephone calls and the \$30 gift cards as compensation for the participant's time.

Eligible patients were then provided a written summary explanation of research as well as a copy of the interview questions. After the patient agreed to participate, a cancer center staff member scheduled them for a 60- minute interview appointment and provided her with a phone number to call to complete the interview. If scheduled for an interview, the subject was also provided a \$30 Walmart gift card at the time of scheduling to compensate them for their time.

Upon scheduling the interview, the cancer center staff member recorded the name of the patient and the patient's Subject Identification Code (SIC- based on their respective cancer facility and a number) on the List of Patients and Study Identification Codes. This information was stored in a HIPAA- secure location as a reference for no- show interviews or other issues. The cancer center staff member then notified the study coordinator, Marcy Bencivenga, of the scheduled interview and only the SIC, who then communicated the information to me depending on who was available to perform the interview. The master list of patient names and Study Identification Codes is stored on the password- protected computer in the locked office of the Principal Investigator of the larger study, Dr. Eugene Lengerich of the Pennsylvania State University.

Chapter 2.3: Interviews

Phone interviews were conducted from December 2014 to March 2015 by two Collaborative Institutional Training Initiative (CITI) - certified investigators: Lydia Glick (myself) and Marcy Bencivenga. A total of 25 women were interviewed; one additional woman called but declined to participate and one missed the scheduled call, but was later interviewed. Each interview was recorded on an Olympia recorder. Along with the master SIC list, the recordings are kept in a locked desk and a password- protected computer belonging to the principle investigator.

Participants and the interviewer called the 800- conference number at the scheduled time. The interviewer proceeded to ask if it remained a good time to perform the survey. If it was, the interviewers asked for consent to continue with the questions. If given, the interviewers then

began recording the interview and documented the start time. Participants were able provide their first name (if desired) and to opt out of any questions they did not wish to answer. After finishing the interview, the recording device was turned off and the time finished was documented.

Chapter 2.4: Interview Protocol

The survey consisted of 30 questions, 16 of which included open-ended probes to further the conversation. Initial questions covered a number of topics including exclusion criteria and demographics. Next, four topics were investigated: diagnosis and treatment, healthcare provider communication, pharmacy experience and barriers to treatment (see Appendix A; questions pertinent to this thesis included). The average conversation length was $M = 32:25$ minutes ($SD = 10:08$); the shortest conversation lasted 14:05 minutes while the longest was 57:17 minutes.

Chapter 2.5: Analysis Plan

Transcripts were created for each interview and question numbers 1-20 were analyzed for this particular study. All 25 interviews were used to provide data- one interview was from the Indiana Regional Medical Center, fourteen interviews from Susquehanna Health and ten from the Meadville Medical Center. The content of the answers were coded in alignment with the theory of reasoned action (Ajzen & Fishbein, 1980), including the attitudes, subjective norms and perceived behavioral control of the participants throughout their experiences with breast cancer diagnosis and care. The frequency of content was compared by demographics or experience using Chi-square tests.

Chapter 3

Results

Chapter 3.1: Prompt to Care

The first prompt pertained to how the participants initially entered the medical system to receive care for breast cancer. Of the twenty-five women who responded, 18 (72%) received a mammogram, 6 (24%) felt a lump in their breast and 1 (4%) received a PET (Positron Emission Tomography)- CT scan, all of which indicated the need for further testing and diagnosis.

To understand the feelings associated with these prompts to care, the interview included questions about emotions. Seventeen of the twenty-five (72%) participants interviewed reported feeling emotions when they were prompted to receive care. Eight (47%) reported wanting care, six (35%) were scared and four (24%) expressed feelings of positivity, either towards the eventual outcome or overall. Participant SH11 stated: "It was another bump in the road. I have a very positive attitude." Four (24%) participants reported not being surprised by the results of the prompt to care, as exemplified by participant SH4, "There was a part of me that somewhat expected it at a point in my life just because of my family history." On the other hand, two (12%) of the seventeen who talked about emotions reported being surprised by the results of their prompt to care. Only one of twelve (8%) respondents who discussed their attitudes about care stated specifically that she did not want to receive care for her breast cancer.

To explore the relationship between the participants' prompts to care and their emotional responses to those prompts to care, two chi-square tests were conducted. The first chi-square

compared whether the participant received a mammogram (as their prompt) and whether they experienced fear at the time of their prompt to care. The $X^2(1, N = 25) = 0.11, p = 0.74$. The second chi-square test compared whether the participant felt an abnormal lump (as their prompt) and whether they experienced fear at the time of their prompt. The $X^2(1, N = 25) = 0.38, p = 0.54$. The results of both chi-square tests showed that the type of prompt to care (both mammography and lump prompts) was unrelated to their feelings of fear during these prompts to care.

Chapter 3.2: Diagnosis

A total of 19 participants reported the length of time from detection (aka their prompt to care) to diagnosis. The average interval was 21 days ($M = 21.05$ days, $SD = 20.99$ days); the shortest interval was one day and the longest was 90 days. When asked if they felt their healthcare providers were supportive during this time, 23 respondents (100%) reported that they felt their providers were supportive.

Emotions with regard to the diagnosis were also investigated. Twenty- one of twenty-five participants reported that they experienced emotions during the diagnostic testing and discussion with their physician. Eight (38%) reported that they felt optimistic, seven (33%) related that they were simply “O.K with it”, five (24%) felt anxious and four (19%) felt surprised. Interestingly, two (10%) participants stated that they felt no emotion with regards to the diagnosis, and none of the participants who reported emotions said that they felt resentful about the diagnosis. Participant MMC3 exemplified the reports of no emotion when she said, “I really didn't think too much about it... [I'm] not a dweller.... [I] just wanted to get it taken care

of.” Both participants who said they felt no emotion about their diagnosis stated that they did not dwell on it, and instead simply saw this as another task that had to be accomplished.

Chapter 3.3: Friends and Family Reactions

The next topic of discussion was the reactions of the friends and family of the participant to their diagnosis of breast cancer. Twelve of twenty- five (48%) participants reported that their friends and family (denoted as “supporters”) encouraged them to seek out a diagnosis, while none reported that they were discouraged from seeking out a diagnosis. Sixteen of twenty- five (64%) respondents said they perceived their family and friends as supportive.

When asked if their supporters provided an opinion about which cancer facility to receive care at, eight of twenty- five (32%) said they had, while seventeen (68%) said they had not or left it up to the patient. For example, participant SH13 cited her supporters’ knowledge that she would make the decision herself: “No, ‘cause they know me, and I just go ahead and take care of that [picking a treatment facility] myself.” To determine the role supporters’ emotions play in the experiences of patients, participants were asked about the emotions they perceived their friends and family experienced with regards to the diagnosis. Out of all participants, fifteen (60%) reported that their supporters experienced some sort of emotion with regards to seeking and receiving the diagnosis. Eight (53%) of the fifteen said their supporters were upset, seven (47%) said afraid and two (13%) said surprised.

It is possible that their supporters’ feelings and opinions on care facility were related. To explore this possibility, a chi-square test was conducted comparing whether they were upset or not, and whether they had an opinion or not. The $X^2(1, N = 25) = 2.06, p = 0.15$. A chi-square

test was also conducted comparing whether they were afraid or not, and whether they had an opinion on care facility or not. The $X^2(1, N = 25) = 0.05, p = 0.82$. The results of both tests showed that the supporters' state of emotional distress was unrelated to whether they expressed an opinion about the facility for treatment.

Chapter 3.4: Treatment

Treatment for breast cancer is relatively standardized; for instance, the National Comprehensive Cancer Network routinely publishes ubiquitously- used, data- driven guidelines for health care professionals on the optimal ways to treat cases of cancer (NCCN, 2015). However, given the number of potential treatments, I felt it was important to investigate how the feelings of control patients have over their treatments influence their experiences with cancer care.

Twenty- four (96%) of the respondents received surgery, twenty- two (88%) received radiation and eight (32%) received chemotherapy (these numbers account for only the number of therapies that were received; some participants receive a combination of therapies). When asked if they felt they had control over which therapy they received, twenty- two (92%) of twenty- four respondents said they did feel they had control, while two (8%) said they did not feel they had control over their treatment. Twenty- two (92%) out of twenty- four participants also said they did not turn down a treatment, while two (8%) said they did turn down a treatment.

Chemotherapy was the treatment participants often expressed concerns about receiving; its side effects are probably the most well known and most visible. Many of the respondents also did not want to inconvenience or burden others taking care of them. Participant SH9 was one such

participant, who said that she was hesitant to take chemotherapy. In her own words, “You get sick to your stomach all the time, so...I didn't want to be a burden to somebody.” All (100%) of the twenty- five respondents said their family and friends supported their treatments. However, one (5%) participant said her family and/ or friends, while supporting her treatment, did not believe it to be the best treatment choice.

Chapter 3.5: Future Intentions

A critical part of the study was to determine whether the participants intended to continue to receive care for their breast cancer. All of the twenty- five respondents (100%) said that they intended to seek further care. Some also stated that they also felt they *had* to receive care. For example, Participant SH7 said, “I pretty much feel like I want to do it [seek medical care], and I have to do it.”

Further investigation revealed that the most common method of monitoring (to determine when or if they needed more care) was by the prescheduled appointments with physicians every few months. Nineteen (76%) of respondents went by their appointment schedule, while ten (40%) routinely received mammograms. Four (16%) performed self- exams, while one (4%) stated that she was personally “monitoring her symptoms”.

Chapter 3.6: Encouraging Others

To determine the network norms of the women in Appalachia, the participants were prompted to talk about how they discussed their experiences with breast cancer with others. Nineteen of twenty- four (79%) respondents said they encouraged others to seek detection for

breast cancer (often encouraging other women to get regular mammograms), while five (21%) said they did not.

The respondents often encouraged their female family members and friends; four of the five respondents (80%) who gave a reason for encouraging others cited a family history or genetic component as the motivating factor to do so. Of the five women who said they did not encourage others, four (80%) said it was because the women in their networks already sought routine detection and care, while one (20%) stated she did not because breast cancer did not run in her family (with regards to encouraging family members). Participant SH9 made perhaps the most summary comment on the norms surrounding encouraging other women to seek out care for their breast cancer: “I tell anybody, if we were talking about it, I would tell them: do not go without, you know, even if you don't have insurance...”

Chapter 4

Discussion

The goal of this thesis was to investigate the experiences of women in Appalachia in their pursuit of care for breast cancer. Telephone interviews were recorded and the attitudes, subjective norms and perceived behavioral control of the participants analyzed according to the theory of reasoned action (Ajzen & Fishbein, 1980). Chi-square tests showed that there was no difference between the participants' prompt to care and their emotions, as well as no difference between the emotions of participants' supporters and their expression of an opinion about where the participant should receive care. I found that there were two positive drivers for women who received care for their breast cancer: perceived behavioral control and subjective norms. Participants felt they controlled where they received care and the treatments they received. Additionally, there was a norm of early detection in the form of routine mammography. Inconsistent with the theory, attitudes did not seem to play a significant role in the experiences of the participants. I also found that emotions acted as a novel driver not predicted by the theory of reasoned action. These findings informed theoretical implications for the theory of reasoned action and practical implications for cancer centers and physicians to implement.

Chapter 4.1: Theory of Reasoned Action and Experiences with Care

One aim of this thesis, in interviewing the women of Appalachia who did get care, was to reveal the presence of hypothesized drivers of behavior. The theory of reasoned action predicts that the drivers of a behavior include the attitudes, the subjective norms and the feelings of behavioral control the person experiences with regard to the behavior (Ajzen & Fishbein, 1980). The results revealed consistencies as well as inconsistencies with the theory of reasoned action (Ajzen & Fishbein, 1980). The only attitude that was explicitly reported was the desire to receive care after their prompt, which was expressed by a minority of participants. The uniformity and number of participants who reported it is surprising and inconsistent with the theory of reasoned action, which states that attitudes partly drive a person's intentions to perform a behavior. I believe these results are a product of the study design rather than a failure of the theory; it is unsurprising that people recruited from cancer centers- those who have and continue to receive care- possess attitudes that favor the behavior to receive care. Perhaps the lack of specific attitudes reported by the participants speaks more to the selection of study participants than a difference of attitudes between this sample and others. It is also possible that the knowledge and discussion surrounding breast cancer is so ubiquitous in our society (e.g. pink ribbons, various walks and other events) that the attitude of wanting care for breast cancer is nearly assured and thus not considered by the participant as necessary to report.

A lack of attitudes appeared to be the only inconsistency with the theory. The interviews revealed strong perceptions of behavioral control: almost all of the participants (22 of 24) reported feelings of behavioral control. The choice of facility was most often left up to the patient, with only 32% of the friends and family of the patient sharing an opinion on which facility they should received care. Participants also overwhelming (92%) felt they were able to

control the treatments they received. Though some supporters expressed concern about the type of treatment, there was little overall rejection of the participants' treatments. These results suggest that perceived behavioral control is a common feature that acts as a positive driver for these women who receive care, and potentially encourages them to continue to seek care. It highlighted the importance of empowering patients to make care decisions on where and what treatment(s) they receive.

A second positive driver for these women who received care was a subjective norm of routine mammography in the sample of Appalachian women. Seventeen of twenty- five women (68%) were prompted to care by a problematic mammogram that they regularly received; according to recent Medicare claims data, only 53% of Appalachian women aged 65 or older had received a mammogram within two years of their breast cancer diagnosis (Anderson et. al, 2014), suggesting the sampled population proportionally underwent more routine screening than the entire Appalachian population. Nineteen of twenty- four said that they encouraged others to get routine mammograms or didn't encourage others to get mammograms because the women in their network already received them. This suggests how commonplace mammography is in the daily life of women in this sample, not only as an important health activity but also as a topic of conversation within these networks.

Chapter 4.2: Novel Drivers

One important theme that was revealed during the course of the study was the persistent occurrence of emotions. When asked about their feelings regarding a number of topics, ranging from their prompt to care to their therapy, they reported feeling a wide range of emotions

including fear, optimism and surprise. The emotions of their supporters were significant enough to be remembered. The theory of reasoned action does not take into account emotions; undergoing breast cancer diagnosis and treatment is an emotional process, and it should be unsurprising that emotions may influence medical decisions and impressions. These results indicate the need to include measures of emotions in survey tools and interventions designed around the theory of reasoned action.

Chapter 4.3: Practical Implications

One of the most striking results of the study was the number of friends and family who expressed no opinion on where the participants sought care for their breast cancer. The quotes and data showed that many of the participants felt they had control and were able to make care decisions for themselves. These results are consistent with previous studies identifying the feelings of strength and independence as crucial to the Appalachian identity (Helton & Keller, 2010; Paskett et. al, 2011). Cancers centers (and physicians) should therefore continue or increase efforts to support the patients as well as the friends and family of patients. Support groups provide an opportunity people to ask questions and discuss treatment options; these are also potential opportunities for patients to learn about communication methods to discuss and assert their treatment decisions, and for their supporters to learn about the importance of the patients making decisions about their treatment. Every opportunity should be taken to educate all parties- inside and outside of the exam room- about their options and how to positively express their opinions.

The second role cancer centers can play in encouraging women to continue to receive care for breast cancer is connecting former patients with current patients, thereby facilitating the spread of positive norms about seeking care. The participants in the study encouraged others to seek testing in care, rather than hiding their experiences to seem independent and not burdensome. Cancer centers might create a volunteer program or support network to facilitate these connections. As women who have undergone breast cancer treatment, they are well-positioned to understand the nuances of treatment and survivorship: they can share their experience, encourage others to continue to seek care, and respect the range of survivor identities that exist for women who have had breast cancer (Helgeson, 2011; Kaiser, 2008) It is also possible that these programs, with Appalachian women helping other Appalachian women, might strike a “truer cord” with participants compared to a support group facilitated by “outsiders”.

Last, the manner in which physicians share information with patients seems to be critical in allowing patients to feel control over their care decisions. While a defined standard of care exists with regard to the optimal treatment for the breast cancer case in question, the results of this study are indicative of the importance of presenting treatments as options. It is the job of the physician to not only create the optimal plan for the patient, but also to present all of the therapeutic options and to *educate* the patient on why the physician’s plan is best. Treatment for cancer is not an insignificant commitment; it is time- consuming, expensive and often painful. An element of control over the treatment they receive may encourage women to stay in care and make them more committed to the treatment.

Chapter 4.4: Limitations

This study is not without limitations. First, the sample was largely homogenous: the participants lived in and were treated in a single state, shared a similar Appalachian identity, were recruited from one of three cancer centers, and had similar access to medical resources. These results, while providing insight into an important group with health disparities, may only apply to a small geographical and cultural subsection of Appalachia. Second, the sample size was small. The very nature of identifying exceptional survivors, and asking them to participate in lengthy phone interviews limited the number of available pool from which to recruit. Finally, the survey did not include questions about the stage of the various participants' cancer. It is possible that the prognosis has an effect on participants' attitudes towards care, feelings of control and subjective norms that inform intentions and behaviors. Further surveys should take this into consideration and statistically control for this variable.

Chapter 5

Conclusions

The results of this study provide insights into the experiences of women with breast cancer in Appalachia, a persistently underserved and poorly- understood area. The theory of reasoned action was a useful model to explain women's entrance and continuation of medical care for their breast cancer. While there were no unifying attitudes surrounding medical care, there were strong feelings of control over cancer center and treatment the participants underwent. Additionally, the participants encouraged others to receive routine mammograms or care, highlighting for others the importance of early detection and treatment. These two drivers are potentially what helped women seek out care and remain in the medical care system, and merit further investigation for their role in breast cancer care experiences and decisions. Emotions, not addressed by the Theory of Reasoned Action, also provided an additional explanation for the participant's actions and intentions to seek care. Taken together, the results provide the basis for practical steps cancer centers and physicians can take to help women continue to seek care, hopefully addressing the existing health disparity in Appalachia.

Appendix A

Adjuvant Study Interview Questions

Study ID: STUDY00000906

Demographic Questions

1. Were you diagnosed with estrogen receptor positive breast cancer in the previous 12 months?
2. Have you filled at least one prescription for tamoxifen (*Nolvadex*) or aromatase inhibitor (anastrozole (*Arimidex*), letrozole (*Femara*) or exemestanes (*Aromasin*) within the previous 12 months?
3. Are you going through menopause or have you gone through menopause?
4. Are you able to speak, read and communicate well in English?
5. What is your age?
6. What county do you live in?
7. How would you describe where you live? (*urban, suburban or rural*)
8. What is the highest degree or level of school you have completed?
9. Are you currently covered by health insurance?
10. What type of insurance or health coverage do you have?
Probes:
 - Self- pay (no insurance)
 - Medicare/Medicaid
 - Third party (insurance company)
 - HMO or PPO
 - Other
11. What adjuvant hormone therapy were you prescribed?
Probes:
 - Tamoxifen (*Nolvadex*)
 - Aromatase inhibitors:
 - Exemestane (*Aromasin*)
 - Letrozole (*Femara*)
 - Anastrozole (*Arimidex*)
12. What is the total number of medications you take?
13. Do you need any assistance in taking your medications?

Diagnosis and Treatment

14. What prompted you to seek medical care? How did your medical care for breast cancer start?

Possible Probes:

- Did you feel a lump?
- Did you have a problematic mammogram?
- Where you getting care for something else?
- How did you feel about seeking medical care? (*Relief, worry, it seemed like a sign of weakness, etc.*)

15. What was your experience with getting a diagnosis for breast cancer?

Possible Probes:

- Did it take a long time to get a diagnosis?
- Were your health providers supportive during diagnosis?
- How did you feel about seeking diagnostic services? (*Hesitant, resentful, optimistic*)

16. How did your close family and friends react during your diagnostic experiences (all that happened from signs or symptoms through tests and diagnosis)?

Possible Probes:

- Did they encourage you to get a diagnosis?
- Did they discourage you from going? Why?
- Did they encourage you to go to a specific care facility or provider?

17. In addition to the adjuvant hormone therapy, what kinds of treatment have you received for breast cancer?

Possible Probes:

- Radiation, Chemotherapy, Surgery, Other?
- Did you feel that you had control over which therapy you received?
- Were you encouraged to get a treatment that you have turned down?
- Were your friends and family supportive of your treatment?
- Were there any treatments or care that they did not support?

18. Do you intend to seek further medical care for your cancer in the future?

Possible Probes:

- If yes, how are you monitoring yourself to know whether you need to go back?
- If no, why not?
- Do you want to seek further medical care for your cancer in the future?

19. Have you encouraged anyone else in your family to seek diagnosis or care related to breast cancer?

Possible Probes:

- If so, who and why?
- If not, why not?

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Relevant Experiences

Volunteer at the Manisha Singh Punarjeevan Niwash New Life Center, Nepal

Summer 2012

- Provided urgent and comprehensive care for malnourished, HIV- positive children
- Educated children at the center in Mathematics and English
- Drafted reports on national health surveys for supporting NGO's and performed cost analyses for maintenance of the center's dairy herd using Microsoft Word and Excel
- Received grant from the Schreyer Honors College to support this experience

Research Assistant with Dr. Rachel Smith

Summer 2013- Present

- Research the experience of women with breast cancer in Appalachia in collaboration with Dr. Eugene Lengerich

- Assist with the survey design and analysis of antibiotic resistance communication study

- Collaborative Institutional Training Initiative/ Institutional Review Board certified

Mount Nittany Medical Center Emergency Department Volunteer

Summer 2013- Present

- Knowledgeable of Health Insurance Portability and Accountability Act to safeguard patient information
- Trained in barrier protection protocols and various contact precautions for infectious diseases

Pennsylvania Department of Health Intern: "Get Smart" Antibiotic Resistance Campaign

Spring 2015- Present

- Design social media posts to increase the public's awareness of antibiotic resistance
- Edit and provide feedback on the biweekly Get Smart newsletter

Employment

Hershey Medical Clerkship Model

Summer 2013- Present

- Depict the role of a teenage girl receiving check-up for 3rd and 4th year medical students on Pediatrics Rotation
- Evaluate, critique and provide feedback to students based on obtainment of complete medical history and physician-patient interaction

Resident Assistant, North Halls

Spring 2013- Summer 2015

- Oversaw fifty residents and enforce residence hall policy of the Pennsylvania State University
- Organized social and educational events for residents
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Publications

- Smith, R., Zhu, X., Shartle, K., **Glick, L.**, & M'ikanatha, N., Understanding the Public's Intentions to Purchase and to Persuade Others to Purchase Antibiotic-Free Meat. *Health Communication* (in press).

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