GEOGRAPHIC BARRIERS TO EARLY BREAST CANCER DETECTION IN CENTRAL ILLINOIS

BY

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THESIS

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Abstract

Even with remarkable advancements in breast cancer detection and treatment, barriers exist to obtaining regular and effective screening and treatment. This thesis investigates the following research question: what geographic, economic, and social barriers do breast cancer patients face in accessing screening and treatment services? The study area for this research is central Illinois, a region containing a mix of urban and rural settlements and an economically and socially diverse population. I focus on the breast cancer patient population served by Carle Foundation Hospital and Clinic, a major health care provider in the region, based out of Urbana, Illinois.

This project utilizes a mixed methodology, which includes quantitative and qualitative components. For the quantitative component, GIS maps were created based on Carle Cancer Registry data for 2005-2009 to show the overall pattern of breast cancer cases and identify hotspots of late stage breast cancer. The maps show a clear distance decay pattern with the highest concentration of patients living in Champaign-Urbana near the main Carle hospital facility. A possible cluster of late-stage cases was observed in Villa Grove, IL, but this is most likely just a random occurrence.

For the qualitative component, a survey was mailed to over 800 breast cancer patients to help understand the barriers faced in obtaining breast cancer services. The response rate was approximately 40 percent. Financial, scheduling and time management barriers were frequently cited, while geographic barriers such as transportation and weather were less important. Education and
communication were common concerns, as women stated that they were not receiving clear and useful education about the disease during or after diagnosis and treatment. Recommendations for reducing these barriers are provided in the concluding chapter.
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CHAPTER 1
INTRODUCTION

Breast cancer is an important health problem in the United States. In 2008, 182,460 women were diagnosed with the disease, and it is estimated that that 126 out of every 100,000 women will contract the disease during their lifetimes (National Cancer Institute, 2008). Over 40,000 women will die from this disease during this year alone (National Cancer Institute, 2008). The mortality and morbidity caused by breast cancer merit immediate attention and action from the medical and public health communities. Increasing the number of women who receive regular mammograms could theoretically reduce the large number of deaths from breast cancer. Even with great advances in diagnostic technologies, mammograms and self-examination remain the widely-accepted standards for diagnosing breast cancer early. If breast cancer is diagnosed early enough in the disease, mortality rates are greatly reduced; diagnosis at a late-stage, after the disease has spread beyond the initial site, is associated with higher mortality. In addition, patients diagnosed with breast cancer have a better survival rate if they are able obtain the care needed on a regular basis, and if barriers to diagnosis and treatment are eliminated (AAFP, 2007). The goal of this research is to assess geographic, social and economic barriers to breast cancer screening and treatment in central Illinois.

Many Americans are familiar with breast cancer because of the mass awareness and educational campaigns that have been implemented throughout the United States, but a brief overview of the medical aspects of the disease will provide essential background for this research project. Like other cancers, breast cancer is defined as an uncontrolled
growth of cells. The cancer can result from a genetic mutation, exposure to carcinogens or other factors, which may result in the spread of cancer throughout the body, not just in the area initially infected. It is common for breast cancer to start in the milk producing glands in the breast, called the lobule. However, breast cancer can be located just about anywhere in the breast tissue. These cancerous cells can invade healthy cells, resulting in serious impairment of organs and tissues. When first diagnosed, breast cancer is divided into stages that describe how far the cancer has spread and the tumor size. The stages range from zero to four, with stage four representing disease that has spread to distant tissues. In this project, we chose stage 2 and later to be classified as ‘late stage breast cancer’. Stage two was chosen because this is the point at which the cancer has started to spread to other parts of the body, not just in the breast tissue.

Certain barriers and boundaries, including geographical, social, and economic issues, affect those who seek medical screening and treatment for breast cancer. An example of a geographical barrier or boundary is the distance a patient must travel in order to receive screening or treatment for breast cancer. Patients who face long travel distances may forgo screening or treatment services because of the time and cost of travel. An example of a social barrier is how a patient feels about the care facility at which she is being treated. Does she like the doctors or nurses taking care of her and is there good communication between them? Finally, economic barriers include financial problems with insurance companies or lack of funds to pay for treatment and diagnostic services. Everyone encounters these barriers but some groups of people encounter more barriers than others. In this research project, I assess the barriers and boundaries that deny people diagnosed with breast cancer access to early detection and proper medical care.
The study takes place in Central Illinois, and it specifically focuses on breast cancer patients treated at the Carle Foundation Hospital, a major health care provider located in Urbana, Illinois. Carle Foundation Hospital is a non-for profit institution that specializes in total patient care and also medical research. The research question I am trying to answer is:

- What geographical, social, and economic barriers do women face in accessing breast cancer screening and diagnosing services and how do these affect the risk of a late stage diagnosis?

The research will use a mixed methodology consisting of both quantitative and qualitative methods. The methodology involves first identifying hot spots of late stage breast cancer patients and then conducting a survey of patients to understand barriers to health care access. In the first part, a series of kernel density maps are created to determine where breast cancer patients come from and to identify areas with a high concentration of late-stage cancer patients. The maps are based on quantitative data collected by the Carle Hospital Cancer Registry over the last five years. These maps show, for the Carle patient population, what areas have breast cancer clusters. The qualitative section of the project involves administering a survey questionnaire to breast cancer patients to see what problems they have encountered while trying to seek medical screening or treatment. After these problems have been identified, I will be able to help assess the predicaments women face and perhaps offer solutions. Barriers faced in receiving proper screening and diagnosis are assessed both for late-stage breast patients and for those who were not diagnosed with late stage breast cancer. The patients who were surveyed came from the Carle Hospital, and the Mills Breast Cancer Institute,
which is part of Carle Hospital. An important factor was having the patients cooperate and fill out the survey. Permission to conduct the survey was obtained from the Institutional Review Board at the University of Illinois and a similar review board at Carle Foundation Hospital.

The theoretical framework underlying this research derives from the “dimensions of access” which are used in understanding access to health care. The dimensions of access relate the issue of medical treatment accessibility to geographical, social, and economic barriers and opportunities that patients face. The focus is on enabling factors that affect the use or non-use of screening and diagnosing options for some people (Anderson, 1995). There are five factors in the “dimension of access” theoretical framework. The specific dimensions are: availability, accessibility, accommodation, affordability and acceptability (Wyszewianski 2002). Affordability is influenced by the cost of medical care and the patient's ability and willingness to pay for care. Availability describes the match (or mismatch) between health care resources, such as personnel, and patients' needs for care. Accessibility refers to geographic accessibility, the distance, time and cost of travel to reach needed health care services. Accommodation describes how well health services are organized in relation to the needs, constraints and preferences of clients. This includes, for example, the hours of operation, how telephone communications are handled, waiting times, and referral requirements. Acceptability refers to social and cultural characteristics of health care providers that influence patients’ willingness to use services and their levels of comfort with and understanding of the services received. “These characteristics include the age, sex, social class, and ethnicity
of the provider (and of the client), as well as the diagnosis and type of coverage of the client” (Wyszewianski 2002, 1443).

The dimensions of access framework suggests that many factors come together in affecting access to health care and creating barriers and opportunities to effective and early diagnosis and treatment. Which factors are important is likely to vary depending on the health problem of interest and the place and population context. This research determines the important dimensions of access for a sample of breast cancer patients in central Illinois.

This work is not only important to Champaign County and its surrounding rural areas, it is important to the entire country. Efforts to improve access to health care facilities may change due to the discovered boundaries and barriers that are shown in this project. For example, the results may show that women face transportation barriers in gaining treatment for breast cancer. In such a case, the results might suggest that we develop a transportation system for people who live a great distance away from the location where they receive treatment for breast cancer. Human life is at stake here and saving a life may be the most important research project of all.

The chapters that follow describe in detail the findings of this project from a quantitative and qualitative point of view. Chapter Two is composed of a literature review that presents much needed background information to help explain the methodological approach in this study. Chapter Three will discuss the data collected and the methods that were used during research to obtain this data. Again, the data used in this project was both quantitative, from a cancer registry, and qualitative, which includes the survey of breast cancer patients. Chapter Four discusses the results of the data, both
quantitative and qualitative. Chapter Five concludes the research by discussing the major findings. Additionally, limitations to the research will be noted along with ideas for future research and policy implications.
Background Information, Terminology, and Staging of Breast Cancer

Breast cancer is the most common malignancy among American women except for skin cancer. After lung cancer, breast cancer kills the most women in the United States when it comes to cancer diseases. Four histologic types categorize breast cancer. Ductal carcinoma, the most frequently diagnosed, is breast cancer that has only infected the ducts of the breast and has not spread beyond the basement membrane. If treated quickly before spread, the cure rate is generally above 98% (Ukanonu et al. 2007, 32). Lobular carcinoma is the second most common type of breast cancer, and it occurs in the milk glands. When lobular carcinoma is diagnosed as “in situ”, it is generally not considered to be malignant, but is a risk factor for successive growth. If the lobular carcinoma is invasive to other parts of the body surrounding the breast, it can cause serious illness and even death. Finally, two uncommon forms of breast cancer that only affect 3% of all patients include inflammatory breast cancer and Paget’s disease (Stenchever et al. 2001, 368-390).

According to Abeloff et al. (2004), the size of the tumor is inversely related to the survival rate of a patient with breast cancer. Larger tumors at the time of first diagnosis are associated with a higher the risk of death from breast cancer. The stage of breast cancer describes size of the tumor and extent of spread or metastasis. There exists a very intensive staging process for breast cancer. Five stages, ranging from zero to four, help
explain the extent of disease in a patient at the time of diagnosis. In these stages, many subsections exist that help to more exactly diagnose a cancer.

Stage zero represents the finding that no evidence of a primary tumor, regional lymph node metastasis, or distant metastasis exists. Stage one equates to the finding of a tumor which is 2cm or smaller at its greatest dimension. No regional lymph node metastasis or distant metastasis is noted. Stage 2 is used when the disease has spread to adjacent lymph nodes. This stage can be followed by either an A or B postscript. Stage 2A means that a tumor greater than 2cm but smaller than 5cm at its greatest dimension was found. Stage 2B can represent a tumor greater than 5cm across at its greatest dimension. Metastasis to ipsilateral axillary lymph nodes is also noted with no distant metastasis. Stage 3 describes a more advanced stage of disease and has A, B, and C postscripts. In stage 3 disease, tumor sizes can range anywhere from a quite small tumor to much larger sizes, but there is direct extension (spread) of the disease to the chest wall or skin. Metastasis to ipsilateral axillary lymph nodes fixed to one another or to other structures is possible. Stage 4 includes characteristics of all of the preceding stages along with “distant metastasis”, commonly known as spreading of the cancer to other parts of the body (Stenchever et al. 2001, 368-390).

The higher the breast cancer stage at the time of first diagnosis, the more difficult it is to treat and cure the disease. The risk of dying from breast cancer increases with cancer stage – people diagnosed with advanced disease are more likely to die from the disease than those diagnosed with early-stage (stages 0 and 1) disease.
Risk Factors for Breast Cancer

A person’s risk of developing breast cancer varies with age, gender, family history and other socio-demographic factors. Lee et al. (2007) claim that the incidence of breast cancer has a direct relationship with the age of a woman. Older women are more likely to develop breast cancer than younger women. The risk is almost non-existent for a girl in her teenage years, but a woman above the age of 40 is much more likely to develop breast cancer. Helmrich et al. (1983) mention other risk factors such as ethnicity, diet, and overall health in regards to obesity. Women who are post-menopausal and obese are much more likely to develop breast cancer (Helmrich et al. 1983). Related to this, a well-balanced diet, high in grains, vegetables, and fruits while minimizing intake of red meats, fats and alcohol, helps to decrease the risk for obesity, in turn decreasing a woman’s chances of developing breast cancer.

In the U.S., white, non-Hispanic women have a higher risk of developing breast cancer while blacks and Hispanics have lower incidence levels. This disparity may be a result of socio-economic factors (Lee et al. 2007). It is possible that white, non-Hispanic women are being diagnosed more with breast cancer, while minority women go undiagnosed or are diagnosed late due to financial or social barriers that don’t allow them to obtain proper screening. Black women are more likely to die from breast cancer than are white women, and black women are more likely to be diagnosed with late-stage disease (Deshpande et. al., 2008).

Women’s risk of breast cancer is also related to behavioral and genetic factors. Ukaonu et. al. (2007) explain that the use of exogenous estrogen in older woman can increase the risk of breast cancer. Women who used combined hormone replacement
therapy had a higher risk of developing breast cancer than those who did not, although the risk may be due to progestin, not estrogen. These findings have been widely debated and the data are inconclusive at this time. Genetic factors are important in breast cancer. A history of breast cancer in the family has been shown to increase the risk of breast cancer in a relative (Hartman et al. 2005, 353). Breast cancer risk has been linked to certain mutations in the BRCA1 and BRCA2 genes. On the other side, researchers claim that breastfeeding a biological child will reduce the risk of breast cancer by acting as a defensive feature (Hartman et al. 2005, 353). It is evident that many factors exist to produce and prevent breast cancer in women. One form of prevention that is not biological but is an effective way to help thwart the severity of breast cancer is regular screenings. Engaging in regular screenings will help increase detection, which decreases the risk for late stage breast cancer diagnosis and decreases the opportunity for tumor synthesis and growth.

Breast Cancer Screening and Access to Screening

To detect breast cancer early, one must be screened properly, which can include a mammography, ultrasound, biopsy, and other medical diagnosis practices along with self-examination. The American College of Radiation (2007) states that a mammography is a “low dose x-ray aimed at the breast to help find breast cancer through the detection of masses or calcifications.” Mammography screenings greatly reduce the risk of mortality from breast cancer in women aged 50 to 74. It is recommended that women in this age bracket undergo a regular screening mammography. To be cost efficient, a woman should schedule a mammography every two years (Kerlikowske et al. 1995, 153).
Social, economic, and geographic barriers create hardships for women who require regular screenings and prevent them from receiving the recommended screenings. As a result, the use of mammography varies from place to place. In a study of mammography utilization in Wisconsin, McElroy et. al (2006) found that mammography use was much higher in Dane County when compared to the rest of the state. This was attributed to the three barriers commonly seen in breast cancer screening; Geographic, social, and economic factors.

*Geographic Barriers*

Geographic barriers, known as “accessibility” in the dimensions of access framework, greatly influence access to breast cancer screening. The physical distance to health care facilities may persuade a woman either to travel or not travel to receive life saving screenings. The travel time, cost, and conditions in which a woman travels to her appointment can greatly affect her attitude towards screening and her ability to obtain screening services (MacKinnon et al. 2007). A woman could feel that the burden of traveling a great distance is not worth the inconvenience of a mammogram, or she may not have enough time available in her daily schedule to travel long distances for mammography screening. Because of these factors, for many kinds of health care services we see a distance decay pattern: people who live close to a health care facility are more likely to use the facility than those who live far away, so utilization decreases as distance increases (Cromley and McLafferty 2002). In the Dane County study, the screening centers were located in or in close proximity to Madison, Wisconsin, which is located in Dane County. This means that people living within the county did not have to
travel a great distance to receive proper care. Also, the population of Dane County consists predominately of higher income and educated people who are more aware of the importance of screening. This and the short distance of travel were directly correlated with high screening rates (MacKinnon et. al. 2007).

Geographic barriers are especially important for women who live in rural areas. These women may be unable to obtain regular screening because they do not have access to health-care within a reasonable distance (Kerlikowske et. al. 1995). Access to screening may fluctuate across geographic space because the geographic distribution of health care facilities is uneven (Wang et. al. 2008).

**Economic and Social Factors**

Economic and social factors such as poverty have been directly linked with low usage of mammography screenings. Poverty and low income are associated with lack of health insurance and/or lack of access to primary care which in turn lead to low use of mammography screening. For example, a Florida study found that black women have lower breast cancer incidence but higher rates of mortality than white women. This paradox is due to black women not being able to receive regular breast cancer screenings, citing insurance problems and low socioeconomic status as the prime reasons. In contrast, this study found that the white population was wealthier on average and they could afford to obtain regular mammograms (MacKinnon et. al. 2007). Economic barriers have been observed in many studies, and the results are consistent: Women with a lack of health insurance typically have lower rates of mammography utilization than do women with health insurance (Schuler et. al. 2008). Overall, a larger proportion of minority women
than white women do not receive regular breast cancer screenings. Some of this is due to lack of health insurance. African American women and Hispanic women have higher rates of not being medically insured which partly accounts for their low rates of mammography screening (Schuler et al. 2008, 1484). Among people who do not have health insurance, Chinese and White, non-Hispanic women are less likely to receive a mammogram (Schuler et al. 2008, 1484).

Research has been conducted on the relationship between late stage breast cancer and social factors in the state of Illinois. Wang et al. (2008) analyzed geographic differences in late-stage breast cancer in Illinois and the role of socioeconomic and spatial factors. They found that people living in areas of high socioeconomic disadvantage were more likely to be diagnosed with late-stage breast cancer. The risk of late diagnosis was also higher for women living in areas with poor geographical access to primary care physicians, indicating a combination of spatial and socioeconomic barriers. Similarly, the MacKinnon et al. (2007) research team found that minorities and socioeconomically disadvantaged people have lower incidence rates of breast cancer but higher mortality rates because they are unable to seek or obtain screening services. Even if disadvantaged people live near a screening center, they sometimes do not seek help because of economic, cultural and social barriers.

**Connections and Gaps in the Literature**

Breast cancer research is an important topic in the medical and medical geography research communities. This project has taken many lessons from past projects, while providing new insights about late-stage breast cancer and access to screening and
treatment in the context of central Illinois. Many past geographic studies of breast cancer rely primarily on quantitative data (MacKinnon et al. 2007; Wang et. al. 2008). In contrast, this research uses a mixed methodology that includes qualitative data collected through a survey of breast cancer patients. The survey helps to uncover patients’ own perspectives on barriers to breast cancer screening and treatment. Some studies, including the study by McElroy et. al. (2007) mentioned earlier, have used survey methods to examine barriers for breast cancer patients (see Schuler, Chu & Smith- BINDman, 2008). These studies indicate that a mix of geographic, social and economic factors are important in affecting women’s use of breast cancer screening and treatment services and that different factors are important in different geographic contexts and for different populations.

My research looks at perceived barriers to screening and treatment within the population served by a single health care provider in central Illinois. The study population is economically and socially diverse and includes both urban and rural residents. I use quantitative mapping of breast cancer patients to show the geographic distribution of the study population and to identify geographical clusters, if any, of late-stage breast cancer cases. Unlike previous mapping studies, I use address-level data which makes it possible to create more exact maps that show where patients live in relation to the Carle Hospital facility. In the qualitative component of the study, barriers to screening and treatment as perceived by breast cancer patients are assessed.

Researchers such as Wang et al. (2008) and McElroy et al. (2006) found geographical and social barriers such as travel time, distance to screening facilities, socioeconomic conditions, access to health care, and availability to be large problems. In urban areas,
mammography services are generally accessible and available but socioeconomic status plays a large part in whether or not screening will occur. In rural areas, geographical boundaries such as travel time and limited availability of doctors or clinics come into focus. Because the study population is both urban and rural, I expect to find that both socioeconomic and geographic barriers are important. I expect to see a distance decay result. More Carle breast cancer patients will come from nearby areas than from places far away, and the people living farthest away from the screening facilities will have the highest rates of late stage breast cancer. In the urban areas of Champaign and Urbana, I expect to find that socioeconomic barriers are important. In addition, this research will give an inside look to what the patients diagnosed with late stage breast cancer believe the barriers affecting them were before they sought treatment.
CHAPTER 3
DATA AND METHODS

Introduction to Mixed Methods

This study uses a mixed methods technique that encompasses both quantitative and qualitative forms of data collection. Qualitative methods are used to find out about the dimensions to access -- geographical, social, or economic barriers -- that limit women’s access to breast cancer screening and treatment. Using only quantitative data would not provide insights about the barriers women actually face. The qualitative section of the study is important for designing effective policies to improve diagnosis and treatment for breast cancer patients. Solely looking at numerical statistics and in this case maps, will not be very helpful in improving our current health care system. Using only qualitative data collection is also limited, however. Geographical and economic dynamics emerge from statistical information that can only come from objective quantitative data. Combining the two kinds of methods will increase the chance for success in this project.

The study focuses on the area served by Carle Hospital, which encompasses a fairly large area in the state of Illinois -- central Illinois -- and extends into surrounding states. The United States Census Bureau estimates that Illinois’ population is over 12 million with fewer than one million living in central Illinois. The study area is centered on Urbana, located in east-central Illinois, which is where Carle Foundation Hospital is located.

The quantitative data come from the Carle Cancer Registry. The Carle Cancer Registry includes no geographical boundaries, rather anyone who seeks treatment for
breast cancer from a Carle medical provider is included in this registry. The Carle Cancer Registry also provides the sampling frame for the survey component of this study. Surveys were mailed to patients listed in the Cancer Registry; however responding to the survey was completely voluntary. The fact that the study only includes Carle breast cancer patients means that the results of the study may not represent barriers for all breast cancer patients in central Illinois. Still, Carle is a major health care provider in the region, so I expect that the results are typical for the region.

Quantitative Data Collection and Mapping

The ultimate objective of the quantitative aspect of the research project was to create maps to show the geographical distribution of breast cancer cases and late-stage cases among Carle Cancer Registry patients. GIS software was used to create the maps. These maps help to locate high-density areas of breast cancer cases for women diagnosed with cancer at different stages. The goal was to identify hot spots of late stage breast cancer, and, in turn aid in our search for trends in social, economic, and geographical characteristics of the breast cancer patients. The data collected from the Carle Cancer Registry was extremely recent data, for the five year period, 2005-2009. The data show that Carle Cancer Center diagnosed 1108 women with breast cancer.

The data set from Carle contained information about the patient’s age, race, insurance (yes/no) and clinical stage at diagnosis. Clinical stage refers to the stage of breast cancer (stages 1-4) when the disease was first diagnosed by Carle. Higher stages indicate that the tumor was large and/or the disease had spread beyond the breast at the time of diagnosis. Unfortunately, stage data was missing for a large number of patients
(546), because many patients had not been assigned a clinical stage at the time of diagnosis. Also, this ‘unknown’ category exists because documentation of cancer stage was not as precise in 2005 and 2006 as it is now. Even a few years ago, the data documentation from hospitals about cancer stage was poor. Another reason for the unknown category is the fact that patients diagnosed at other facilities are often referred to Carle and thus included in the Carle Registry; however Carle may not have access to the clinical stage information from the original facility.

The data included not only the zip codes of the women with breast cancer, but also the addresses. This sort of data is called point data because it can be used to determine the precise location of the patient’s home. With point data, medical privacy laws are very important. Personally identifiable information such as patient address is protected under federal privacy regulations. Under the terms of IRB approval from the University of Illinois and Carle, I did not have access to the patient address data. To be able to use the addresses of the breast cancer patients, Carle designated a research employee to input the data into the GIS mapping software program, to conduct geocoding of the data and to perform all GIS analyses. This was done to make sure to maintain the confidentiality of the patient data while making these maps. University of Illinois researchers were not permitted to see the data or to interact directly with the GIS. I was permitted to be in the room during the GIS processing so that I could oversee the GIS mapping and answer questions from the Carle employee about GIS operations.

The patient addresses were assigned geographic coordinates via a geocoding process. Geocoding is the process of assigning locations to data based on geographic identifiers such as addresses. The TIGER/Line street file from 2003 for the state of
Illinois was used for geocoding. Geocoding the addresses properly required the research employee to set the sensitivity of geocode matching to 65%. A majority (632) of the addresses matched immediately while 232 did not. It was soon discovered that P.O. boxes and incorrect labeling of addresses were commonplace for the 232 unknown matches. These locations were geocoded manually by the Carle researchers with my direction.

To display areas with high or low concentrations of breast cancer patients, kernel density maps were created. Kernel estimation is a procedure for representing the density of points as a continuous surface – a ‘weather map’ – in which peaks represent places containing large numbers of points and valleys places with few points. In this study, peaks on the kernel map represent areas with many Carle breast cancer patients and valleys areas with few patients. Kernel estimation involves moving a circular “window” across the point map and estimating the density of points within the window. In calculating density, each point is weighted based on its distance from the center of the circle: points located near the center receive a larger weight than those located further away (Cromley & McLafferty 2002).

Four maps were created from this activity. These maps were designed to show differences in breast cancer stage, based on the stage information in the Carle Cancer Registry. The first map portrayed all of the breast cancer cases, including all stages, displayed across the state of Illinois. The second map was a zoomed-in map displaying only cases in Central Illinois. The third and fourth maps were specific to late stage breast cancer patients. Following previous studies, late-stage was defined as stage two through stage four. These maps also followed the two previous ones in that one was for the entire state of Illinois, and the other was for Central Illinois. Geographically speaking, I defined
the limits of Central Illinois as follows: Bloomington, Illinois is the far western and northern city. Danville is the farthest eastern location, and Charleston is the southern baseline for Central Illinois. Carle Hospital is situated in the middle of this region, and it draws most of its patients from this area.

The data also included a few instances of people coming from out of state to receive screening and treatment at Carle medical locations. These were omitted in the mapping, along with those who were the only person in their town to be diagnosed by Carle. For instance, let us suppose a woman from Galena, Illinois travels to a Carle satellite facility to receive breast cancer screening. If she was documented as having breast cancer and she was the only woman who was from Galena in the last five years to have been diagnosed by a Carle health provider, she would not be mapped for privacy reasons. The minimum number of women diagnosed in a town had to be two or greater to be mapped in this project. These privacy restrictions were specified in the IRB agreement that covered this research project.

This data set is limited in several ways. It only includes patients diagnosed by Carle who are included in the Carle Cancer Registry. Thus, breast cancer patients who were diagnosed at other hospitals in the region are not included in the data set. Also, as mentioned earlier, cancer stage information was missing for many of the patients. On the positive side, the project data is very specific which helps the research move away from strictly using zip code data. The maps show much more detail than those at the zip code level. A slight homogeneity in demographics may exist by only using data from one health care provider, but the data is much more detailed than that which would be available through governmental public health agencies.
Qualitative Data

The qualitative section of the research is a very important component of the mixed methods approach. This part of the investigation was created to dive deeper into the processes behind women’s access to breast cancer screening and diagnosis. A twenty-three-question survey was designed to illicit information from breast cancer patients who were included in the Carle Cancer Registry database. The survey focused on geographical, social, and economic factors that may limit women’s access to early breast cancer screening and effective treatment. The survey asked about issues like transportation access, medical insurance, distance to primary care physician, language and other cultural barriers, and demographics such as age, marital status and education (Appendix A). The survey also included several open-ended questions about barriers to care and recommendations for improving care.

Over 800 surveys were mailed out to women who received a breast cancer diagnosis within the last 5 years at a Carle medical location. The survey was accompanied by an information sheet that stated the purpose of the survey and its voluntary nature (Appendix B), and an envelope with pre-paid postage to send it back to Carle’s research department in Urbana, Illinois. No personally identifiable information such as name or address was requested on the survey or return envelope. Thus, the responses were completely anonymous. The recipients were told in the letter that they had a two-month time window to complete and send back the surveys to Carle if they wished to participate.
The survey had a very high response of 357 returns for 858 sent out, yielding a response rate of just over 40 percent. According to the researchers at Carle who worked on this project, the months of November and December are great for survey responses because the patients feel a sense of care and duty to mankind during the holiday season. To assess the patient’s knowledge of her disease stage, the surveys were sent out in color-coded forms based on clinical stage: Stage 1 had a yellow border, stage 2 had a pink border, stage 3 had a red border, and stage 4 and a blue border. The colors were chosen at random and have no significance to the study. The surveys for patients with unknown stage did not have a colored border. We included patients with unknown stage at diagnosis because their thoughts and subjective data about barriers to care are important. Presumably their cancer was staged at a later date, after the time of diagnosis. The color-coding of the surveys made it possible to compare patients’ perceptions of their cancer stage with the clinical stage data from Carle to get at questions of knowledge and education. Were the patients educated enough by their health care providers to understand what stage of breast cancer they had at their initial diagnosis?

Upon receipt, each questionnaire was thoroughly read and entered into a spreadsheet for further analysis. Each question was designated its own column in a spreadsheet, and the responses were recorded by either a letter designating the response, or, for the open-ended questions, the patients’ comments were directly entered.

**Conclusion**

The mixed methodology was a great combination technique that provided much needed and new information in regards to barriers to breast cancer screening and
treatment in central Illinois. Quantitative data analysis and mapping was useful for providing an overarching sense of where Carle’s breast cancer patients come from and to visualize places where the risk of late-stage diagnosis is high. Adding this to a strong qualitative survey analysis produced a synergistic response. The definitive goal of this project was to use these methods to identify geographical, social, and economic barriers to breast cancer screening in Central Illinois.
CHAPTER 4
QUANTITATIVE RESULTS

The quantitative results in this project analyze the spatial distributions of breast cancer patients treated at Carle Hospital and late-stage breast cancer patients. The goals of the analysis are to examine where patients come from, to provide a geographic context for the analysis of the survey results, and to see if there is any spatial clustering of late-stage breast cancer patients. Four maps were created using ARC GIS software. The maps were created at a Carle satellite facility in Urbana, Illinois. With tight restrictions on what data could be visible to a non-Carle-healthcare worker’s eye, a team of researchers from the health-care facility helped in preparing the maps, as described in Chapter 3.

The overall data set consists of the 858 women in the Carle Cancer Registry data set for 2005-2009. Through kernel density mapping, we were able to create four maps showing the density (number per square mile) of Carle breast cancer patients in the study region. The first two maps show the geographical distribution of all breast cancer patients; the second two maps show the distribution of patients whose cancer was diagnosed at a late-stage.

All Breast Cancer Cases
The first map features all breast cancer cases treated by Carle in the past five years.

Breast Cancer Density Map for all Carle Cases

Figure 1: Density of Carle breast cancer patients in the state of Illinois, 2005-2009
Carle provides care all over the state, however the map cannot display single point densities because that would violate privacy laws. As expected, the largest density of breast cancer patients occurs in Central Illinois. Areas of high density appear around the major cities in the region such as Bloomington-Normal and Danville, and in smaller towns near Champaign-Urbana such as Mahomet and Rantoul. A few cases are visible in the rest of the state, but these are difficult to see in such a large map. This map displays a distance decay pattern. The highest density of cases occurs near the main Carle facilities in Champaign-Urbana. The density of patients decreases as the distance from Champaign-Urbana increases.
The second map zooms in to show all cases in Central Illinois.

Figure 2: Density of Carle breast cancer patients in central Illinois, 2005-2009
As shown in Figure 2, the highest incidence of breast cancer occurs in the Champaign-Urbana area in Central Illinois, where a large population resides, and where Carle Hospital is located. This is an expected outcome, Carle’s patients usually come from Champaign County and that makes perfect geographical sense. Hospitals and other health care providers tend to draw patients from nearby areas. Less travel is appealing to those in need of medical care, and people living far away are more likely to use competing health care facilities. Research has shown repeatedly that geographical distance is a vital aspect to healthcare utilization, and the maps in Figures 1 and 2 illustrate this pattern (Cromley & McLafferty 2002).

Maps of Late-stage Breast Cancer Patients

The next two maps focus only on late-stage breast cancer patients treated at Carle. The first map shows the entire state in relation to late stage breast cancer,
Figure 3: Density of Carle late-stage breast cancer patients in the state of Illinois, 2005-2009.
Figure 3 shows a similar pattern to the maps which displayed all of the breast cancer cases. Central Illinois is the hot spot for late-stage breast cancer patients treated by Carle Hospital. This map is difficult to interpret because the area shown is so large in comparison to the spatial distribution of cases. We can see, however, that areas of medium to high density include highly populated cities such as Danville and Bloomington in Illinois. Carle has satellite locations all over Central Illinois, in cities such as Mahomet, Danville, Bloomington, and Charleston. These locations make it easy for people to access healthcare, and they appear as distinct high density locations on all the breast cancer maps.
The final map shows a close up view of Central Illinois and the Carle Hospital late stage breast cancer patients.

Breast Cancer Stage II-IV Density Map

Figure 4: Density of Carle late-stage breast cancer patients in Central Illinois, 2005-2009.

The density values that appear on the map show areas in which two or more women per square mile have been diagnosed at Carle with late stage breast cancer in the last five
years. It is expected the large urban areas such as Champaign-Urbana, Danville, and Bloomington will have high densities of late-stage patients because they also have high densities of breast cancer cases overall. These large urban centers appear as clusters on Figure 4 as they do on Figure 2, the map showing density of all breast cancer patients. The map in Figure 4 also shows several rural towns that have a high density of late-stage breast cancer cases including towns like Monticello and Tolono. The rural towns that show up on this map are all within expected limits (based on their total number of cases) except for Villa Grove, Illinois which is located southeast of Champaign. There were more than two late stage breast cancer patients from this town treated at Carle within the last five years – a number that is high in relation to the local density of breast cancer cases. Further research will have to determine what factors play into this occurrence. The most likely scenario is that this is just a random cluster of late-stage cases, but environmental factors, social factors, and transportation factors should all be analyzed to determine if some specific barriers are increasing the risk of late breast cancer diagnosis for women in this town. Social factors could include family histories, community beliefs about healthcare, and financial constraints that make it difficult to obtain regular mammography screening. The transportation factors could include a great distance to healthcare clinics, car-ownership, or possibly lack of interstate driving. Environmental factors are complicated and difficult to diagnose over a short period of time.

Conclusion

In summary, the maps show a clear distance decay pattern indicating, as expected, that Carle’s breast cancer patients primarily come from Central Illinois, especially from
Champaign-Urbana and other nearby towns. The density of patients is highest in Champaign-Urbana, where Carle Hospital is located, and it generally decreases with increasing distance from the hospital facility. Nearby cities such as Danville and Bloomington also contain high concentrations of Carle breast cancer patients. The spatial distribution of late-stage breast cancer patients is similar to that for all breast cancer patients, except for a possible cluster in and around Villa Grove. The small number of cases in this cluster, however, suggests that it may just be a random occurrence.
This chapter describes the results of the qualitative survey analysis of breast cancer patients. The chapter begins with an overview of the number and locations of survey respondents. The remaining sections are organized in relation to stage of breast cancer. I discuss the survey findings first for women with early stage disease (Stage 1). The next section explains the research findings for those diagnosed with late stage breast cancer, which includes stages II through IV. Because stage data was missing for a large number of the respondents, in the third section I discuss the results for the “unstaged” cases. Each section is organized in a similar way. The initial paragraph will give a brief summary of the demographic findings, followed by a paragraph explaining any barriers encountered when patients sought medical care for breast cancer. These barriers include but are not limited to; education about breast cancer, financial problems, and geographical barriers to obtaining screening and treatment services. The last part of the chapter summarizes and compares the results for all groups.

Geographic Distribution of Survey Respondents

Overall 357 women responded to the survey: 94 were diagnosed with stage 1 breast cancer; 44 with late-stage (stages 2-4) cancer; and 219 whose stage was unknown. The respondents came from most parts of the Carle Hospital service area. Figure 5 provides a map representing the geographic distribution of the survey respondents by zip
code. The map shows a strong similarity between where the survey respondents live and the earlier map showing the density of breast cancer cases (Figure 1). Champaign-Urbana has the highest number of respondents and the highest number of breast cancer cases in the Carle Cancer Registry data. A small distance decay is represented in the map of survey respondents, meaning that the farther one travels from Carle Hospital, the smaller the number of respondents. However, some outlying communities also have clusters of respondents because they are large metropolitan areas such as Bloomington and Danville. As shown in Figure 5, respondents to the survey are widely distributed. They represent populated urban areas and small rural communities. The most likely cause for the great response from women in the Champaign-Urbana area is the fact that many women are treated for breast cancer locally which may raise awareness of the value of research on access to breast cancer care. Living in a university town setting may increase recognition of the importance of scientific studies such as this one. This awareness may have led to more cooperation in responding to the survey. The next sections examine the survey responses by stage of breast cancer.

**Stage 1 Breast Cancer Cases: Survey Analysis**

The average age of the ninety-four patients who returned the stage-one breast cancer survey was sixty-five years. The majority of patients fall between sixty and eighty years of age. Almost all respondents were white, non-Hispanic: Only two of the 94 stage one women surveyed were not white, non-Hispanic. The vast majority of women in the stage-one group have attended at least some college or they have attained higher
education degrees. Only four percent of the women responded in the survey that they do not have a high school degree (Figure 6).

Most respondents had a regular health care provider. Only one of the stage one respondents reported they did not have a primary care physician. A small number of women stated they have also been in contact with a nurse practitioner or oncologist for healthcare treatments in regards to their breast cancer. The stage one women who were treated for breast cancer by healthcare personnel other than their primary care physician generally lived close to the health care provider: of these women, none lived more than 5 miles from the healthcare facilities they use.

Geographic barriers were somewhat important for this group of respondents. Five percent of the stage one women did not own a vehicle; however, none of these women listed transportation as a barrier to obtaining breast cancer screening and treatment. A moderate percentage (10%) of women who own a vehicle and drive themselves or have someone else drive them stated that the distance to their breast cancer screenings and treatments was a major barrier. The average distance travelled for this group of women was 15.4 miles. Almost thirty percent of the women surveyed had to travel over ten miles. Thus, this group was heavily drawn from areas somewhat distant from the Carle facility. Reflecting the racial and ethnic homogeneity of the survey respondents, none reported language barriers.

The main barrier cited in this group was insurance or money problems (30%). For some women, low income appeared to limit the ability to obtain breast cancer screening, although the relationship seems to be complex (Figure 7). Both women living in low-income and high-income households reported that they had problems with paying
their medical bills, paying for transportation, or dealing with insurance complications. These results suggest that economic barriers cut across income groups, supporting the idea that no matter what income bracket a patient belongs to, paying for health care and dealing with medical insurance are difficult challenges.

Late Stage (Stages 2-4) Breast Cancer Cases: Survey Analysis

The demographic characteristics of the late-stage breast cancer cases are similar to those of early-stage patients. The average age of the late stage women who returned the surveys was sixty-two years and the majority of patients fell between fifty and eighty years. All of the women said they were of white, non-Hispanic background, and English was their primary language. This means that language or cultural barriers are not likely to be relevant for this group of women. This homogeneity of the respondents is partly to be expected due to the demographics of central Illinois, but still the absence of minority respondents raises an important set of questions: Do black and Hispanic residents in Central Illinois face barriers in receiving breast cancer screenings so they are not diagnosed? Do they use hospitals other than Carle Hospital? Or were they less likely than the white population to respond to this survey?

The late-stage respondents were also similar in education level to early-stage respondents. Education varied but no person in this group had less than a high school diploma or GED (Figure 8) The income levels also varied, but each woman claimed to have health insurance (Figure 9)

All of the women who returned the late stage surveys said they have a primary care physician, and they do not visit with nurse practitioners for their breast cancer
screening appointments. Five percent of the women surveyed in this group said they do not own an automobile but they have other means of transportation such as family members or public transportation to help out. The average distance travelled for breast cancer screening was just over seven miles. Very few of the women cited travel distance as a barrier to breast cancer screening. Over 75% of the women who returned the surveys reported living within ten miles of their screening center. This finding was the same as for the early-stage group as well. Thus, there was no difference in distance to care between the early- and late-stage respondents, which suggests that in general, Carle’s breast cancer patients do not face a barrier in regards to great geographical distances travelled for health care or screenings. It also indicates that those with late-stage disease do not face longer travel distances to care than those whose disease is diagnosed early.

The main barrier that women faced in this group was knowledge and education about breast cancer. A large portion of the women in this group said they had trouble understanding what the doctor was telling them. The need for more or clearer information was frequently mentioned. The late-stage respondents would like to have education classes available that allow women diagnosed with breast cancer to learn more and share their experiences. One woman said that a breast health navigator or a person who is able to speak in easy-to-understand terms would be very helpful after the diagnosis. This could suggest that the healthcare professionals are not spending enough time speaking with their clients after they issue a diagnosis. Twenty-six women reported their household income on the survey. The need for education does not appear to be tied to poverty or low income. Fifty percent of those women stated that they live on less than $39,000 dollars a year. However, they did not cite money as a major barrier to breast
cancer screening. The majority of women who said they faced barriers to care said it was the follow-up education that affected them the most.

These findings for late-stage patients combine patients in stages 2, 3 and 4. This was necessary due to the small number of respondents (10) in stages 3 and 4. There were no obvious differences in responses based on stage, but it would be good to collect data for a larger sample of stage 3 and 4 breast cancer patients to see if those with highly advanced disease at diagnosis face unique barriers in obtaining screening and treatment. Despite this limitation, getting feedback from late-stage breast cancer patients on access to screening and treatments provided invaluable information on barriers to care.

Breast Cancer Patients with Stage Unknown

For most of the women who responded to the survey (219 women to be exact), the breast cancer stage was unknown. These were women who came from other health facilities outside of the Carle Cancer registry, or whose cancer stage was not properly documented at the time of diagnosis. However, the insights gained from these surveys are invaluable, because these women represent such a large share of all breast cancer patients. Although from these survey responses, I cannot draw any general conclusions about how barriers relate to cancer stage, I can understand the kinds of barriers faced by breast cancer patients in general.

The ages of these women were very diverse, ranging from the early 40’s to the late 90’s. Over 90% of the women were white, non-Hispanic and spoke English as a primary language. Language and cultural barriers never were reported as barriers to breast cancer screening by the women in this group.
The average distance travelled by these women for health care services was just over 11 miles. Only a handful of women cited transportation or geographical barriers as a barrier to screening. An unforeseen problem reported by many respondents was “weather,” which can be an important barrier to travel for health care, especially during the winter. Insurance dilemmas, high medical costs, and scheduling difficulties topped the list of most commonly reported problems for this group. Scheduling difficulties included problems with finding a baby-sitter, making a phone call to the health care provider, or changed appointments. A common problem noted by the women in this group was time management. Several respondents stated that good time management was a key to success. All of the women who answered the question about having insurance said they had some type of insurance whether it be employee, government, or private. Thus, affordability and accommodation barriers were commonly mentioned by the respondents in this group.

Figure 10 displays the most commonly addressed barriers to breast cancer screening in percentages broken down into early stage (1), late stage (2-4), and unknown stage according to the women surveyed. Geographical factors such as distance travelled to screenings were not reported as barrier nearly as much as financial barriers and scheduling. Late-stage patients cited financial issues as their largest concern, and financial barriers were also very important for the other two groups of respondents. Finding the time to miss work or even to schedule the appointment were also important to all stages of breast cancer patients, indicating that accommodation barriers are significant concerns among the Carle breast cancer patient population.
Conclusion

A wide variety of women answered the survey conducted in this research. They come from different backgrounds that we as researchers will never fully understand; but they shared invaluable insights about their disease and the process they have lived through. Most of the women who responded to the survey were white, non-Hispanics who speak English as a primary language. Therefore, none reported language barriers when it comes to breast cancer screenings. The geographical distance to health care was only reported as a problem a few times in the surveys, and some women mentioned difficulties with transportation and weather. Concerns about the geographic availability of health care services were rare. The data suggest that very few women had to travel more than ten miles to receive their breast cancer screening. The travelling was completed mostly by women who own their own automobiles and operate them, and the rest reported that they had a friend or relative drive them or they took public transportation. Financial issues were mentioned by a larger number of respondents, but the broad array of women very rarely cited that economic factors made their breast cancer care at Carle impossible. More respondents raised concerns about knowledge, communication and education that emerged when they interacted with health care professionals.

The kinds of barriers mentioned did not differ between early- and late-stage respondents (Figure 10). Patients from all stages mentioned that a major barrier was related to knowledge and communication with doctors. A possible reason for this may be that women who are diagnosed with breast cancer may feel a deep anxiety and curiosity about the disease that cannot be diminished within the short amount of time spent in a
doctor’s office. Women must live with their newly discovered disease all hours of the day and not just at the health care facility. The gap between patients’ desire for education and the time spent speaking with a trained health care professional may lead to a patient’s dissatisfaction. These concerns did not seem to differ by cancer stage. In general, I did not find any particular barriers that might have led to delayed screening and thus increased risk of late diagnosis.
Figure 5: Number of survey respondents by zip code
Figure 6: Education levels for stage 1 breast cancer survey respondents.
Figure 7: Household income for stage 1 survey respondents.
Figure 8: Education levels for survey respondents with late-stage breast cancer.
Figure 9: Household income levels for survey respondents with late-stage breast cancer.
Figure 10: Most commonly addressed barriers to breast cancer screening and treatment by cancer stage.
CHAPTER 6
CONCLUSION AND RECOMMENDATIONS

This research analyzed the geographic dimensions of breast cancer among patients served by Carle Hospital in central Illinois and barriers to screening and treatment. Mixed methods were used in analyzing these issues. The quantitative portion of the research project yielded four maps created by ARC GIS software in cooperation with Carle Foundation Hospital. 858 women were mapped based on their stage of breast cancer at diagnosis from the data in the Carle Cancer Registry. Kernel density maps showed hot spot areas throughout the state of Illinois and more specifically in Central Illinois. Highly populated cities in Central Illinois such as Champaign, Urbana, Bloomington, and Danville had the highest density of breast cancer at all stages and late stages II-IV. Villa Grove, Illinois, a rural town south of the main Carle campus, was the only city to have an unexpectedly high density of late stage breast cancer. The phenomena could be coincidental or related to geographical, social, or economic factors.

The survey responses yielded a wealth of detailed information about women’s perceptions of barriers to breast cancer screening and treatment. The women who answered the surveys were fantastic volunteers that helped further breast cancer research in terms of understanding existing barriers to screening. They offered solutions, complaints, and real-life stories that help provide an understanding of the challenges associated with accessing breast cancer screening and treatment in central Illinois. All of
the groups of women cited insurance problems, money, time conflicts or scheduling, transportation, and education as important barriers to breast cancer screening and diagnosis. Of the five dimensions of accessibility, availability, accommodation and affordability were frequently mentioned as important issues in accessing health care. Some of these issues are broader social and economic challenges that are difficult for health care providers and public health organizations to address. For example, it is difficult for a local hospital or physician to remove financial barriers such as insurance predicaments or low-income levels. Financial barriers may be best addressed at a state or national government level rather than by specific health-care providers.

However, some of the other findings of this research suggest direct policy changes that are much more feasible to implement. An overwhelming number of women throughout all cancer stages stated that they would like to have better education in relation to their breast cancer diagnosis. It is not that they feel they don’t know what a mammogram is or how important screening can be, but that they feel lost after diagnosis in terms of what to do next. One patient said, “Doctors need to spend more time with patients holistically rather than just biopsy to surgery.” The doctors and oncologists are busy people who don’t have the necessary time to sit down and speak with women about how the disease is progressing and what will need to be done. Group meetings and classes could help these women understand their diagnosis and treatment better and to benefit from the support of others facing a similar diagnosis. It would also be beneficial to have specific health care employees such as nurses or nurse practitioners specializing in post-diagnosis breast cancer. These trained professionals could help bridge the communications gap between doctors and breast cancer patients.
The survey findings also suggest a gap between patient and medical knowledge of breast cancer stage. Carle Cancer registry provided this project with data that explained the diagnosis stage at which a patient came into the Carle database. With this knowledge, the research team sent out color-coded surveys based on what we knew to be their initial diagnosis stage. There was often a mismatch between the diagnosis stage reported by the patient and the one recorded in the Carle Registry. It was not uncommon for a patient to report in the survey that, for example, she had been diagnosed with stage two, when in fact she was diagnosed with stage one. An even more disturbing phenomenon was that over 20% of the women did not know what stage they had at the time of the survey. The women need more education and follow up within the health care system to improve their understanding of the disease and to enhance the quality of care. Individualized or small group education seems to be favored among the women who were surveyed.

Geographic barriers, including limited access to transportation, were important for a small subset of women who reported difficulties in arranging transportation and weather-related travel problems. Transportation services for people who live a certain distance away from a clinic would be helpful to reduce geographic barriers, but these services are expensive to operate and may only serve a small number of women. Creating special transportation services for cancer patients is not likely to be fiscally sound with rising gas prices and diminished governmental funding for public transportation. Social networking on the Internet could help people with transportation needs. Developing networks that allow patients to interact with one another could create ride sharing while also helping to create friendships with others suffering from the same disease. It would be advantageous to any health-care institution to expand social
networking opportunities because these activities are cost efficient and highly effective in promoting well-being.

Future research on breast cancer is pertinent to the success of disease management and finally finding a cure. The breast cancer community is strong and large across the United States, and it is often seen as the vocal promotional leader against a specialized disease. This research has identified a number of barriers that are important to breast cancer patients in central Illinois, and that may be raised by advocacy groups both in this region and nationwide as they work to achieve improvements in care.

Despite these important policy implications, this research has several limitations. Health care privacy laws limit researchers’ ability to analyze more thoroughly the diseases we wish to control or cure. Privacy laws are clearly necessary, however they diminish the possibilities of detailed geographic research investigation. In this project, the density mappings were done at an address level which represents a substantial improvement over previous studies that use zip code data. But the fact that I was not permitted to use the GIS directly meant that it was not possible to explore the data and create the most effective maps.

The qualitative part of the study also had limitations, mainly due to variations in survey responses. Increasing the number of women surveyed would make the research much better for future projects by better representing the full cross-section of breast cancer patients. This project only covered women who were treated within the Carle healthcare system. This limits the project geographically, so it may not be representative of other areas of the United States. There were few ethnic and racial minority respondents to the survey, so it is impossible to evaluate the specific barriers relevant for
these groups. The respondents to the survey were varied in their incomes; however, this project may have neglected very poor populations who did not return the survey. It is also possible that people from certain cultures might not send the survey back the first time they receive it because of language barriers or general fears about responding. To get a more representative sample, a second wave of surveys should be sent out. Despite these limitations, this study has revealed many important barriers that breast cancer patients face in receiving regular and effective screening and treatment in central Illinois. This research project should be used as a stepping-stone to further the study of barriers to breast cancer screening all over the United States.
Appendix A

Geographic Barriers to Early Breast Cancer Detection in Central Illinois
Patient Survey

1) Do you have a primary care physician?
   a. Yes (if yes, proceed to question 2 and 3)
   b. No (if no, proceed to question 4)

2) How far must you travel for a check-up with your primary care physician (in miles)?

3) What town must you travel to for an appointment with your primary care physician?

4) If you do not have a primary care physician, what type of provider delivers your care? (Examples: Nurse Practitioner, Registered Nurse)

5) Do you own a vehicle?
   a. Yes
   b. No

6) How do you get to your medical check-ups?
   a. Drive alone
   b. Driven by friends or family members
   c. Public transportation
   d. Walk
   e. Other means of transportation __________

7) What are some barriers that may make it difficult for you to attend regular check-ups with a primary care physician? (Examples: money, time, insurance problems, language differences, unfriendly staff, lack of information, child care, religious beliefs, other)
a. Did any barriers make it hard for you to obtain screening and/or care for breast cancer when you were first diagnosed?

b. Do any of these barriers still exist today?

8) What is your race/ethnicity?
   a. White, non-Hispanic  
   b. African-American  
   c. Hispanic  
   d. Asian-Pacific Islander  
   e. Native American  
   f. Other __________

9) What is your age?

10) What is the highest level of education you have completed?
   a. Less than high School  
   b. High School/GED  
   c. Some College  
   d. 2-year College Degree (associates)  
   e. 4-year College Degree (BA, BS)  
   f. Graduate Degree (eg. Masters, PhD, JD, MD)

11) What is your annual household income?
   a. Less than $20,000  
   b. $20,000-$39,999  
   c. $40,000-$59,999  
   d. $60,000-$79,999  
   e. $80,000-$99,999  
   f. $100,000-$149,000  
   g. More than $150,000

12) Do you have health insurance?  
   a. Yes  
   b. No

13) If you have health insurance, what is your source of health insurance? (Examples: Medicare, Medicaid, Private, HMO)

14) What town do you live in or near?

15) What is your zip code?

16) What is the primary language you speak?
17) What is your current marital status?
   a. Single, Never Married
   b. Married
   c. Separated
   d. Divorced
   e. Widowed

18) Do you have any children at home?  a. Yes  b. No

19) If yes, please list the numbers of children by age
   ≤ 5 years _______
   5-16 years _______
   > 16 years _______

20) What stage of breast cancer did you have at the time you were diagnosed?
   a. Stage 0
   b. Stage 1
   c. Stage 2
   d. Stage 3
   e. Stage 4
   f. Stage 5
   g. Unsure

21) What stage of breast cancer do you currently have?
   a. Stage 0
   b. Stage 1
   c. Stage 2
   d. Stage 3
   e. Stage 4
   f. Stage 5
   g. Unsure

22) Please share any other insights or observations that may help explain any barriers to medical care you may have experienced.

23) Can you think of any resources that may be helpful to you in overcoming any of these barriers?
Appendix B

Research Study on Barriers to Early Breast Cancer Detection in Central Illinois: Information Sheet

The Department of Geography at the University of Illinois Urbana-Champaign together with Carle Foundation Hospital Mills Breast Cancer Institute is sponsoring a survey for patients diagnosed with breast cancer. The focus of our survey is on geographical, social, and economic barriers women face in accessing breast cancer screening and diagnosing services. The questionnaire should take only 10-15 minutes to complete. Your input will help us better understand the problems women encounter when trying to seek medical screening or treatment. This survey is being conducted by Sara McLafferty, Professor of Geography at the University of Illinois at Urbana-Champaign, and Travis Leonard, a Masters student in Geography. Findings from the survey will be incorporated in Mr. Leonard’s M.A. thesis research project.

Your participation in this survey is completely voluntary. No one will know your identity and the results are completely anonymous. The researchers will share the overall results with the medical and academic community in the form of papers, M.A. thesis, and/or conference presentations, but no names, or any other personally identifying information will be used. Whether or not you decide to participate in this survey will in no way affect the patient care that you receive at Carle. Risks of participating in this survey are minimal and are not anticipated to exceed those that exist in daily life.

You may stop taking this survey at any time and may skip any question(s) you do not wish to respond to. Please do not write your name, address or any other personally identifying information on the survey form or envelope. When you have completed the survey, please place it in the pre-addressed, stamped envelope provided, seal it, and return the envelope via US Mail to the Carle Research Office.

Questions about this research study should be directed to the Principal Investigator, Dr. Sara McLafferty, or Travis Leonard. Dr. McLafferty can be reached at 217-244-1771 or smclaff@illinois.edu. Travis can be reached at 805-403-6942 or leonard4@illinois.edu. You may also contact Dr. Patricia Johnson at 217-383-4009 or patricia.johnson@carle.com. Questions about your rights as a research participant should be directed to the Carle Institutional Review Board Office at 217-383-4366 or irb@carle.com or the University of Illinois at Urbana-Champaign Institutional Review Board Office at 217-333-2670 or irb@uiuc.edu.

Thank you in advance for participating in this survey.
Please return the attached survey by November 13, 2009.
References


"BreastCancer.org - Breast Cancer Treatment Information and Pictures."


