EXPLORING WOMEN'S PERCEPTIONS OF BARRIERS AND FACILITATORS RELATED TO THE BREAST HEALTH CONTINUUM OF CARE

by

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University of Pittsburgh, 2011

Breast cancer remains the most common type of female cancer across all populations in the United States. However, a gap remains in understanding the perceptions women have as they relate to breast health and the breast health Continuum of Care, which includes screening, diagnosis, treatment, and follow-up care. Many existing studies lack appropriate data which explore these perceptions. Through a partnership between the University of Pittsburgh Graduate School of Public Health and the Pittsburgh Affiliate of Susan G. Komen for the Cure®, community-based participatory research was used to examine and understand the range of factors which affect a woman's ability to engage in the Continuum of Care. Concept mapping, an intensive, structured conceptualization process that produces a framework for how a group views a particular topic, was used. A strength of the method is that participants actively contribute to the research process through the generation of data, ensuring the final outcome is representative of their perspectives versus that of the researcher.

Thirty-one women and one man from three areas in western PA (Pittsburgh, Meadville, and Huntingdon) participated in the concept mapping sessions. They identified 94 factors perceived to be related to the breast health Continuum of Care. Examples of factors include trust in doctors, cost of transportation, number of treatment choices, and cancer diagnosis no longer is

a death sentence. Results were shown in a seven cluster concept map. Notable difference in cluster importance by location were explored. The public health significance of this research offers insight into the deficiencies and strengths of the health care community in addressing breast health and breast cancer needs of women. These findings are important for further research as it relates to women's perceptions around breast health and breast cancer. The research and partnership between the Graduate School of Public Health and Komen Pittsburgh has the potential to influence advocacy efforts, create a healthier environment in western PA, and inform testable hypotheses for future qualitative and quantitative, multi-level research on this topic.

TABLE OF CONTENTS

PREFACE XI

1.0 INTRODUCTION 1

2.0 BACKGROUND 3

2.1 SCOPE OF THE PROBLEM NATIONALLY 3

2.2 SCOPE OF THE PROBLEM IN WESTERN PENNSYLVANIA 4

2.3 THEORY 5

2.4 KNOWN FACTORS 6

2.5 THE BREAST HEALTH CONTINUUM OF CARE 7

2.6 SUMMARY 9

3.0 METHODS 10

3.1 COMMUNITY-BASED PARTICIPATORY RESEARCH APPROACH 10

3.2 CONCEPT MAPPING 12

3.2.1 Target Population 13

3.2.2 Data Collection 14

3.2.3 Brainstorming 15

3.2.4 Sorting and Rating 16

3.2.5 Data Analysis 18

4.0 RESULTS 20

4.1 AIM 1: FACTORS RELATED TO THE CONTINUUM OF CARE 20
4.1.1 Information and Resources 21
4.1.2 Communication and Health Choices 21
4.1.3 Support 22
4.1.4 Emotions and Beliefs 22
4.1.5 Experiential Barriers 23
4.1.6 Insurance and Financial Issues 23
4.1.7 Logistical Barriers 24
4.2 AIM 2: RELATIONSHIP OF FACTORS TO THE CONTINUUM OF CARE 25
4.2.1 Initial Screening 30
4.2.2 Treatment 32
4.2.3 Repeat Screening 34
4.3 AIM 3: COMPARING PITTSBURGH, HUNTINGDON, AND MEADVILLE 35
4.3.1 Initial Screening 36
4.3.2 Treatment 39
4.3.3 Repeat Screening 40
5.0 DISCUSSION 41
5.1 PRACTICE IMPLICATIONS 41
5.2 RESEARCH IMPLICATIONS 44
5.3 LIMITATIONS AND STRENGTHS 45
6.0 CONCLUSION 48

APPENDIX A: IRB APPROVAL LETTER 49

APPENDIX B: INFORMED VERBAL CONSENT SCRIPT 51

APPENDIX C: PARTICIPANT RATING SHEETS 53

APPENDIX D: DEMOGRAPHIC QUESTIONS 58

BIBLIOGRAPHY 59

LIST OF TABLES

Table 1. Participant Sorting Questions Based on Parts of the Breast Health Continuum of Care.25

Table 2. Factor Ratings. 27

Table 3. Cluster Table with Ratings. 27

LIST OF FIGURES

Figure 1. Breast Health Continuum of Care (Education Training Manual, 2010). 8

Figure 2. Research Timeline. 12

Figure 3. Seven Cluster Map. 19

Figure 4. Breast Health Continuum of Care Color-Coded for Participant Rating Scales..... 26

Figure 5. Initial Screening Cluster Ratings. 30

Figure 6. Treatment Cluster Ratings. 32

Figure 7. Repeat Screening Cluster Ratings. 34

Figure 8. Pittsburgh and Huntingdon Initial Screening Pattern Match Comparison. 37

Figure 9. Huntingdon and Meadville Initial Screening Pattern Match Comparison. 38

Figure 10. Meadville and Pittsburgh Initial Screening Pattern Match Comparison. 39

PREFACE

I have thoroughly enjoyed this research process, beginning with my initial research submission to Pitt's Institutional Review Board (IRB) in August 2010, to the collaboration with generous community partners and participants last fall, to analyzing the wealth of gathered data this winter as I wrote my thesis. I have conducted research which I am proud of, that has both personal meaning and practice implications for the entire public health community.

I see my public health career and knowledge base continuing to grow in the future by utilizing community-based participatory research approaches. I enjoy working with people; concept mapping allows a researcher to work in the community and learn from them. I have learned that gaining entrée and trust of the community is essential. As a researcher, I need to approach communities with honesty and integrity, and be open to learning from them because they are the experts on the topic. I have to be aware of ethical concerns, such as breaches in confidentiality and the possibility that participants may feel uncomfortable in a group setting sharing their personal experiences.

I am thankful for the mentoring of Drs. Jessica Burke and Ruth Modzelewski. We have all worked hard for the past eight months, and put many hours into this research process. True and meaningful relationships were formed, and Ruth and Jessie never lacked support and faith in me or encouragement when I needed it the most. For that, I am most grateful.

I have truly learned much more than the words of this thesis can even begin to express, and am humbled to have been a part of this partnership. My hope is that the addition of this important breast health research to the public health community can benefit many. My academic public health journey is not ending…it is only just beginning.

1.0 INTRODUCTION

Breast cancer remains the most common type of female cancer across all populations in the United States. However, a gap remains in understanding the perceptions women have as they relate to breast health and the breast health Continuum of Care, which includes screening, diagnosis, treatment, and follow-up care. Many existing studies lack appropriate data which explore these perceptions.

A partnership was formed between the University of Pittsburgh Graduate School of Public Health and the Pittsburgh Affiliate of Susan G. Komen for the Cure®. Community perceptions of breath health were explored based on the question, "What factors, either positive or negative, impact a woman's ability to engage in the breast health Continuum of Care?" Concept mapping, a community-based participatory research method was used to examine and understand the range of facilitators and barriers which affect a woman's ability to engage in the Continuum of Care.

This thesis provides background information on the scope of breast cancer both nationally and in western Pennsylvania, theory and known factors from literature, and explains the breast health Continuum of Care. The community-based participatory research approach and the method of concept mapping are outlined, including data collection, methods, and results. Researchers focused on three research aims:

1) factors related to the Continuum of Care, 2) relationship of factors to the Continuum of Care, and 3) comparing Pittsburgh, Huntingdon, and Meadville results. Research and practice implications are discussed, as well as limitations and strengths of using concept mapping for research.

2.0 BACKGROUND

In order to understand why this research is important to the field of public health, it is necessary to understand the scope of breast cancer nationwide and within western Pennsylvania, screening adherence theory, known factors from literature that limit women from engaging in breast health care, and the Continuum of Care as it relates to breast health.

2.1 SCOPE OF THE PROBLEM NATIONALLY

According to the Centers for Disease Control and Prevention (CDC), breast cancer is the first leading cause of cancer death among Hispanic women and is the second among white, black, Asian American, and American Indian women (CDC, 2010). It is the second leading cause of all female deaths in the United States (Menon, et al, 2007). Breast cancer affects women of all races, ages, and socioeconomic status – and the best way to prevent this disease is for all women over the age of 40 to receive annual screening mammograms (Komen, 2010). However, in looking at all eligible women who should receive a mammogram because they are over the age of 40, between 30% and 40% of women do not get mammograms (CDC, 2010; ACS, 2010). In fact, the number of women who receive yearly mammograms is actually dropping. The American Cancer Society (ACS) reports that the actual percentage of women aged 40 and older who reported having a mammogram within the past two years dropped from 70% in 2000 to 66% in 2005.

Breast cancer incidence rates have been decreasing; however, "the decrease in breast cancer incidence rates due to lower prevalence of mammography use gives the appearance of a decline in the rate of disease, but in fact reflects under-diagnosis or delayed diagnosis and not a true decrease in disease occurrence" (ACS, 2010). Annual mammography screening for all women could detect breast cancer at earlier stages and perhaps save lives.

2.2 SCOPE OF THE PROBLEM IN WESTERN PENNSYLVANIA

Statewide statistics from the Pennsylvania Department of Health show that breast cancer continues to be the leading cancer site for females, accounting for 27% of all female cancer cases diagnosed in 2005, and is the second most frequent cause of death. In 2005, almost 30% of breast cancer cases were diagnosed at the regional or distant stages of the disease. Late diagnoses result in poor five-year survival rates.

The total population of the Komen Pittsburgh Affiliate's 30-county region is approximately four million and 51.3%, or over two million, are female. The city center of Pittsburgh has the largest population, with 311,218 people. The service region is largely rural, with only 11 of the 30 counties having populations greater than 100,000. Over 13% of women ages 18-65 are lacking insurance coverage. About 40% of women in the Komen Pittsburgh Affiliate region do not receive annual screening mammograms. Average mortality rate is 26.47 per 100,000 women (Modzelewski, Jones, & Hagopian, 2011).

2.3 THEORY

Literature points to ways to predict adherence to mammography screening, and one way is to use health behavior theory. By using the Transtheoretical Model (TTM), researchers Menon, et al, (2007) separated mammography behavior into six distinct stages:

- Precontemplation (never had a mammogram and not planning on getting one within six months)
- Contemplation (never had a mammogram but planning to in the next six months)
- Action (has had a mammogram within the past 12 months)
- Relapse Precontemplation (has had a mammogram in the past but not planning on getting on within six months)
- Relapse Contemplation (has had a mammogram in the past and is planning on getting one within six months)
- Maintenance (has been adherent with mammograms for two years)

Using and understanding these stages of the TTM and knowing where a woman's thoughts and perceptions are in the utilization of mammography can help public health professionals plan and execute effective interventions. However, for interventions to be effective, the action of mammography and maintenance needs to take place.

It is essential to know and understand what barriers and/or facilitators either prevent or increase the likelihood that a woman will receive annual screening mammograms. Identifying their perceived barriers and facilitators will aid public health and medical professionals in targeting education and advocacy efforts, in hopes to reduce the number of women who do not

receive mammograms annually. Breast cancer deaths could be reduced by 22% each year if women were to receive annual screening mammograms (Gierisch, Earp, Brewer & Rimer, 2010).

2.4 KNOWN FACTORS

Literature suggests a number of reasons why women do not adhere to annual mammography. Researchers Gierisch, et al, define annual screening adherence as "having a second mammogram 10 to 14 months after a previous mammogram" (2009). Barriers to breast cancer adherence, also referred to in literature as maintenance, can be operationalized into sociodemographic and medical variables and attitude and belief variables (Gierisch, Earp, Brewer & Rimer, 2010). Some of the barriers associated with routine mammograms include lack of time, forgetting to make another appointment, and cost. The researchers found that the more barriers women self-reported, the less likely they were to adhere to mammograms (Gierisch, et al, 2009). Even reporting only one barrier could lead to nonadherence (Gierisch, Earp, Brewer, Rimer & 2010). Financial barriers are also an important factor in preventing annual mammography use. "Health insurance coverage is strongly associated with access to healthcare, including use of mammography" state authors Makuc, Breen, Meissner, Vernon, and Cohen (2001). In 2008, 46.3 million persons in the United States were uninsured (U.S. Census Bureau, 2010).

However, positive facilitators can increase the likelihood that a woman will receive annual screening mammograms. In one study, African American and Hispanic women noted that the best facilitator to receiving a mammogram was a recommendation for screening by a trusted clinician. Other facilitators included knowing their family medical history and insurance coverage (Ogedegbe, et al, 2005). Another study done by researchers Lerman, Rimer, Trock,

Balshem, and Engstrom reported that "both a family history of breast cancer and heightened perceived vulnerability to breast cancer were associated positively with repeat mammography participation" (1990).

Conducting research and collecting data and statistics on mammography adherence and maintenance is a relatively new area of study. Gaps include few research studies on adherence for women in their 40s (Gierisch, et al, 2009), and a complete understanding of what barriers women face and the facilitators women use to affect their decision-making in whether or not to receive an annual screening mammogram.

2.5 THE BREAST HEALTH CONTINUUM OF CARE

Knowing what previous literature and theory states about mammogram adherence can be helpful for public health professionals; however, no research has been completed that specifically targets women's perceptions as they related to breast health, breast cancer, and the breast health Continuum of Care.

The breast health Continuum of Care (see Figure 1) is used by Susan G. Komen for the Cure® and "represents one's movement through the healthcare system to screen for breast cancer, and if necessary diagnose and treat breast cancer" (Education Training Manual, 2010). There are four parts to the continuum: screening, diagnosis, treatment, and follow-up care. It is a cyclical process, with a woman entering into the continuum with her initial screening mammogram. Ideally, she receives a normal reading and then moves on to follow-up care either with her primary care physician (PCP) or her gynecologist who recommends her for continued

annual screening mammography. If instead she receives an abnormal reading, she enters the diagnostic aspect of additional testing to determine the nature of the abnormal mammogram.

If additional testing of further breast imaging studies and/or biopsy does not detect cancer, then the woman would continue with follow-up care with her PCP or gynecologist. If a positive diagnosis of breast cancer is determined, then the woman proceeds into treatment. Each woman's treatment options are different, and she should make choices appropriate for her life. Once treatment is completed, the woman should remain within the continuum under follow-up care to ensure the longest possible survivorship (Modzelewski, Jones, & Hagopian, 2011).

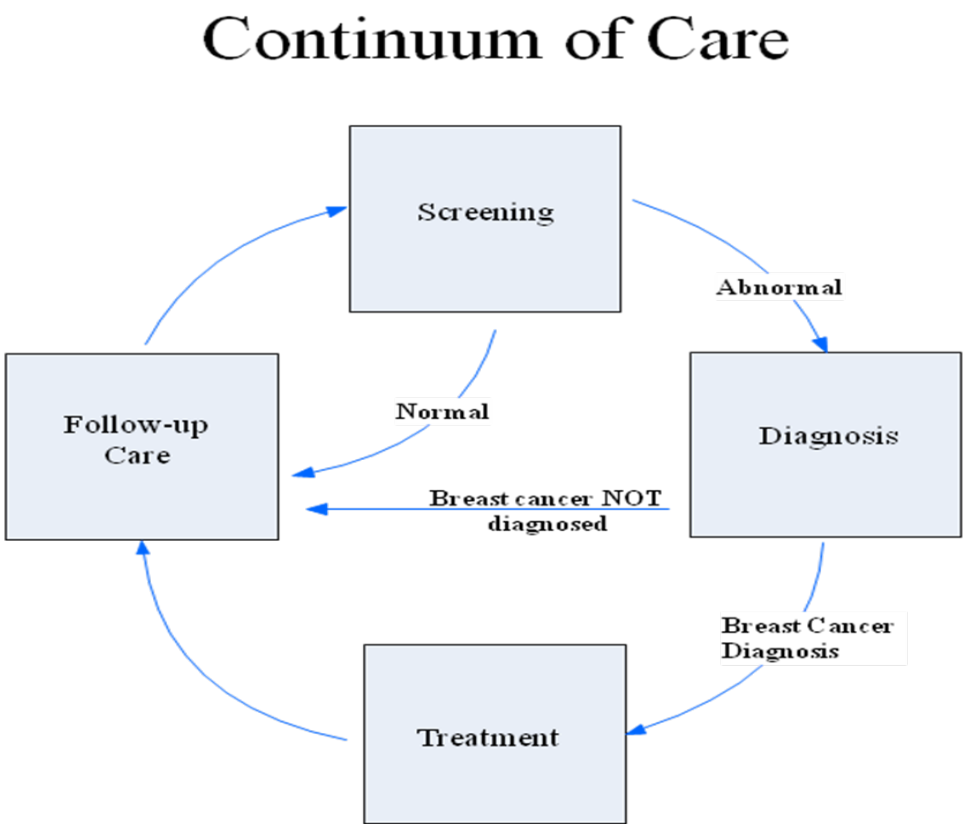

Figure 1. Breast Health Continuum of Care (Education Training Manual, 2010).

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2.6 SUMMARY

This thesis asks the question, "What factors, either positive or negative, impact a woman's ability to engage in the breast health Continuum of Care?" The answers to this question provide key insights that will further research as it relates to breast health and the breast health Continuum of Care. Specifically the aims are to find out: 1) what factors are related to the Continuum of Care?; 2) what is the relationship of these factors to the Continuum of Care?; and 3) is there a difference in comparing Pittsburgh, Huntingdon, and Meadville?

3.0 METHODS

3.1 COMMUNITY-BASED PARTICIPATORY RESEARCH APPROACH

Breast cancer is a complex problem that requires an innovative approach to understand the range of factors that are associated with the disease and women's perceptions about the disease. Community-based participatory research (CBPR) is an approach that can be used to address this issue within the community. It is defined as "a collaborative approach to research that equitably involves [all partners] in all aspects of the research process. Partners contribute unique strengths and shared responsibilities to enhance understanding of a given phenomenon…and integrate all knowledge gained with action to improve the health and well-being of community members" (Israel, et al, 1998). Community-based participatory research is gaining increased recognition, especially in the field of public health (Israel et al, 2005).

A partnered approach was used for all data collection activities and analysis. In the spring of 2010 researcher Jennifer Jones, MPH-candidate and Pitt student at the Graduate School of Public Health, was an intern working on a breast health grant with Magee Womancare International. The grant was funded by the Pittsburgh Affiliate of the Susan G. Komen for the Cure®. Through the internship, she began a professional working relationship with Ruth Modzelewski, PhD, Mission Coordinator at Komen Pittsburgh. During this same time, Jones enrolled in the Community-Based Participatory Research and Practice certificate program under

the direction of Jessica Burke, PhD, Assistant Professor at the Graduate School of Public Health. Through conversations with Modzelewski, Jones found out that Komen Pittsburgh was beginning to work on their 2011 Community Profile Report and needed an intern to assist with the project. Because the certificate has a practical internship requirement, Jones began an internship at Komen Pittsburgh and a community partnership was formed.

The research team consisted of Jones, Modzeleweski, and Burke. All three members collaborated on a weekly basis throughout the entire research process. Concept mapping was decided by the team to be the best method to collect data from the community. Concept mapping is an innovative and unique way to gather community perceptions around a focused topic. Jones and Modzelewski attended and led all six concept mapping sessions (two sessions each at three different locations) and Burke facilitated one concept mapping session at the Pittsburgh location. Jones entered all participant data into the Concept Systems computer software, and the whole research team analyzed the results and discussed practice implications and limitations. Jones worked with Komen Pittsburgh an average of 10 hours per week for eight months (August 2010 to March 2011). Modzelewski was able to use the data in the bi-annual 2011 Komen Pittsburgh Community Profile Report, written by Jones and Modzeleweski. Refer to Figure 2 for a more detailed research timeline.

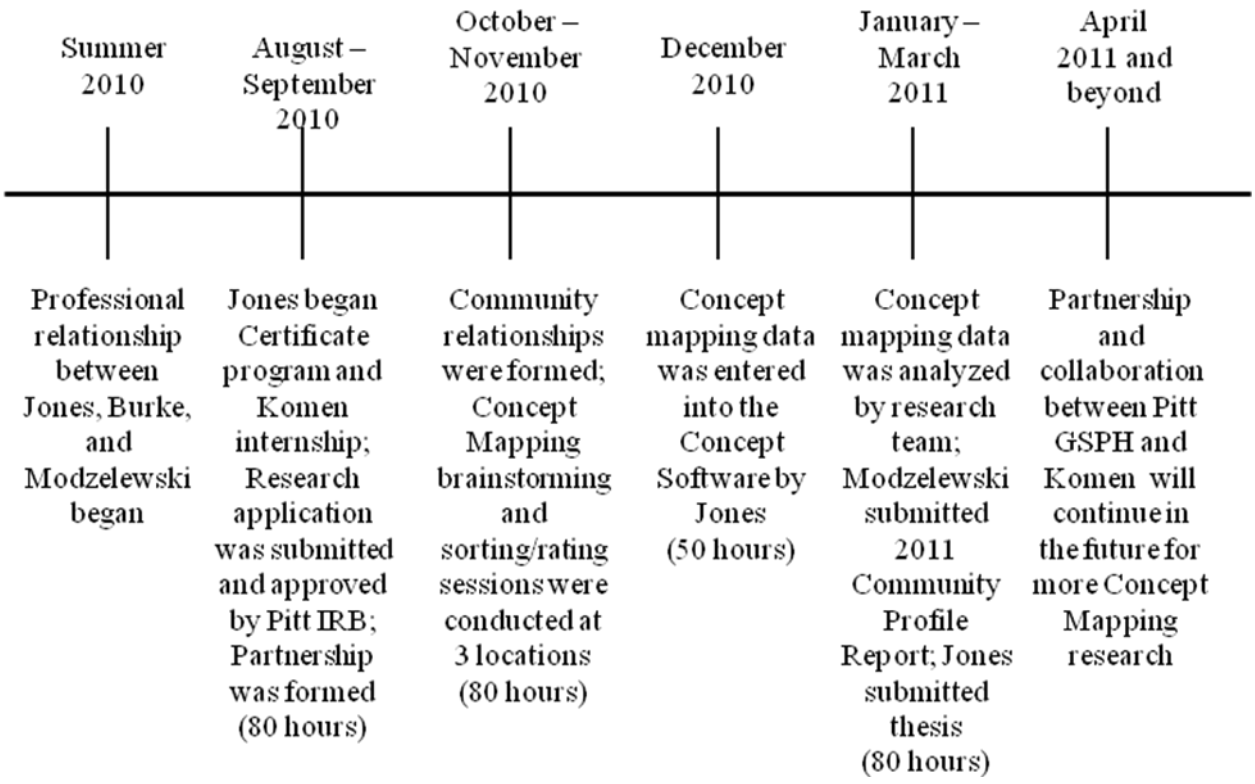

Figure 2. Research Timeline.

The community-based participatory research process was a group effort between all members of the research team. Each member was committed to the project and a strong and meaningful partnership was created between the Graduate School of Public Health and Komen Pittsburgh; the partnership is one that will continue in the future.

3.2 CONCEPT MAPPING METHOD

This study used concept mapping as a participatory method in regards to breast health and breast cancer. Concept mapping has been used in public health, but never to address the topic of cancer. It has been used effectively in public health to study and neighborhood violence, intimate partner

violence, and mental well-being, and to draw conclusions on these issues (Burke, 2005; Burke, 2009; O'Campo, 2008). Using concept mapping can help the public health arena gain an understanding of perceptions related to the breast health Continuum of Care. Concept mapping allows researchers to examine and understand the range of factors, both positive and negative, which affect a woman's ability to engage in the Continuum of Care. Concept mapping also allows participants to be active members of the research process. It is a descriptive method which is designed to generate hypotheses and gain an in-depth understanding of the topic of interest (Burke et al, 2005). Identifying and addressing the deficiencies and strengths will enable more women to be engaged in the continuum.

3.2.1 Target Population

In 2009, the Pittsburgh Affiliate of Susan G. Komen for the Cure® completed a Community Profile Report. The report focused on demographic and statistical information collected from their service region. Other data collected included program and service information from the counties, such as the number of hospitals, mammography providers, Mammogram Voucher Program (MVP) sites, and breast cancer support groups for each county. The report found that most western PA counties do not have direct or close access to resources and public transportation, which could be identified as a barrier to the Continuum of Care. The report also pointed out that while some counties do have a high availability of resources, incidence and/or mortality rates were still high. The areas of Pittsburgh, Huntingdon, and Meadville were chosen because their perceptions could provide valuable information into the strengths and deficiencies of the Continuum of Care.

Concept mapping sessions were conducted in three locations in western Pennsylvania: Pittsburgh, Huntingdon, and Meadville. These locations were chosen by Komen Pittsburgh because they are within the 30-county western PA service region of Komen Pittsburgh. The three sites that participated in the concept mapping sessions represented different parts of western Pennsylvania. Pittsburgh was the urban site, which had many resources available; Huntingdon was the rural site, where the county had only one hospital and it was possible that women would need to travel long distances (up to an hour and a half) to receive breast health services; and Meadville was the "in-between" site – a rural setting that had breast health services available on-site, but yet was situated between two larger cities (Erie and Pittsburgh) with abundant resources. Komen Pittsburgh wanted to know if differences were seen in the areas of initial screening, treatment, and diagnosis based on geographic location and the availability of breast health resources.

3.2.2 Data Collection

Many hours of preparation by the research team was completed before concept mapping sessions began. The concept mapping data collection process was completed the same for each of the three areas. Activities consisted of two meetings: the first was a brainstorming session and the second was a sorting and rating session. The brainstorming sessions allowed participants to discuss factors associated with the breast health Continuum of Care and the sorting and rating sessions allowed participants to organize the factors into piles that "made sense" to them and then rate the factors according to their perceived level of importance around three topics – initial screening, treatment, and repeat screening. All data collection methods and activities were reviewed and approved by the University of Pittsburgh Institutional Review Board (see

Appendix A for approval letter). Participants for the concept mapping sessions were recruited using flyers and word of mouth by breast health coordinators and patient navigators in the given area. The following paragraphs discuss in detail each activity.

3.2.3 Brainstorming

Three brainstorming sessions of approximately two hours in length were held in Pittsburgh, Huntingdon, and Meadville during the months of October and November 2010. Thirty-nine women participated in the sessions (seven in Pittsburgh, 16 in Huntingdon, and 16 in Meadville). Before beginning the brainstorming session, each participant was required to give verbal informed consent, knowing that they can withdraw from the study at any time (see Appendix B for script). Participants were asked to discuss their thoughts around the focal question, "What factors, either positive or negative, impact a woman's ability to engage in the breast health Continuum of Care?"

Before open discussion started responding to the question, a detailed explanation of the breast health Continuum of Care was given to each woman, including a visual diagram they could reference (refer to Figure 1). The breast health Continuum of Care model illustrates the steps necessary in providing comprehensive breast health and breast cancer care. Women were informed that the model outlines the four key areas of breast health: screening, diagnosis, treatment and follow-up care.

Each woman was asked to share with the group based on either her own personal experience or based on what she has heard from other women in the community. Concept mapping is best when used in small group settings because it captures the lived experiences of

target populations and explores factors that are associated with specific health outcomes (Burke, et al, 2005).

During the session, the facilitator (either Jones or Modzeleweski) wrote down each generated phrase and idea. The items were written down on a flip chart for the entire group to see. Each participant was encouraged to add to the discussion, and at the end of the session the group reviewed the list and agreed that it was exhaustive and represented both their individual and collective perspectives.

The three combined brainstorming sessions outputted 209 factors related to the Continuum of Care (60 factors from Pittsburgh, 75 from Huntingdon, and 74 from Meadville). However, many of the items were repeated or similar across the three locations. An example of this is "volunteers to be with patients" (Pittsburgh), "support system is helpful for women" (Huntingdon), and "friends/husbands can be support system" (Meadville). These three individual items were combined to be "community strength can assist in support." The entire research team spent multiple hours combining the separate factor lists to create one master list of 94 distinct factors (see Table 3 for complete list). This list represented all of the ideas generated in the brainstorming sessions from Pittsburgh, Huntingdon, and Meadville. The final master factor list was then used in the sorting and rating sessions.

3.2.4 Sorting and Rating

Three sorting and rating sessions of approximately two hours each were held in Pittsburgh, Huntingdon, and Meadville during the months of November and December 2010. The sessions consisted of two parts. Thirty women and one man participated in the sorting activity (nine women and one man in Pittsburgh, 11 women in Huntingdon, and 10 women in Meadville).

Thirty-one women and one man participated in the rating activity (10 women and one man in Pittsburgh, 11 women in Huntingdon, and 10 women in Meadville). The difference in the number between sorting and rating is that one participant from Pittsburgh did not complete the sorting activity correctly and her data was not used. Many of the participants in the sorting and rating sessions also participated in the brainstorming sessions; however each participant was required to give verbal informed consent (see Appendix B for script), knowing that they could withdraw from the study at any time.

During this session, participants were asked to sort the 94 items from the master list into similar piles based on their individual interpretation of the meaning of the items. Each participant was given a packet that contained 94 index cards. A single phrase or idea (factor) was typed on each card. The factors were also number 1-94 (see Table 3 for factors with their corresponding number). The numbers were generated by the computer software program and have no impact on the factors. Once the factors were sorted into similar piles, participants gave each pile a label (word or phrase) that in their opinion described the pile. The participant labels capture the theme of the piles and can later be examined during data analysis.

During the same session, participants were also asked to rate each item relative to how they perceived its importance as a barrier or facilitator to initial screening, treatment, and repeat screening. Three different rating sheets (see Appendix C), along with the Continuum of Care diagram (refer to Figure 4) were also found in the packet. The rating sheets each addressed a different area of the Continuum of Care – initial screening, treatment, and repeat screening. The participants were asked to rate the factors on a scale of 1-5, with one being 'not at all important' and five being 'very important'. The researchers stressed to the participants the importance of rating the factors on a continuum (not all 1's or all 5's) to allow for better analysis.

After completion of the sorting and rating, the last thing participants did was fill out a demographic questionnaire (see Appendix D). The questionnaire contained questions related to the participant's age, zip code, education level, job status, and survivor status.

Once completed, all sorted and labeled factor piles, rating sheets, and demographic questionnaires were placed back into the packet for the researcher to collect. Each packet, along with the rating sheets and demographic sheet, had an identification number for each participant so data would be anonymous and had no identifier to the participant.

3.2.5 Data Analysis

The rating data was used to generate maps for data analysis which indicate how the participants viewed the strength of association between the factors and the parts of the Continuum of Care. The data from each participant was entered into a computer software program. Researchers looked at the data and decided upon a seven cluster map (refer to Figure 3) which was used to analyze the data based on the strength of associations between the items from the sorting sessions that were completed by the participants. Utilizing the Concept Systems software by entering each participants sorting and rating data into the system, multidimensional scaling analyses were performed. A series of maps were used to illustrate the location of each item and how it relates to other items based on proximity. The types of maps created include a point map, point cluster map, cluster ratings map, and pattern match. From these maps, data can be understood and hypotheses and theories can be generated.

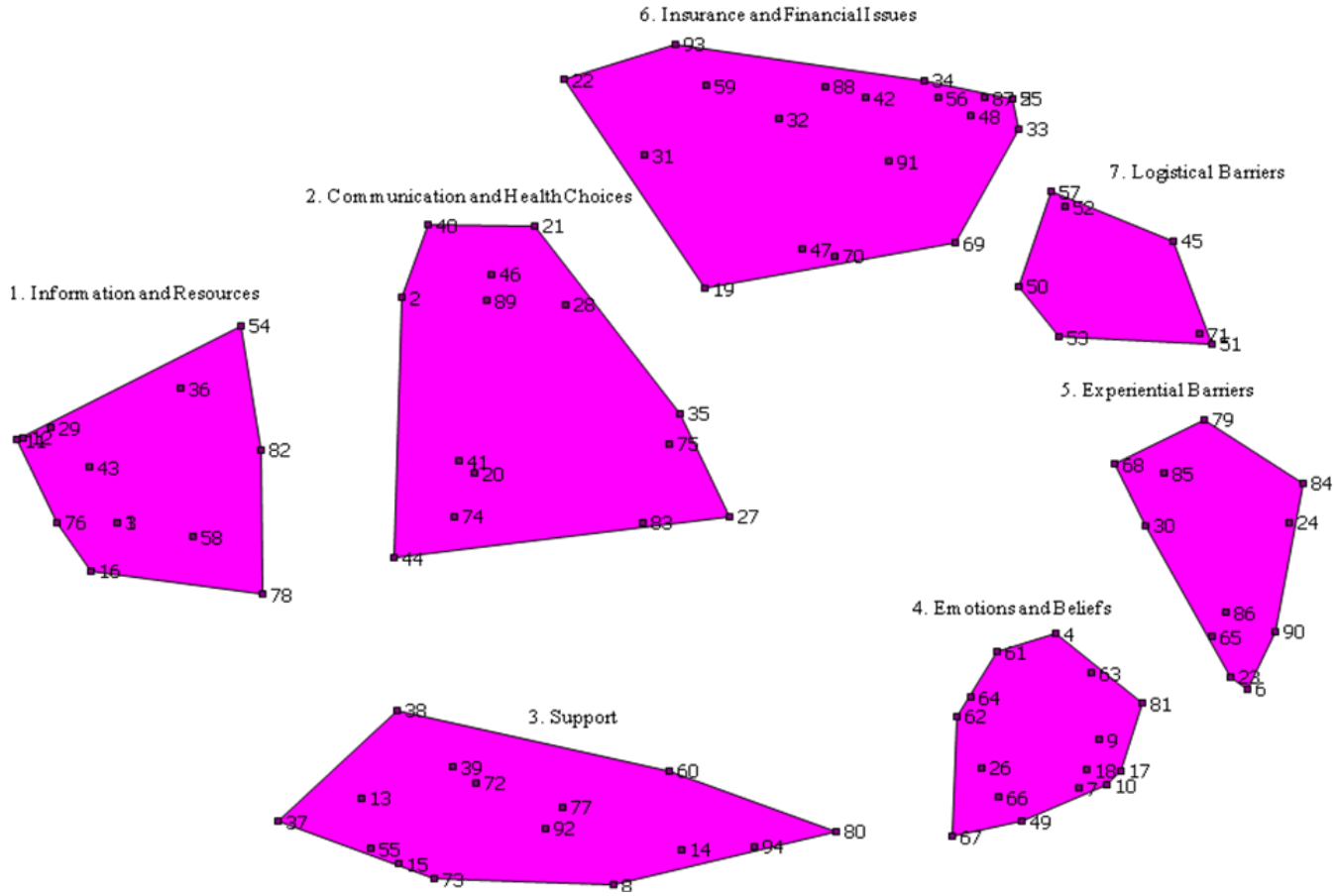

Figure 3. Seven Cluster Map.

Another part of the results analysis is to run a patter match analysis. Pattern matching compares "average cluster ratings for a rating variable between demographic groups, points in time, or other variables" (Kane and Trochim, 2007). The pattern match comparison produces a ladder-like graph (refer to Figures 8-10) that can be used to determine consensus across groups or how consistent the results are across the groups, shown by a correlation coefficient of *r*. Kane and Trochim (2007), note that a correlation coefficient of $r = .73$ or higher show a the overall correlation is high. Most pattern match comparisons are done at the cluster level. Utilizing pattern matches during analysis allows researchers to rate priorities and can be used in evaluation.

4.0 RESULTS

4.1 AIM 1: FACTORS RELATED TO THE CONTINUUM OF CARE

The first research aim was to indentify the range of factors women perceived to be related to the breast health continuum of care. Ninety-four distinct factors were generated from the focal question, "What factors, either positive or negative, impact a woman's ability to engage in the Continuum of Care?" Factors include: education about breast screening (1), doctor/patient communication (28), shared experiences around diagnosis (13), fear of process (9), trust of doctors (84), high cost of insurance deductibles (5), and need for prescription to get mammogram (52), among others. For a complete list see Table 3. The 94 factors were organized into seven clusters. The number of clusters was chosen by the consensus of the research team. The researchers also reviewed a six cluster map, eight cluster map, and nine cluster map; however, it was decided that a seven cluster map was the best representation of the data.

The seven clusters are: 1. Information and Resources, 2. Communication and Health Choices, 3. Support, 4. Emotions and Beliefs, 5. Experiential Barriers, 6. Insurance and Financial Issues, and 7. Logistical Barriers. The names of the clusters were decided upon by the researchers, based on the labels the participants used during the sorting process. Some of the clusters were easier to label than others; however, all the cluster names capture the essence of the statements within.

4.1.1 Information and Resources

This cluster contains 13 items that refer to the participants views on ways to receive breast health and/or breast cancer information and resources. Other category labels were "ways to learn breast health information and share information" and "education – 'knowledge is power.'" Specific items in the cluster include: Komen website as source of information (12), scattered information sources (36), and breast information available at alternative sites, like beauty and nail salons (76). Items within the cluster that are the closest related are education about breast screening (1) and education of general public about breast health (3). These factors were located directly on top of each other and had the same proximity, which means that every single participant put these two factors in the same sorting pile.

4.1.2 Communication and Health Choices

There are 14 different items within this cluster, and examples include: dedicated breast health care specialists (2), knowledge about how and where to access services (35), and comfort level in sharing with physician (75). The cluster comprises factors that participants felt to be related to communication and its relationship to health care practitioners and health care options. Participants also labeled the cluster as: "check out your choices" and "medical care and treatment and relationship with doctors/medical community." Items that have close association within the cluster are treatment options for patients (20) and annual mammogram reminder (41), while items that are not as closely related within the cluster are medical complications/history (27) and patient/health organization relationship (40).

4.1.3 Support

The Support cluster contains 15 factors that participants felt were important after a woman is diagnosed with breast cancer. Other cluster labels from the participants include: “dealing with survivorship” and “personal emotional responses.” The cluster contains items such as community strength can assist in support (37), “what is the big deal” survivor tactic approach (60), and experience was different than expected (94).

The items in this cluster were all fairly similar in meaning. From the cluster map, the items that were shown to be most closely related were support from faith/God/church (15), breast cancer support groups (55), and survivors are mentors and advocates for breast health (73).

4.1.4 Emotions and Beliefs

The Emotions and Beliefs cluster contains 15 items; however, in comparison with the other 15-item cluster (Support), the cluster numbers are closer, meaning the items are more closely related. For items in a cluster to be closely related, the majority of participants would have sorted them together in the same pile. The participant labels for this cluster included titles such as: “emotional issues unique to individuals but not applicable for everyone”; “myths why we don’t take care of ourselves”; “fears, beliefs, cultures on breast cancer”; and “emotions, perceptions, reality of what women bring.” The majority of the participant labels contained either the word emotion or belief, or some variation, so the cluster label is appropriate. Examples of the items in this cluster are: stress/feeling of being overwhelmed (49), religious beliefs (26), and fear of mammograms/mammograms may hurt (81).

4.1.5 Experiential Barriers

This cluster consists of factors the participants viewed as possible negative factors associated with the Continuum of Care. Many of the factors can be labeled as barriers, or factors that make obtaining a screening mammography, treatment, and follow-up care difficult. Examples of factors include language barrier (24), illiteracy (30), and long time to wait for results (68). The participants labeled this cluster as "difficulty of tests/results", "culture concerns about breast health and breast cancer that need to be addressed", and "reasons for delaying mammograms." The two items that are most closely associated within the cluster are cultural beliefs/norms (6) and taboos concerning a woman's body (23).

4.1.6 Insurance and Financial Issues

The sixth cluster encompasses all the factors related to money and insurance, and is the largest cluster, with 19 related items. The factors in the cluster range from insurance deductibles to access issues to paperwork. Specifics include: financial guidance (22), insurance restrictions based on pre-existing conditions (48), and access to transportation (91). Many of the participant category labels were similar: "financial liabilities", "money problems", "money concerns", and "financial guides and insurance". In the cluster, the items high cost of insurance deductibles (5) and uninsured/underinsured (25) were directly on top of each other, again meaning that each participant sorted those two items in the same pile.

4.1.7 Logistical Barriers

At seven items, the cluster of Logistical Barriers has the smallest number of factors. It comprises items such as lack of primary care physician (51), need for prescription to get mammogram (52), and doctors may want to see patient first/liability issues for doctors (53). This cluster is made up of system factors that make it difficult to get a mammogram, tests, or results. Other category labels include: “reasons/excuses to avoid or not seek screening or treatment”, “physician responsibility”, and “difficulty of tests/results”. In this cluster, the items lack of primary care physician (51) and scheduling mammograms/tests/treatments may be difficult (71) are the most closely associated.

4.2 AIM 2: RELATIONSHIP OF FACTORS TO THE CONTINUUM OF CARE

Another important part of the results analysis is to understand the importance of each of the factors and clusters as they relate to the Continuum of Care. Participants were asked to rate each factor three times on a scale of 1-5, with one being 'not at all important' and five being 'very important'. The three rating scales were based on the parts of the Continuum of Care.

Table 1. Participant Sorting Questions Based on Parts of the Breast Health Continuum of Care.

Part of the Continuum of Care	Question
Initial Screening	What is the importance of each of these factors on a woman receiving her first mammogram?
Treatment	If a woman is diagnosed with breast cancer, how important are each of these factors on her receiving treatment?
Repeat Screening	For a woman who has had a mammogram or been treated for breast cancer, how important are each of the factors for her repeat screening (mammogram, CT scan, etc)?

To aid in the rating process, participants were give another version of the breast health Continuum of Care, which was color-coded with pink, green, and blue (see Figure 4). The colors each represented a different part of the Continuum of Care. The research team felt this would make rating easier for the participants.

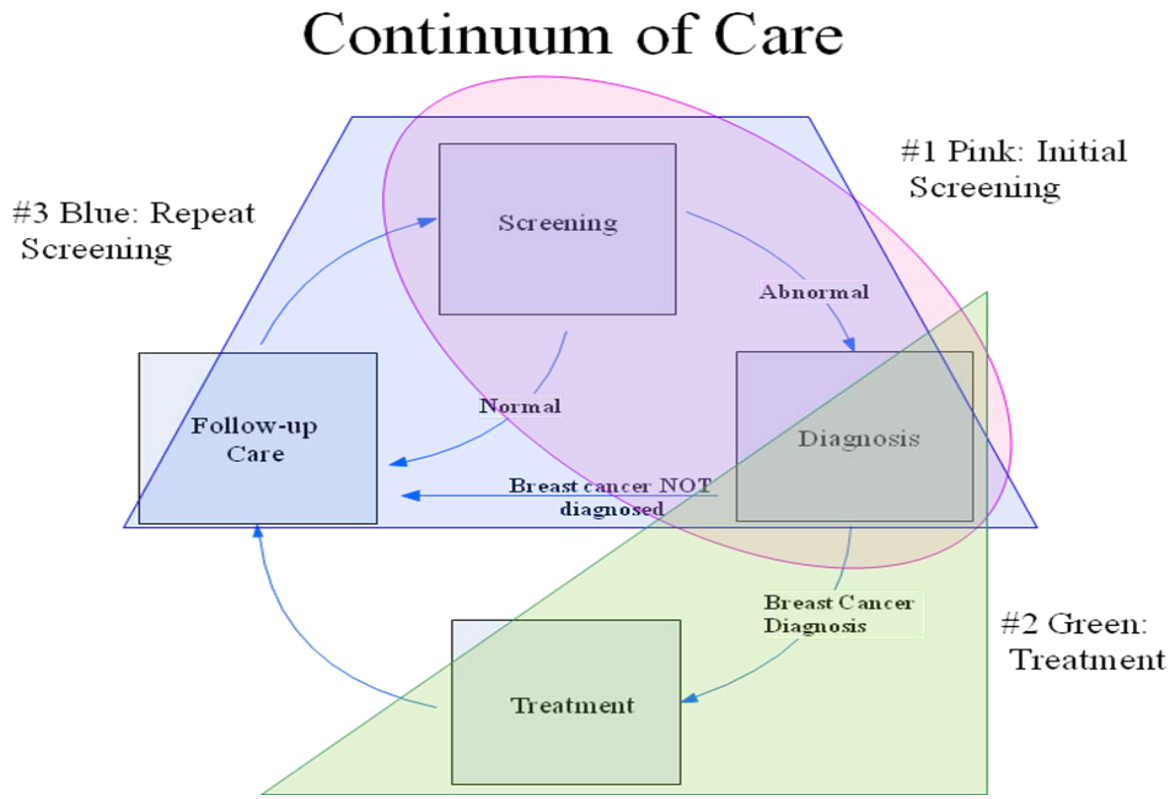

Figure 4. Breast Health Continuum of Care Color-Coded for Participant Rating Scales.

Initial screening rankings for factors ranged from a low of 2.16 to a high of 4.84, treatment rankings ranged from a low of 2.00 to a high of 4.81, and repeat screening rankings ranged from a low of 1.94 to high of 4.84. Results are shown in the following table, divided into seven clusters with the corresponding factors. Results were then divided into categories of high, moderate, and low.

Table 2. Factor Ratings.

High	Factors rated 3.80 and higher
Moderate	Factors rated between 3.79 and 2.90
Low	Factors rated 2.80 and lower

Table 3. Cluster Table with Ratings.

Cluster/ item name (item number)	Initial screening rating	Treatment rating	Repeat screening rating
Cluster 1: Information and Resources			
Education about breast screening (1)	High	Moderate	High
Education of general public about breast health (3)	High	Moderate	Moderate
Social media (e.g. Facebook, Twitter) (11)	Low	Low	Low
Komen website as source of information (12)	Moderate	Moderate	Moderate
Support from scientific evidence (16)	High	High	High
Access to internet for information (29)	Low	Moderate	Low
Scattered information sources (36)	Moderate	Moderate	Moderate
Advertisements of screening mammography events (43)	Moderate	Low	Moderate
Health care staff need education to know where to send patients (54)	High	High	High
Women need to be proactive about breast health (58)	High	High	High
Breast information available at alternative sites, like beauty and nail salons (76)	Moderate	Low	Low
Family history (BRCA1 or BRCA2) (78)	High	Moderate	Moderate
Want specific/detailed information about breast cancer and treatment (82)	Moderate	High	Moderate
Cluster 2: Communication and Health Choices			
Dedicated breast health care specialists (2)	High	High	High
Treatment options for patients (20)	High	High	High
Number of providers equals choice (21)	Moderate	Moderate	Moderate
Medical complications/history (27)	High	High	High
Doctor/patient communication (28)	High	High	High
Knowledge about how and where to access services (35)	High	High	High
Patient/health organization relationship (40)	High	High	High
Annual mammogram reminder (41)	Moderate	Moderate	High
Breast care coordinators guide women (44)	Moderate	High	High
Coordination between doctor's offices (46)	High	High	High
Confusing screening guidelines (74)	High	Moderate	High
Comfort level in sharing information with physician (75)	High	High	High
Actively participate in personal health decisions (83)	High	High	High

Table 3. Continued.

Health care providers look at whole person (mind/body/soul/spirit) (89)	Moderate	High	High
Cluster 3: Support			
Pennsylvania culture celebrates survivorship (8)	Moderate	Moderate	Moderate
Shared experiences around diagnosis (13)	Moderate	High	High
Personal emotional strength (14)	High	High	High
Support from faith/God/church (15)	Moderate	High	High
Community strength can assist in support (37)	Moderate	High	Moderate
Increased life expectancy/cancer is not longer a death sentence (38)	Moderate	High	High
Long-term side effects on health/fertility (39)	Low	High	Moderate
Breast cancer support groups (55)	Moderate	High	High
"What is the big deal" survivor tactic approach (60)	Low	Moderate	Moderate
Support after tests/treatments are completed (72)	Moderate	High	High
Survivors are mentors and advocates for breast health (73)	Moderate	High	High
Family/friends/companion support at tests/treatment/doctor visits (77)	Moderate	High	High
Impact on family/children/friends (80)	Moderate	High	High
Positive reinforcement "its going to be okay" (92)	Moderate	High	Moderate
Experience was different than expected (94)	Moderate	Moderate	Moderate
Cluster 4: Emotions and Beliefs			
Myths about breast cancer risk (4)	Moderate	Moderate	Moderate
Cancer diagnosis equals deficiency/embarrassment (7)	Low	Moderate	Low
Fear of process (9)	Moderate	High	Moderate
Fear of results/diagnosis (10)	High	High	High
Anger (17)	Low	Moderate	Low
Stress/feelings of being overwhelmed (18)	Moderate	High	High
Religious beliefs (26)	Moderate	Moderate	Low
Fear of discrimination (49)	Low	Moderate	Moderate
Comfort level in discussion breast health (61)	Moderate	High	High
Age affects perceptions of breast health (62)	Moderate	Moderate	Moderate
Young women may feel immortal, may not think they can get breast cancer (63)	Moderate	Low	Moderate
Women put other things before getting a mammogram, may feel "bulletproof" (64)	Moderate	Low	Moderate
Motivation (66)	High	High	High
Fear of recurrence (67)	Moderate	High	High
Fear of mammograms/mammograms may hurt (81)	Moderate	Low	Low
Cluster 5: Experiential Barriers			
Cultural beliefs/norms (6)	Moderate	Moderate	High
Taboos concerning a woman's body (23)	Low	Low	Low
Language barrier (24)	Moderate	Moderate	Low
Illiteracy (30)	Moderate	Moderate	Moderate
Too busy for themselves, moms take care of others before themselves (65)	High	Moderate	Moderate
Long time to wait for results (68)	Moderate	Moderate	High

Table 3. Continued.

Doctors are complacent/don't think it is important to have breast exams (79)	Moderate	Moderate	Moderate
Trust of doctors (84)	High	High	High
Consistent false positive mammograms (85)	Moderate	Low	Moderate
Tests can be painful (86)	Moderate	Moderate	Moderate
Fear of doctors (90)	Moderate	Moderate	Moderate
Cluster 6: Insurance and Financial Issues			
High cost of insurance deductibles (5)	High	High	High
Health care provider and patient interactions (19)	High	High	High
Financial guidance (22)	Moderate	High	High
Uninsured/underinsured (25)	High	High	High
Access to childcare and/or eldercare (31)	Moderate	Moderate	Moderate
Access to public transportation (32)	Moderate	Moderate	Moderate
Cost of transportation (33)	Moderate	High	Moderate
Assistance that exists can have limitations (34)	Moderate	High	Moderate
Financial screening resources for area (42)	High	Moderate	High
Health care providers services limited by time (47)	Moderate	High	Moderate
Insurance restrictions based on pre-existing conditions (48)	Moderate	High	High
Funding for programs is always unsure (56)	Moderate	Moderate	Moderate
Understandable information about insurance coverage (59)	High	High	High
Policies about reporting varies between health care providers (69)	Low	Moderate	Moderate
Restrictions to access medical records (70)	Low	Moderate	Moderate
Trouble with insurance company for certain tests (87)	High	High	High
Insurance can be confusing/lots of paperwork (88)	High	High	High
Access to transportation (91)	Moderate	Moderate	Moderate
Long-term financial stress (93)	Moderate	High	High
Cluster 7: Logistical Barriers			
Distance to appointments/tests/treatments (45)	Moderate	High	High
Paperwork for appointments/tests/treatments (50)	Moderate	High	Moderate
Lack of primary care physician (51)	High	Moderate	Moderate
Need for prescription to get mammogram (52)	High	Moderate	High
Doctors may want to see patient first/liability issues for doctors (53)	Moderate	Low	Moderate
Medical professionals need to be creative on where to get funding (57)	Moderate	Moderate	Moderate
Scheduling mammograms/tests/treatments may be difficult (71)	High	High	High

The high/moderate/low rating scale has been used in concept mapping research in the past and has been shown to be a useful way to understand a factor's relative importance (O'Campo, et al, 2005). Knowing the relative rating of each factor individually and as it relates

to its' cluster organization is importance for practice implications and further research regarding breast health and breast cancer.

4.2.1 Initial Screening

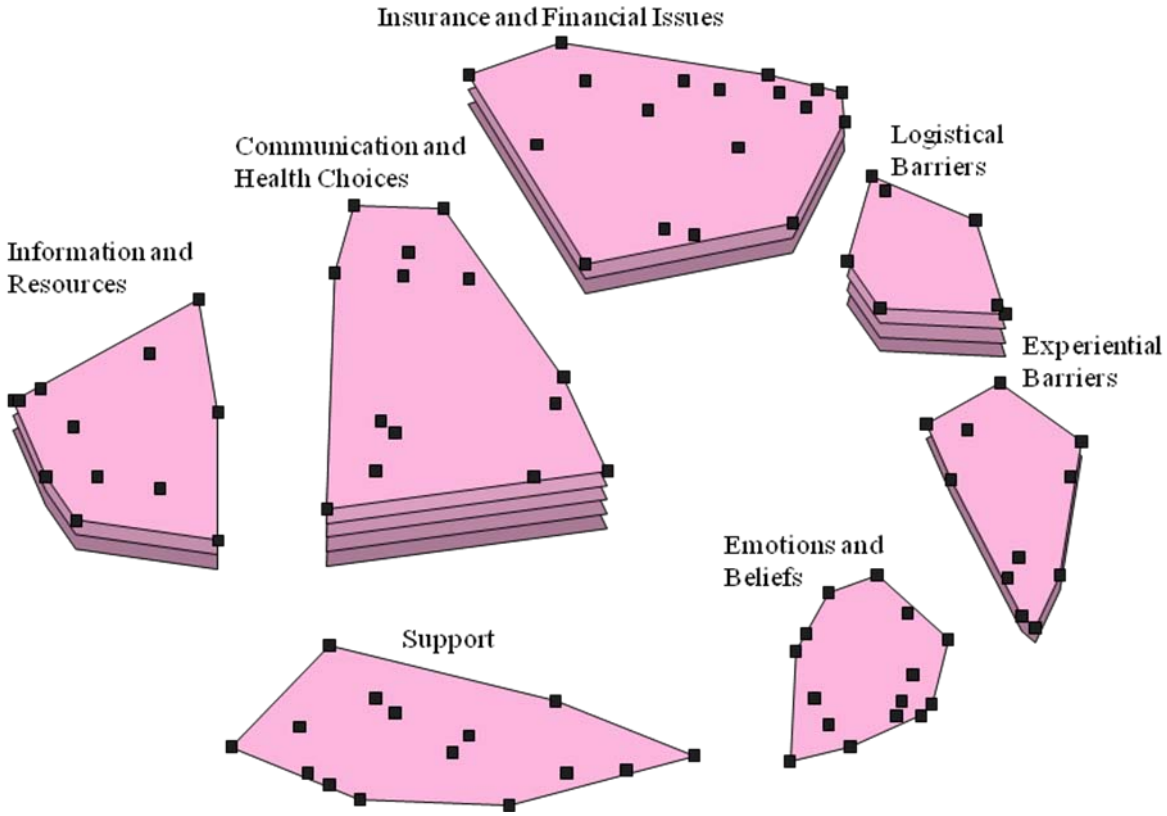

Figure 5. Initial Screening Cluster Ratings.

The highest ranking cluster for initial screening was Communication and Health Choices. The cluster items had an average rating of 3.95 out of a 5 in important. Within this 14-item cluster, ten of the items were ranked as high importance for initial screening. Those items were dedicated breast health care specialists (2), treatment options for patients (2), medical complications/ history (27), doctor/patient communication (28), knowledge about how and where to access services (35), patient/health organization relationship (40), coordination between doctor's offices

(46), confusing screening guidelines (74), comfort level in sharing with physician (75), and actively participate in personal health decisions (83). Out of these, the item that received the highest individual ranking was doctor/patient communication (28) with a 4.44 ranking out of 5. The other four items in the cluster received a moderate ranking; none of the items receive lower than a 3.2 rating.

The second most important cluster for initial screening was Logistical Barriers. This cluster is the smallest cluster, with seven items. Three of the items were rated as high importance: lack of a primary care physician (51), need for prescription to get mammogram (52), and scheduling mammograms/tests/treatments may be difficult (71). Logistical Barriers received a cluster ranking of 3.77, and the highest ranked item was scheduling mammograms/tests/ treatments may be difficult (71) with a 4.25 ranking.

4.2.2 Treatment

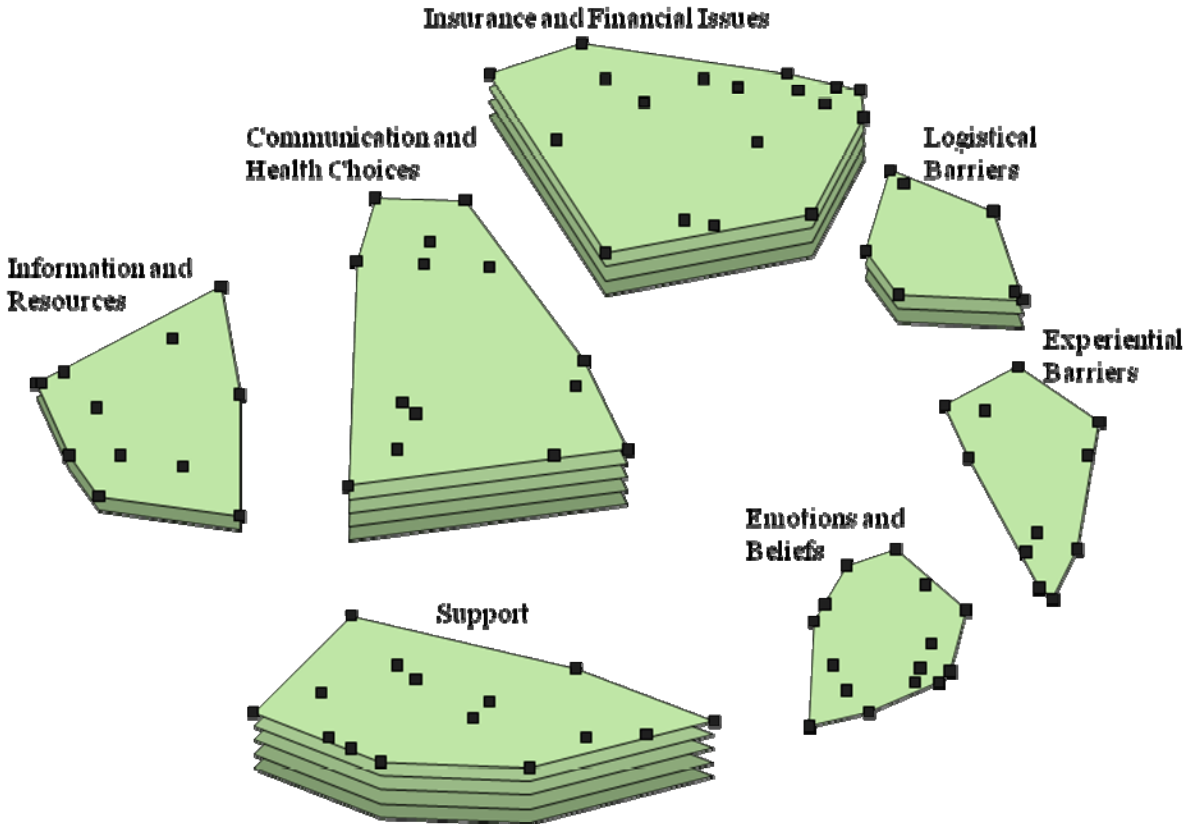

Figure 6. Treatment Cluster Ratings.

When asked to rate the factors in regards to a positive cancer diagnosis and treatment, Communication and Health Choices still ranked first with a 4.25 rating. Support was the second highest cluster, with a 4.07 rating. In comparison, for initial screening, Support was the lowest ranked cluster.

Communication and Health Choices still had a majority of high ratings, with 11 of the 14 items ranked high. The only difference for treatment was that breast care coordinators guide women (44) and health care providers look at whole person (mind/body/soul/spirit) (89) went from a moderate to a high rating and confusing screening guidelines dropped from high to

moderate. There was a tie for the highest ranked item, with treatment options for patients (20) and doctor/patient communication (28) both receiving a 4.81 rating.

The Support cluster contains 15 items, and only three of the items were rated as moderate. The 12 highest ranked items were shared experiences around diagnosis (13), personal emotional strength (14), support from faith/God/church (15), community strength can assist in support (37), increased life expectancy/cancer is not longer a death sentence (38), long-term side effects on health/fertility (39), support after tests/treatments are completed (72), survivors are mentors and advocates for breast health (73), family/friends/companion support at tests/treatments/doctor visits (77), impact on family/children/friends (80), positive reinforcement "its going to be okay" (92), and experience was different than expected (94). Of these, personal emotional strength (14) ranked the highest with a 4.72 average rating.

4.2.3 Repeat Screening

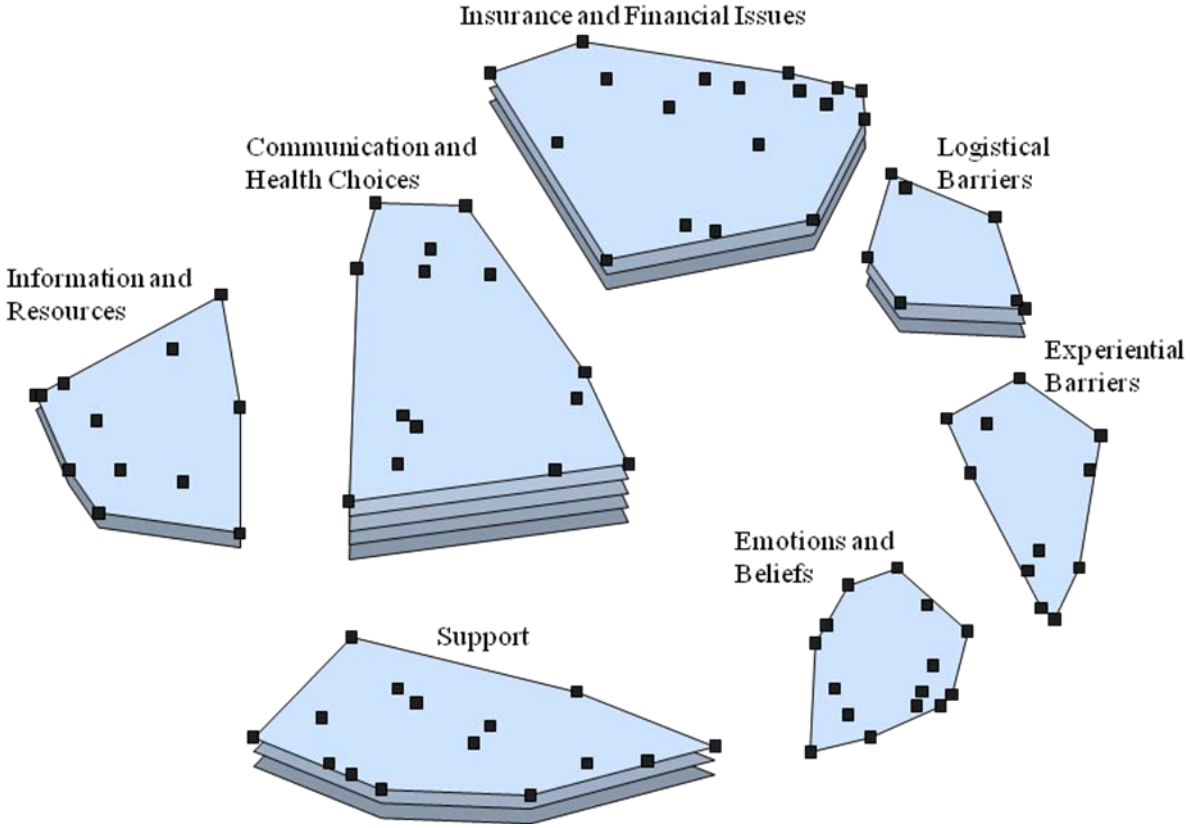

Figure 7. Repeat Screening Cluster Ratings.

Communication and Health Choices was again the highest ranked cluster for repeat screening. It received a 4.27 average cluster rating and 13 of the 14 items were ranked as high. The only item that received a moderate ranked was number of providers equals choice (21). This item was also the only item that received all moderate ranking across the three Continuum of Care rankings. Doctor/patient communication (28) was again the highest ranked item in the cluster with a 4.84 ranking. It is important to note that this item was had the overall highest ranking amongst the 94 factors, with an overall average rating of 4.7.

The second highest ranked cluster was again Support. Nine of the 15 items were rated as high, including all of the items that were listed above in treatment. The three items that went

from high to moderate for the repeat screening ranking was community strength can assist in support (37), long-term side effects on health/fertility (39), and positive reinforcement "its going to be okay" (92). Of those that received high rankings, personal emotional strength (14) and support after tests/treatments are completed (72) ranked the highest with a 4.38 rating. Overall, Support for repeat screening received a 3.85 cluster rating.

Insurance and Financial Issues came in a close third behind Communication and Health Choices and Support with a cluster rating of 3.81. It was also ranked as third importance in the initial screening and treatment ratings. Insurance and Financial Issues is a 19-item cluster and is the contains the most items in comparison with the other clusters. The cluster rankings ranged from low to high, but six of the items received a high ranking across the three areas. Those items are: high cost of insurance deductibles (5), health care provider and patient interactions (19), understandable information about insurance coverage (59), trouble with insurance company for certain tests (87), and insurance can be confusing/lots of paperwork (88). In the repeat screening ranking, health care provider and patient interactions was the highest ranked, with a number of 4.75. It was also the highest ranked item across all three areas, with an average ranking of 4.6.

4.3 AIM 3: COMPARING PITTSBURGH, HUNTINGDON, AND MEADVILLE

The three sites that participated in the concept mapping sessions represented different parts of western Pennsylvania. Data between the three sites were compared to see if there were differences in the areas of initial screening, treatment, and diagnosis according to geographic location.

4.3.1 Initial Screening

The biggest difference across the three locations was seen in analyzing initial screening data. For initial screening, Meadville had on average a higher ranking than both Pittsburgh and Huntingdon. Huntingdon placed support as second to last in level of cluster importance for initial screening. Huntingdon and Meadville ranked Communication and Health Choices as most important and Pittsburgh ranked Logistical Barriers as number one. In comparing initial screening pattern match between the three places, a substantial difference is seen in Meadville, who has a correlation with Pittsburgh of only $r = .19$ (refer to Figures 8-10).

The biggest difference to notate is that Pittsburgh ranked Support as the cluster of lowest importance, with a 2.68 average rating. Meadville ranked support as the third highest cluster, with an aver rating of about 4.0. Also important to note, the lowest average value Meadville gave any cluster was a 3.50. That is 0.82 higher than Pittsburgh's lowest rating, and only 0.27 lower than Pittsburgh's highest average. Overall, Meadville rated all factors higher than both Pittsburgh and Huntingdon.

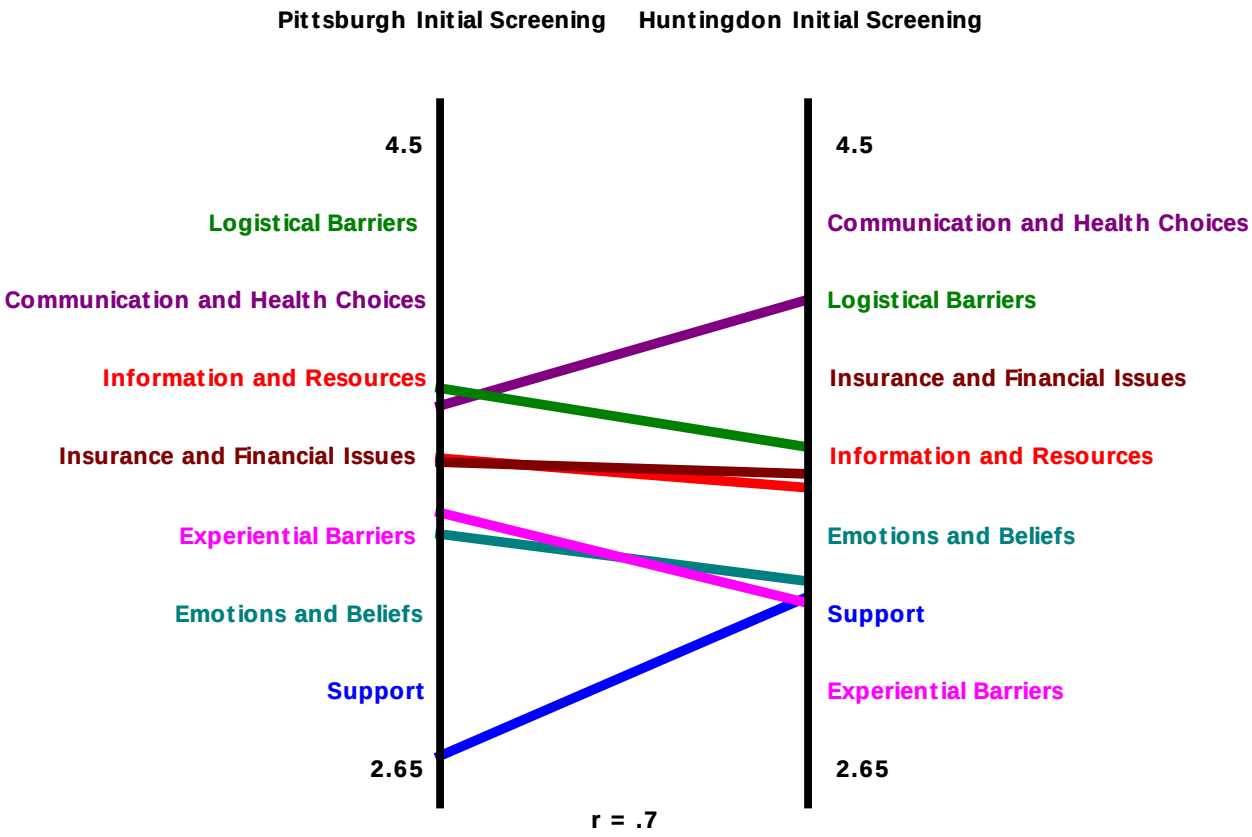

Figure 8. Pittsburgh and Huntingdon Initial Screening Pattern Match Comparison.

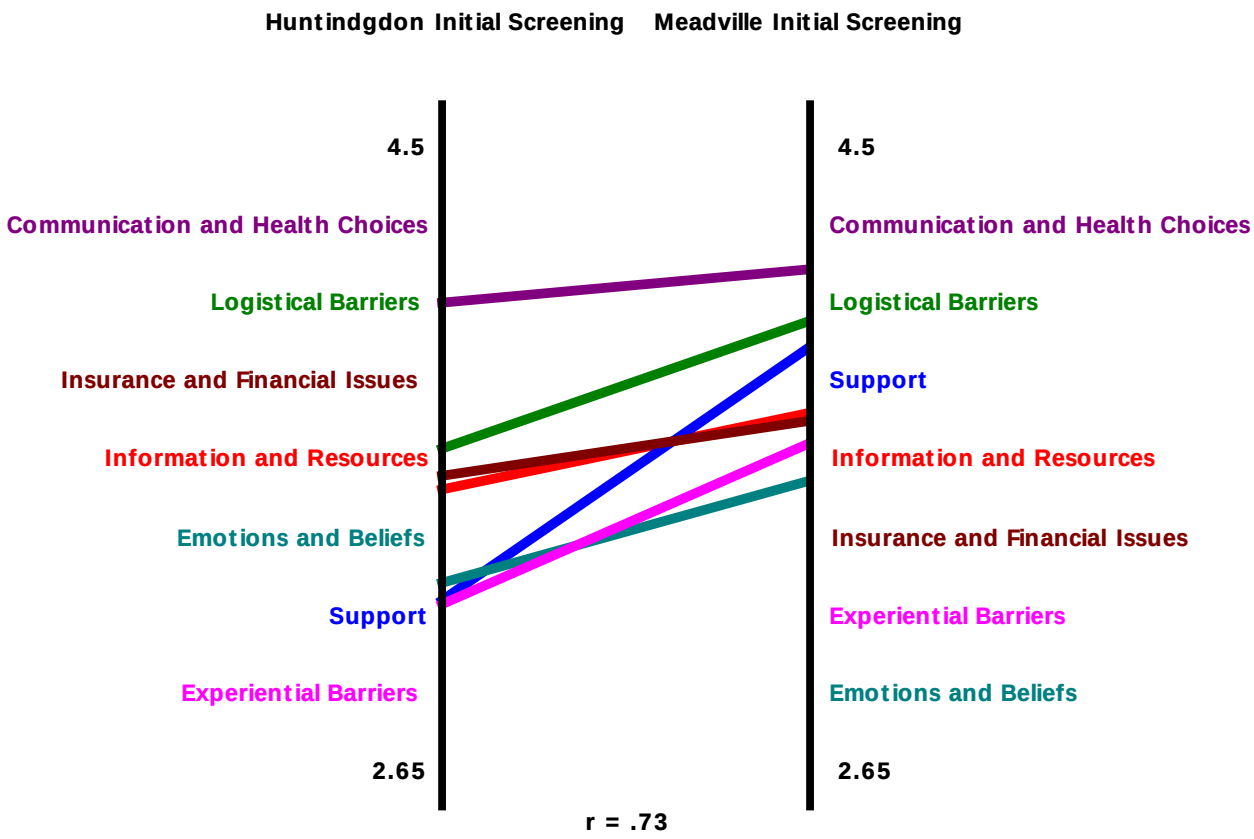

Figure 9. Huntingdon and Meadville Initial Screening Pattern Match Comparison.

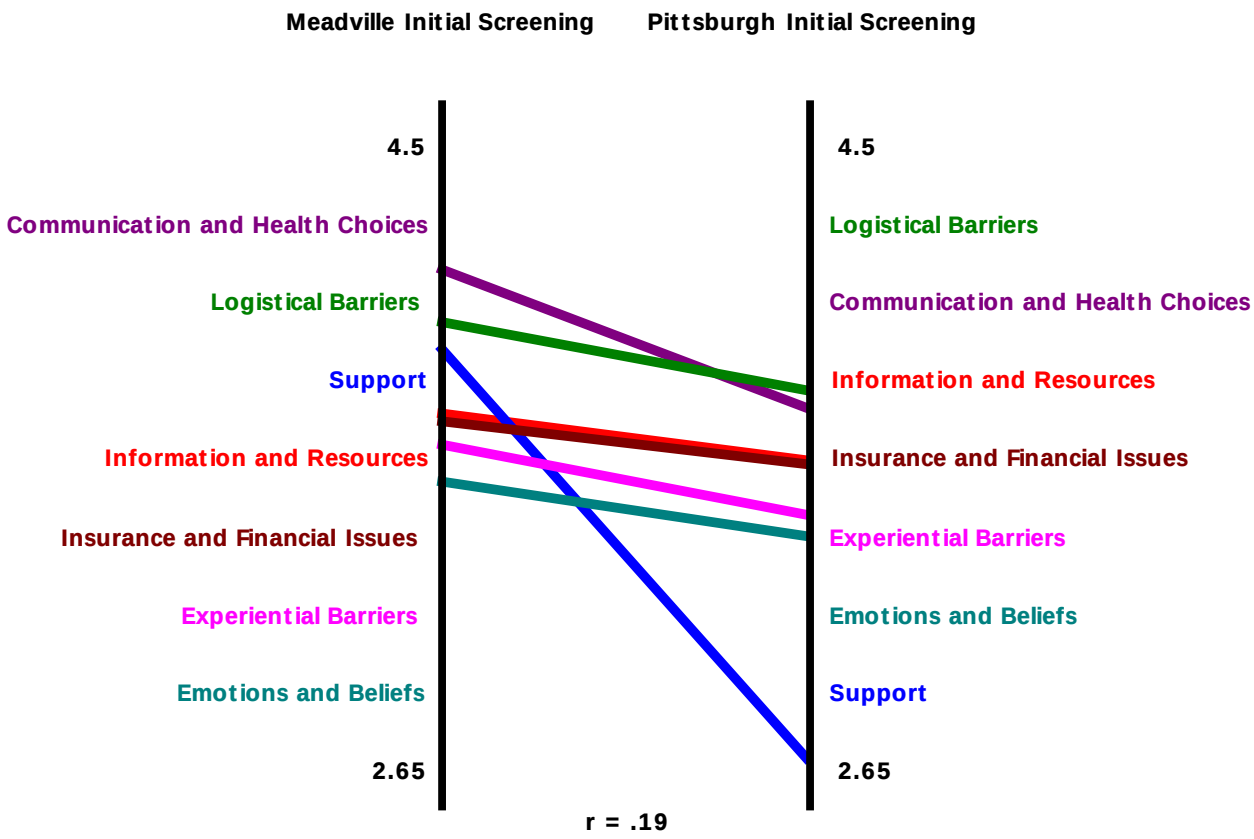

Figure 10. Meadville and Pittsburgh Initial Screening Pattern Match Comparison.

4.3.2 Treatment

In comparing pattern matches for the area of treatment, no differences were found. All three locations had a high correlation. Pittsburgh and Huntingdon had a correlation of r = .95, Huntingdon and Meadville had a correlation of r = .96, and Meadville and Pittsburgh had a correlation of r = .89. All three places ranked Communication and Health Choices as the most important cluster, Support was second, and Insurance and Financial Issues as third. Also important to note for practice implications, Experiential Barriers was the lowest ranking cluster in all three places.

4.3.3 Repeat Screening

In comparing pattern matches for the area of repeat screening, no differences were found. The correlations were overall both high and similar. Pittsburgh to Huntingdon and Huntingdon to Meadville were correlated $r = .94$. Meadville to Pittsburgh dropped slightly with an $r = .83$ correlation. Again, the cluster Communication and Health Choices was the highest ranked. Both Huntingdon and Meadville ranked Support as second for repeat screening, and Pittsburgh ranked Insurance and Financial Issues second.

5.0 DISCUSSION

The concept mapping results provide unique insights into the range of factors associated with the breast health Continuum of Care. The research findings have both practice and research implications, and using concept mapping has limitations and strengths.

5.1 PRACTICE IMPLICATIONS

Community-based participatory research is participant-driven and allows the participants to be active members of the research process. In analyzing the data, it is evident that while group opinions did vary slightly across the three locations, the general consensus when it came to ranking the importance of the parts of the Continuum of Care, and sorting the factors into clusters, was that the key factors in the Continuum of Care involve communication and health choices for women. This is seen in both the cluster table (refer to Table 3) and the pattern matches (see Figures 8-10). The Communication and Health Choices cluster can be broken down and analyzed by the individual factors that make up the cluster and their importance. As mentioned in the results section, nine out of the 14 items within that cluster were rated as high importance throughout all three ranking areas of initial screening, treatment, and repeat screening. These results should be shared with health care providers.

The sorting and rating sessions allowed participants to express their opinions and individual perceptions on the association and importance of the 94 group-identified factors. The computer system was then able to generate group-average cluster-level and ranking data. This data was able to be analyzed both across location groups and participant demographic data, providing the researchers with a wealth of information to dissect.

Research results should be shared with medical professionals such as doctors, nurses, radiologists, breast health coordinators, social workers, public health workers, and patient advocates in order to restructure their thoughts about breast health and breast cancer to be more focused on the known women's perceptions found from this research.

In the Information and Resources cluster, participant ratings show variations between low, moderate, and high importance when comparing initial screening, treatment, and repeat screening ratings. The item social media (e.g. Facebook, Twitter) (11) is the only factor that participants viewed as low importance throughout all three ratings, however support from scientific evidence (16) ranked high across all three areas. By using this data, researchers in the field can understand where women place importance on the information they receive and work to improve patient reception of key breast health messages.

The Communication and Health Choices cluster ratings show that participants viewed all items within this cluster as being extremely important. This is important for public health professionals in planning interventions based on the Continuum of Care for breast cancer. It also can be used to support training for medical doctors who work with women's health issues and breast cancer (gynecologists, primary care physicians, radiologists, oncologists)

In the Support cluster, only one item stayed ranked as high across the three ratings – personal emotional strength (14). The participants viewed this item as being the most important

and necessary means of support. Women undergoing treatment for breast cancer need personal motivation. Interventions to raise this within diagnosed women could improve their morale and perhaps save lives. Also important to point out, 12 out of the 15 items were rated as being of high importance when asked the rating question "if a woman is diagnosed with breast cancer, how important are each of these factors on her receiving treatment?" It is obvious from their responses that support is more essential during treatment of breast cancer than during any other time in the Continuum of Care.

In the Emotions and Beliefs cluster, two out of the 15 items were rated as high throughout – fear of results/diagnosis (10) and motivation (66). This is important because one has a negative connotation and one has a positive connotation as it relates to the Continuum of Care. Understanding the meaning behind the rankings will take further research into the area of breast cancer and breast health.

In the Logistical Barriers cluster, only one item was ranked high in all three areas: scheduling of mammograms/tests/treatments may be difficult (71). This item is perceived to be the biggest and most important logistical barrier women face in the Continuum of Care. Medical professionals and healthcare organizations need to know the facilitators and barriers women have in order to address those to encourage women to stay in the continuum and to bring previously unengaged women into the cycle.

Results can also be shared with governmental figures in order to influence policy change as it relates to the insurance and financial issues women see as barriers to receiving screening. Six of the 19 items within that cluster received a high ranking across the board. These items were perceived as the most important within the cluster: high cost of insurance deductibles (5), health care provider and patient interactions (19), uninsured/underinsured (25), understandable

information about insurance coverage (59), trouble with insurance company for certain tests (87), insurance can be confusing/lots of paperwork (88).

These practice implications around the breast health Continuum of Care are most poignant because they have been expressed by the women who policy and breast cancer affects.

5.2 RESEARCH IMPLICATIONS

These findings have implications for future research on women's perceptions related to the breast health Continuum of Care. Concept mapping captures the lived experiences of participants. Ways to further this research include using a broader sample of women. This includes examining specific characteristics such as age, race, socioeconomic status, insurance status, and education level. By targeting specific demographics and using concept mapping to gather multi-level quantitative and qualitative data, more insight into the continuum will be understood.

Another way gain insight is to include breast healthcare providers into the discussion of the continuum. Comparisons can then be drawn to notate if there are differences in the perceptions of providers around the continuum. This will generate discussion between the two groups – providers and recipients – and can bring the two groups together to ensure all parties are on the same level of understanding regarding barriers and facilitators to accessing the breast health Continuum of Care.

Concept mapping results can be critical information for planning interventions around the Continuum of Care. The results can inform researchers, breast health advocates, and Komen

Pittsburgh on the ways to bring more women into the continuum and ensure they stay in the cycle.

Further, a qualitative survey for patients requesting more information and meaning around the individual factors can be sought. For example, Communication and Health Choices was the most important cluster across the areas of initial screening, treatment, and repeat screening. Specific questions about doctor/patient communication or patient/health organization communication can be further discussed and broken down to provide tangible ways to accomplish both at a high level, for maximum quality of care.

5.3 LIMITATIONS AND STRENGTHS

There are several limitations worth noting. One limitation of this research was that the concept mapping participants were already at least minimally engaged in the breast health Continuum of Care. Being engaged means that prior to the research they had a higher level of knowledge and motivation that other individuals in their respective communities may not possess (for example, women who have never had a mammogram). In the participant recruitment process we did not actively seek out individuals who were not engaged in the continuum. Those individuals may be able to further provider us with a deeper understanding of the breast health Continuum of Care, especially in regards to barriers that may prevent them from screening.

Participants were also not recruited based on demographic characteristics such as race, age, sex, survivor status, education level, or socioeconomic status. The majority of participants were white, middle-class women over age 50. Because the three groups were fairly homogenous,

and there was only one male who completed the activities, different characteristics and perspectives could provide new insight into the research topic.

Another limitation was that there were only two meeting sessions with the concept mapping participants – a brainstorming session and a sorting/rating session. Due to time constraints, the researchers were not able to take the generated data back to the three communities. After the data was entered into the computer software system, the researchers decided on the optimal number of clusters for the point cluster map, as well as the category label for each cluster. While the researchers felt like they captured the perceptions of the participants, there was no participant input in the process. Standard concept mapping allows for a third interpretation session, where the participants view the cluster map and can further guide the researchers in their assessment of the data. Taking the data back into one or all the communities could provide further meaning and insight into the factors and ratings associated with the continuum.

This limitation is also seen within the clusters, due to the fact that the researchers decided the number of clusters to analyze. One example can be found in the Insurance and Financial Issues cluster. In this cluster there is one item that seems out of place and may not be directly related to insurance and financial issues. In a seven cluster map, the computer software sorted the item health care provider and patient interactions (19) in the insurance and financial issues cluster. However, in looking at the point cluster map, item 19 is also in close proximity to the Communication and Health Choices cluster. By using the distance between factors on the point cluster map, while item 19 is sorted in cluster six, it is more associated with item 28, doctor/patient communication, in cluster two, than with item 33, cost of transportation. It is

possible that if the number of clusters were to change due to participant feedback, item 19 could be in a different cluster.

Using concept mapping as a research method also has many strengths. Because it is community-based participatory research, all 94 factors derived from the brainstorming sessions had a unique, individual experience behind the words. Participants were able to express their perceptions in a dynamic group process of data collection and were able to help steer the direction of the brainstorming sessions. The parts of the breast health Continuum of Care were discussed in great detail, allowing researchers to understand the breadth of knowledge the participants were able to bring to the discussion.

The cluster maps generated from the participant sorting and rating sessions allowed the researchers to have a strong insight into the breast health Continuum of Care from the community recipients. The participants were able to rank all factors in accordance with how important they perceived them to be. The relationship between the factors and the Continuum of Care provide information to Komen Pittsburgh as they continue to work in western Pennsylvania communities. Data such as this has never been collected as it relates to breast health and the Continuum of Care, especially from a participant-focused analysis. These results advance the understanding of this topic. Concept mapping about the breast health Continuum of Care captured the "lived experiences" of the participants and researchers were able to understand several research aims with one method. These finding have implications for further research addressing the breast health Continuum of Care.

6.0 CONCLUSION

Breast cancer continues to be the most common cancer among all women in the United States. One in eight women in their lifetime will be diagnosed with breast cancer (ACS, 2010). These statistics alone represent the demand and necessity of this research in this area. The key persons to help researchers gather information are the women who are, or will be, affected by this disease, either directly or indirectly.

A strong community partnership was formed between the University of Pittsburgh Graduate School of Public Health and the Pittsburgh Affiliate of Susan G. Komen for the Cure®, and it is a partnership that will continue in the future. By exploring community perceptions of breath health, three research aims were examined and met.

The community-based participatory research method of concept mapping is still relatively new within the field of public health research. Because it uses a mixed methods approach of both qualitative and quantitative research, it provides valuable insight into the direct perceptions of participants. Concept mapping has never been completed in the field of breast health and breast cancer research. In summary, these findings yielded information about the factors of the breast health Continuum of Care for future practice and research concerning breast health. These findings are an essential starting point for further research.

APPENDIX A

IRB APPROVAL LETTER

University of Pittsburgh

Institutional Review Board3500 Fifth Avenue

Pittsburgh, PA 15213

(412) 383-1480

412) 383-1508 (fax)

http://www.irb.pitt.edu

Memorandum

To: Jessica Burke, Ph.D.

From: Sue Beers, Ph.D., Vice Chair

Date: 8/31/2010

IRB#: PRO10080610

Subject: Community Needs Assessment for the Pittsburgh Affiliate of Susan G. Komen for the Cure®

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(2) Tests, surveys, interviews, observations of public behavior.

Please note the following information:

If any modifications are made to this project, use the “Send Comments to IRB Staff" process from the project workspace to request a review to ensure it continues to meet the exempt category.

Upon completion of your project, be sure to finalize the project by submitting a "Study Completed" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX B

INFORMED VERBAL CONSENT SCRIPT

The purpose of this research project is to determine the community needs in the 30 county Komen Pittsburgh region as it relates to breast health and the continuum of care, including screening, diagnosis, treatment and follow-up care. To determine the needs, qualitative concept mapping sessions will be conducted with breast healthcare recipients.

If you are willing to participate in this study, you will be asked to participate in two, 1-2 hour concept mapping sessions. A researcher will ask you to share your experiences in regards to the breast health continuum of care. You can skip any questions that you do not want to answer.

There is the possible risk that you may feel some emotional discomfort when participating in the concept mapping sessions, but you will not be required to answer any questions or provide any information that makes you uncomfortable. Also, there is a potential risk of an accidental breach of confidentiality; therefore, we have taken the following steps to maintain your confidentiality:

All records related to your involvement in this research study, will be stored on a password-protected computer or locked office accessible only by the researchers. Your identity on these records as well as on any related study documentation will be indicated by your subject

identification number rather than by your name, and the information linking your subject identification number with your identity will be kept separate from the research records and interview responses. No identifiers, such as your name, will be shared.

Your participation is voluntary, and you may withdraw from this study at any time. Your ongoing participation in the community needs study will not be affected if you choose to not participate in or withdraw from this study. You will be given a copy of this form.

APPENDIX C

PARTICIPANT RATING SHEETS

Rating Questions

Initial Screening: What is the importance of each of these factors on a woman receiving her first mammogram?

Treatment: If a woman is diagnosed with breast cancer, how important are each of these factors on her receiving treatment?

Repeat Screening: For a woman who has had a mammogram or been treated for breast cancer, how important are each of the factors for her repeat screening (mammogram, CT scan, etc)?

Rating Items

1	2	3	4	5	(1) education about breast screening
1	2	3	4	5	(2) dedicated breast healthcare specialists
1	2	3	4	5	(3) education of general public about breast health
1	2	3	4	5	(4) myths about breast cancer risk
1	2	3	4	5	(5) high cost of insurance deductibles
1	2	3	4	5	(6) cultural beliefs/norms
1	2	3	4	5	(7) cancer diagnosis equals deficiency/embarrassment
1	2	3	4	5	(8) Pennsylvania culture celebrates survivorship
1	2	3	4	5	(9) fear of process
1	2	3	4	5	(10) fear of results/diagnosis
1	2	3	4	5	(11) social media (e.g. Facebook, Twitter)
1	2	3	4	5	(12) Komen website as source of information

1	2	3	4	5	(13) shared experiences around diagnosis
1	2	3	4	5	(14) personal emotional strength
1	2	3	4	5	(15) support form faith/God/church
1	2	3	4	5	(16) support from scientific evidence
1	2	3	4	5	(17) anger
1	2	3	4	5	(18) stress/feelings of being overwhelmed
1	2	3	4	5	(19) health care provider and patient interactions
1	2	3	4	5	(20) treatment options for patients
1	2	3	4	5	(21) number of providers equals choice
1	2	3	4	5	(22) financial guidance
1	2	3	4	5	(23) taboos concerning a woman's body
1	2	3	4	5	(24) language barrier
1	2	3	4	5	(25) uninsured/underinsured
1	2	3	4	5	(26) religious beliefs
1	2	3	4	5	(27) medical complications/history
1	2	3	4	5	(28) doctor/patient communication
1	2	3	4	5	(29) access to internet for information
1	2	3	4	5	(30) illiteracy
1	2	3	4	5	(31) access to childcare and/or eldercare
1	2	3	4	5	(32) access to public transportation
1	2	3	4	5	(33) cost of transportation
1	2	3	4	5	(34) assistance that exists can have limitations
1	2	3	4	5	(35) knowledge about how and where to access services
1	2	3	4	5	(36) scattered information sources
1	2	3	4	5	(37) community strength can assist in support
1	2	3	4	5	(38) increased life expectancy for survivors/cancer is no longer a death sentence
1	2	3	4	5	(39) long-term side effects on health/fertility
1	2	3	4	5	(40) patient/health organization relationship
1	2	3	4	5	(41) annual mammogram reminder
1	2	3	4	5	(42) financial screening resources for area

1	2	3	4	5	(43) advertisements of screening mammography events
1	2	3	4	5	(44) breast care coordinators guide women
1	2	3	4	5	(45) distance to appointments/tests/treatments
1	2	3	4	5	(46) coordination between doctor's offices
1	2	3	4	5	(47) health care providers services limited by time
1	2	3	4	5	(48) insurance restrictions based on pre-existing conditions
1	2	3	4	5	(49) fear of discrimination
1	2	3	4	5	(50) paperwork for appointments/tests/treatments
1	2	3	4	5	(51) lack of primary care physician
1	2	3	4	5	(52) need for prescription to get mammogram
1	2	3	4	5	(53) doctors may want to see patient first/liability issues for doctors
1	2	3	4	5	(54) health care staff need education to know where to send patients
1	2	3	4	5	(55) breast cancer support groups
1	2	3	4	5	(56) funding for programs is always unsure
1	2	3	4	5	(57) medical professionals need to be creative on where to get funding
1	2	3	4	5	(58) women need to be proactive about breast health
1	2	3	4	5	(59) understandable information about insurance coverage
1	2	3	4	5	(60) "what is the big deal" survivor tactic approach
1	2	3	4	5	(61) comfort level in discussion breast health
1	2	3	4	5	(62) age affects perceptions of breast health
1	2	3	4	5	(63) young women may feel immortal, may not think they can get breast cancer
1	2	3	4	5	(64) women put other things before getting a mammogram, may feel "bulletproof"
1	2	3	4	5	(65) too busy for themselves, moms take care of others before themselves
1	2	3	4	5	(66) motivation

1	2	3	4	5	(67) fear of recurrence
1	2	3	4	5	(68) long time to wait for results
1	2	3	4	5	(69) policies about reporting varies between health care providers
1	2	3	4	5	(70) restrictions to access medical records
1	2	3	4	5	(71) scheduling mammograms/tests/treatments may be difficult
1	2	3	4	5	(72) support after tests/treatments are completed
1	2	3	4	5	(73) survivors are mentors and advocates for breast health
1	2	3	4	5	(74) confusing screening guidelines
1	2	3	4	5	(75) comfort level in sharing information with physician
1	2	3	4	5	(76) breast information available at alternative sites, like beauty and nail salons
1	2	3	4	5	(77) family/friend/companion support at tests/ treatment/doctor visits
1	2	3	4	5	(78) family history (BRCA1 or BRCA2)
1	2	3	4	5	(79) doctors are complacent/don't think it is important to have breast exams
1	2	3	4	5	(80) impact on family/children/friends
1	2	3	4	5	(81) fear of mammograms/mammograms may hurt
1	2	3	4	5	(82) want specific/detailed information about breast cancer and treatment
1	2	3	4	5	(83) actively participate in personal health decisions
1	2	3	4	5	(84) trust of doctors
1	2	3	4	5	(85) consistent false positive mammograms
1	2	3	4	5	(86) tests can be painful
1	2	3	4	5	(87) trouble with insurance company for certain tests
1	2	3	4	5	(88) insurance can be confusing/lots of paperwork
1	2	3	4	5	(89) healthcare providers look at whole person (mind/body/soul/spirit)

1	2	3	4	5	(90) fear of doctors
1	2	3	4	5	(91) access to transportation
1	2	3	4	5	(92) positive reinforcement "its going to be okay"
1	2	3	4	5	(93) long-term financial stress
1	2	3	4	5	(94) experience was different than expected

APPENDIX D

DEMOGRAPHIC QUESTIONS

1. What is your age? _____
2. What is your gender? _____ M _____ F
3. What is the zip code you are currently living in? _____
4. Do you currently have health insurance?

   _____ Yes

   _____ No

   _____ Medical Assistance
5. What is your survivor status?

   _____ Have never been diagnosed with breast cancer

   _____ Currently am fighting breast cancer

   _____ Have had breast cancer in the past

   _____ Years breast cancer free

BIBLIOGRAPHY

American Cancer Society Website. December 12, 2010. <http://www.cancer.org>.

Burke JG, O'Campo P, Peak GL, Gielen AC, McDonnell KA, Trochim WMK. "An Introduction to Concept Mapping as a Participatory Public Health Research Method." *Qualitative Health Research.* 2005 December; 15(10): 1392-1410.

Burke J, O'Campo P, Salmon C, Walker R. "Pathways Connecting Neighborhood Influences and Mental Well-being: Socioeconomic Position and Gender Differences." *Social Science & Medicine.* 2009; (68): 1294-1304.

Centers for Disease Control and Prevention Website. October 4, 2010. <http://www.cdc.gov>.

Education Training Manual. Susan G. Komen for the Cure®. 2010.

Gierisch JM, Earp JA, Brewer NT, Rimer BK. "Longitudinal Predictors to Nonadherence to Maintenance of Mammography." *Cancer Epidemiol Biomarkers Prev.* 2010; 19(4): 1103-11.

Gierisch JM, O'Neill Sc, Rimer BK, DeFrank JT, Bowling JM, Skinner CS. "Factors Associated with Annual-Interval Mammography for Women in Their 40s." *Cancer Detect Prev.* 2009 July; 33(1):72-28.

Israel BA, Eng E, Schulz AJ, Parker EA. (2005). *Methods in Community-Based Participatory Research in Health.* San Francisco, CA: Jossey-Bass.

Israel BA, Schulz AJ, Parker EA, Becker AB. "Review of Community-based Research: Assessing Partnership Approaches to Improve Public Health." *Annual Review of Public Health*. 1998; (19): 173-202.

Kane, Mary and Trochim, William M.K. *Concept Mapping for Planning and Evaluation.* Sage Publications Ltd. 2007.

Lerman C, Rimer B, Trock B, Balshem A, Engstrom PF. "Factors Associated with Repeat Adherence to Breast Cancer Screening." *Preventative Medicine.* 1990 May; 19(3): 279-290.

Makuc DM, Breen N, Meissner HI, Vernon SW, Cohen A. "Financial Barriers to Mammography: Who Pays Out-of-Pocket?" *Journal of Women's Health.* 2001; 16(3):349-360.

Menon U, Champion V, Monahan PO, Daggy J, Hui S, Skinner CS. "Health Belief Model Variables as Predictors of Progression in Stage of Mammography Adoption." *Am J Health Promot.* 2007; 21(4): 255-261.

Modzelewski RA, Jones J, Hagopian L. 2011 Community Profile Report, Pittsburgh Affiliate of Susan G. Komen for the Cure®. Submitted March 2011.

O'Campo P, Burke J, Peak GL, McDonnell KA, Gielen AC. "Uncovering Neighbourhood Influences on Intimate Partner Violence Using Concept Mapping." *J Epidemiol Community Health.* 2005; 59: 603-608.

Ogedegbe G, Cassells AN, Robinson CM, DuHamel K, Tobin JN, Sox CH, Dietrich AJ. "Perceptions of Barriers and Facilitators of Cancer Early Detection Among Low-income Minority Women in Community Health Centers." *J Natl Med Assoc.* 2005 February;97(2): 162–170.

Susan G. Komen for the Cure Website. December 3, 2010. <http://ww5.komen.org>.

United States Census Bureau Website. October 4, 2010. <http://www.census.gov>.