

AN AFROCENTRIC PERSPECTIVE: NEEDS OF BREAST CANCER SURVIVORS

A DISSERTATION

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BY

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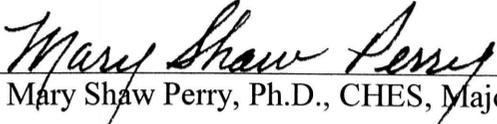
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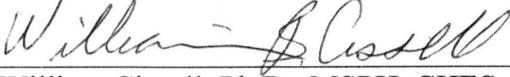
To the Dean of Graduate Studies and Research:

I am submitting herewith a dissertation written by Claudia S. Coggin, M.S., CHES, entitled "An Afrocentric Perspective: Needs of Breast Cancer Survivors." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Ph.D. with a major in Health Studies.



Mary Shaw Perry, Ph.D., CHES, Major Professor

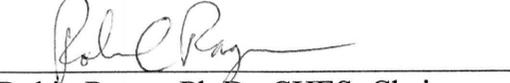
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“It is never too late to be what you might have been.” – George Sand

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ABSTRACT

An Afrocentric Perspective: Needs of Breast Cancer Survivors.

Claudia Stickney Coggin

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The number of breast cancer survivors has continued to increase over the last 10 years. Surviving a cancer diagnosis changes all aspects of a woman's life forever. The purpose of this study was to identify the needs of Black/African American breast cancer survivors using a Delphi Technique and to determine the resources available, accessible and used by these breast cancer survivors. The researcher applied a combination of qualitative and quantitative methods to analyze the data.

Nominations for a panel of experts (participants) were solicited from the Sisters Network, Inc., a national African American breast cancer support group, and other service providers. Invitation letters and a Round One Questionnaire were sent to 216 Black/African American breast cancer survivors. One hundred forty participants returned completed surveys. Ninety of the 140 participants returned a self-addressed label indicating their willingness to continue in the study. Each of the 90 participants was mailed the Round Two Questionnaire and 81 returned the questionnaire. Eighty-one participants were mailed the Round Three Questionnaire. Sixty-two returned the third and final questionnaire of the Delphi Technique process.

Black/African American breast cancer survivors identified their most important needs to be: (1) to have a full range of affordable, accessible, acceptable, and appropriate medical care and other support services (2) to have a loving, caring family (3) to know who to contact for information regarding breast cancer symptoms or related health problems (4) to have strong faith and relationship with God and (5) to have adequate resources for self-care and care for their family.

The study findings can be used to guide health educators in designing and implementing culturally appropriate programs to assist Black/African American breast cancer survivors to access and utilize available support services. Further, health educators could assist breast cancer support groups, service providers, and other community organizations design educational programs/services that are culturally appropriate for Black/African American breast cancer survivors. Efforts to address survivorship needs of diverse groups of women require knowledge and understanding of the needs of all women who experience and survive breast cancer.

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CHAPTER I

INTRODUCTION

Problem and Its Background

Clearly, the number of breast cancer survivors has continued to increase over the last 10 years. Surviving cancer changes all aspects of a woman's life forever. What are the quality of life or psychosocial issues that a woman struggles with to maintain her balance in life? Where does a breast cancer survivor turn for support? Typically the answer is family, friends, medical facilities, faith community, and/or support groups. The American Cancer Society (ACS) and other non-profit volunteer agencies, hospital systems, and cancer centers sponsor support groups as sources of education and coping skills for breast cancer survivors and caregivers. Is the current range of support resources responsive to the minority ethnic groups? Should they be? Are the care and coping needs of African American women unique? These questions are not fully answered in the current research literature.

A review of the literature revealed few studies that have been done address the psychosocial and/or quality of life issues of African American breast cancer survivors compared to the large number of studies for White breast cancer survivors. Furthermore, few studies have examined the availability, accessibility, and cultural appropriateness of programs, services, and interventions that meet the needs of African American breast cancer survivors. However, this research study was conducted with the Sisters Network,

Inc., the only national African American breast cancer support group, and other service providers to identify the needs of African American breast cancer survivors. Identifying the needs of African American breast cancer survivors should result in information that can be used to guide the design and implementation of an array of programs and services that should be available to African American breast cancer survivors.

Purpose of the Study

The purpose of this study was to identify the needs of Black /African American breast cancer survivors using a Delphi Technique. Additionally, the study sought to identify the resources available, accessible and used by Black/African American breast cancer survivors.

Research Questions

The following research questions guided the study:

1. What are the most important needs of Black/African American breast cancer survivors?
2. What are the physical well-being needs of Black/African American breast cancer survivors?
3. What are the social well-being needs of Black/African American breast cancer survivors?
4. What are the psychological (emotional) well-being needs of Black/African American breast cancer survivors?
5. What are the spiritual well-being needs of Black/African American breast cancer survivors?

6. What are the financial well-being needs of Black/African American Breast cancer survivors?
7. What are the resources available to Black/African American breast cancer survivors for coping with the disease?
8. What resources are accessible to Black/African American breast cancer survivors to cope with living with breast cancer?
9. What are the resources and services most often used by Black/African American breast cancer survivors?
10. How do Black/African American breast cancer survivors rate the resources and services available to them?

Definition of Terms

1. African American – a term used to refer to blacks born in America (Huff & Kline, 1999), as well as participants who define themselves as African American.
2. Black – the term used by the U.S. Bureau of the Census to denote an individual's race (Huff & Kline, 1999).
3. Breast cancer survivor – any woman who has received a diagnosis of breast cancer and has had treatment for removal of a malignant tumor.
4. Breast cancer support group – an organized group whose purpose is to discuss disease related issues and quality of life issues in connection with a breast cancer diagnosis.
5. Delphi Technique – a process used to establish group consensus (Delbrecq, Fan de Ven, & Gustafson, 1975).
6. Financial well-being – issues associated with the monetary costs of breast cancer.

7. Panel of experts – persons who participate in the Delphi Technique. The participants will be breast cancer survivors.
8. Physical well-being – “defined ... as ‘the control or relief of symptoms and the maintenance of function and independence (10)’ ” (Ferrell et al., 1997b, p. 400).
9. Psychological well-being – “seeking a sense of control in the face of life threatening illness characterized by emotional distress, altered life priorities, and fears of the unknown, as well as positive life changes” (Ferrell et al., 1998, p. 1).
10. Quality of life issues – “ ‘a personal sense of well-being encompassing physical, psychological, social and spiritual dimensions (10)’ ” (Ferrell et al., 1997b, p. 399).
Quality of life issues also include relationships with children, spouses or partners, other family members and friends, self-image, and sexuality.
11. Social support – information, advice, or tangible aid provided through contact with the social network that has beneficial effects on the recipient (Maunsell, Brisson, & Deschenes, 1995).
12. Social well-being – “ ‘a way to view not only the cancer or its symptoms, but also the person surrounding the tumor; it is the means by which we recognize people with cancer, their roles, and relationships (10)’ ” (Ferrell et al., 1997b, p. 400).
13. Spiritual well-being – “the ability to maintain hope and derive meaning from the cancer experience that is characterized by uncertainty. Spiritual well-being involves issues of transcendence and is enhanced by one’s religion and other sources of spiritual support” (Ferrell et al., 1998, p. 2).

Limitations and Delimitations

The study was limited and delimited by the following:

1. The study was limited to participants who were Black/African American female breast cancer survivors nominated by breast cancer support groups or service providers referred to the investigator, therefore limiting generalizability.
2. The study was delimited to English speaking participants.
3. The study was limited to participants capable of responding to a written format of the questionnaire.
4. The study was delimited by the fact that all study data was self-reported by the participants.
5. The study was limited by the fact that participants were able to drop from the study after receiving the letter of invitation to participate in the Delphi process.

Assumptions

For the purpose of this study, the following were assumed:

1. Participants answered all questions honestly.
2. Each participant on the mailing list had an equal and independent opportunity to complete the questionnaire and return it.
3. The sample consisted of participants who were interested in improving the survivorship experience of Black/African American women.
4. Each participant was qualified to be a member of the panel of experts.
5. The participants answered questions based on their own survivorship experience and not of other women.

Significance of the Study

A diagnosis of breast cancer is no longer a death sentence to women. According to Ferrell et al. (1997a), the National Cancer Institute (NCI) reported there were 1,721,700 breast cancer survivors in 1994. In 1999, NCI increased the number of breast cancer survivors to two million in the United States. Breast cancer survivors are advocates for the recognition of quality of life (QOL) issues and the role these issues play in the survivorship experiences through personal appearances on television talk shows, newspaper testimonial stories, internet sites and books. Lee (1997) concluded that cancer survivors are an “under-researched and underserved population” (p. 309).

With increased numbers of breast cancer survivors, researchers have begun to investigate long-term survivorship issues, including quality of life issues, of these women. Ferrell et al. (1997a, 1997b, 1998) conducted research among breast cancer survivors and identified four domains of QOL. The identified QOL domains include physical well-being, social well-being, psychological well-being, and spiritual well-being. The concept that social support may positively influence the course of breast cancer has gained favorable recognition primarily because of a 1989 study by Spiegel, Bloom, Kraemer, and Gottheil (Maunsell, et al. 1995). Spiegel et al. (as cited in Maunsell et al.) reported that their research results showed a significantly longer survival rate among patients with metastatic breast cancer randomized to receive a supportive intervention plus medical care as compared with the patients who received medical care only. From this study, it was concluded that participation in a support group may positively effect survival rate of breast cancer patients. In addition, Maunsell et al.

reported only five studies that looked at the impact of social support on breast cancer survivor outcomes. In their quantitative content analysis of interview responses, Samarel et al. (1998) were unable to determine the relationship of women's adaptation to breast cancer and their participation in support groups. These investigators (Samarel et al.) suggested further research in the area was needed with participants who represented greater education and ethnic diversity. A study by Bourjolly (1999b) investigated the differences in health locus of control between Black and White women with breast cancer and recommended additional research with ethnically diverse participants. A related study (Ashbury, Cameron, Mercer, Fitch, & Neilsen, 1998) has shown that a peer-led support program in Canada, Reach to Recovery, can be effective in enhancing the quality of life for breast cancer survivors.

No studies were found focusing on establishing group consensus on the psychosocial issues and needs of Black/African American breast cancer survivors. This study used the Delphi Technique to collect data. The Delphi Technique combines qualitative and quantitative methods to analyze the data. The method is useful when participants ("expert panelists") are separated geographically. Through the series of surveys the researcher is able to arrive at a consensus on issues from the input of expert panelists.

In conclusion, there are gaps in the existing literature regarding the experiences and/or needs of Black/African American breast cancer survivors. Most research studies mentioned have had limited participation by Black/African American women and the majority of researchers recommended that future research include more diverse

populations. Few research studies were found that focused solely on Black/African American breast cancer survivors and their needs. Before culturally appropriate services and/or interventions that improve the survivorship experience of Black/African American breast cancer survivors can be developed, the needs of this particular community of women must be assessed.

CHAPTER II

REVIEW OF LITERATURE

Breast cancer is the most commonly diagnosed cancer among women and ranks second among cancer deaths. In 2001, ACS estimated that one in eight women will develop breast cancer in their lifetime and the risk of developing breast cancer increases with age. Additionally, ACS (2001) estimated 239,300 new cases of invasive cancer and in situ breast cancer would be diagnosed. In the 1940s, the 5-year survival rate for localized breast cancer for all women was 72% (ACS). ACS reported in 2001, that the analysis of current data revealed the survival rates of all women are: “86% at five years after diagnosis; 76% after 10 years; 58% after 15 years; and 53% after 20 years” (ACS, p.5). In other words, more women are living longer after initial diagnosis.

The most common cancer for African American women is breast cancer (31%) followed by lung cancer (12%) and colon and rectal cancer (12%) (ACS, 2000). African American women have the highest death rate from breast cancer while White women are more likely to have a higher incidence rate of breast cancer (Meadows, 2000). One factor may be that African American women are being diagnosed at later stages (Meadows). In spite of these grim statistics, the survival rate for African American women has increased (ACS, 2001). An African American woman who has survived for five years after diagnosis has a 76% chance to survive another five years and if she has already survived ten years, she has an 85% chance to survive an additional five years (ACS).

This chapter presents the findings from the review of the literature. Topics covered are: a) breast cancer – the disease, incidence, mortality, survival rates among African American and White women; b) breast cancer in African American women - the disparities, survivorship research, quality of life research, quality of life research and African American women; and c) use of Delphi Technique, applications to breast cancer research.

Breast Cancer – The Disease

The Disease

Diseases called cancers cause body cells to change and grow out of control and form a lump or tumor. Breast cancer tumors begin in the breast tissues and can be either benign or malignant. Benign tumors are abnormal growths, but do not spread and are not life threatening. There are two types of malignant tumors. In situ tumors have not spread beyond the area where they began, usually in the duct or lobule areas of the breast. Invasive or infiltrating cancers start in the ducts or lobules and have grown through the walls to invade the surrounding tissues. Stage of the disease refers to the seriousness or how far the cancer has spread when it is first discovered and diagnosed. Local stage describes tumors that are confined to the breast. Tumors that have spread to the lymph nodes are regional stage tumors. A metastasized or distant stage tumor indicates cancer cells have spread to distant sites in the body (ACS, 2001).

Incidence

Breast cancer is the most common cancer, excluding skin cancer, for all women and accounts for nearly one in three cancers diagnosed (ACS, 2001). ACS predicted

approximately 192,200 new cases of invasive cancer and 47,100 additional cases of in situ breast cancer would be diagnosed in 2001, resulting in 239,300 new cases of breast cancer.

The risk of breast cancer for all women increases with age. In 1994-1998, 75% of the new cases and 84% of the cancer deaths occurred in women 50 and older. In the same time period, younger women, ages 20-24 and all races combined, had an incidence rate of 1.5 cases per 100,000 population; and women ages 59-75 had the highest incidence rate of 489.7 cases per 100,000 (ACS, 2001).

The invasive breast cancer incidence rate identifies three distinct phases since 1973. Phase one is the time period between 1973 and 1980 when incidence was constant. Phase two is the time period between 1980 and 1987 when breast cancer incidence increased by approximately 4% per year. Between 1987 and 1998, phase three, incidence rate increased by 0.5% per year (ACS, 2001). ACS credits increased detection of breast cancer through use of mammography screening for the rapid increase in the years 1987-1980 or phase two. Discovery rate of smaller treatable tumors (<2.0 cm) more than doubled and the discovery rate of larger tumors (3.0 cm greater) decreased 27%. The slower increase in the discovery rate in the 1990s reflects the use of mammography screening and earlier stage diagnoses is for tumors (ACS). The detection of in situ breast cancer has increased over the past 25 years while invasive breast cancer incidence rates have remained constant. Again, researchers credit earlier detection of breast cancer (e.g. increased use of mammography) in women rather than an increase in occurrence (ACS).

Age is a factor when examining incidence rates of breast cancer. Incidence rates of invasive breast cancer increased two and one half times faster for women age 50 and older than women under 40 between 1973 and 1998 (ACS, 2001). It is important to note that breast cancer incidence did not increase for women under the age of 40 during this time. During these years the incidence rates of ductal carcinoma in situ (DCIS) did increase for women of all ages, but at a faster rate for women over 50 (ACS). Higher usage of mammography by women accounts for the increased rate (ACS).

According to ACS, the

Perceptions of increasing numbers of breast cancer cases in young women in the late 1980s and early 1990s are largely due to the growth and aging of the US population, as many “baby boomer” women reached ages 25-40 at that time. (ACS, p. 4).

Breast cancer rates for women less than 40 years of age have, since 1985, actually declined an average of 1.3% per year (ACS, 2001). ACS also reports that between 1992 and 1998, the incidence rates remained unchanged for women of all racial and ethnic groups.

The *Healthy People 2010 Objectives for Improving Health* document by the U.S. Department of Health and Human Services (USHHS) and Centers for Disease Control (CDC) and Prevention contains 28 broad goals to serve as a work plan to improve the health of the United States population by 2010 (USHHS, 2000). Goal number three of the aforementioned document is to “Reduce the number of new cancer cases as well as the illness, disability, and death caused by cancer” (USHHS, p.3-9). Objective 3-3 is specifically to “Reduce the breast cancer death rate” with the target rate at 22.3 deaths per

100,000 females from the baseline of 27.9 per 100,000 in 1998 which is a 20% improvement (USHHS, 2000, p. 3-12).

Mortality

The mortality rates between 1950 and the late 1980s remained stable, but between 1989 and 1995, the death rates for all races decreased by 1.6% per year. Between 1995 and 1998, the reported decline was 3.4% annually. Between 1990 and 1998 the highest death rate declines were for White women 50 or less (31% per year) and 21% per year for women over 50. Improvements in breast cancer treatments and benefits of mammography screening are credited for this decline. Female breast cancer deaths in 2001 were expected to reach 400,200 (ACS, 2001).

Survival Rates Among African American Women and White Women

Age at diagnosis, stage at diagnosis, race/ethnicity, and socioeconomic factors influence the survival rates. Relative survival rates after diagnosis reported by ACS (2001) is 86% at five years, 76% after 10 years, 58% after 15 years, and 53% after 20 years. For women who have survived five years, 81% of White women and 76% of African American are expected to survive another five years. Of all women who have survived 10 years, 87% of White women and 85% of African American women are predicted to survive another five years. The survival rates for breast cancer increases with age until age 75. Additionally, ACS reports for women <45 the survival rate is 82%, for ages 45-54 (86%), for ages 55-64 (87%), ages 65-74 (88%) and 84% for women 75 and older. Tumors may be more aggressive and less responsive to hormonal therapies in younger women (ACS). Having a diagnosis of advanced stage of cancer lowers the

survival rate for women. Socioeconomic factors including a lack of health insurance are associated with lower survival as well as lower income.

Breast cancer and Black/African American Women - The Disparities

The Disparities

Numerous authors note the disparity of breast cancer incidence, mortality, and survival between African American women and White women (Long, 1993; Chu, Tarone, & Brawley, 1999; Phillips, 1999; Phillips, Cohen, & Moses, 1999; Joslyn & West, 2000; Streeter & Saddler, 2001; Krieger, 2002; Jones & Chilton, 2002). A diagnosis of advanced breast cancer is three times more likely for low-income African American women than higher-income African American women (ACS, 2001). In *Cancer Facts & Figures for African Americans* (ACS, 2000), it is noted that over the past 30 years there have been three distinct phases in breast cancer incidence for African American women. From 1973 to 1980 the rates were stable, then a rapid rise during 1980-1987, and another stable era from 1988-1997. The rapid rise in rates in the 1980s is attributed to the increased education and screening efforts tailored for these underserved women. In 2001, an estimated 19,300 new cases of breast cancer were expected to be diagnosed in African American women and approximately 5,800 deaths from breast cancer. Only lung cancer exceeds breast cancer among causes of cancer deaths for this population. The rate of newly diagnosed cases is approximately 13% lower in African American women than White women, but the death rates are 28% higher. This may be explained by the later stages at diagnosis or a greater possibility of being diagnosed with estrogen-receptor-negative or more aggressive tumors. For African American women,

when the breast cancer is diagnosed at a local state, the 5-year survival rate is 89%. If the cancer has spread regionally, the 5-year survival rate decreases to 64%; and if the cancer has metastasized to a distant site, the 5-year survival rate is only 15% (ACS).

Clearly, the survivorship experience of African American women is different from that of White women. Almost 10 years ago, Long, (1993), noted the disparity rate of breast cancer survival between African American and White women has existed for 30 years. From an extensive literature review, Long concluded that “the literature revealed five major factors that appear to account for the disparity: (a) low socioeconomic status; (b) advanced stage of disease at diagnosis; (c) diagnostic and treatment delay; (d) biological and constitutional characteristics; and (e) treatment differences (Long, p.1).” Moormeier’s (1996) extensive review of articles and clinical studies supports Long’s list of the disparity factors. However, Phillips and Smith (2001) point out that “Moormeier asserted that perhaps of all variables influencing breast cancer outcomes for this population, the contribution of socioeconomic status (SES) on survival is perhaps the most difficult to clarify” (p.275).

Survivorship Research

In 1999 the National Cancer Institute (NCI) reported there were two million survivors of breast cancer in the United States (NCI, 1999). The National Coalition for Cancer Survivorship *Networker* newsletter defines “a cancer survivor is anyone with a history of cancer from the time of diagnosis and the remainder of life” (as quoted in Leigh & Logan, p.577, 1991). Mullan (1985), founder of the National Coalition for Cancer Survivors, devised three categories of survivorship: acute, extended, and

permanent. The acute survival phase is dominated by medical, surgical, radiological treatment. The remission or termination of basic or rigorous treatment regime defines the extended survival phase. This period includes “watchful waiting” and includes periodic examinations or therapy (Wyatt, Kurtz, & Liken, 1993, p. 440). The permanent survival phase is characterized by a sufficiently small disease activity which means that the cancer is likely to be arrested. With the advent of prevention education and screening, better detection methods, and new treatments, more research is directed toward QOL in all phases of survivorship. A recent article by Noreen Aziz, Program Director of the Office of Cancer Survivorship, and Julia Rowland, Director of the Office of Cancer Survivorship at the National Cancer Institute within the National Institutes of Health reviewed “the current state of knowledge about the impact of cancer on ethnoculturally diverse and medically underserved survivors” and urged that additional research for these populations is needed (Aziz & Rowland, 2002, p. 789). Survivorship issues mentioned include patterns of coping; sexual dysfunction; influence of family and community resources; impact of health care system and access to and use of medical care; lifestyle factors; and health behaviors (Aziz & Rowland).

Quality of life Research

As the numbers of survivors of breast cancer have increased so have the numbers of researchers interested in quality of life (QOL) issues. This growing area of research is in response to the medical community’s desire to adequately address survivorship issues/needs. The concept of QOL is broad and, in general, refers to a sense of well being in multiple dimensions of life. Specific definitions differ slightly by each

researcher. In the broad sense, Grant, Padilla, Ferrell and Rhiner (1990) describe the concept of QOL as “ an extensive range of physical and psychological characteristics and limitations that describe an individual’s ability to function and to derive satisfaction in doing so”(p. 260). However, by limiting it to health-related the QOL and definition narrows to “the level of well-being and satisfaction associated with an individual’s life and how this is affected by disease, accidents, and treatments” (Grant et al., 1990, p. 260). Dow, Ferrell, Leigh, Ly & Gulasekaram (1996) proposes that QOL “encompasses interactions of physical, psychological, social (home and work), and spiritual well-being of long term survivors of cancer” (p. 262). The personal perceptions of this dynamic process will vary throughout the survivorship experience (Dow, 1990).

Within the QOL definition are an encompassing set of attributes or dimensions used by researchers (Grant et al., 1990). In a review of instruments to assess the quality of life of patients, Grant et al. listed attributes of QOL which included physiological well-being, physical well-being, sequelae of disease and treatment, social and interpersonal well-being, and financial and material well-being. Other researchers summarized the attributes into four domains: physical-well being, social well-being, psychological well-being, and spiritual well-being. (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Ferrell et al., 1996; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997a, 1997b; Ferrell et al. 1998; Dow et al., 1996).

Grant et al. (1990) listed several purposes to justify the research to measure the QOL. One purpose is to assess the responses to specific cancers; a second is to examine management of system responses; another is to compare patients’ responses to more than

one treatment as well as show the effects of specific rehabilitative strategies for cancer patients (Grant et al.). Evaluation of the QOL issues augments the traditional patient evaluation of the impact of the cancer diagnosis by the medical professionals.

A qualitative study using focus groups by Ferrell et al. (1997a) contributed to the body of knowledge of QOL. Twenty-one breast cancer survivors participated in the focus groups providing a rich source of information to be shared regarding QOL issues. A later study by Ferrell et al. (1997b, 1998) used individual interviews as a method of gathering in-depth information regarding QOL and validating the QOL model developed earlier.

Wyatt et al. (1993) explored QOL with women who had survived breast cancer five years or more using the holistic Ferrell Model (Ferrell et al., 1995). Through focus groups Wyatt gathered information and four QOL themes emerged. Theme One was the integration of the Disease Process into Current Life; Theme Two was the Change in Relationships with Others; Theme Three was Restructuring of Life Perspective; and Theme Four was Unresolved Issues. The coding categories for Theme One came from the physical domain of the Ferrell Model while Theme Two came from both the social and psychological domains. Theme Three came from three domains (social, psychological, spiritual) and Theme Four came from the social and psychological domains (Wyatt et al.).

Experiences with diagnosis and treatment of breast cancer continue to affect the lives of survivors both positively and negatively (Ferrans, 1994, Wyatt et al., 1993). Ferrans' research in 1994 furthered the development of her earlier work with a

Conceptual Framework for Quality of Life for breast cancer survivors. In the Framework, there are five aspects of QOL and within each both positive and negative aspects are listed. The five aspects are Health and Functioning Domain, Psychological/Spiritual Domain, Family Domain, and Social and Economic Domain (Ferrans).

Using Ferrans and Powers Quality of Life Index-Cancer Version measurement tool, Lee (1997) assessed the QOL issues of 100 women who were volunteers with the ACS Reach for Recovery program. The study explored the relationship between social support, type of breast cancer surgery, length of times since surgery, geographic location and overall QOL for program ACS volunteers. A major theme identified was helping which included sharing knowledge or providing knowledge and giving emotional support. The results of the data analysis revealed that giving back and gaining personal satisfaction was a motivating reason to volunteer for ACS Reach for Recovery. When stratified by age, the older group (50-65) avoided negative experiences or turned a bad experience into one that was beneficial and assisted others to have a more positive experience than they had had themselves (Lee, 1997).

A 1996 evaluation of 294 long time breast cancer survivors who were members of the National Coalition for Cancer Survivors reviewed the positive and negative outcomes QOL (Dow et al., 1996). The researchers used the Ferrell model of four QOL domains (subscales) to categorize responses. In the physical well-being domain, fatigue, aches and pains, fertility concerns, and sleep problems were negative outcomes. Fear of a second cancer, spread of cancer, distress of initial diagnosis, and distress of treatment

were among the negative outcomes in the psychological well-being domain subscale. Also included were self-concept, anxiety, and depression among the moderate outcomes. Sexuality concerns, family distress, and financial burdens were negative outcomes while support from others and personal relationships were more positive subscale outcomes in the social well-being domain. In the spiritual well-being domain, uncertainty of the future was the most negative outcome with spiritual and religious activities moderately negative. Hopefulness, having a life purpose, and positive change have the best outcomes on the spiritual well-being subscale.

In summary, what did these QOL studies reveal? Consistent findings among the studies revealed that first, QOL is important to breast cancer survivors at all stages. Second, breast cancer survivors don't live their lives in specific domains or areas and there is a crossover between the domains described in the Ferrans model and the Ferrell model. There are changes and degrees of intensity in the domains of QOL that occur over time. In the physical domain, breast cancer survivors reported pain assessment and management were a recurrent issue. Within the social realm, the women's role and ability to function at home and work were of greatest concern. The impact of the cancer on the family was of great concern to the breast cancer survivors. Within the psychological area, common dominant themes were sources of psychological distress, concern for the future, and emotional responses. The spiritual well-being domain reflected other concerns beyond religiosity such as "altered priorities, altered life meaning and transcendence/life after death" (Ferrell et al., p.7, 1998).

Quality of Life Research and African American Breast Cancer Survivors

QOL issues are significant for Black/African American breast cancer survivors as they are for White breast cancer survivors. African American women are more likely to be diagnosed with late stage breast cancer, less likely to survive, and are more likely to be at a lower socioeconomic level (Northouse et al., 1999). There is increasing attention being paid to this segment of the population among researchers.

In 1994, Powell reviewed the existing literature on African American women and the social and psychological aspects of breast cancer. This researcher found “the psychological literature on adjustment to breast cancer in African-American women is far too limited (p.137). Powell observes that

“Breast cancer is a growing field; nevertheless one must be critical in extrapolating this information and applying it to women who were not the primary subjects of investigation. However, as a knowledge base and a starting point, this information should help to illuminate the role of biopsychosocial factors in the management of breast cancer from the screening through the post-treatment phase in African-American women” (p.138).

A 1994 study that looked at the relationship between social ties, stage of disease and survival in of 525 African American women and 486 White women found significant differences between the two groups (Reynolds et al., 1994). Perceived emotional support (functional) rather than social network (structured) may influence prognosis of breast cancer as suggested by the data collected in this study.

To obtain more information about how breast cancer affects African American women, Ashing-Giwa and Ganz (1997) conducted a study using three qualitative methods. The key-informant interview method provided a broad range of information

from 11 professional African American females and one male. Their professional background (physicians, nurses, and administrators) provided diverse points of view. Twenty-three African American women participated in the two focus-group interviews. Eight African American women provided additional information during in-depth interviews. A strong spiritual belief system identified the physician as the secondary healer with God or the Creator as the primary healer. In this study, the researchers found a lack of adequate social support for many of the women and recommendations included advocacy efforts and support groups to assist women. Many of those interviewed lacked information about their diagnosis, treatments, and general cancer knowledge. Further research to evaluate and strategies to improve the reported poor patient-physician relationships was suggested. The researchers noted the differences between the information gleaned from each of the three methods and concluded that ethnicity and poverty influence the women's experiences with breast cancer and other chronic illnesses. Their recommendations for further research included identifying the areas where the survivorship experiences of African American women and White women are alike and where they are different and to examine the risk factors associated with psychosocial issues of African American survivors (Ashing-Giwa & Ganz, 1997).

In an attempt to determine differences in QOL between African American and White breast cancer survivors, Ashing-Giwa, Ganz & Petersen (1999) recruited women who had participated in a prior study and who were five years or more from first cancer diagnosis. One-hundred-seventeen African American women and 161 White women participated in the mailed survey. The results of the survey analysis confirmed that a

variety of factors (overall health, socioecologic context, socioeconomic status, partnership status, and living situation) affect QOL (Ashing-Giwa et al.). Further this study challenged the level of assumption that ethnicity determines QOL.

Bourjolly (1999b) attempted to determine if race predicted the origin of locus of control in breast cancer survivors. Individual interviews of 61 White women and 41 African American women were conducted. The study determined there was no significant differences in locus of control for African American women and White women. The research results did, however, emphasize the importance of assessing women for feelings of powerlessness then providing interventions to assist them to gain a sense of control regarding prognosis and treatment options through appropriate interventions. Assisting women to believe they can have control in health care decisions may make breast cancer less frightening. Further analysis of the research data looked at social functioning in a comparative design between African American women and White women. Social functioning was defined as “a person’s actual performance of activities associated with current life roles” (Bourjolly, Kerson, & Nuamah, p. 2, 1999a). The result of the analysis showed that African American women scored lower in both social functioning and household activities assessments. These researchers recommend routine assessments and interventions be developed to intervene and assist women in adjusting to role changes that are due to physical limitations as a result of the breast cancer diagnosis and treatment.

Northouse et al. (1999) surveyed 98 African American women with breast cancer to examine their QOL and identify factors in their lives that affected their QOL. The data

were collected in the participant's home using standardized self-report instruments administered on a one-on-one basis. The research revealed that the women reported a fairly high quality of life and were generally optimistic. The researchers noted that this is contrary to often-cited fatalism attitude among African Americans (Northouse et al.). The second finding in this study stressed "the importance of assessing how women view their illness and helping those women with more stressful view of the illness to find ways to lessen it" (Northouse et al., p. 458). The third finding of Northouse et al. urged professionals to "assess symptom distress among breast cancer survivors and assist them to manage it" (p. 458). The researchers recommended additional research to verify their findings and development of interventions that would assist African American breast cancer survivors to maintain a high QOL.

Bourjolly and Hirschman (2001) also looked at the similarities in coping strategies in African American and White breast cancer survivors, and, in addition, analyzed the differences in sources of support. The differences in sources of support can impact the type of support provided for patients' needs. Emotional reactions to a cancer diagnosis have been well documented in the literature. In this study, both African Americans and White women used social support as a coping strategy, but they differed in the structure and function of social support networks. An early assessment of the coping strategies and social support networks may be beneficial to long term treatment and quality of care.

Wilmoth and Sanders (2001) convened two focus groups to specifically identify issues confronting African American women following a diagnosis of breast cancer. From these focus groups, five themes emerged. Body image and appearance, social

support, menopause issues, and learning to live with a chronic illness were themes that are not unique to African American women and appear as concerns to White women as well. However, an issue identified by this study, which does appear to be unique is “health activism” (Wilmoth & Sanders, p. 878). Health activism is defined as “the desire to increase awareness of breast cancer in the African American community” (Wilmoth & Sanders, p. 878). Although the theme of adjustment to living with a chronic disease is a concern for all women, African American women believe their experience to be different due to ethnicity and culture and thereby, difficult for the non-African American health care professionals to understand. Wilmoth suggests that sisterhood is a common theme among African American women and therefore a support group that uses the sisterhood theme could be an avenue for outreach to the community. These recent studies and findings prompted a call for additional QOL research that includes larger numbers of Black/African American breast cancer survivors.

Use of Delphi Technique.

The Delphi Technique is a multiple survey process for establishing group consensus. According to Moore (as cited in Gilmore & Campbell, 1996), the name comes from the ancient Greek Oracle at Delphi who would predict the future. This technique is particularly useful with respondents who are widely separated geographically as in this study. According to Delbecq, Van de Ven, & Gustafson (1975), there are seven characteristics of the Delphi Technique that facilitate decision-making performance:

- 1) The isolated generation of ideas in writing produces a high quality of ideas.

- 2) The process of writing responses to the questions forces respondents to think through the complexity of the problem, and to submit specific, high-quality ideas.
 - 3) Search behavior is proactive since respondents cannot react to the ideas of others.
 - 4) The anonymity and isolation of respondents provides freedom from conformity pressures.
 - 5) Simple pooling of independent ideas and judgments facilitate equality of participants.
 - 6) The Delphi process tends to conclude with a moderate perceived sense of closure and accomplishment.
 - 7) The technique is valuable for obtaining judgments from experts geographically isolated.
- (Delbecq et al., 1975, p. 34-35)

In addition Delphi can be used to identify priorities, problems, set goals, and to clarify differences (Delbecq et al., 1975).

This method of group facilitation seeks to arrive at consensus on the opinions of the “panel of informed individuals or experts” (McKenna, 1994, p. 1221 as quoted in Hasson, 2000, p. 1010). The commitment of the expert panel is related to their interest in the topic. Hasson comments that if the participants are directly affected by decisions made as a result of the surveys then they are more likely to want to be involved in the Delphi process. Usually “gatekeepers” (Hasson, p.1010) or other administrative individuals serve as nominators of the expert panel. Because the Delphi Technique requires a series of surveys adequate time for mailings must be planned, the participants must be skilled in written communication, and participants must be motivated (Delbecq et al., 1975). In the first questionnaire (round one), participants are asked broad questions to elicit numerous responses. The second questionnaire is based on the responses of the first round. The third questionnaire permits the expert panel to review previous responses and make an individual judgment as to the importance of each item on the questionnaire.

Benefits of the third round include closure for the study and showing areas of agreement and areas of diversity of opinion as well as identifying areas of future research and planning.

Applications to Breast Cancer Survivorship Research

The Delphi Technique is most successful when there is sufficient time to process multiple mailings and analyze responses and when participants are highly knowledgeable, have good communication skill level, and are motivated by the topic.

The Delphi Technique was selected as the methodology for this qualitative study in order to establish consensus on the most important needs of Black/African American breast cancer survivors. In addition, this method was chosen because of the wide spread geographic location of the participants.

Summary

White women are more likely than African American women to be diagnosed with breast cancer, but African American women are more likely to die of the disease. Krieger (2002) suggests that the net results of combining the relatively high incidence and relatively high mortality puts African American women in the United States with the highest breast cancer mortality rates in the world. Breast cancer is not a “disease of affluence” (Krieger, p. 612), but one that needs “more accurate and complex assessment of social disparities in risks of being diagnosed with and dying from breast cancer” (Krieger, p. 612).

These statistics show that women are living beyond the initial diagnosis of breast cancer. If women are living longer as breast cancer survivors, then what are the issues

that contribute to their overall QOL? Cancer survivors have been characterized as “an under-researched and underserved population.” (Lee, 1997, p. 309). However, minority populations are traditionally under-represented in research studies because of low participation (Aziz & Rowland, 2002).

Among the reviewed studies, the quantitative studies had fewer Black/African Americans participants (Dow et al., 1996, Ferrell, 1997b, Lee, 1997). The qualitative studies reviewed used varied methods such as focus groups (Ferrell, 1997a, Wyatt et al., 1993, Ashing-Giwa & Ganz, 1997), mailed surveys with open-ended questions (Ferrans, 1994), and in-depth interviews (Ferrell et al., 1996, 1997a, 1997b, Carter, 1993, Ashing-Giwa & Ganz, 1997) and reported higher participation by Black/African Americans. A qualitative method of data collection was chosen for this study. “Qualitative methods are specific research tools that allow one to discover new knowledge and to generate hypotheses through open dialogue between researcher and participant” (Ashing-Giwa & Ganz, p. 20). Northouse et al. (1999) commented regarding their quantitative study that “the addition of a qualitative assessment may have added to the richness and depth in understanding factors that affect the quality of life of African American women with breast cancer” (p. 458). One study was reviewed that used the Delphi Technique to gather information from African Americans (Fongwa, 2002). Aziz and Rowland (2002) recommended using qualitative approaches to gather information from ethnic minority and medically underserved groups.

In September 2000, 130 participants (health advocates, cancer survivors and other experts) gathered in Washington, DC for a Summit Meeting Evaluating Research on

Breast Cancer in African American Women. Results of the discussions identified priority areas for research to attempt to address the disparity in the rate of breast cancer survival between African American and White women. Although great strides in clinical, basic science, and behavioral research have been made, African American women continue to be disproportionately affected by breast cancer. In a summary of this meeting, Jones and Chilton, (2002) list “psychosocial and behavioral issues, survivorship, and quality of life” (p.542) as priority areas of research in addition to biomedical areas.

This chapter provided a brief review of the literature related to breast cancer incidence, mortality, and survival rates, and survivorship issues for breast cancer survivors, specifically African American women. The majority of the reviewed researchers in the QOL studies recommended including a more diverse population of women to capture broader views regarding QOL across populations. Black/African American women were under represented as participants in the studies. The QOL literature may not accurately reflect the needs and/or QOL issues for Black/African American breast cancer survivors. Clearly the literature reviewed indicates a need for further research that can identify the unique needs of the Black/African American breast cancer survivors.

CHAPTER III

METHODOLOGY

The methodology of this qualitative study is discussed in relation to its population, procedures used to select and sample the selected population, development of the instruments used to measure the variables, procedures used to collect the data, and analytical methods used to treat the data.

Population and Sample

The study population included Black/African American breast cancer survivors from geographically diverse areas of the United States. In this study, the population was delimited to Black/African American women who described themselves as African American, Black, or of African descent who were born in the United States and who had received a diagnosis of breast cancer and had treatment or removal of a malignant tumor. The study population was further delimited to participants capable of responding to a written format of the questionnaire.

The first phase of the research entailed a nomination process by identifying a panel of experts (participants) to answer the multiple questionnaires. An agreement was negotiated with the Executive Director of the Sisters Network, Inc., a national African American breast cancer survivor's organization to access the organization's chapter presidents. The Executive Director agreed to allow the investigator to contact each of the presidents of the 33 affiliate chapters (Karen Jackson & Mary Shaw Perry, personal

communication, February 1, 2002). Invitation letters asking for nominations to the panel of experts were sent to each of the 33 chapter presidents from the investigator (Appendix A). In addition, the investigator assisted the co-investigator with a leadership workshop for the presidents and vice-presidents of the Sisters Network, Inc., at the 4th Annual African American Breast Cancer Conference. During the session both investigators had an opportunity to explain the study, the Delphi Technique, and expected outcomes. In addition, other providers of service to breast cancer survivors known to the investigator were sent letters explaining the study protocol and inviting them to nominate women to serve on the panel of experts (Appendix B). A total of 33 affiliate chapter presidents and five other service providers for a total of 38 sources were contacted. A total of 216 women were nominated to serve as a panel of experts by the Sisters, Inc. chapter presidents and the service providers.

Protection of Human Participants

The University of North Texas Health Science Center Texas College of Osteopathic Medicine Institutional Review Board for the Protection of Human Subjects (IRB) reviewed and approved the research application. Approval for the research was received on January 25, 2002 (Appendix C). A separate application was submitted to The Texas Woman's University Human Subjects Review Committee and was approved on February 13, 2002 (HSRC) (Appendix D). In the applications the investigators requested a waiver from the requirement to obtain informed consent based on the fact that the only record linking the participants and the research would be the questionnaire/consent document and the principal risk would be the potential harm resulting from a breach of

confidentiality. The Principal Investigator and the Co-Investigator would not have access to the identifier information that links the responses with the individual participants. At the end of five years from the date of the completion of the study, all records will be shredded and destroyed. In the initial invitation letter, the participants were advised that the participation in the study was voluntary, that their information would be kept confidential and that they had the right to withdraw from the study without penalty at any time. The letter explained that the information was confidential, and no individual participants would be identified, and all information would be reported as aggregated or group data in all reports or publications. The first questionnaire (Round One Questionnaire) and each of the subsequent questionnaires were reviewed and approved by the IRB prior to sending to the participants.

Procedures

Grant Application

The investigator applied for and received a grant from University of North Texas Health Science Center at Fort Worth Intramural Research Committee in the amount of \$6,600 (Appendix E). The funding was sufficient for the consumables, postage, and a graduate research assistant. The investigator acted as grant's Principal Investigator and the Co-Investigator was from Texas Woman's University.

The Nomination Process

The Delphi Technique is a process that involves multiple mailings to participants to allow for consensus building on issues through the completion of two or more

questionnaires. A flow chart was developed to track the number of rounds and responses to each round (Appendix F).

Between March 4 and April 4, 2002, letters were sent to presidents of the 33 chapters affiliated with the Sisters Network, Inc., and to five other service providers inviting nominations of participants (panel of experts). The letter asked the recipient to submit as many nominations as they would like including themselves if they met the criteria (Appendix A). Each letter to the Sisters Network, Inc. chapter presidents included a letter of support from the Executive Director of the Sisters Network, Inc. (Appendix G). All letters included a self addressed stamped envelope. The letter requested the nomination list to be returned by a date within 10 days of the date the letter was mailed. Also, when the investigator met with the presidents and vice-presidents of the chapters at the national conference of the Sisters Network Inc., Inc. in Detroit, additional self-addressed stamped envelopes and nomination forms (Appendix H) were made available.

A total of 216 nominations were received from the chapter presidents and service providers. The names and addresses were compiled in an Access database for ease of querying and merging to personalize the letters for the first questionnaire (Round One) and to print address labels. Appropriate stationery (letterhead and envelope) with an Afrocentric design was purchased. A postcard with the same Afrocentric design was developed and used as a reminder card. The stationery selected would be readily identifiable when received by the participants. The names from each chapter and each provider were coded in order to track returned questionnaires from Round One. Each

chapter list was given a code with the letter S plus a number of 1-33 and each provider code was given the letter P plus a number 1-5. The United States Postal Service was used for all mailings and all items were mailed using first class postage rates.

Round One

For the first mailing packet, an initial invitation letter (Appendix J), a copy of the Round One Questionnaire (Appendix K) and a self-addressed stamped envelope was sent to each person nominated by either the Sisters Network, Inc. or by one of the service providers through the postal service (Appendix I). The cover letter was printed on Afrocentric design letterhead with matching envelope. A total of 216 invitation letter packets were sent. The letter requested that the questionnaire be returned by a date 10 days from the date of the letter. The investigator created a questionnaire receipt log for the research assistant to record the date the questionnaires were returned. For security, the research assistant made a working copy of each questionnaire on yellow paper as the questionnaires were returned. Each copy of the Round One Questionnaire had a blank label attached to it, the participants were asked to print their name and address on the label to indicate their willingness to continue to participate; and the label would be used to send them the Round Two Questionnaire. The instructions on the questionnaire assured the participants that the label would be separated from the questionnaire and that no effort to link label and questionnaire would be made.

Round One Reminder Card

One week after the invitation letter to participate and the Round One Questionnaire was mailed, a reminder postcard was mailed to each potential participant (Appendix L).

Round One Response

The questionnaires were logged in as they arrived and the yellow working copy of each was made. Ninety questionnaires were returned with the label that was initially attached to the questionnaire completely filled out. There were 50 individuals who sent the questionnaires with no self-addressed label and therefore could not participate any further in the Delphi Technique process. However, their demographic information could be used as part of the participant profile for Round One. Responses from Round One letter packets were received from May 7, 2002 to July 3, 2002. It was noted that even though each letter stated a requested return date, often the date was ignored in all rounds. Combining those returned with labels and those returned with no label, a total 140 responses out of 216 initial mailings were received for Round One.

Round Two

The Round Two Questionnaire was prepared using the responses from the Round One Questionnaire. Ninety Round Two packets were sent through the United States Postal Service to participants who had returned self-addressed labels. Each packet included a cover letter (Appendix M) inviting the expert panel member to complete the Round Two Questionnaire, a Round Two Questionnaire (Appendix N), and a self-addressed stamped envelope. The letter listed requested that the questionnaire be returned in 10 days from the date of mailing. The cover letter was printed on Afrocentric design letterhead with matching envelope. The questionnaire was printed on light pink paper with an attached small signed note from the investigator thanking the expert panel

member for participating. Each questionnaire was coded to identify nomination affiliation and to enable the research assistant to log in the responses.

Round Two Reminder Card

One week after the invitation letter to participate and Round Two Questionnaire were mailed, a reminder postcard was mailed to each participant (Appendix L).

Round Two Response

The returned questionnaires were logged in as received and the coding removed from the questionnaires by the research assistant. A total of 81 responses out of the 90 mailed Round Two Questionnaires were returned.

Round Three

The Round Three postal mailing included the cover letter (Appendix O), the Round Three Questionnaire (Appendix P), and a self-addressed, stamped return envelope. The cover letter was printed on the Afrocentric design letterhead with matching envelope. The questionnaire was printed on light green paper with an attached small signed note from the investigators thanking the participants for their responses. Five Round Two Questionnaires were received after the initial mailing. These three participants were mailed a Round Three mailing at a later date for a total mailing to 81 participants.

Round Three Reminder Card

One week after the invitation letter to participate and Round Three Questionnaires were mailed, a reminder postcard was mailed to each participant (Appendix L).

Round Three Response

Seventy-five Round Three Questionnaires were returned. Of the 75 received, 47 questionnaires were completed according to the instructions. Twenty-eight Round Three Questionnaires were not completed according to the instructions. The investigators determined that the instructions were not clear to these participants. The investigators developed a revised instruction sheet to explain the ranking procedure. A cover letter (Appendix Q) and the second Round Three Questionnaire with an example of the ranking procedure (Appendix R) was mailed to the participants who returned the incomplete questionnaires. The purpose of the second mailing of the Round Three Questionnaires was to provide another opportunity for participants to rank order or prioritize needs of breast cancer survivors. A total of 24 of the 28 participants responded to the second mailing of the Round Three Questionnaire. The returned questionnaires were logged in as received and the coding removed from the questionnaire by the research assistant. Nine Round Three Questionnaires were received that were, again, incorrectly completed. The research assistant called each of these nine participants to verify responses on the questionnaire. The data from the nine participants were excluded from the data analysis because the participants failed to rank the responses. A total of 15 responses from Round Three Questionnaires were received from the second mailing and are included in the final analysis. Therefore, a total of 75 Round Three Questionnaires were received. However, only the responses of 62 were included in the data analysis.

A total of three successive rounds of correspondence with the panel of experts occurred in this study. A fourth letter with a feedback questionnaire was proposed, but

the investigator determined that little new information would be forthcoming. The fourth questionnaire was not sent.

Instrumentation

The initial research instrument contained two sections. First, a section to collect demographic information and a second section with the open ended questions. The contents of Rounds Two and Three Questionnaires were developed after preliminary analysis of the preceding rounds. The advisory board, the development of the initial instrument and subsequent instruments, and preliminary data analysis of the data are described in this section.

Advisory Board

Black/African American breast cancer survivors and service providers known to the investigator and the co-investigator were invited to serve on an advisory committee to review the Round One Questionnaire thereby increasing the reliability and validity of the questionnaire (Appendix S). A conference call was arranged to convene the board. Each member of the board received a letter inviting them to participate and informing them of the scheduled time of the call (Appendix T). Following the conference call each member was sent a copy of the questionnaire and asked to send their comments to the investigator.

Development of Round One Questionnaire

The Round One Questionnaire consisted of two parts developed by the investigator (Appendix K). Part I (Participant Profile) included items from a document previously developed for use in a statewide HIV/AIDS needs assessment by the co-investigator. Part I had 17 short answer questions. Part II (Assessing Needs of Breast Cancer Survivors)

had two open-ended questions with multiple parts based on the research questions. Upon return of the Round One Questionnaire the self-addressed mailing label was separated from the questionnaire and put in an envelope to be used to mail the Round Two Questionnaire. In the questionnaire receipt log the research assistant noted when the questionnaire was returned (date received) as well as if the label was received. Each questionnaire was reviewed to see if the requested information was complete.

Preliminary Analysis of Round One

Part I of the Round One Questionnaire allowed for collection of demographic information. The purpose of the demographic information was to establish a profile of the panel of experts. A total of 140 Round One Questionnaires were returned. The responses on Part I (short answer questions) were entered into an Excel sheet database. A summary of the statistical analysis of the demographic information is presented in Chapter IV.

The responses from the open-ended questions were typed verbatim from the questionnaires into separate Microsoft Word computer master folders labeled as most important needs of breast cancer survivors and “most important needs” a) physical needs, b) social needs, c) emotional needs, d) spiritual needs, and e) financial needs. The six separated lists were printed. Three reviewers from diverse backgrounds and ethnicity read each list. A separate color highlighter was assigned to each of the five needs lists. Each reviewer color-coded each list with the appropriate color for each need. The investigator discussed the coding with each of the other reviewers. Emerging themes were discussed and agreed upon. At the completion of the analysis of Round One, the

full responses from the respondents were reviewed to ensure all relevant themes were included. From those lists and the agreed upon themes, the Round Two Questionnaire summary statements were developed by the investigator.

Development of Round Two Questionnaire

The statements from responses to Round One (summarized and reworded from the original statements) were listed in table format under each question or category (Appendix N). No attempt was made to place the statements in any particular order. Expert panel members were asked to respond to each statement by indicating their level of agreement or disagreement according to a five-point Likert scale. The 5-point Likert scale ranged from “strongly agree” (1) to “strongly disagree” (5). In addition, there was a section at the end of the second page for comments. Statements from the Comment section of the questionnaire were typed into separate computer folders and reviewed to see if there were new themes to be included in Round Three questionnaire.

Preliminary Analysis of Round Two

To analyze the Round Two Questionnaire, the Likert scale numeric response to each statement from each participant was entered into a Excel spread sheet. This analysis method allowed the investigator to calculate the total number of times the participants rated each statement as number “strongly agree “ (1) to “strongly disagree” (5) on the Likert scale. If a panel member chose not to respond (blank response), no score was entered therefore lowering the total number of responses for that item. All comments were typed as written in a separate computer file.

Development of Round Three Questionnaire

For the Round Three Questionnaire, the needs statements from Round Two Questionnaire were rearranged and placed in random order (Appendix P). Each need statement was not numbered so as to not influence the participant when assigning ranking numbers. No new statements were added. The expert panel members were asked to indicate their preference (most important need) for the statements by ranking the statements within each of the categories. The five categories differed in the number of statements contained. The number of statements in each area ranged from 1-8, 1-8, or 1-5. For example, in a section that had eight statements, panel members were asked to rank the statement that they felt was most important as number one, the second most important as number two, and so forth until the least most important need was ranked as number eight.

Preliminary Analysis of Round Three

To analyze the Round Two Questionnaire, the numeric rank response to each statement from each participant was entered into an Excel spreadsheet. This method allowed the investigator to calculate the total number of times the participants ranked each statement as number 1-8, 1-7 or 1-5 depending on the category. If a panel member chose not to respond (blank response), no score was entered therefore lowering the total number of responses for that statement. From this numeric analysis, the investigator was able to determine the most important needs in each of the categories by the higher total number of times the participants ranked the statement number one.

Treatment of the Data

Round One

A total of 216 invitation letters with Round One Questionnaire were initially mailed to nominated expert panel members. A total of 140 were returned by the time the Round Two Questionnaire was mailed. Of those received, 90 participants returned the self-addressed mailing label indicating a desire to continue in the study. A total of 50 questionnaires were returned with no self-addressed label and could not participate in Round Two or Round Three Questionnaire mailings. The demographic information was compiled to describe the group as a whole and to create a participant profile. The data from the Excel database was transported into the Statistical Package for the Social Sciences (SPSS, version 10.0). The investigator and a biostatistician analyzed the demographic information from Part I of the Round One Questionnaire.

The investigator and two other health professionals completed the content analysis of the responses from Part II of the Round One Questionnaire. Recurrent themes or similar statements were counted based on the key words or ideas from Ferrell's Quality of Life model applied to breast cancer as well as terms that the investigator added (Ferrell, 1997b).

Round Two

From the collective responses to Round One, key words, repetitive ideas, and emergent themes were noted and guided the development formation of the statements for the Round Two Questionnaire (Appendix N). Seven statements in the categories of the most important physical well-being needs, and eight statements in the most important

social well-being needs were noted. Five statements in the most important psychological well-being needs and five statements in the most important spiritual well-being needs were listed, while eight statements occurred in the most important financial well-being needs.

Responses from the Round Two Questionnaire were entered into an Excel database as they were received. The Likert scale numeric response to each need statement from each participant was entered. The investigator was able to calculate the total number of times the participants rated each statement as a number “strongly agree (1) to “strongly disagree” (5) on the Likert scale. Where a panel member skipped or chose not to respond and left a blank for the statement then no score was recorded thus lowering the total number of responses for a particular statement. The investigator summarized the “strongly agree” and “agree” responses for each category in summary tables to view the preliminary level of consensus (Appendix U). Responses from the comment section of the questionnaire were recorded in a master Microsoft Word computer file. Eighty-one of the 90 mailed Round Two Questionnaires were returned.

Round Three

The numeric rank response to each need statement from each participant was entered into an Excel spreadsheet. The investigator calculated the total number of times the participants ranked each statement as number 1-8, 1-7, or 1-5 depending on the category. If a panel member chose not to respond (blank response), no score was entered therefore lowering the total number of responses for that statement. This process established the level of consensus among the expert panel members thus identifying the

most important needs of Black/African American breast cancer survivors in each of the six categories.

Summary

This qualitative study used the Delphi Technique to reach consensus on the most important needs of Black/African American breast cancer survivors. Nominations for a panel of experts were solicited from chapter presidents of the Sisters Network, Inc. and other providers of services to breast cancer survivors. Invitation letters were sent to 216 Black/African American breast cancer survivors. A total of 62 participants completed three rounds of the Delphi Technique.

CHAPTER IV

RESULTS

The purpose of this study was to identify the needs of Black/African American breast cancer survivors. In this chapter, the findings from this qualitative study are presented as they pertain to the following research questions:

1. What are the most important needs of Black/African American breast cancer survivors?
2. What are the physical well-being needs of Black/African American breast cancer survivors?
3. What are the social well-being needs of Black/African American breast cancer survivors?
4. What are the psychological (emotional) well-being needs of Black/African American breast cancer survivors?
5. What are the spiritual well-being needs of Black/African American breast cancer survivors?
6. What are the financial well-being needs of Black/African American Breast cancer survivors?
7. What are the resources available to Black/African American breast cancer survivors for coping with the disease?
8. What resources are accessible to Black/African American breast cancer survivors to cope with living with breast cancer?

9. What are the resources and services most often used by Black/African American breast cancer survivors?
10. How do Black/African American breast cancer survivors rate the resources and services available to them?

Demographic characteristics of the participants are presented first in this chapter, followed by the most important needs of Black/African American breast cancer survivors in each of the five Quality of Life (QOL) categories. The summary of resources available, accessible, and frequently used by the participants is presented next. A summary of the findings concludes the chapter.

Descriptive Characteristics of the Participants

Two-hundred sixteen letters with a Round One Questionnaire were sent to Black/African American breast cancer survivors inviting them to participate in the Delphi Technique survey process. The demographic information presented here reflects the data from the invitation letter and the Round One Questionnaire received from 140 women who returned the Round One Questionnaire (Appendix K).

The participants were divided into three regions by the state in which they reside. The investigator was guided in classifying geographic regions as East, West, and Central by the region classification in *the National Geographic Atlas of the World* (National Geographic Society, 1981). Refer to Table 1 for geographic distribution of participants. Participants also were able to self-assign to a rural, urban, or suburban area to describe where they lived. The participants were heavily concentrated in the central United States and few lived in rural areas. Refer to Table 2 for the distribution of the participants in

urban, suburban, and rural communities. The distribution of participants between urban and suburban was 65 and 64 respectively and only five participants reported living in a rural area.

Table 1

Geographic Regions

Region (States Included)	f	%
East (Maine, New Hampshire, Vermont, Massachusetts, Connecticut, Rhode Island, Pennsylvania, New York, New Jersey, Delaware, Maryland, Virginia, North Carolina, South Carolina, Tennessee, Mississippi, Alabama, Georgia, Florida)	50	35.7
Central (North Dakota, South Dakota, Nebraska, Kansas, Minnesota, Iowa, Missouri, Wisconsin, Illinois, Indiana, Ohio, Michigan, Kentucky, Texas, Oklahoma, Arkansas, Louisiana)	85	60.7
West (Washington, Oregon, Montana, Idaho Wyoming, California, Nevada, Arizona, New Mexico, Utah, Colorado)	5	3.6

Table 2

Urban, Suburban, and Rural Distribution

Classification	f	%
Urban	65	46.4
Suburban	64	45.7
Rural	5	3.6

Note. Classification was not determined for six participants.

The demographic characteristics of the participants are shown in Table 3. The age ranged from 30 to 83 years with an average age of 53.98 and the largest proportion (34.8%) was in the 50-59 age range. The annual incomes of the sample population fell in all the ranges listed. Combining the two upper end ranges (\$40,000-\$49,000 and \$50,000 plus) indicated that 63 (45.7%) of the respondents earned an annual income of \$40,000 or greater. One hundred nineteen (84.9%) participants reported either completing some college courses, graduating from college, completing some graduate school courses or graduating from a graduate program. The relationship status ranged from single (never married), legally and common law married, partnered, separated, divorced, and widowed. The majority of the women were either married/partnered (43.5%) or separated/divorced (30.8%). Most women had no children (52.9%) or had one child (28.6%). Seventy-nine women (60%) reported working full time or part time while 35 (25%) were retired.

Table 3

Demographic Characteristics of the Participants

Variable	N	%	M
Age			53.98
30-39	11	(7.9)	
40-49	38	(27.2)	
50-59	49	(34.8)	
60-69	29	(20.8)	
70-79	12	(8.4)	
>80	1	(0.7)	
missing	0		
Income ^a			
0-\$9,900	12	(8.7)	
\$10,000-\$19,999	15	(10.9)	
\$20,000-\$29,999	26	(18.8)	
\$30,000-\$39,999	22	(15.9)	
\$40,000-\$49,999	27	(19.6)	
>\$50,000	36	(26.1)	
missing	2	(1.4)	
Education ^b			
Some high school	3	(2.1)	
High School Graduate	9	(6.4)	
Technical/Trade School Graduate	6	(4.3)	
Some courses/Completed College	80	(57.1)	
Some courses/Completed Graduate School	39	(27.8)	
Missing	3	(2.1)	

Table 3 continued

Demographic Characteristics of the Participants

Variable	N	%	M
Relationship Status^c			
Single (never married)	17	(12.1)	
Married/partnered	61	(43.5)	
Divorce/Separated	43	(30.8)	
Widowed	19	(13.6)	
Missing	0		
Children			
None	74	(52.9)	1.77
One	40	(28.6)	
Two	11	(7.9)	
Three	8	(5.7)	
>Four	5	(3.6)	
missing	2	(1.4)	
Occupation^d			
Full time	75	(60.0)	
Part time	4	(2.9)	
Unemployed	11	(7.9)	
Retired	35	(25.0)	
Missing	15	(10.7)	

Note. ^{a,b,c,d}The mean was not calculated.

The number of years of survivorship ranged from 1 year to 34 years. The average number of years of survivorship was 6.63 and the most frequently reported years of survival was two years (Table 4).

Table 4

Number of Years of Survivorship

Number of Years	f	%
1	20	13.6
2	22	15.7
3	16	11.4
4	10	7.1
5	9	6.4
6	7	5.0
7	9	5.7
8	8	5.7
9	7	5.0
10	2	1.4
11	7	5.0
12	3	2.1
14	4	2.9
15	5	3.6
16	1	0.7
17	3	2.1
21	2	1.4
22	1	0.7
25	2	1.4
29	1	0.7
34	1	0.7
Total	140	100.0
Missing	0	

Note. Mean number of years of survivorship is 6.63 years.

Findings by Research Question

The combination of qualitative and quantitative data provided the answers to the research questions. Questions one through six were answered by the information gathered by the Delphi Technique. The demographic data provided answers to questions seven through nine. Data were not collected to provide answers to question 10.

In the Round One Questionnaire, the five open-ended questions asked the participants to list their most important physical, social, spiritual, emotional, spiritual and financial needs. Responses were coded and themes identified. From this information the statements were developed in each need category. Summary statements were developed and then became statements for the Round Two Questionnaire. The participants were asked to rank each statement in order of importance using a five-point Likert scale. The frequency of the level of “strongly agree” and “agree” for each statement was calculated (Appendix U). The Round Three Questionnaire was developed using the same statements in each category and the participants ranked the statements in order of importance. The Delphi Technique allowed for the establishment of consensus of the most important needs of Black/African American breast cancer survivors in each of the categories. The replies of 62 Black/African American breast cancer survivors were analyzed for the third and final round of the Delphi Technique. The responses from this group are reflected in the analysis of the Round Three Questionnaire. The research findings are as follows:

Research Question 1. What are the most important needs of Black/African American breast cancer survivors?

A total of 31 needs in five need categories were identified by the population sample. Research questions three through six explore each category. Black/African American breast cancer survivors identified their most important need as: “to have a full range of available, affordable, accessible, acceptable, and appropriate medical care and other support services” (55%). Their second most important need was “to have a loving, caring

family (55%); to know who to contact when I have symptoms and/or health problems related to the breast cancer” (55%). The third and fourth most important needs were “to have a strong faith and have a relationship to God” (87%) and “to have an adequate income to take care of myself and/or my family” (51%).

Research Question 2. What are the physical well-being needs of Black/African American breast cancer survivors?

The most important physical need identified by Black/African American breast cancer survivors was “to have a full range of available, affordable, accessible, acceptable, and appropriate medical care and other support services” (55%). The second most important physical need was “to be relieved of muscle, bone and joint pain caused by treatments or aggravated by the treatments” (17%). The third most important physical need was “to know what kind of foods to eat to maintain health and a healthy weight” (12%). Table 5 reports the participants’ frequency of ranking the physical need statements as the number one need.

Table 5

Ranking of Physical Need Statements

Physical Need Statement	Total number of times ranked as most important need	%
1. To have a full range of available, affordable, accessible, acceptable, and appropriate medical care and other support services.	33	55
2. To be relieved of muscle, bone and joint pain caused by treatments or aggravated by the treatments.	10	17
3. To know what kind of foods to eat to maintain health and a healthy (good) weight.	7	12
4. To be active and able to participate in activities.	6	10
5. To get the proper amount of sleep and rest.	3	5
6. To be able to get information, supplies, and treatment for lymphedema.	1	1
7. To know how to exercise and/or be able to exercise regularly.	0	
TOTAL RESPONSES	60	

Note: n = 62

Research Question 3. What are the social well-being needs of Black/African American breast cancer survivors?

The most important social needs identified by Black/African American breast cancer survivors was “to have a loving, caring family” (55%). The second most important social need was “to have caring, concerned, respectful, health care professionals and/or personnel” (25%). The third most important social need determined

by the participants was “to go out in my community and tell my story; and to educate other African American women about breast cancer and screenings” (15%). Table 6 reports the participants’ frequency of ranking the social need statements as the number one need.

Table 6

Ranking of Social Need Statements

Social Need Statement	Total number of times ranked as most important need	%
1. To have a loving, caring family.	33	55
2. To have caring, concerned, respectful, health care professionals and/or personnel.	15	25
3. To go out in my community and tell my story and to educate other African American women about breast cancer and screenings.	9	15
4. To have access to a support group of breast cancer survivors.	3	5
5. To have loving, caring friends.	0	
TOTAL RESPONSES	60	

Note: n = 62

Research Question 4. What are the psychological (emotional) well-being needs of Black/African American breast cancer survivors?

Two statements were equally ranked as the most important emotional need determined by the Black/African American breast cancer survivors was “to know who to contact when I have symptoms and/or health problems related to breast cancer” (20%) and “to feel at ease about my health” (20%). The third most important emotional need

for Black/African American breast cancer survivors was “to have the support of my family and friends” (16%). Table 7 reports the participants’ frequency of ranking the emotional need statements as the most important need.

Table 7

Ranking of Emotional Need Statements

Emotional Need Statement	Total number of times ranked as most important need	%
1. To know who to contact when I have symptoms and/or health problems related to the breast cancer.	12	20
2. To feel at ease about my health.	12	20
3. To have the support of my family and friends.	10	16
4. To have current and reliable information about the advances in therapy, medications, side effects and/or treatments.	10	16
5. To feel secure and worry free	7	11
6. To see black survivors involved in activities that bring awareness to the community.	5	8
7. To feel better about my self-image or to have a more positive self image.	4	7
8. To be able to express my fears, concerns, and dreams.	1	2
TOTAL RESPONSES	61	

Note: n = 62

Research Question 5. What are the spiritual well-being needs of Black/African American breast cancer survivors?

The most important spiritual needs identified by the Black/African American breast cancer survivors was “to have a strong faith and have a relationship with God” (87%). The second and third most important spiritual needs of Black/African American breast cancer survivors was “to pray and meditate on the Word of God” (7%); and “to know that I am not alone in the journey” (5%). Table 8 reports the participants’ frequency of ranking the spiritual need statements as the number one need.

Table 8

Ranking of Spiritual Need Statements

Spiritual Need Statement	Total number of times ranked as most important need	%
1. To have a strong faith and have a relationship with God.	52	87
2. To pray and meditate on the Word of God.	4	7
3. To know that I am not alone in the journey.	3	5
4. To be surrounded by a caring church family.	1	2
5. To be able to attend church.	0	
TOTAL RESPONSES	60	

Note: n = 62

Research Question 6. What are the financial well-being needs of Black/African

American Breast cancer survivors?

The most important financial need of Black/African American breast cancer survivors was “to have an adequate income to take care of myself and/or my family” (51%). The second most important financial need was “to have adequate insurance coverage for surgeries, treatments, and/or medications” (29%). The third most important financial need of Black/African American breast cancer survivors was “to be able to afford medical care and support services” (11%). Table 9 reports the participants’ frequency of ranking the financial need statements as the number one need.

Table 9
Ranking of Financial Need Statements

Financial Need Statement	Total number of times ranked as most important need	%
1. To have an adequate income to take care of myself and/or my family.	33	51
2. To have adequate insurance coverage for surgeries, treatments, and/or medications.	19	29
3. To be able to afford medical care and support services.	7	11
4. To be able to pay for utility bills.	2	3
5. To be able to pay housing.	2	3
6. To be able to pay for food.	1	2
7. To be able to pay for prosthesis and bras.	1	2
8. To have access to reliable, affordable transportation.	0	
TOTAL RESPONSES	65	

Note: n = 62 Participants ranked more than one statement as #1

Research Question 7. What are the resources available to Black/African American breast cancer survivors for coping with the disease?

There is an array of resources available to Black/African American breast cancer survivors. For purposes of this study, the resources were categorized into health insurance resources, financial assistance benefits/programs, medical care service location, and cancer treatment/care services (including medical and social support). Questions 11, 12, 13, and 14 from the Round One Questionnaire attempted to answer this research question. The participants did not list any additional resources or benefits beyond those that appeared in the questionnaire. See Appendix K for the complete questionnaire.

Research Question 8. What resources are accessible to Black/African American breast cancer survivors to cope with living with breast cancer?

Among the insurance resources available and accessed by Black/African American breast cancer survivors, the most frequently reported was work related insurance (74%) followed by Medicare (7.8%). Of equal frequency, participants reported having insurance through previous employment (COBRA), a private source of insurance and having no insurance. Refer to Table 10 for further information.

Table 10

Utilization of Insurance Type

Type of Insurance	f	%
Insurance through work	86	74.0
Medicare	9	7.8
COBRA	6	5.2
Private Insurance (not through work)	6	5.2
No Insurance	6	5.2
Medicaid	2	1.7
Public Assistance	1	.9

Note. Insurance usage was not reported by 24 participants. n = 116

The benefits or resources available and accessed by the participants included Social Security Retirement Income (6.3%), Social Security Disability Income (16.1%), and other retirement income benefits (40.9%). Approximately one third (47) of the participants indicated they were not eligible for benefits. The percentages were calculated by dividing the number of individuals enjoying each benefit by the 93 participants eligible for benefits. Some participants were enjoying more than one benefit (not mutually exclusive). Refer to Table 11 for further information.

Table 11

Utilization of Financial Benefits/Programs

Type of Benefit	f	% ^a
Retirement Benefits	38	40.9
Social Security Disability Income	15	16.1
Social Security Retirement Income	6	6.3
Long Term Disability	4	4.3
Rent Supplement	4	4.3
Food Stamps	3	3.2
TANF (AFDC)	2	2.2
Veteran's Assistance	1	1.1
Worker's Compensation	1	1.1
Short Term Disability	1	1.1

Note. ^a93 participants were eligible for benefits & 47 were not

Medical care and treatment services available and accessed by Black/African American breast cancer survivors were often received in a hospital clinic (55%) or community health clinic or private physicians office (50.7%) followed by an HMO/managed care clinic (23.6%). Refer to Table 12 for further explanation.

Table 12

Utilization of Location of Medical Care and Services

Type of Care/Service	f	%
Hospital/Hospital Clinic	77	55.0
Community Health Clinic/Private Physician's Office/Clinic	71	50.7
HMO/Managed Care Clinic	33	23.6
Public Health Clinic	1	0.7

Note. Participants could select more than one location. n=140

Among the cancer treatment and services accessed by the participants, surgery was the most frequently utilized followed by oncology services (81.4%), chemotherapy (63.6%), and radiation (56.4%). Support group services (77.9%) were the most frequently utilized non-medical service. Refer to Table 13 for further information.

Table 13

Utilization of Cancer Treatment/Care/Social Support Services

Type Support Services	f	%
Surgery	125	89.3
Oncologist	114	81.4
Support Group	109	77.9
Chemotherapy	89	63.6
Radiation Therapy	79	56.4
Family Doctor	72	51.4
Cancer Clinic	26	78.6
Clinical Trial	14	10.0

Note. Participants could select more than one service. n=140

Research Question 9. What are the resources and services most often used by

Black/African American breast cancer survivors?

The most often used resources and services reported by Black/African American breast cancer survivors in the benefits category are retirement (both Social Security and private) and disability resources. Hospitals and their clinics and private physician offices or clinics were the location where participants chose to receive medical care services and benefits. The most often used treatment and care services are surgery, chemotherapy and services of an oncologist, followed by support group.

Research Question 10. How do Black/African American breast cancer survivors rate the resources and services available to them?

An oversight in the development of the research questionnaire did not allow the participants to rate resources and services. No rating scale was included in the questionnaire. This oversight is being addressed by the co-investigator through the Susan G. Komen Extending Boundaries Project. The co-investigator developed a new and separate questionnaire to collect the missing data. The results of extension study are beyond the scope of this study and will be reported at a later date.

Summary

The most important needs of Black/African American breast cancer survivors who participated in the study were highly concentrated in the central United States and resided in urban settings. The participants were middle income and had a high level of education. The primary needs identified were a full range of affordable, accessible, acceptable, and appropriate medical care and other support services, to have a loving, caring family, to know who to contact for information regarding breast cancer symptoms or related health problems, to have a strong faith and relationship with God, and to have adequate resources for self-care and care for their family.

CHAPTER V
SUMMARY, DISCUSSION,
CONCLUSIONS, AND RECOMMENDATIONS

The final chapter is presented in four sections. The first, the summary, presents an overview of the entire study. It includes a description of participants, methods, and statistical results. The second is the conclusion with a restatement of the research questions and a summary statement of the answers to the research questions. The third is a discussion of the findings of the study. The recommendation section presents the logical significance of the results of the study, recommendations for future research, and the implications for health education.

Summary of the Study

The purpose of this study was to identify the most important needs of Black/African American breast cancer survivors using a Delphi Technique. Additionally, the study identified the resources available, accessible and used by Black/African American breast cancer survivors. A literature review revealed gaps regarding the experiences and/or needs of Black/African American breast cancer survivors

Participants

The study was limited to participants who were Black/African American, born in the United States, who had received a diagnosis of breast cancer, and had treatment for a malignant tumor. The breast cancer survivors were nominated to serve on the panel of

experts (participants) by breast cancer support groups or service providers. A broad range of ages, years of survivorship, income, education, and geographic location of the participants was reported.

Data Collection Method

This study used the Delphi Technique, a multiple survey qualitative research method to collect data. This process allows for a high level of consensus on issues and is particularly useful when participants are separated geographically. The first phase of the study was to form an advisory panel whose members were African American breast cancer survivors. The function of the advisory panel was to discuss the protocol of the study and to review the Round One Questionnaire. The second phase of the research was to identify a panel of experts (participants) to answer the surveys. Presidents of 33 chapters of the Sisters Network, Inc., a national African American breast cancer survivor's organization, plus five other service providers nominated women to form the panel of experts. Each of the nominated women (member of the panel of experts) was sent an invitation letter plus the Round One Questionnaire (Appendix K). Additionally, the panel of experts who chose to participate completed two more questionnaires. See Appendix F for a flow chart of the Delphi Technique process used in this study.

Results of Analysis

Two hundred-sixteen invitation letters with the Round One Questionnaire were sent to the panel of experts (participants) inviting their participation in the Delphi Technique process. The invitation letter, asked the women to complete a mailing label and return it indicating their willingness to participate in the successive rounds of the Delphi

Technique process. A total of 140 of the 216 women returned the Round One Questionnaire for a return rate of 65%. Ninety questionnaires of the 140 (64%) were returned with the mailing label completed; 50 (36%) returned the questionnaire, but with no label. Seventy-six (35%) failed to respond. The investigator mailed 90 Round Two Questionnaires and 81 were returned for a return rate of 90%. In Round Three, 81 women were mailed the third and final questionnaire and 62 were returned correctly completed (77%). A total of 62 women completed the three rounds of the Delphi Technique. The final response/participation rate in the study was 29% (62/216). However, the participation rate from the group of women (90) who indicated their willingness to continue by returning the mailing label in Round One, there was a 69% return rate (62/90). The Delphi Technique requires sustained interest by the participants in the topic to maintain a high return rate. The investigator theorizes there were several factors that might have influenced the high return rate after Round One. First, the investigator had established links with the Sisters Network, Inc. two years prior to the study. Both the investigator and co-investigator have participated in the past two annual survivorship conferences sponsored by Sisters Network, Inc. Second, the study was promoted at the 2002 Sisters Network, Inc. Conference in Detroit. Third, a letter of support from the founder and Executive Director of the Sisters Network, Inc. encouraged participation. Although the participants self-selected, they responded to a letter of invitation from the investigator. It is possible that participants with a higher level of education were more likely to respond to the invitation to participate. Those with low literacy skills may have been excluded due to the necessity of responding to a letter and

reading the questionnaire as well as writing answers to open-ended questions. Also significant is the fact that there were no tangible incentives offered to the participants. The University of North Texas Health Science Center Institutional Review Board prohibits the use of incentives.

The demographic information from 140 participants was analyzed using Statistical Software for the Social Sciences (SPSS, version 11). In Round One, the participants listed their most important physical, social, spiritual, emotional, spiritual, and financial needs. The investigator listed all responses in separate computer files, printed the results and coded each set with colored highlighters. Themes were identified and two outside reviewers verified the results. Summary statements in each category were developed. In the Round Two Questionnaires the participants were asked to respond to the statements and rank each statement in order of importance to them on a 5-point Likert scale. The summary of the total “strongly agree” and “agree” responses for each statement was calculated (Appendix U). The Round Three Questionnaire was developed using the same statements in each category. The participants were asked to rank the statements in each category in order of importance to them. The Delphi Technique allowed for the establishment of consensus of the most important needs of Black/African American breast cancer survivors. The detailed findings are presented in Chapter IV.

Conclusions

This study was conducted with Black/African American participants. The Participants identified 31 needs in five categories (physical, social, emotional, spiritual,

and financial). The high level of consensus among the participants regarding the research questions was indicated by Delphi Technique results.

Research Questions 1-6

1. What are the most important needs of Black/African American breast cancer survivors?
2. What are the physical well-being needs of Black/African American breast cancer survivors?
3. What are the social well-being needs of Black/African American breast cancer survivors?
4. What are the psychological (emotional) well-being needs of Black/African American breast cancer survivors?
5. What are the spiritual well-being needs of Black/African American breast cancer survivors?
6. What are the financial well-being needs of Black/African American Breast cancer survivors?

The most important needs of Black/African American breast cancer survivors are access to affordable, acceptable, and appropriate medical care and other support services including knowing who to contact for health information. Support from the loving, caring family and caring, concerned health care professionals was also important. To have strong faith in God and to have adequate financial resources to care for self and family were equally important.

In addition, physical needs included the relief of muscle, bone, and joint pain and to know the nutritional requirements to maintain health. Social needs included family support and caring, concerned and respectful health care professionals and/or personnel, and to educate other members of the their community about breast cancer prevention. To know whom to contact for symptom or health related information and to feel at ease about health concern were identified as emotional needs. A strong faith in and relationship with God topped the list of spiritual needs. To have adequate income to care for self and family was the primary financial need.

Research Questions 7-10

7. What are the resources available to Black/African American breast cancer survivors for coping with the disease?
8. What resources are accessible to Black/African American breast cancer survivors to cope with living with breast cancer?
9. What are the resources and services most often used by Black/African American breast cancer survivors?
10. How do Black/African American breast cancer survivors rate the resources and services available to them?

The most often reported benefits available were insurance, retirement benefits and disability resources. Most of the reported medical care and services were delivered in private hospitals and clinics. Few of the public assistance benefits and resources were utilized. The majority of the cancer treatment/care and social support services reported utilized were for medical services. In the utilization of cancer treatment, care or social

support services, the participants reported using a support group as social support (77.9%) almost as often as the medical services of a surgeon (89.3%) and oncologist (81.4%).

No rating scale was included in the questionnaire to answer question 10. The investigator and co-investigator failed to include questions that would allow the participants to rate the resources and services available to them.

Discussion of the Findings

The Most Important Needs of Black/African American Breast Cancer Survivors

This study can help researchers identify the QOL needs of Black/African American women and to assess if they are the same or different than those reported in studies whose primary participants have been White women.

The most important physical needs reported were (1) to have a full range of available, affordable, accessible, acceptable, and appropriate medical care and other support services and (2) to have relief for muscle, bone, and joint pain caused by treatments or aggravated by the treatments. Pain and financial burden were two of several reported negative outcomes by Dow et al. (1996) in a research study with almost 300 breast cancer survivors. It appears that access to care and pain management issues are not unique to Black/African American breast cancer survivors. Northhouse (1999) urged health care professionals to assist breast cancer survivors with symptom assessment and management.

The most important social needs were (1) to have a loving, caring family and (2) to have caring, concerned, respectful health care professionals and/or personnel. Also

mentioned was a desire to educate other African American women about breast cancer and screenings. The findings of Wyatt et al (1993) reports that breast cancer can cause a dramatic change in life perspective and can increase a woman's desire to be of service to others. The act of sharing their experiences with others can add meaning to their own lives (Wyatt et al.). Lee (1997) also reports the desire to give back to the community as one of the motivations to volunteer for the ACS Reach for Recovery program. The survivorship experience also appears to encourage a desire to be a resource for other African American women in the community. Support groups may be beneficial in many ways from assisting a survivor to find information and resources to being a comfortable place to express fears, concerns, and dreams. The desire to educate and "to go out and tell my story" described here, as a social need, supports Wilmoth and Sanders' (2001) concept of "health activism" (p. 878). Wilmoth and Sanders point out the theme of sisterhood is a common theme among African American women and suggested utilizing it as an educational strategy to reach African American women. This study supports the use of that strategy and the role of the Sisters Network, Inc.

The most important psychological (emotional) needs of Black/African American breast cancer survivors were (1) to know who to contact with health problems associated with breast cancer and (2) to feel at ease about their health. Equally important was the need to have current, reliable knowledge about advances in therapy, medications, side effects and/or treatments. One of the frequently cited reasons for the differences in survival statistics between African American and White women is treatment option. Ashing-Giwa and Ganz (1997) provided found their participants lacked information

about diagnosis, treatments, and general cancer issues. Bourjolly (1999b) found no significant differences in locus of control for African American and White women, but the research results did emphasize the importance of assessing women for feelings of powerlessness then providing interventions to assist them to gain a sense of control regarding prognosis and treatment options. Knowledge may enhance a woman's sense of power and having current information about breast cancer, treatments, procedures, therapies, medications, etc. may reduce fear and anxiety.

To have a strong faith and have a relationship with God was an overwhelming important spiritual need with the Black/African American breast cancer survivors. This need is supported by other research (Ashing-Giwa & Ganz, 1997; Phillips & Smith, 2001) that has reported African American women viewing God as the ultimate healer and believing in the power of prayer. Dow et al. (1996) reported less emphasis on religiosity and more emphasis on hopefulness and having a life purpose. Dow et al.'s report concurs with Ferrell's research in 1998 that reflected other concerns beyond religiosity such as "altered priorities, altered life meaning and transcendence/life after death" (p.7).

The most important financial needs for Black/African American breast cancer survivors were to have adequate income to care for themselves and their families and to have adequate insurance coverage for surgeries, treatments, and/or medications. In a study with 117 African American and 161 White breast cancer survivors, Ashing-Giwa et al. (1999) concluded that socioeconomic and life burden factors could be attributed to the QOL outcomes of breast cancer survivors. Adequate financial resources appear to be equally challenging for Black/African American and White breast cancer survivors.

Resources Accessible to and Used by Black/African American Breast Cancer Survivors

An array of resources is available to breast cancer survivors. Percentage of insured participants, financial benefits/service programs, utilization and location of medical care and support services were examined from the information. In this study the majority (92.2%) of participants had health insurance either through work, Medicare, COBRA or private insurance.

The financial benefits/programs used by the 140 participants who responded were primarily retirement benefits, Social Security Disability Income, Social Security Retirement and long-term disability. Approximately one-third (47) of the participants indicated they were not eligible for benefits listed. Forty-five percent of the participants reported their income was \$40,000 or more per year.

The most often-used cancer treatment/care/social support services listed by the participants were medically related (e.g. surgery, oncologist, chemotherapy, and radiation). Support group was the second most frequently selected choice and the only non-medical option.

Hospital/hospital clinics and community health clinic/private physician's office/clinic were the most likely locations where participants would receive care and services. The level of income (45.7% > \$40,000) could explain the utilization of these facilities. One participant listed using a public health clinic.

It is generally recognized that cultural beliefs and attitudes influence health practices. It also is customary to generalize results from one subset of a population to the entire population. For example, "findings on AAW from lower SES and older age

groups, are generalized to all AAW” (Phillips & Smith, 2001, p. 278). Phillips and Smith (2001) proposes “that there may be greater within-culture diversity than between-culture diversity, findings from low SES AAW cannot be generalized to middle SES AAW” (p.278). The majority of the participants in this sample were older and middle-income status and most had graduated from high school or completed work in higher education. Therefore, it is doubtful that the information from this study could be generalized to the entire population of African American breast cancer survivors.

Recommendations

This pilot research study provides information that may be useful to breast cancer support groups and other service providers. However, other questions remain that could be answered with further research. The researcher makes the following recommendations for future research.

1. Use the same study population to gather data rating the breast cancer services.
2. Replicate the study simultaneously in other states, regions of United States in order to capture rural, suburban, and urban data. This study population was geographically diverse, but heavily concentrated in Texas and in urban and suburban locations.
3. Replicate the study and include a more diverse range of socioeconomic and education levels among the participants.
4. To conduct future research into the quality of care services received among Black/African American breast cancer survivors.
5. Replicate the study in other ethnic cultures (e.g. Asian, Hispanic) using other research methods (focus groups, interviews).

6. Explore ways to increase the participation rate.
7. Involve cultural, ethnic support groups in the planning process that reflect the population being researched.

These recommendations serve to enhance the knowledge needed to address survivorship needs of Black African American women.

Implications for Health Education

The information obtained from this research provides valuable insight to the needs of Black/African breast cancer survivors. Health educators could use the information gained from this pilot study to advocate improving availability, accessibility, and affordability of care and support services for Black/African American breast cancer survivors. Furthermore, we can provide assistance in developing an “ideal” array of care and support services that are culturally appropriate to meet the needs of Black/African American breast cancer survivors. With new discoveries and treatments related to breast cancer survivors can have realistic hopes for recovery. Service providers can utilize health educators to provide cultural competency training for all levels of health professionals who interact with breast cancer survivors. Above all, programs, services and benefits must be culturally appropriate, available, accessible, and affordable for all breast cancer survivors.

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APPENDIXES

APPENDIX A

Invitation to Nominate Panel of Experts to Sisters Network Inc. Chapter Presidents

Invitation to Nominate Panel of Experts to Sisters Network Inc. Chapter Presidents

Chapter President
Sisters Chapter
Address, etc

Dear (chapter president name):

I am a doctoral candidate completing a research study with Dr. Mary Shaw-Perry of Texas Woman's University, to determine the needs of African American breast cancer survivors. The title of the study is *An Afrocentric Perspective: Needs of Breast Cancer Survivors*.

As president of your Sisters Network chapter you are an important link. I would like to invite you to nominate African American breast cancer survivors from your chapter to participate in our expert panel and answer our survey. The nominees should meet the following criteria: (a) African American and (b) United States citizen. You may nominate as many ladies as you would like. Please send me a list of name and address of women who you think would like to express their opinions about the survivorship needs of African American women. Participation is voluntary.

Nominations will be accepted through (DATE). Please use the enclosed self-addressed, stamped envelope to submit the list or e-mail to ccoggin@hsc.unt.edu. Please be assured that nominations will be kept confidential and only Dr. Shaw-Perry and I will have access to the list of names for this project.

Thank you for your willingness to participate in the first phase of this important work. Please do not hesitate to contact Dr. Shaw-Perry or me for further information.

Sincerely,

Claudia Coggin, MS, CHES,
Principal Investigator
817/735-2360

ccoggin@hsc.unt.edu

Department of Health Studies, Texas Woman's University, Denton, TX

Mary Shaw-Perry, Ph.D, CHES

Research Advisor

940/898-2965

mshaw@twu.edu

APPENDIX B

Invitation to Nominate Panel of Experts to Service Providers

Invitation to Nominate Panel of Experts to Service Providers

Date

Address

Dear :

I am a doctoral candidate completing a research study with Dr. Mary Shaw-Perry of Texas Woman's University, to determine the needs of African American breast cancer survivors. The title of the study is *An Afrocentric Perspective: Needs of Breast Cancer Survivors*.

You are an important link. I would like to invite you to nominate African American breast cancer survivors from your chapter to participate in our expert panel and answer our survey. The nominees should meet the following criteria: (a) African American and (b) United States citizen. You may nominate as many ladies as you would like. Please send me a list of name and address of women who you think would like to express their opinions about the survivorship needs of African American women. Participation is voluntary.

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Thank you for your willingness to participate in the first phase of this important work. Please do not hesitate to contact Dr. Shaw-Perry or me for further information.

Sincerely,

Claudia Coggin, MS, CHES,
Principal Investigator
817/735-2360
ccoggin@hsc.unt.edu
Department of Health Studies, Texas Woman's University, Denton, TX

Mary Shaw-Perry, Ph.D., CHES
Research Advisor
940/898-2865
mshaw@twu.edu

APPENDIX C

University of North Texas Health Science Center at Fort Worth
Texas College of Osteopathic Medicine
Institutional Review Board
Letter of Approval

UNIVERSITY of NORTH TEXAS HEALTH SCIENCE CENTER at Fort Worth
TEXAS COLLEGE OF OSTEOPATHIC MEDICINE
INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN SUBJECTS

BOARD ACTION

IRB PROJECT #: 21-48 DATE SUBMITTED: December, 2001

PRINCIPAL INVESTIGATOR: Claudia Coggin, MS, CHES

PROJECT TITLE: An Afrocentric Perspective: Needs of Breast Cancer Survivors

PROTOCOL #: N/A

DEPARTMENT: School of Public Health TELEPHONE EXTENSION: _____

In accordance with UNT Health Science Center policy on the protection of human subjects, the following action has been taken on the above referenced project:

Approval, when given, is **only** for the project as submitted. **No changes** may be implemented without first receiving IRB review and approval.

Project has received approval through December 31, 2002

Informed Consent approved as submitted on _____
Only consent documents which bear the official UNTHSC IRB approval stamp can be used with subjects.

Study Protocol dated _____ approved as submitted.

Protocol Synopsis approved as submitted on January 25, 2002

Amendment _____ to the protocol approved as submitted.

Based upon the recently completed Continuing Review (IRB Form 4), project has received continued approval through _____

Project has been approved, contingent upon the modifications outlined below being incorporated. In order to receive final approval, you must submit one "highlighted" copy and one "clean" copy of the revised protocol synopsis, informed consent and advertisement to the IRB for review.

Consideration of the project has been tabled pending resolution of the issue(s) outlined below.

Project is disapproved for the reason(s) outlined below.

Completion of project is acknowledged and all required paperwork has been received.

Project is approved as submitted for expedited review under the provisions of 45 CFR 46.110, #7.

In addition, the study meets the conditions mandated by 45 CFR 46.115 (d), #1, #2 and #3 and the conditions mandated by 45 CFR 46.117 (c), #2 and a waiver from the requirement to obtain informed consent is granted.

Chairman, Institutional Review Board

January 25, 2002
Date

White Copy - PI

Yellow Copy - IRB Office

Pink Copy - Department File

IRB Form 2 revised 9/01
MA 01-3434

APPENDIX D

**Texas Woman's University
Institutional Review Board
Letter of Approval**

**TEXAS WOMAN'S
UNIVERSITY**

INSTITUTIONAL REVIEW BOARD
P.O. Box 425619
Denton, TX 76204-5619
Phone: (940) 898-3375
Fax: (940) 898-3416
e-mail: IRB@twu.edu

February 13, 2002

Ms. Claudia Coggin

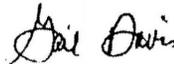
Dear Ms. Coggin:

Re: An Afrocentric Perspective: Needs of Breast Cancer Survivors

The above referenced study has been reviewed by a committee of the Institutional Review Board (IRB). This study was determined to be exempt from further TWU IRB review because it has been reviewed and approved by an IRB at the University of North Texas Health Science Center (UNTHSC) and all research activities will take place at that location.

Another review by the IRB is required if your project changes. If you have any questions, please feel free to call the Institutional Review Board at the phone number listed above.

Sincerely,



Dr. Gail Davis, Chair
Institutional Review Board - Denton

cc. Dr. Susan Ward, Department of Health Studies
Dr. Mary Shaw-Perry, Department of Health Studies
Dr. Sondra Ferstl, Office of Research & Grants Administration
Graduate School

APPENDIX E

**University of North Texas Health Science Center at Fort Worth
Intramural Research Committee
Funding Letter**



UNIVERSITY of NORTH TEXAS
HEALTH SCIENCE CENTER at Fort Worth

★
Education, Research,
Patient Care and Service

September 10, 2001

Claudia Coggins, MS, CHES and Mary Shaw-Perry, Ph.D., CHES
Departments of Social and Behavioral Sciences, School of Public Health
University of North Texas Health Science Center at Fort Worth

Dear Ms. Coggins,

I am pleased to inform you that you have been awarded a grant from Faculty Research funds in the amount of \$6,600.00 for your project entitled "Psychosocial Needs of American African Cancer Survivors". Your proposal scored 74.18% which ranked sixteenth out of the twenty two submitted. In the second tier of the review process the Council assessed funding of the proposals. It will be necessary for you to:

1. Read and sign the attached Notice of Grant Award signifying your acceptance of the conditions of the award.
2. Set up your budget for the fiscal year ending August 31, 2002 (you must forward a completed budget packet directly to the Office of Grant & Contract Management to activate your account).

Funds will be available immediately and must be expended before August 31, 2002. It is important to note that Faculty Research funds cannot be carried over from one fiscal year to the next.

NOTE: Please be advised that if pending extramural funding is approved and funded for this project, Faculty Research funds will be withdrawn.

Best of luck in your research endeavors.

Sincerely,

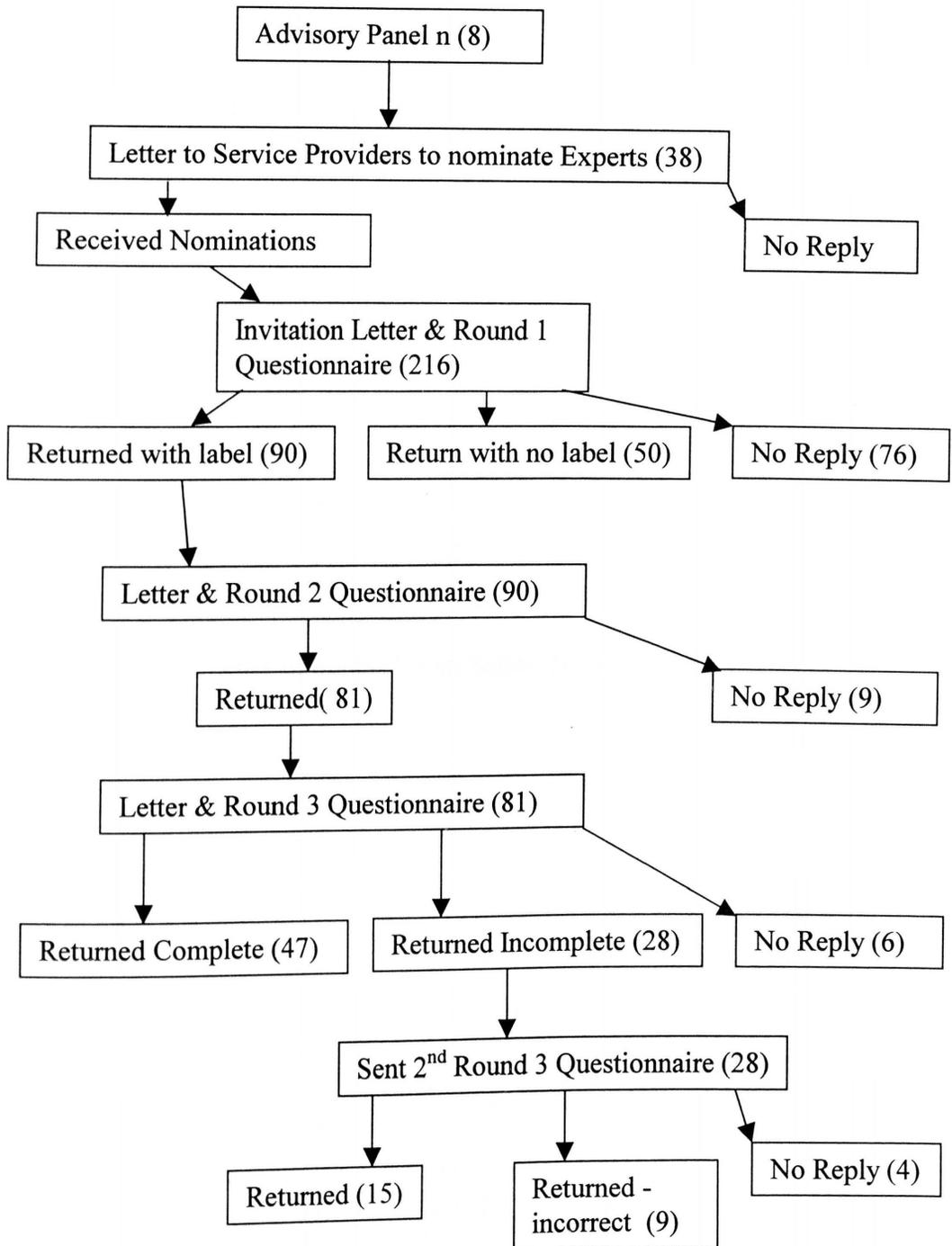
R.W. Gracy, Ph.D.
Chairman, Intramural Research Committee

Attachment

APPENDIX F
Delphi Technique Flow Chart



Flow Chart for Delphi Technique

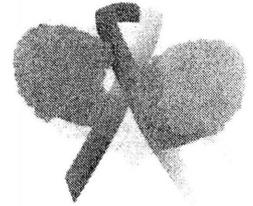


APPENDIX G

Letter of Support from Sisters Network, Inc.

Sisters

NETWORK, INC.



A NATIONAL AFRICAN-AMERICAN BREAST CANCER SURVIVORS' ORGANIZATION™

NATIONAL OFFICE
11116 W. BEAUX
KAREN E. JACKSON
Chairman

BEVERLY GAVIN
Vice President

CAROL BURTON-ALLEN
Secretary

REGINALD D. PATRICK
Treasurer

JUDY HOWARD
Member

JOEL B. FLOWERS
Member

TRACY COOK-BREWTON
Member

SCOTT A.
STANLEY, M.D.
LISA A. NEWMAN, M.D.
Chief Medical Advisor

RICHARD EUBANKS, M.D.
HAROLD FRIEDMAN, M.D.
EDWIN T. JOHNSON, M.D.
LOVELL JONES, Ph.D.
LASSALLE D. LEFFALL, JR. M.D.
RICHARD R. LOVE, M.D.
LAVINIA MIDDLETON, M.D.
OLUFUNMILAYO OLOPADE, M.B.
NORMA ROBERSON, RN, Ph.D.
TANYA W. STEPHENS, M.D.

March 28, 2002

Dear Chapter Presidents,

During our last Teleconference call we were fortunate to have Dr Mary Shaw-Perry join our discussion to explain her research project. This project, *An Afrocentric Perspective: Needs of Breast Cancer Survivors* is strongly supported by the National Office and myself. Dr. Shaw-Perry and her doctoral student, Ms Claudia Coggin, will share their findings with us. This information will strengthen our position as advocates and enhance our grant applications.

Please respond to their invitation to nominate ladies from your chapters.

Sincerely,

Karen E. Jackson
National President

NATIONAL HEADQUARTERS
8787 WOODWAY DRIVE • SUITE 4206 • HOUSTON, TEXAS 77065
713.781.0255 • FAX 713.780.8998
(Toll Free) 1.866.781.1808
www.sistersnetworkinc.org
e-mail: sisnet4@aol.com

APPENDIX H
Self-Nomination Form

Self-Nomination Form

for Research Study

An Afrocentric Perspective: Needs of Breast Cancer Survivors

Thank you for assisting us,
Claudia Coggin, MS, CHES,
Principal Investigator
817/735-2360
ccoggin@hsc.unt.edu
Department of Health Studies, Texas Woman's University, Denton, TX

Mary Shaw-Perry, Ph.D., CHES
Research Advisor
940/898-2865
mshaw@twu.edu

Please complete the information below and return in the attached self-addressed postage paid envelope.

Name:

Mailing Address:

Phone number:

Email:

APPENDIX I

List of Sisters Network, Inc. Chapters and Service Providers

Sisters Network, Inc. Chapter Name and Location and
Service Providers Contacted for Nominations

Women of Essence-Los Angeles, CA Chapter

Sisters Surviving, Baltimore, MD Chapter

Sisters Network Dallas, TX Chapter

Sisters Network, Oakland CA Chapter

Sisters Network of Center, New Jersey Chapter

Sisters Network Long Island, NY Chapter

Mahogany Sisters Network, Queens, NY Chapter

Sisters Support Sisters, Baton Rouge, LA

Sisters Network, Austin TX Chapter

Sisters Network, Northeast Florida Chapter

Sisters Network, Atlanta, GA Chapter

Sisters Network, Las Vegas, NV Chapter

Sisters Network, Andrews, SC Chapter

Sisters Network, Passaic/Bergen Counties Chapter

Sisters Network, Rochester, NY Chapter

Sisters Network, Upstate South Carolina Chapter

Sisters Network, Nashville, TN Chapter

Sisters Network, San Francisco, CA Chapter

Sisters Network, Suffolk County, L.I.N.Y. Chapter

Sisters Network, Detroit Metropolitan Chapter

Sisters Network, Seattle, WA

Sisters Network, Omaha, NE Chapter

Sisters Network, Richmond, VA

Sisters Network, Buffalo, NY

OTHER SERVICE PROVIDERS

Faces of Survivors, Arlington, TX

The Celebrating Life Foundation, Dallas, TX

Cancer Care Services, Fort Worth, TX

Doris Kupferle Breast Center, Fort Worth TX

Universal Health, Fort Worth, TX

APPENDIX J

Invitation Cover Letter for Round One Questionnaire

Invitation Letter for Round One Questionnaire

Member name
Address
City

Dear Sisters member (use name)

You have been nominated by the president of your Sisters Network Chapter to participate in a national research study entitled, *An Afrocentric Perspective: Needs of Breast Cancer Survivors*. Your president identified you as an expert who can give us valuable information regarding breast cancer survivorship.

Enclosed is the questionnaire. Part I has questions about you and your history of breast cancer. In Part II we would like your opinions about your needs as a breast cancer survivor.

Participation in this research study is voluntary. If you decide to participate in this important study you will be asked to complete three (3) other short questionnaires over the next three months. All information is confidential and will be reported as group responses only. You may withdraw from the study at any time without penalty or loss of benefits that you are otherwise provided

Please return your completed questionnaire in the enclosed self-addressed stamped envelope by (DATE). Please complete the attached mailing label with your correct mailing information and enclose it with the questionnaire. When we receive your envelope, the mailing label will be separated from the questionnaire and your responses on the questionnaire will remain confidential.

Thank you for agreeing to participate. If you have any questions, please feel free to contact either Dr. Shaw-Perry or me.

Sincerely,

Claudia Coggin, MS, CHES,
Principal Investigator
817/735-2360
ccoggin@hsc.unt.edu

Department of Health Studies, Texas Woman's University, Denton, TX

Mary Shaw-Perry, Ph.D, CHES
Research Advisor
940/898-2965
mshaw@twu.edu

APPENDIX K

Round One Questionnaire

An Afrocentric Perspective: Needs of Breast Cancer Survivors Questionnaire
Part I - Participant Profile

This information is confidential and will only be used to describe the participant group. You may withdraw from the study at any time.

PLEASE ANSWER THE FOLLOWING QUESTIONS BY PLACING A CHECK ON THE LINE OR PROVIDING THE REQUESTED INFORMATION

1. Where do you live in the United States (geographic region)?

- Northeast
- East
- Southeast
- Midwest
- West
- Southwest

1. What best describes where you live?

- rural area
- urban area
- suburban area

3. What is your date of your birth _____
Month Year

4. Number of years of survivorship _____

5. Year of breast cancer diagnosis _____

6. What best describes your current relationship status?

- Single (Never Married)
- Legally Married
- Common Law
- Partnered
- Separated
- Divorced
- Widowed or partner died
- Other: _____

(please turn page)

7. Please indicate the number of children in your household

- None
- One child
- Two children
- Three children
- Four or more children

8. What is the highest level of education you completed?

- Grade school
- Some high school
- High school graduate/GED
- Technical or Trade School
- Some college
- Completed college
- Graduate level courses
- Other _____

9. What describes your **current job** (work) situation? (**Check all that apply to you.**)

- Full-time job
- Part-time job
- Working part time on disability
- Not working - on full disability
- Not working - student
- Not working - looking
- Not working
- Retired
- Other: _____

Specify

10. Which of the following best describes your current yearly income?

- 0 - \$9,999
- 10,000 - \$19,999
- 20,000 - \$29,999
- 30,000 - \$39,999
- 40,000 - \$49,999
- greater than \$50,000

(please turn page)

11. What kind of health insurance do you have? **(Check all that apply to you.)**

- None, I have no health insurance
- Insurance through work
- COBRA (insurance paid through your last employer)
- Private insurance, not through work
- Medicare

If yes, is it managed by an HMO?

- YES
- NO

Medicaid

If yes, is it managed by an HMO?

- YES
- NO

Veterans

Public Health Assistance

Other: _____

12. Which of the following benefits do you receive? **(Please check all that apply to you.)**

- Food Stamps
- Long term disability
- Rent supplement
- Short term disability
- Supplemental Security Income SSI
- Social Security Disability Income (SSDI)
- Veterans assistance
- Worker's compensation
- Annuity/Life insurance payments
- Retirement
- WIC
- TANF (AFDC)
- Not eligible for benefits

Other public assistance _____

13. Where do you receive your medical care? **(Please check all that apply to you.)**

- Hospital/Hospital Clinic
- Community Health Clinic/Center Private Physician's Office/Clinic
- HMO/Managed Care Clinic
- Public Health Clinic (provides diverse clinical services)

Other: _____

(please turn page)

14. Please indicate the kind of cancer treatment/care services you have used. **(Please check all that apply to you.)**

- support group
- family doctor
- oncologist
- chemotherapy
- cancer clinic
- Clinical trial
- radiation therapy
- surgery
- other _____

15. Do you have any disabilities?

- Yes What type? _____
- No

If YES to any disabilities other than breast cancer. How often do you need assistance related to your disability in obtaining cancer related services?

- Never
- Rarely (no more than once a week)
- Some of the time (one to four times a week)
- Often (five or more times a week)

16. Have you been unable to get needed services because of the following circumstances or disabilities? **(Please check all that apply to you.)**

- Wheelchair bound
- Hard of hearing
- Legally deaf
- Visually impaired (not correctable by eyeglasses)
- Blind
- Mentally impaired
- Chemical dependency (alcohol, illicit drugs)
- Other: _____
Specify

(please turn page)

Part II – Assessing Needs of Breast Cancer Survivors

PLEASE ANSWER EACH QUESTION. YOUR OPINION WILL HELP US BETTER UNDERSTAND THE NEEDS OF BREAST CANCER SURVIVORS.

1. *What are your most important needs as a breast cancer survivor.*

1.)

2.)

3.)

2. *What are your most important:*

A. Physical needs

1.)

2.)

3.)

B. Social needs

1.)

2.)

3.)

(please turn page)

C. Emotional needs

1.)

2.)

3.)

D. Spiritual needs:

1.)

2.)

3.)

E. Financial needs:

1.)

2.)

3.)

Thank you for completing this questionnaire. You will receive the second questionnaire soon.

Please complete the attached label below with correct mailing information. It will be removed immediately upon receipt of the questionnaire and saved for the next mailing of questionnaires. Your name will not be attached or identified in any way to this questionnaire. Your answers are confidential and information will only be reported as part of a group report. The researchers will not have access to the information that links the responses with individual participants.

APPENDIX L

Reminder Postcard Text

Reminder Postcard Text

WE NEED YOUR HELP!

About one week ago we sent you a questionnaire asking your opinion about needs as a breast cancer survivor.

If you have already returned the questionnaire, please accept our sincere thanks. If not, please return it today. Only a small number of African American women received the questionnaire therefore your opinion is valuable and will help us report the experiences of a diverse group of African American breast cancer survivors.

We need your help and appreciate your time. If you did not receive the questionnaire, or it has been misplaced, please call us at 817/735-2360 and we will mail another one to you immediately.

Thank you,
Claudia Coggin
Univ. of North Texas Health Science Center
Ft Worth, TX

Dr. Mary Shaw-Perry
Texas Woman's University
Denton, TX

APPENDIX M

Cover Letter for Round Two Questionnaire

Cover Letter for Round Two Questionnaire

Date

Dear Expert Panel Member,

Thank you for agreeing to assist us with this national needs assessment research study. Enclosed is a summary of the responses received in round one questionnaire. Please read the directions and return the questionnaire to us by (date). Your opinion is very important to us.

Participation in this research study is voluntary. You may withdraw from the study at any time without penalty or loss of benefits that you are otherwise provided.

Thank you for agreeing to participate. If you have any questions, please feel free to contact either Dr. Shaw-Perry or me.

Sincerely,

Claudia Coggin, MS, CHES,
Principal Investigator
817/735-2360
ccoggin@hsc.unt.edu

Mary Shaw-Perry, Ph.D, CHES
Research Advisor
940/898-2965
mshaw@twu.edu

Department of Health Studies, Texas Woman's University, Denton, TX

APPENDIX N

Round Two Questionnaire

An Afrocentric Perspective: Needs of Breast Cancer Survivors Questionnaire #2

This information is confidential. You may withdraw from the study at any time

DIRECTIONS:

- 1.) ***Please read each of the statements below.***
- 2.) ***Circle the number that indicates how much you AGREE or DISAGREE with each statement.***

YOUR OPINION IS VERY IMPORTANT TO US!

The most important Physical Needs for me as an African American breast cancer survivor are:

	Strongly Agree 1	Agree 2	Undecided 3	Disagree 4	Strongly Disagree 5
1. To know how to exercise and/or be able to exercise regularly	1	2	3	4	5
2. To know what kind of foods to eat to maintain health and a healthy (good) weight	1	2	3	4	5
3. To get the proper amount of sleep and rest	1	2	3	4	5
4. To be active and able to participate in activities	1	2	3	4	5
5. To be relieved of muscle, bone and joint pain caused by treatments or aggravated by the treatments	1	2	3	4	5
6. To be able to get information, supplies, and treatment for lymphedema	1	2	3	4	5
7. To have a full range of available, affordable, accessible, acceptable, and appropriate medical care and other support services	1	2	3	4	5

The most important Emotional Needs for me as an African American breast cancer survivor are:

	Strongly Agree 1	Agree 2	Undecided 3	Disagree 4	Strongly Disagree 5
1. To have current and reliable information about the advances in therapy, medications, side effects and/or treatments	1	2	3	4	5
2. To feel secure and worry free	1	2	3	4	5
3. To be able to express my fears, concerns, and dreams	1	2	3	4	5
4. To feel at ease about my health	1	2	3	4	5
5. To know who to contact when I have symptoms and/or health problems related to the breast cancer	1	2	3	4	5
6. To see black survivors involved in activities that bring awareness to the community	1	2	3	4	5
7. To have the support of my family and friends	1	2	3	4	5
8. To feel better about my self image or to have a more positive self image	1	2	3	4	5

The most important Social Needs for me as an African American breast cancer survivor are:

	Strongly Agree 1	Agree 2	Undecided 3	Disagree 4	Strongly Disagree 5
1. To have access to a support group of breast cancer survivors	1	2	3	4	5
2. To have a loving, caring family	1	2	3	4	5
3. To have loving, caring friends	1	2	3	4	5
4. To go out in my community and tell my story; and to educate other African American women about breast cancer and screenings	1	2	3	4	5
5. To have caring, concerned, respectful health care professionals and/or personnel	1	2	3	4	5

The most important Spiritual Needs for me as an African American breast cancer survivor are:

	Strongly Agree 1	Agree 2	Undecided 3	Disagree 4	Strongly Disagree 5
1. To be surrounded by a caring church family	1	2	3	4	5
2. To know that I am not alone in the journey	1	2	3	4	5
3. To have strong faith and have a relationship with God	1	2	3	4	5
4. To pray and meditate on the Word of God	1	2	3	4	5
5. To be able to attend church	1	2	3	4	5

The most important Financial Needs for me as an African American breast cancer survivor are:

	Strongly Agree 1	Agree 2	Undecided 3	Disagree 4	Strongly Disagree 5
1. To have adequate insurance coverage for surgeries, treatments, and/ or medications	1	2	3	4	5
2. To be able to pay for housing	1	2	3	4	5
3. To be able to pay utility bills	1	2	3	4	5
4. To be able to pay for food	1	2	3	4	5
5. To have access to reliable, affordable transportation	1	2	3	4	5
6. To be able to pay for prosthesis and bras	1	2	3	4	5
7. To be able to afford medical care and support services	1	2	3	4	5
8. To have an adequate income to take care of myself and/or my family	1	2	3	4	5

ADDITIONAL COMMENTS:

APPENDIX O

Cover Letter for Round Three Questionnaire

Cover Letter for Round Three Questionnaire

Date

Dear Expert Panel Member,

Thank you for agreeing to assist us with this national needs assessment research study. Enclosed is a summary of the responses received in round two questionnaire. Please read the directions and return the questionnaire to us by (date). Your opinion is very important to us.

Participation in this research study is voluntary. You may withdraw from the study at any time without penalty or loss of benefits that you are otherwise provided.

Thank you for agreeing to participate. If you have any questions, please feel free to contact either Dr. Shaw-Perry or me.

Sincerely,

Claudia Coggin, MS, CHES,
Principal Investigator
817/735-2360
ccoggin@hsc.unt.edu

Department of Health Studies, Texas Woman's University, Denton, TX

Mary Shaw-Perry, Ph.D, CHES
Research Advisor
940/898-2965
mshaw@twu.edu

APPENDIX P

Round Three Questionnaire

An Afrocentric Perspective: Needs of Breast Cancer Survivors Questionnaire #3

This information is confidential. You may withdraw from the study at any time

DIRECTIONS:

3.) Please read each of the statements below.

4.) Please rank EACH statement to tell us how important the statement is to you. Place a #1 by the statement most important then a #2 by the next most important statement, then #3 then #4 and so on until the last # is the one that is least important to you.

YOUR OPINION IS VERY IMPORTANT TO US!

I.

My most important PHYSICAL NEEDS as an African American breast cancer survivor are:

Rank the statements 1 to 7 with #1 being the most important to you

<u>STATEMENT</u>	<u>#</u>
To be relieved of muscle, bone and joint pain caused by treatments or aggravated by the treatments.	
To know how to exercise and/or be able to exercise regularly.	
To be active and able to participate in activities	
To be able to get information, supplies, and treatment for lymphedema.	
To get the proper amount of sleep and rest	
To know what kind of foods to eat to maintain health and a healthy (good) weight.	
To have a full range of available, affordable, accessible, acceptable, and appropriate medical care and other support services	

II.

My most important EMOTIONAL NEEDS as an African American breast cancer survivor are:

Rank the statements 1 to 8 with #1 being the most important to you

<u>STATEMENT</u>	<u>#</u>
To feel better about my self image or to have a more positive self image.	
To see black survivors involved in activities that bring awareness to the community.	
To feel secure and worry free.	
To be able to express my fears, concerns, and dreams.	
To know who to contact when I have symptoms and/or health problems related to the breast cancer.	
To feel at ease about my health.	
To have the support of my family and friends.	
To have current and reliable information about the advances in therapy, medications, side effects and/or treatments.	

III.

My most important SOCIAL NEEDS as an African American breast cancer survivor are:

Rank the statements 1 to 5 with #1 being the most important to you

<u>STATEMENT</u>	<u>#</u>
To go out in my community and tell my story; and to educate other African American women about breast cancer and screenings.	
To have access to a support group of breast cancer survivors.	
To have loving, caring friends	
To have a loving, caring family	
To have caring, concerned, respectful health care professionals and/or personnel	

IV.

My most important SPIRITUAL NEEDS as an African American breast cancer survivor are:

Rank the statements 1 to 5 with #1 being the most important to you

<u>STATEMENT</u>	<u>#</u>
To be surrounded by a caring church family.	
To be able to attend church.	
To know that I am not alone in the journey.	
To pray and meditate on the Word of God.	
To have strong faith and have a relationship with God.	

V.

My most important FINANCIAL NEEDS as an African American breast cancer survivor are:

Rank the statements 1 to 8 with #1 being the most important to you

<u>STATEMENT</u>	<u>#</u>
To have access to reliable, affordable transportation.	
To be able to pay for prosthesis and bras.	
To be able to pay for housing.	
To be able to pay utility bills.	
To be able to pay for food.	
To be able to afford medical care and support services.	
To have adequate insurance coverage for surgeries, treatments, and/or medications.	
To have an adequate income to take care of myself and/or my family.	

ADDITIONAL COMMENTS (feel free to write on back):

APPENDIX Q

Cover Letter for Second Mailing of Round Three Questionnaire

Dear Sisters,

You have been so cooperative in returning the surveys in a timely manner! We have received 59 completed surveys in Round 3. Unfortunately many of you did not complete the final survey according to the directions. Please **HELP ME** to complete this important report for African American breast cancer survivors. Complete the Round 3 survey according to the directions on the next page.

Here We Go...I need you to prioritize the statements!! PLEASE!!!

Remember that often service providers need to prioritize and allocate funds for service delivery based on what YOU have determined is most important or urgent!!!

Please do the following for us:

- **Prioritize** the statements in each section of the survey
- **Complete** all 3 pages and
- **Return by August 12, 2002**

Thank you for your attention to this important matter. Please call me if you have questions and/or comments.

Mary Shaw-Perry, Ph.D., CHES
Texas Woman's University 940-898-2865
drmperry@aol.com

APPENDIX R

Example Page for Second Round Three Questionnaire Mailing

EXAMPLE

An Afrocentric Perspective: Needs of Breast Cancer Survivors Questionnaire #3

This information is confidential. You may withdraw from the study at any time

DIRECTIONS:

5.) Please read each of the statements below.

6.) Please rank EACH statement to tell us how important the statement is to you. Place a #1 by the statement most important then a #2 by the next most important statement, then #3 then #4 and so on until the last # is the one that is least important to you.

YOUR OPINION IS VERY IMPORTANT TO US!

I.

My most important PHYSICAL NEEDS as an African American breast cancer survivor are:

Rank the statements 1 to 7 with #1 being the most important to you

<u>STATEMENT</u>	<u>#</u>
To be relieved of muscle, bone and joint pain caused by treatments or aggravated by the treatments.	5
To know how to exercise and/or be able to exercise regularly.	6
To be active and able to participate in activities	1
To be able to get information, supplies, and treatment for lymphedema.	3
To get the proper amount of sleep and rest	2
To know what kind of foods to eat to maintain health and a healthy (good) weight.	4
To have a full range of available, affordable, accessible, acceptable, and appropriate medical care and other support services	7

This order means that # 1 is the most important statement to you and # 2 is the next most important statement to you and # 3 is next most important.

APPENDIX S

Invitation Letter for the Advisory Board

Invitation Letter for the Advisory Board

(Date)

(Address)

Dear:

We are in the process of initiating the research study, *An Afrocentric Perspective: Needs of Breast Cancer Survivors*. We have received a small grant through the University of North Texas Health Science Center to conduct a pilot study.

We would like to invite you to serve on the advisory committee to review the questionnaire and to assist with the nomination of the panel of experts. The advisory committee will meet via conference calls to discuss the procedures and to review the questionnaires. We anticipate having four conference calls beginning (date).

The summary of the project is enclosed. Upon completion of the study, we will provide you a summary of our findings. You will be able to use the information in your advocacy role to improve the quality of life for African American breast cancer survivors.

Thank you for your support of this study. Please call or email your response to our invitation. We will be glad to supply further information. We look forward to hearing from you soon.

Sincerely,

Claudia Coggin, MS, CHES,
Principal Investigator
817/735-2360
UNT Health Science Center
School of Public Health
ccoggin@hsc.unt.edu

Mary Shaw-Perry, Ph.D, CHES
Research Advisor
940/898-2865
Department of Health Studies,
Texas Woman's University
mshaw@twu.edu

Enclosure

Afrocentric Perspective: Needs of Breast Cancer Survivors Research Project Summary

What is the purpose of the research project?

The purpose of this qualitative research study utilizing a Delphi Technique assessment strategy is to: 1) identify the psychosocial needs of African American Breast cancer survivors and 2) to examine the role that culturally appropriate support groups can play in improving the quality of life for African American breast cancer survivors.

How will we collect the information?

An advisory committee made up of invited breast cancer support network members who will assist by advising the researchers. Through this network we will ask for nominations of participants from each of the affiliate chapter presidents. We will ask for the name and address of each participant nominated. We would like to include a letter of support from the founder and national president as well as from the affiliate chapter president that can be included with the survey

We will use the Delphi Technique to gather the information. The Delphi Technique will involve a series of four (round #1, #2, #3, & #4) mailed questionnaires. The survey will consist of two parts. Part I of the round #1 questionnaire will include expert panel member eligibility criteria and demographic that will establish a profile of the panel. Part II will consist of three open-ended questions based on the research questions. The responses of round #1 will be analyzed and summarized to become the second round of questions. In round #2, the panel members will be asked to indicate their level of agreement or disagreement to each question or statement according to a Likert scale. For round #3, the wording will be adjusted based on comments in response to round #2. Participants will be asked to rank their preference for the statements. Round #4 is the final feedback questionnaire and it will invite comments on the process involved in the research and will assist in identifying directions for future research. Each cover letter will have the names, addresses, e-mail addresses, and phone numbers of the researchers to enable participants to contact the researchers to ask questions regarding the study.

How we propose to protect the identity and privacy of each participant.

A blank label will be attached to each questionnaire. The label will be coded to match the master list of participants or panel of experts nominated by the breast cancer service providers. Each participant will be asked to self-address the label. The label will be coded to match the master list of participants or panel of experts nominated by the breast cancer support network group. The label will be separated immediately from the questionnaire by the research assistant and placed in an envelope to be used for the mailing label of the next questionnaire. The code on the label will be used to track response rates. No effort to link label and questionnaires will be made. The Principal Investigator and Co-Investigator will not have access to the identifier information that links the responses with the individual participants. No subject identifiers (e.g. name, social security number, etc.) will appear on the survey instrument. All reports and potential publications will report aggregate information only – subjects will not be identified. Every effort will be made to protect the confidentiality of each participant.

At the end of five years from the date of the completion of the study, all records will be shredded and destroyed. All reports and publications will report group data. Individual participants will not be identified.

APPENDIX T

List of Advisory Board Members

Advisory Board

Karen Jackson
Executive Director Sisters Network, Inc
Houston, TX

Lois Williams
Images at St Paul's Hospital
Dallas, TX

Karen Williams
Arlington, TX

Yolanda Snow
Arlington, TX

Dorothy Reed
Somerset, New Jersey

Sharon Andrews
Midwest City, Oklahoma

Betty Salsbury
Fort Worth, TX

Rosena Clark-Turner
Fort Worth, TX

APPENDIX U

Summary of Analysis of Round Two Questionnaire

Summary of the Analysis of Responses to Round Two Questionnaire

Table 1

Most Important Physical Needs Shown by “Strongly Agree” and “Agree” Responses

Physical Need Statement	Total # of “Strongly Agree” or “Agree”
1. To have a full range of available, affordable, accessible, acceptable, and appropriate medical care and other support services.	80
2. To be able to get information, supplies, and treatment for lymphedema.	78
3. To know what kind of foods to eat to maintain health and a healthy (good) weight.	77
4. To be active and able to participate in activities.	77
5. To get the proper amount of sleep and rest.	76
6. To know how to exercise and/or be able to exercise regularly.	75
7. To be relieved of muscle, bone and joint pain caused by treatments or aggravated by the treatments.	71

Table 2

Most Important Emotional Needs Shown by “Strongly Agree” and “Agree” Responses

Emotional Need Statement	Total # of “Strongly Agree” or “Agree”
1. To have current and reliable information about the advances in therapy, medications, side effects and/or treatments.	81
2. To have the support of my family and friends.	81
3. To feel at ease about my health.	80
4. To know who to contact when I have symptoms and/or health problems related to the breast cancer.	80
5. To be able to express my fears, concerns, and dreams.	79
6. To feel secure and worry free.	79
7. To see black survivors involved in activities that bring awareness to the community.	78
8. To feel better about my self image or to have a more positive self image.	76

Table 3

Most Important Social Needs Shown by “Strongly Agree” and “Agree” Responses

Social Need Statement	Total # of “Strongly Agree” or “Agree”
1. To have a loving, caring family.	81
2. To have caring, concerned, respectful health care professionals and/or personnel.	81
3. To have loving, caring friends.	79
4. To go out in my community and tell my story/ and to education other African American women about breast cancer and screenings.	77
5. To have access to support group of breast cancer survivors.	75

Table 4

Most Important Spiritual Needs Shown by “Strongly Agree” and “Agree” Responses

Spiritual Need Statement	Total # of “Strongly Agree” or “Agree”
1. To have a strong faith and have a relationship with God.	81
2. To pray and meditate on the Word of God.	81
3. To know that I am not alone in the journey.	78
4. To be able to attend church.	76
5. To be surrounded by a caring church family.	75

Table 5

Most Important Financial Needs Shown by “Strongly Agree” and “Agree” Responses

<i>Financial Need Statement</i>	<i>Total # of “Strongly Agree” or “Agree”</i>
1. To have adequate insurance coverage for surgeries, treatments, and/or medications.	80
2. To have an adequate income to take care of myself and/or my family.	80
3. To be able to afford medical care and support services.	79
4. To be able to pay utility bills.	78
5. To be able to pay for food.	78
6. To be able to pay for housing.	77
7. To have access to reliable, affordable transportation.	77
8. To be able to pay for prosthesis and bras.	74