



Published in final edited form as:

*J Cancer Educ.* 2014 December ; 29(4): 619–625. doi:10.1007/s13187-013-0592-8.

## African American breast cancer survivors participating in a breast cancer support group: Translating research into practice

Anjanette A. Wells, PhD, MSW<sup>1</sup>, Lauren Gulbas, PhD<sup>2</sup>, Vetta Sanders-Thompson, PhD, MSW<sup>1</sup>, En-Jung Shon, MSW, MA<sup>3</sup>, and Matthew W. Kreuter, PhD, MPH<sup>1</sup>

<sup>1</sup>Brown School of Social Work, Washington University in St. Louis

<sup>2</sup>Department of Anthropology, Dartmouth College

<sup>3</sup>Mandel School of Applied Social Sciences, Case Western Reserve University

### Abstract

**Background**—Despite an overall decline in mortality, breast cancer is the most commonly diagnosed cancer and the second most common cause of cancer death among African American women. As such, clinicians should prepare to address the unique sociocultural and psychological concerns encountered by African American women breast cancer survivors.

**Objective**—To examine, using qualitative methods, the main coping facilitators used by African American women as they transition across the cancer continuum. The identification of these facilitators was then aligned with culturally sensitive interventions most useful with women coping with cancer, along the cancer continuum.

**Methods**—This was a secondary analysis of 20 video-taped stories of African American breast cancer survivors collected as a part of the Washington University Center for Excellence in Cancer Communications project. The interview began with a discussion of how the survivor first became aware she had breast cancer, followed by a series of open-ended probes used to explore the following themes: coping, relationships, health care system experiences, follow up care, and quality of life living with breast cancer.

**Results**—Survivors discussed their experiences and advice for targeting needs at each cancer stage, from *screening* to *diagnosis*, *treatment*, and then *survivorship*. Survivor narratives point to key evidence-based clinical intervention strategies at each stage of the cancer trajectory.

**Conclusion**—This study found that survivors see a cyclical cancer course, whereby African American breast cancer survivors serve an important role in the lives of unscreened women, newly diagnosed women, and women in treatment.

---

Corresponding author: Anjanette Wells, PhD, Assistant Professor, George Warren Brown School of Social Work, Washington University in St. Louis, (Address): 210 Brown Hall, Campus Box 1196, One Brookings Drive, St. Louis, MO 63130-4899, (Office): 314-935-3375, (Fax): 314-935-8511, awells@gwbmail.wustl.edu.

**Co author's contact information:** Lauren Gulbas, Office Phone: (603) 646-6449, lauren.e.gulbas@dartmouth.edu

Vetta Sanders-Thompson, Office Phone: (314) 935-3702, vthompson22@wustl.edu

En-Jung Shon, Phone: (314) 443- 9765, exs350@case.edu

Matthew W. Kreuter, Office Phone: (314) 935-7301, mkreuter@wustl.edu

#### Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article. No competing financial interests exist

## Keywords

African American; breast cancer; cancer trajectory; intervention; survivorship

---

## Introduction

While breast cancer mortality has been declining since the 1990s due to increases in awareness, early detection and treatment [1], not all women have benefited equally [2]. While overall incidence of breast cancer is lower in African American women than in White women, African American women diagnosed with breast cancer are 38% more likely than White women to die from the disease [1], and the African American decline in mortality rate has been slower than that observed for White women [2, 3].

Disparities in breast cancer mortality in part reflect differential trends in stage at diagnosis [4, 5]. One trend of concern is that the rate of late-stage diagnosis for White women has remained stable over the past 35 years while rates for African American women have steadily increased. Delayed diagnoses contribute to poor outcomes and African American women have significantly lower 5-year survival than White women (78% vs. 90%, respectively) [1]. In addition, compared to White women, African American women are less likely to receive timely and stage-appropriate breast cancer treatment and are less likely to adhere to and complete treatment [6, 7]. Thus, facilitating treatment compliance is another equally important strategy for decreasing African American breast cancer mortality.

Increasingly, social workers, psychologists and others with counseling skills are called to work with women across the cancer continuum, whether related to decisions and concerns that arise due to suspicious screening results, or psychological sequel of breast cancer diagnosis and treatment. It is important that these clinicians be prepared to address the issues encountered by individuals diagnosed with cancer, as well as the unique psychosocial issues encountered by patients due to their cultural attitudes, beliefs and social context.

Incorporating spirituality and social support strategies have been utilized to increase screening and treatment adherence and reduce breast cancer disparities for Black women. Spirituality has been found to play an important role in mammography utilization[8] and has been related to breast cancer treatment adherence and coping at various stages of treatment [9]. Similarly, social support provides a way of coping with breast cancer [10]. With regard to cancer screening behaviors, family networks are associated with both recent cancer screening and the intention to screen for cancer [11]. In addition, African Americans often rely on informal sources of health care advice such as family members and church based support [12], suggesting a potential influence on treatment adherence particularly among a survivor group that has reported difficulty talking about the disease [13].

This qualitative study, a secondary analysis of video-taped stories of African American cancer survivors collected as a part of Washington University Center for Excellence in Cancer Communications project [14], examines the main coping facilitators used by African American women as they transitioned across the cancer continuum. These facilitators are associated with interventions perceived as more culturally sensitive and useful when used

strategically along the cancer continuum with women having less successful experiences coping with cancer.

## Methods

Results are drawn from data collected during a larger mixed-method project that investigated African American women survivors' perspectives and experiences of breast cancer diagnosis and treatment. Participants were recruited through project partnerships with five St. Louis breast cancer support groups for African American survivors. Research participants in the qualitative portion of the overall study included 46 African American women diagnosed with breast cancer and 13 family members of African American women diagnosed with breast cancer. A survivor was operationalized as having been diagnosed and being alive at the time of videotaping for the original study. Participant survivorship ranged from < 1 to > 23 years. Survivors ranged in age from 46 - 76, with the average age of women in our sub-sample being 56.8 ( $SD = 9.42$ ). The majority of participants were between ages 40 and 49 when first diagnosed [14]. All 46 women were not included in this current study for two reasons. First, this article stems from part of a broader aim to explore, pilot, and test qualitative coding and analysis of video material. And second, it is important to recognize that "the effectiveness of qualitative research is derived not from large sample sizes, but from the collection of detailed narratives by research participants who provide reflection on and critical discussion of their personal experiences" [15, 16] We elicited stories from 20 African American women who had been diagnosed with breast cancer. In this paper, we focus on the sub-sample of qualitative interviews with 20 Black women diagnosed with breast cancer.

### Qualitative Interview

The parent study used Wengraf's (2001) biographic narrative interview method [17]. The interview guide was open-ended to allow participants' to narrate her breast cancer experience in her own words and encourage her to speak openly and in detail. The interview began with a discussion about how the survivor became aware she had breast cancer. Based on the course of the narrative, a series of open-ended probes were asked to explore the following themes: coping, relationships, experiences with the health care system, follow up care, and quality of life living with breast cancer. All interviews were video-taped and conducted by a project manager trained in conducting qualitative interviews.

### Qualitative Data Analysis

Because video tapes were not transcribed, the analysis of video data entailed a cyclical and iterative process of watching, recording interview case summaries, coding, and analyzing the data. First, the research team developed guidelines for writing interview case summaries. These guidelines were flexible, but also encouraged systematic preparation of case summaries by emphasizing key themes for team members to focus on while watching the video-recordings. To develop the guidelines, each team member watched two interviews (totaling six interviews), taking notes on important ideas, concepts, meanings, and experiences. During a meeting, team members presented and discussed their preliminary findings, and from this discussion, a set of guidelines were developed. The guidelines

ensured that when watching subsequent videos, researchers noted how participants talked about and described important themes related to the cancer trajectory. These observations were recorded in an interview case summary, a narrative and descriptive account of the participant's recollection of her experience of surviving cancer. The case summary captured the participants' narrative by reproducing dialogue through direct quotes and paraphrasing. After writing the case summary, a different team member watched the video again, comparing notes with what was recorded in the case summary to check for information accuracy and guard against observer bias.

Once prepared, case summaries were imported into NVIVO 8 for coding and analysis. We utilized an inductive, thematic approach to code data. Once coding was completed, we produced a conceptual cluster matrix to compare codes across participants. By organizing the data in this way, we were able to evaluate the saliency of particular codes and identify patterns in the configuration of codes across participants. A single team member, who re-watched video recordings to ensure the accuracy of data presented in the matrix, checked the information displayed in the matrix.

## Results

Figure 1 illustrates the cyclical cancer course, with each quadrant representing a different phase in the cancer trajectory. Survivors discussed their experiences and advice for targeting needs at each cancer stage, from *screening* to *diagnosis*, *treatment*, and then *survivorship*. This diagram illustrates how the survivorship phase “comes full circle” and transitions back to the earlier point of origin to the screening phase, and other subsequent phases. This cancer trajectory model is different from other linear diagrams, in that the trajectory is not complete at the survivorship phase, but rather shows the continuous relationships of influence in the full experience.

### Screening

Survivors described their pre-diagnostic biomedical knowledge as what it meant to have cancer in general, and their understanding and meaning attached to the term “cancer”, including initial symptoms which influenced their desire to screen for cancer. Although survivors were familiar with the cancer disease and its seriousness, they also perceived their susceptibility and risk to be low, particularly if a cancer history did not personally affect them or a family member. Survivors discussed family members often not talking about cancer, hiding it, or perceiving it as inappropriate for discussion. A common metaphor of this stage was that women reported having inaccurate information about actual screening and preventive procedures: “Prior to my diagnosis I thought breast cancer was the ‘*kiss of death*.’ Once you got to the point of diagnosis, there was little hope for survival. I had not done much studying; no one had talked to me about it.” Many women described not receiving screening because of common misperceptions which might have contributed to delay in screening behavior: “I was only 41. I got it nine or ten years before I needed to worry about breast cancer. I had my baseline mammogram at 39, and then should have had another one at 40 and another one at 41, I think, but I did not.

Despite inaccurate information about screening, survivors described their reasons for seeking initial consultation. Most survivor's did not identify their cancer through conscious preventive measures, but through randomly identifying "a lump", and then conducting a self-breast exam and going to their doctor for diagnostic screening. They described how they first learned about their cancer and how it was first communicated to them: "I had discovered something, and so I did what I understood to be a self-breast exam the way I did them then. And I could feel *the lump* again, so I got up and walked the entire diameter of my house. And then I went back to my bedroom, laid down and did a self-breast exam again, and I found that same lump again, in the same spot. Then, I just started to cry because I just knew."

In retrospect, many women offered advice to encourage African American women to get screening. They were comfortable offering *advice* and suggestions about the importance of screening to educate women. This advice was often framed in a way to reduce fear and uncertainty of mammograms and regular self-breast examinations, while educating them simultaneously. Most descriptions of getting a mammogram were realistic and favored the importance of breast cancer screening: "You all hear scary stories. Don't be afraid. Basically, it is just taking pictures of your breasts. They are going to lay them there and flatten them out, and take a picture. It gives you the advantage of finding whatever is there."

## Diagnosis

Survivors described their initial reaction to hearing they had been diagnosed with cancer. This was defined as metaphors, experiences, and emotions upon learning about their cancer diagnosis. They described negative feelings of "surprise," "anger," "fear," "devastation," "upset," and "hopelessness": "The first time I learned that I had breast cancer, I felt very *upset*." Most often they described the "shock" involved with the initial diagnosis: "That is when they finally ran a mammogram on me and told me it was cancer, breast cancer. That is when the *shock* hit home. When I was diagnosed, I was really in *shock*. I was hurt. And I said 'why me?'"

During the survivors' discussion of their diagnosis, we also see the beginning of a cross-cutting reflection on *spirituality* throughout the rest of the continuum. The spirituality code was applied when there was mention of prayer, God, faith, and/or church. Survivors described being less religious before their diagnosis, but becoming more spiritual when they went through the diagnostic stage. Women described renewed religiosity and a spiritual presence: "When I got the breast cancer diagnosis, it was my faith that first helped me to deal with it. There were often times late at night that I didn't want to call a friend, disturb a friend, or didn't want to call my family, so I had to rely on my faith and my relationship with God."

Women also felt inclined to offer *advice* about the needs of women at this stage in the cancer trajectory. Quotes were coded as advice when survivors offered suggestions and insight about how best to help others. They described the importance of obtaining knowledge at this diagnostic stage, in order to "empower": "Because if you have an idea what is going to happen to you, you know what to expect and then you are less fearful. One of my friends thought chemotherapy was like physical therapy because that's the only kind

of therapy she'd ever had. "The first place I took her was to the cancer information center because that knowledge *empowers* you to fight this disease. If you are afraid, you wouldn't like them to treat you, and then the cancer wins."

## Treatment

Survivors described their cancer treatment experiences and the associated needs at this stage. Survivors reported the increased need for emotional and instrumental support by family, friends, and co-workers: "I don't even know how to describe my husband; I am just so blessed to have him. He stands on his marriage vows - that is all he kept saying during the treatment and the whole ordeal. Another survivor describes treatment during their employment: "The positive experience that I had was because of my co-workers and everybody else. My director allowed me to go to radiation every day, allowed me to go to chemotherapy, and take the day off without even charging it to my vacation or sick time."

Although most expressed favorable family support, there was an example of a survivor not getting the emotional and instrumental support that she needed from family. What is instructive was her ability to find the support within her community: "My father and brother allowed me to come home, and I think that they felt that was the end of their involvement with me. Neither of them ever drove me to an appointment; they never asked if I needed medicine. A neighbor across the street, whose house I am living in now, took me grocery shopping."

Survivors offered *advice* for the treatment stage, which involved the need for women to increase their knowledge and understanding about cancer treatment by *advocating* for themselves during their interpersonal communications with their healthcare professionals: "One of the things that I was taught both by the surgeon and the oncologist was how to be my own best *advocate* because they could not be with me all of the time, and if there were things I could not tolerate, I had to learn to speak up for myself."

## Survivorship

Reflections on spirituality were a prominent theme at this final survivorship stage of the continuum. Women discussed their personal relationship with God and their spiritual meaning-making: "I started to question what God wanted me to learn from these experiences because I believe they are all lessons that we are supposed to get, but I was just bewildered." At times, we also see how spiritual faith might contribute to somewhat of a fatalistic perspective: "You have to have a lot of faith in God, or whatever happens is going to happen, and he is watching over us all the time. But you know we cannot worry about the things that we cannot change."

Survivorship was characterized by both intra- and interpersonal changes, as a result of their cancer diagnosis and treatment experience. These descriptions were mostly favorable and women made meaning of their lives. Survivors identified positive influences on family ties: "As a family, we didn't have much time to get together while growing up. It (cancer) made us closer; we talk more. We prayed a lot, we talked, and we just came together. My daughter, she asks questions; my mom, three sister and their daughters, they ask questions.

Survivors also pointed to the importance of sharing her cancer story with others and becoming involved in community service, as a way of “giving back” and increasing public knowledge about the importance of early screening. The survivor sharing her story provides a catharsis for her, while the recipient of the communication gains important knowledge and advice from someone who has personally experienced breast cancer. “Keep it a secret; let it fester; let it spread; let it be undiagnosed - that is the *death sentence* we want to get away from.”

Survivors also discussed the value of a support group, as a vehicle to sharing and increasing knowledge for women: “We were just so amazed with the women in the group and their strength, faith, and passion. To hear their stories made us feel that one-day we are going to be able to tell our story. I want to inspire others just like they inspired me.”

As illustrated in Figure 1, we see the link from the *survivorship* phase of the trajectory, back to the preventive *screening* phase. Survivors describe their need to give back and share, particularly about the importance of mammograms and self-breast exam screening. This illustration suggests that positive perspectives attained through survivorship can play an altruistic role in the negative state of women who have not been screened. The diagram and the narratives shared are consistent with the collectivist nature of the African American community.

## Discussion

This current qualitative study examined the main coping facilitators used by African American breast cancer survivors in a support group, who successfully processed and coped as they transitioned across the cancer continuum. Consistent with the PEN-3 model, which suggests that cultural factors can serve as barriers and facilitators of screening and treatment adherence, both spirituality and social support were found to play major roles in obtaining mammography. In addition, the diagram and shared narratives illustrate how women’s coping strategies are consistent with the collectivist nature of African Americans.

This study found that survivors had distinct experiences and needs at each stage of the cyclical course of the cancer trajectory. Each survivor described a moment of transition during her cancer experience, from negativity to resilience. Beginning at diagnosis, an emerging strength and resilience stemmed from one main source - spirituality. There was an underlying spiritual reflection and devotion to faith and prayer, which seemed to help survivors make meaning and transition successfully to treatment and survivorship stages. Emotions peaked at diagnosis, followed by a need for emotional and instrumental support, and then meaning-making and sharing, particularly for those women who were in need of a mammogram. Survivor narratives point to key clinical intervention strategies at each stage: 1. For the screening phase, patient education programs and psycho-education might be best; 2. For the diagnostic stage, CBT and coping skills training approaches could be used; 3. For the treatment stage, patient navigation approaches and concrete/practical support could address these needs; and 4. For the survivorship stage, emotional counseling and support groups could be best.

The Health Belief Model constructs can be used to think about important factors for women during their mammogram *screening* decision-making. Consistent with previous screening behavior studies, although survivors were familiar with cancer as a disease and its seriousness, they still perceived themselves to be less susceptible, particularly if a cancer history did not personally affect them or a family member. These narratives illustrate the need to educate women about the importance of screening and what to expect, while also addressing their underlying fears and uncertainty about mammograms.

During the *diagnosis* stage, survivors reported a heightened sense of spirituality, which seemed to help them through the uncertainty and lack of control. Similar to previous literature, there seemed to be a relationship between negative emotions and spiritual strength. This study did not find support for the need for spiritual support transferring to the *treatment* stage of the cancer trajectory. In addition, although the sample is small, the discussions of the women in this study did not suggest rejection of treatment recommendations or treatment delay due to a fatalistic attitude, as often proposed in the literature. Involvement from family, friends and coworkers could strengthen the likelihood that patients would adhere to treatment recommendations. However, this should be taken on a case-by-case basis, as families do not always provide appropriate or sufficient support. During the cancer treatment stage, survivors most needed family, friends, and co-workers to provide concrete support and advocacy. Interestingly, co-workers were identified as a valuable source of support, as many were still trying to maintain employment while undergoing treatment. African American breast cancer patients may experience ongoing psychosocial concerns and barriers in transitioning to successful *survivorship*. Again we see the prominent theme of spirituality and the need for meaning-making. Survivors describe their need to give back and share, particularly about the importance of getting regular mammograms and self-breast exam screenings.

## Conclusion

Despite the many strengths of this study, there are several limitations that need to be considered in future research. First, interview summaries were used as the data collection method, instead of transcribed interview data that was verbatim. Although summaries were thorough and provided sufficient information, there was a chance of researcher bias during data collection. Also, we did not have data on religious affiliation, so it was unclear if some of the results transcended race/ethnicity and were more strongly related to religious affiliation. Moreover, it should be noted that although our sample size is robust for qualitative research [18] caution should be exercised when generalizing our results across other groups of individuals. Another limitation is that this sample may be somewhat biased because it included only women in support groups, and more importantly, church-based support groups. Additionally, there was limited demographic information on this sample and the data did not include demographics on women's education and income which is important in determining the representativeness of the sample. Finally, the nature of a story-telling interview is its retrospective perspective, which might influence poor recall and abstract recollection at the screening, diagnosis, and treatment stages in the continuum.



The analysis of these narratives suggest clinicians provide an early discussion of patients' personal cancer risks and the effectiveness of preventive measures and attempt to involve family members in patient education in order to stimulate *screening* knowledge and motivation to screen, consistent with earlier recommendations. When working with survivors having difficulty coping with their diagnosis, clinicians can facilitate cognitive restructuring and target "irrational" beliefs about the cancer *diagnosis* and *treatment*. Given the emotional distress that can occur at this stage, clinical efforts point to cognitive behavioral therapeutic and coping skills training approaches that target faulty cognitions and negative emotions. Providers can help patients identify a sustainable, supportive network. Although survivors identified informal support networks (i.e., family, friends) to assist with practical treatment needs, a patient navigation model actually matches the needs at this stage by offering practical direction and support, given the unique barriers.

*Survivorship* intervention models should go beyond the acute care phases of the trajectory, and include wellness elements in clinical settings. Survivors seemed to benefit from their support group, which satisfied an important need to give back and share with peers. This phase may be particularly important for women in need of education and reassurance related to screening, and subsequent phases.

## Acknowledgments

The authors thank Andrea Moline, Karen Hidalgo, Patricia Cheung, Susana Bonilla, and Xuxu Qiu for assistance with data collection and coding survivor stories. We are especially grateful to the breast cancer survivors who shared their stories. The Murchison Tabernacle Cancer Support Group, Sistah Connection, The Breakfast Club, Inc., The Witness Project and Mustard Seed were key partners in identifying breast cancer survivors.

**Funding:** This study was supported by a Junior Investigator Award from the National Cancer Institute's Centers of Excellence in Cancer Communication Research program (CA-P50-95815).

## References

1. Altekruse, SF.; Kosary, CL.; Krapcho, M. SEER Cancer Statistics Review, 1975-2007. N.C. Institute, Editor; Bethesda, MD: 2010.
2. Horner, MJ.; Ries, L.; Krapcho, M. SEER Cancer Statistics Review, 1975-2006. N.C. Institute., Editor; Bethesda, MD: 2009.
3. Conway-Phillips R, Millon-Underwood S. Breast cancer screening behaviors of African American women: a comprehensive review, analysis, and critique of nursing research. *Augmented Backus Naur Forum*. 2009; 20:97–101.
4. Dunn BK, Agurs-Collins K, Browne T, et al. Health disparities in breast cancer: biology meets socioeconomic status. *Breast Cancer Research and Treatment*. 2010; 121:281–292. [PubMed: 20437200]
5. Menashe I, Anderson WF, Jatoi I, Rosenberg PS. Underlying causes of the Black–White racial disparity in breast cancer mortality: A Population-Based Analysis. *Journal of the National Cancer Institute*. 2009; 101:993–1000. [PubMed: 19584327]
6. Bickell NA, Wang JJ, Oluwole S, et al. Missed opportunities: racial disparities in adjuvant breast cancer treatment. *Journal of Clinical Oncology*. 2006; 24:1357–1362. [PubMed: 16549830]
7. Hershman DL, Wang X, McBrice, et al. Delay in initiating adjuvant radiotherapy following breast conservation surgery and its impact on survival. *International Journal of Radiation Oncology*. 2006; 65:1353–1360.
8. Holt CL, Lukwago SN, Kreuter MS. Spirituality, breast cancer beliefs and mammography utilization among urban African American women. *Journal of Health Psychology*. 2003; 8:383–396. [PubMed: 14670216]

9. Gibson LM, Hendricks CS. Integrative review of spirituality in African American breast cancer survivors. *Augmented Backus Naur Forum*. 2006; 17:67–72.
10. Warren-Findlow J, Prohaska TR. Families, social support, and self-care among older African-American women with chronic illness. *American Journal of Health Promotion*. 2008; 22:342–349. [PubMed: 18517095]
11. Klassen AC, Washington C. How does social integration influence breast cancer control among urban African-American women? Results from a cross-sectional survey. *BMC Womens Health*. 2008; 8:4. [PubMed: 18254967]
12. Copeland VC, Scholle SH, Binko JA. Patient satisfaction: African American women's views of the patient-doctor relationship. *Journal of Health and Social Policy*. 2000; 17:35–48. [PubMed: 18309585]
13. Ashing-Giwa K. Quality of life and psychosocial outcomes in long-term survivors of breast cancer. *Journal of Psychosocial Oncology*. 2000; 17:47–62.
14. Kreuter MW, Holmes K, Alcaraz K, et al. Comparing narrative and informational videos to increase mammography in low-income African American women. *Patient Education and Counseling*. 2010; 81:S6–S14. [PubMed: 21071167]
15. Gulbas LE, Zayas LH, Nolle AP, Hausmann-Stabile C, et al. Family relationships and Latina teen suicide attempts: Reciprocity, asymmetry, and detachment. *Families in Society: The Journal of Contemporary Social Services*. 2011; 92:317–323.
16. Kvale, S.; Brinkmann, S. *InterViews: Learning the craft of qualitative research interviewing*. 2. Thousand Oaks, CA US: Sage Publications, Inc; 2009.
17. Lutrell W. Working-class women's ways of knowing: effects of gender, race, and class. *Social Education*. 1989; 62:33–36.
18. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006; 18:59–82.

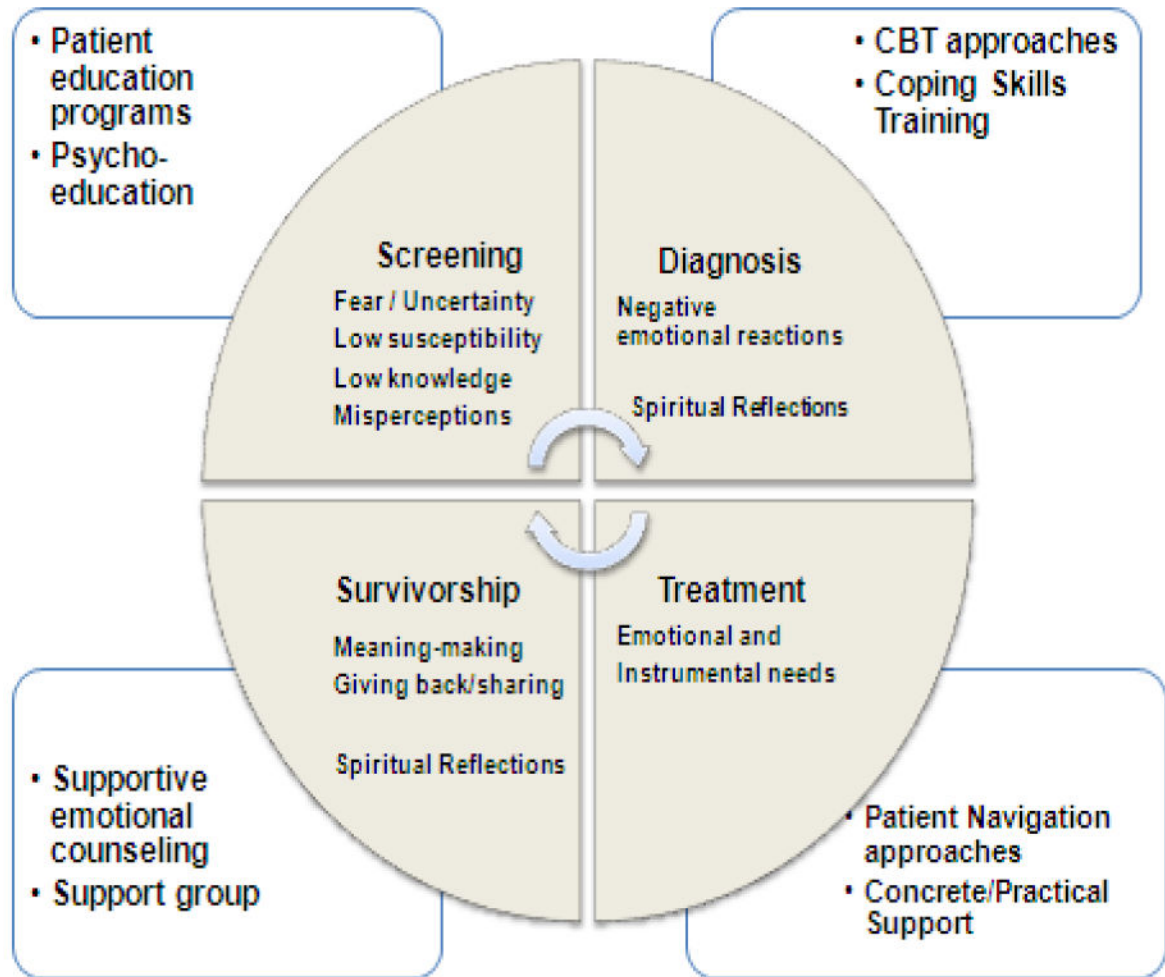


Figure 1. African American Women with Breast Cancer: A cyclical cancer course