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Exploring the Financial Impact of Breast Cancer for African American Medically Underserved Women: A Qualitative Study

Kathleen Darby, PhD,
Cindy Davis, PhD
Wendy Likes, PhD
John Bell, MD

Abstract: In addition to the physical suffering experienced by cancer survivors, there are considerable financial hardships and access barriers to quality health care. The current study explored the financial burden of breast cancer on African American medically underserved women. Four focus groups were conducted in three major cities across Tennessee. Research participants (N = 36) were recruited by the staff of cancer support and treatment programs in the area. Findings revealed that participants' lack of insurance or inadequate insurance resulted in missed, delayed, or fewer treatment opportunities. The financial burden of cancer was not limited to the acute treatment phase. The women in the current study reported extreme economic hardship resulting from this disease into long-term survivorship. This exploratory study confirms the importance of providing care across the continuum to address the complex needs of low-income cancer survivors.

Key words: Breast cancer, minority, underserved, financial, African American.

According to the American Cancer Society (ACS), cancer is the most costly illness in the U.S., exceeding $219 billion in 2007, including $89 billion in direct medical costs and $18.2 billion in lost productivity. Cancer patients with health coverage often find their premiums and out-of-pocket expenses continuing to rise after a cancer diagnosis. Over 28% of individuals diagnosed with cancer have a total burden exceeding 10% of their family income; 11.4% of the families spent in excess of 20%. In a self-reported assessment on the financial burden of cancer for 156 women diagnosed with breast cancer who had insurance, researchers found that out-of-pocket expenses accounted for 41% of their total burden accounting for a monthly mean of $597. The

DR. DARBY is an Assistant Professor at Middle Tennessee State University in Social Work. DR. DAVIS is an Associate Professor at the University of Tennessee College of Social Work in Nashville. DR. LIKES is an Assistant Professor of Nursing at the University of Tennessee in Memphis. DR. BELL is the Director of the University of Tennessee Cancer Institute in Knoxville. Please address correspondence to Cindy Davis, PhD, University of Tennessee, College of Social Work, 193 Polk Ave., Suite E, Nashville, TN 37210; (615) 256-1885; cdavis3@utk.edu.
most commonly reported out-of-pocket or direct medical expenses were medications (80%), physician visits (66%), alternative or complementary health aids (48%), and hospital bills (45%).

The five-year survival rates for breast cancer are significantly poorer for African-American women (77%) than for Caucasian women (90%). A review of the literature provides evidence that women with private insurance have significantly better rates of survival than women with any other insurance status. Minority women insured by Medicaid are more likely to be undertreated for breast cancer once they are diagnosed. Bickell and Chassin reported women enrolled in a Medicaid program and those having no insurance were at a higher risk of not undergoing post-breast-conserving surgery (BCS), radiation therapy, and/or systematic chemotherapy. Findings also suggest uninsured women are less likely to receive radiation therapy after BCS and women insured by Medicaid were less likely than women with private insurance to undergo chemotherapy.

Additionally, a recent study shows race (White) and insurance status (private) are significant predictors of receiving a timely biopsy when presenting for treatment. Findings imply that White women with no history of previous breast cancer and private insurance are more likely to undergo aggressive evaluations than minority women with public or no insurance coverage. However, others have found that the standards of care achieved in the treatment of low-income women covered under a federally funded screening program are comparable to the standards of care achieved in the treatment of all women studied. Coburn et al. used a cohort of 6,876 invasive breast cancer cases from Rhode Island's Cancer Registry (RICR) to investigate the correlation between treatment and insurance status, and found that insurance status is significantly associated with treatment. Women having Medicaid, Medicare, and no insurance were more likely to present to treatment with larger tumors and were less likely to receive reconstructive surgery when compared with women having private health insurance.

Poorer survival rates can be attributed to both late-stage diagnosis and poorer stage-specific survival. According to several review studies, there are numerous factors that contribute to these health disparities, such as lack of health insurance or regular source of care; low levels of health literacy; cultural beliefs; and logistic barriers (e.g., transportation, childcare, work schedule). Equally important is the financial burden that continues well into survivorship. The purpose of this study was to explore the financial burden of breast cancer on African American medically underserved women, with the ultimate aim of developing a culturally sensitive understanding about the social and economic stressors minority women face when diagnosed with breast cancer.

Methods

Focus groups of medically underserved African American women diagnosed with breast cancer were conducted across the state of Tennessee in this exploratory study. Four focus groups were conducted in three major cities in the state (Nashville, Knoxville, and Memphis). Research participants (N = 36) were recruited by the staff of cancer support programs and treatment programs across the state and through recruitment flyers at
various treatment centers and community organizations. All participants were African American women who were breast cancer survivors; the mean age at time of diagnosis was 50 years of age (SD = 11.37 years). The age range varied among participants, with 22% being between 31–45 years of age, 29% between 46–60 years of age, and 50% older than 60 years of age. Participants were offered a $25 gift certificate as an incentive to participate in a focus group.

One of the authors contacted individuals to address any concerns or questions prior to the focus group. All participants voluntarily participated in the project and signed a confidentiality consent form prior to the focus group interviews. In order to be consistent, the same two authors conducted each focus group. The focus groups were given several broad questions designed to elicit data-rich discussions about cancer experiences. A semi-structured discussion guide consisting of open ended questions was used to facilitate discussion. Discussion questions focused on the financial and psychosocial impact of participants’ cancer experiences.

All focus groups were audio-taped and field notes were taken by an observer with masters-level education in social work to document context-specific and non-verbal observations relevant to interpreting the data (e.g., expression of emotion, tone of communication). The analysis was based on the qualitative approach of grounded theory. Grounded theory allows researchers to develop explanations of key social processes that are grounded in empirical data. Open coding of the data began with the first two authors and an advanced clinical masters of social work (MSW) student independently listening to the audio tapes. During open coding the data were broken down into discrete parts, examined closely, compared for similarities and differences, and clarified further in discussions concerning prominent themes reflected in the data. The transcripts were analyzed by means of coding into categories. The categories were then reduced by the use of pattern coding (grouping categories into conceptual sets) to develop themes. This method provided a structure to handle, organize, and derive meaning from the focus group discussion data. It is replicable to the degree that others can scrutinize the data and see from where the themes were drawn. Internal quality and credibility were attained by having three researchers (two of the authors and one expert in qualitative research) independently coded the data and obtained consensus through analysis. Disagreements about themes were resolved through discussions, reviewing tapes, and referring to the verbatim transcriptions until a consensus was reached.

**Results**

Thematic analysis revealed three salient themes around the financial impact of participants’ cancer experiences. The first theme was the lack of access to adequate care if one is unable to pay or is without adequate health insurance coverage. In the current study, a majority of the women agreed that access to equal care and financial concerns added extra stress throughout their cancer experiences. Women expressed the opinion that their insurance status indicated the level of care they received. Many women perceived that their treatment would have been different and better if they had had adequate insurance or more financial support.
I had knots on my breasts and under my arms. I knew it wasn't normal but my doctor wouldn't give me a mammogram because I didn't have any insurance to pay for it. I'm on TennCare [Tennessee's Medicaid] and asked for a second opinion. My doctor asked, "Why are you going after a second opinion? I already told you everything." . . . the type of insurance you have seems to dictate the type of treatment you get . . . . Society has left us no choice. Either you pay or you die, because without insurance the doctors are not going to see you.

For the women in our focus groups who had inadequate or no insurance, the out-of-pocket expense for a $15 co-pay often resulted in missed treatments.

And if you don't have your co-pay, a lot of times they say, "Well, we can reschedule. When is best for you?" meaning "When you have the money, then you can come back."

I was told they needed my co-pay, so I had to explain to them, "I don't have a co-pay, I don't have a job."

I owe over $1,000. They call every day and say "You've got to pay something, or we won't treat you anymore."

The second theme was the long-term financial burden of this disease from the out-of-pocket expenses incurred by these women and their families during and after their cancer experiences. Women who had inadequate or no income and/or no health insurance struggled with how to pay for needed services, while supporting themselves and their families during treatment and into long-term survival. Several women spoke of being the sole support for herself or her family and her fear of being unable to care for her children, or to keep her job and insurance coverage. The financial impact of the cancer was felt long after the treatment phase was complete.

I wiped out my savings taking care of me. My son paid when I no longer had a savings. I thought I was saving to retire early, but I didn't realize that it was going to be paid to save my life. But I was fortunate I had it to pay, before it ran out.

I was still an employee, and when the doctor turned me loose to go back to work, that's when they wouldn't let me come back. I worked for 17 years . . . worked hard; worked smarter . . . they wouldn't let me come back.

I am trying to get disability. I can't work right now. Doctor's orders. I want to work. I have worked all my life.

My job won't wait on me to feel better.

In several instances women discussed their fears and anxieties of becoming homeless or losing their children because they were struggling financially or physically to provide for their children's well-being.

It makes you homeless. You work for years, years, and years and just because I have cancer, I am homeless. That's not fair. That's just not right.
I'm about to get put out. Probably the end of the month . . . because I had to pay my light bill . . . and you got to feed the kids . . . you have to stay at the shelter before you get Section 8 housing.

They take away the insurance, unemployment and everything! I have nothing left.

The final theme was the direct, nonmedical expenses that include such items as childcare, housekeeping, home care, wigs, prostheses, over-the-counter medications, and expenses associated with travel. For those individuals who have health insurance, non-medical items are rarely covered. Cancer insurance and long-term insurance policies are available and help reduce the unforeseen out-of-pocket expenses that create financial burdens for many families who have health insurance. Health insurance supplements are only beneficial to the population that can afford to pay the additional premiums.

When I was taking my treatments, my car broke down and I didn't have any way to get to the center. I finally got a bus card because I couldn't afford to fix the car. Other than the bus, I don't know how I would have got to treatment.

I had insurance, but not enough.

As these women shared their cancer experiences of the financial, physical and emotional toll it took on them, there was a common underlying theme of feeling "alone and lost."

Conclusion

Current research provides information on cost and expenditures associated with direct and indirect medical and non-medical expenditures for cancer patients. However, estimates regarding the different types of cost associated with cancer should be interpreted with caution due to the variations in how researchers define and measure such costs. Indirect costs associated with an illness or disease is defined in terms of lost time from work and costs associated with caregivers, disability, and premature retirement or death. Indirect costs should also include all expenditures incurred by the patient, family members, and anyone caring for the patient. Most cost analyses only calculate the direct medical expenditures experienced by the patient. Arozullah and colleagues found that indirect costs accounted for half of a patient's monthly financial burden.8 For low-income women, these losses can translate into inability to pay for childcare, food, co-payments, and/or transportation. Participants in the current study clearly articulated how their cancer diagnosis affected their ability to pay for other necessities of life.

Less is known about the long-term social and health care costs associated with minority and medically underserved women diagnosed with breast cancer. Regardless of insurance status, the financial burden of all types of cancer is disproportionately greatest among women living in the lowest levels of household income. Although limited by the non-random sampling technique, the current study explored the financial burden of breast cancer on medically underserved African American women, with the aim of
developing a culturally sensitive understanding about the social and economic stressors minority and low-income women face when diagnosed with breast cancer.

Many people, even among those with health insurance, are inadequately covered for a cancer diagnosis and are at risk of health-related financial burdens. For those without any insurance or with minimal insurance, the risk is exponentially greater. The impact of health insurance status on the access and quality of care someone receives and the disproportionate out-of-pocket expenses low-income families bear has been ‘business as usual’ for much too long. For low-income women, lacking insurance or being underinsured may mean missed, delayed, or fewer treatment opportunities. Research clearly indicates the dire consequences of such actions in the mortality rate of these women.1,14

The financial burden of cancer is not limited to the acute treatment phase. The women in the current study reported extreme economic hardship resulting from this disease into long-term survivorship. A recent Institute of Medicine (IOM) report emphasizes the importance of quality services along the full spectrum of the cancer care continuum.35 In large part, literature has focused more on prevention, early detection strategies, and the time period between diagnosis and treatment rather than how needs change across the continuum. Although numerous research studies have been conducted to address the various medical and psychosocial needs of survivors at a given point in their cancer experience, little research has been conducted on the trajectory of support needs for women from time of diagnosis to survivorship and remission.36–38 Existing literature on the changing needs of women at various stages in the illness trajectory provides evidence that supportive care is needed throughout the cancer experience and should no longer be limited to the diagnosis/treatment phase.39 Supportive care models, to date, tend to pivot around crisis points such as diagnosis, treatment, and post-treatment phases rather than seeing the stressors associated with the illness as ongoing.36

The health care system is difficult to understand and sometimes impossible to negotiate. This exploratory study confirms the importance of providing care across the continuum to address the complex demands faced by low-income women diagnosed with breast cancer. Further research on patient navigation models and wellness community models for underserved women with breast cancer across the continuum of care is needed to develop effective best practice models of care to assist women in negotiating the health care system. Change is also needed at a policy level to address access to quality care and the financial burden of cancer on underserved women.

Acknowledgments

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Notes

2. Banthin JS, Bernard DM. Changes in financial burdens for health care: national