

PSYCHOSOCIAL IMPACT OF CANCER IN LOW-INCOME RURAL/URBAN WOMEN: PHASE I

Margaret A. Lyons, PhD, RNCS¹

¹ Assistant Professor, [Capstone College of Nursing](#), University of Alabama, mlyons@bama.ua.edu

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ABSTRACT

Data reported here are from phase one of a larger ongoing study of depression and cancer-related quality of life in low-income rural and urban Southern women who have been diagnosed with breast or cervical cancer. This phase of the pilot project examined the psychosocial impact of a new diagnosis of breast or cervical cancer and identified personal issues and concerns of those diagnosed. A telephone survey design was used to solicit information from 28 low-income rural and urban Southern women regarding diagnosis, treatment, side-effects, available support systems, coping techniques, barriers to treatment, and the significance of God or spirituality during the course of their illnesses. Content analysis indicated that many similarities exist in the experiences of rural and urban women regardless of race, socioeconomic status, or residence. However, many differences exist that negatively impact and contribute to health disparity and an unequal distribution of cancer burden.

INTRODUCTION

The American Cancer Society (ACS) estimates that, in the United States, 211,300 new cases of breast cancer and 13,000 cases of cervical cancer will be diagnosed in 2003 (ACS, 2003). 3,400 cases of breast cancer are expected to occur in Alabama (ACS, 2003) and 2,400 cases will be in Mississippi (ACS, 2003). Although incidence of cervical cancer is dropping, 200 new cases are expected in both Alabama and Mississippi (ACS, 2003). If recent trends continue (ACS, 2003), a majority of these women will be black and/or from high poverty areas (National Cancer Institute, 2003).

Data reported here are from phase one of a larger ongoing study of depression and cancer-related quality of life in low-income rural and urban Southern women who have been diagnosed with breast or cervical cancer. This phase of the pilot project examined the psychosocial impact of a new diagnosis of breast or cervical cancer in rural and urban low-income women in the Deep South and identified personal issues and concerns of those diagnosed. The resulting information facilitated development of the telephone survey instrument used in phase two of the study which investigated depression and cancer-related quality of life issues in a larger sample of women diagnosed with breast or cervical cancer.

This research fills a significant gap in the existing literature. Little information is available concerning the emotional status of African-American women newly diagnosed with cancer and residing in rural, low-income areas of the Deep South or the impact of the diagnosis on low-income white women. Questions prompting this research were the following: What are the issues and concerns of low income rural and urban women as

they manage their illnesses? Are there health disparities related to race, socioeconomic status, or residence affecting these women and if so how do they cope? Information gathered from this study will be used to further knowledge about how these women cope with cancer, ultimately leading to interventions that will reduce health disparity in this population.

THE PROBLEM

The National Cancer Institute considers reducing health disparities to be a special challenge (NCI, 2003). Defined by a National Institutes of Health working group, health disparities are differences in incidence, prevalence, mortality, and cancer burden among select population groups. Gender, age, ethnicity, education, income, social class, disability, geographic location, and sexual orientation characterize these groups (NIH, 2002). It is known that minority women are more likely to be diagnosed at later stages of disease, are less educated, and more likely to die from breast cancer. They are younger, less likely to have insurance or are underinsured, live in poverty, and have more difficulty accessing health care (NCI, 2003). Disparities such as these result in unequal distribution of cancer burden (Miller et al. 1996).

Before the problem of health care disparity can be fully addressed it is important to know what issues confront low-income rural and urban women with breast cancer or cervical cancer. Are they similar to the issues of women who do not live in poverty and who have insurance?

BACKGROUND

A diagnosis of cancer produces more apprehension and worry than any other form of illness; the literature is replete with descriptions of the negative psychological sequelae experienced by women with breast or cervical cancer (Arman, Rehnsfeld, Lindholm, & Hamrin, 2002; Shapiro et al. 2001; Vicksberg et al. 2000). Lackey, Gates, and Brown (2001) described the experience of finding a lump in the breast as a “dual experience trajectory” where the woman is catapulted into a physical trajectory through the healthcare system and an emotional trajectory characterized by deep feelings, emotions, and fears.

Prediagnostic anxiety is a clinically significant issue for women anticipating diagnosis and forced to participate in the “waiting game.” Most women report moderate to high levels of anxiety with consequent reduced effectiveness in attentional functioning while waiting for diagnosis (Lehto & Cimprich, 1999; Poole, 1997). Intrusive thinking and avoidance have been found to be powerful precipitants of psychological distress (Baider & De-Nour, 1997; Epping-Jordan et al. 1999; Lyons, Jacobson, Prescott, and Oswalt, 2002; Primo et al. 2000). Although the time prior to diagnosis is the most difficult for some, some researchers report that the most anxiety provoking period is from diagnosis to treatment (Loveys & Klaich, 1991; Pelusi, 1997; Seckel & Birney, 1996). Uncertainty concerning what will happen if tests are positive, individual interpretation of the cancer diagnosis, and the consequences of the event are important issues that a woman faces regardless of stage of illness. Management of the uncertainty may be a fundamental concern if adjustment is to occur (Mishel, 1988).

There are different responses to the diagnosis and treatment of cancer. Suffering is apparent for most women and can be metaphorically described as a “field of force” affecting all aspects of a woman’s life (Arman, Rehnsfeldt, Lindholm, & Hamrin, 2002). Previous research by this author (Lyons et al. 2002) described the lived-experience of women during the first year following diagnosis as one in which an initial trauma is recognized, retraumatization occurs in the form of treatment effects, and all energies are directed at resolution/healing. However, after an initial period of traumatization distinguished by feelings of hopelessness and helplessness, it is not uncommon for a woman to undergo a transformational process, viewing her ordeal as a “challenge” with inherent “value,” with resultant attribution of positive meaning (Degner, Hack, O’Neil, & Kristjanson, 2003; Koopman et al. 2001; Taylor, 2000).

Cultural background may affect the process of adaptation. African-American women are more likely to view a diagnosis of cancer as a death sentence, suggesting that convictions related to outcome may influence diagnostic delay or treatment refusal (Lackey, 2001). Issues relevant to African-American women not affecting Caucasian women are keloid formation and the inability to find a prosthesis that matches skin tone (Wilmoth & Sanders, 2001). African-American women are more likely to have mastectomies, less likely to have breast reconstruction, less likely to be given a rationale for treatment decisions, and often do not ask questions about their illnesses (Aziz & Rowland, 2002; Lackey, 2001). Positive reappraisal and seeking social support are primary coping strategies used by African-American women with breast cancer and differences in survival rates between African-American women and Caucasian women may partially depend on variations in coping strategies (Bourjolly & Hirschman, 2001).

Critical quality of life issues associated with a diagnosis of breast or cervical cancer include the physical and psychosocial effects of surgery, radiation, and/or chemotherapy. Research consistently points to the devastating effects of side-effects such as fatigue, hair loss, pain and swelling and insomnia (Ferrell et al. 1996; Kissane et al. 1998; Longman, Braden & Mishel, 1996). Women receiving adjuvant chemotherapy often cope with the associated suffering by the use of normalizing strategies, such as concealing emotions, keeping previous routines intact, looking for humor, and restructuring time to meet their own needs (Cowley et al. 2000).

Mediating factors may foretell distress in women with breast cancer. Consistent predictors of distress are avoidant coping (McCaul et al. 1999), uncertainty (Mishel, 1988), depression, and side-effect burden (Badger, Braden & Mishel, 2001), whereas emotionally expressive coping, humor, spirituality, social support, and a fighting spirit are associated with adjustment to the cancer experience (Ebright & Lyon, 2002; Gall, Miquez-de-Renart, & Boonstra, 2000; Henderson, Fogel & Edwards, 2003; Stanton et al. 2000).

Rural/urban residence may impact psychosocial response to a diagnosis of breast or cervical cancer. Hospital closures, homecare cutbacks, deficits in community health service funding, decreases in numbers of physicians, inadequate transportation coupled with lengthy distances, and lack of insurance create unnecessary hardship for many rural women (Bushy, 2000). Additionally, women residing in rural areas report that they do not receive enough emotional or educational support from their caregivers and express more negativity about their medical care (Koopman et al. 2001).

Although morbidity and mortality rates for cervical cancer victims continue to decline, issues similar to the woman with breast cancer affect cervical cancer survivors and are not to be forgotten. Surgical morbidity, chemotherapy toxicity, loss of fertility, body image concerns, sexual concerns, and altered relationships embody the experience of the woman with cervical cancer (Tabano, Condosta & Coons, 2002).

METHODS

Sample

Twenty-eight low-income rural and urban Southern women diagnosed with breast or cervical cancer comprised the sample for this study. Participants were recruited from cancer treatment centers and health departments in Mississippi and Alabama, the Mississippi Breast and Cervical Cancer Early Detection Program, support groups, the American Cancer Society, and word of mouth. Potential participants were given flyers announcing the study and asked to call a toll-free number at the researcher's office if they were interested.

Sixteen of the women were from urban areas of Alabama and Mississippi and twelve were from rural areas in these states. Sixteen women were African-American and twelve were Caucasian. Twenty six were diagnosed with breast cancer, two with cervical cancer. Of those diagnosed with breast cancer, twenty one had undergone a mastectomy and radiation and/or chemotherapy. The remaining four had lumpectomies with follow-up radiation and/or chemotherapy. The two women diagnosed with cervical cancer had undergone hysterectomies. Participants ranged in age from 30 to 76 years. Twenty-three were over the age of 50. About half were married and lived with their spouses. The remaining women were divorced, widowed, never married and/or lived alone or with children. Only one woman was employed, part-time. All had incomes of less than \$30,000, with the majority having incomes of less than \$10,000. Twenty-three women were Medicaid recipients and were diagnosed through their respective state's breast and cervical cancer early detection programs. Two respondents had some type of private insurance; three were Medicare patients. Participants met sample criteria of having been diagnosed with breast or cervical cancer during the previous 12 months, having access to a telephone, and willingness to respond to questions posed by the researcher. Respondents received \$50 for their participation and were asked to sign a consent form that described the purpose and confidential nature of the study. Assurances were given regarding the participant's right to withdraw from the study until such time as all data were analyzed.

Data Collection

Following Institutional Review Board (IRB) approval, participants who had expressed interest in the study were contacted via telephone and given a brief overview of the process and the purpose of the study. Telephone interviews were convenient for accessing women from many different areas of Mississippi and Alabama and are more economical than in person interviewing for data collection (Lavrakas, 1990). A semi-structured open-ended questionnaire elicited information regarding diagnosis, treatment,

side-effects, available support systems, coping techniques, barriers to treatment, and the significance of God or spirituality during the course of the breast cancer experience. A large portion of the interview centered on psychosocial aspects of the breast or cervical cancer experience. The following questions were asked of each respondent: 1) How was your cancer first found? 2) How were you told about your cancer? 3) What were your thoughts and feelings when you first learned that you had cancer? 4) What kind of treatment did you receive? 5) Did you experience side-effects to treatment and, if so, what were they? 6) How did you manage? 7) What kinds of things do you do to prevent illness that you didn't do before? 8) Did you have to take time off from work to manage your illness? 9) Did you have difficulty obtaining or paying for your treatment? 10) What kind of support (family, friends, church, etc) do you have as you go through this illness? 11) What role does God or religion play in your life as you go through the cancer experience? Open-ended questions facilitated the process of dialogue and helping participants to describe their experiences.

Since many of the women received radiation or chemotherapy during daytime hours, telephone interviews were usually conducted in the evenings. Interviews generally lasted 45 minutes to an hour and were punctuated by health-related questions that the respondent asked of the researcher.

Data Analysis

Both manifest and latent content analyses (Wilson, 1989) were used to analyze data obtained from telephone interviews. Content analysis (Boyle, 1994) involves categorizing words and phrases from text data as well as using labels to illustrate concepts. Word counts are useful in enabling the researcher to determine differences in the frequency of the concepts.

RESULTS

Twenty-eight low-income, rural and urban women participated in this study. Results indicated that primary issues for the women in this sample included: finding out, concerns about how they would cope, knowledge deficits and participation in treatment decisions, treatment issues, social support, health promotion, and the role of God or spirituality in their lives.

Finding Out

The women in this study learned of their breast or cervical cancer diagnosis in a variety of ways. Six women were diagnosed with breast cancer following clinical breast exams. Eight women found lumps during breast self-exam and ten women had suspicious lesions on routine mammograms. Two were diagnosed with cervical cancer following PAP smears. All of the women experienced fear and anxiety while waiting for diagnostic confirmation. Many women described being in a state of shock. Some representative comments were the following:

One night I was lying in bed and something told me "you'd better check your breasts." I found a big knot in there. I cried at first because I was scared. Then I called my sister and she told me to "just go to the doctor and find out.

I found it through breast exam. At first I was scared but everyone told me 'don't worry.' Once I found out it was positive all I could do was cry and I thought, 'I have to fight for my life and now I have to fight for my mind.' Guess I'm still in a state of shock.

Those who had to wait for mammogram results expressed a great deal of apprehension. One woman stated:

They made me wait out in this little room and then they called me back to do another mammogram. Then they wanted to do an ultrasound but nobody would tell me anything.

Three of the women seemed to suppress feelings and developed a business-like approach to dealing with their illnesses. One stated:

I didn't cry—still haven't. I just felt like well now you have it. God will take care of you, no matter what happens. Now we just have to do what we need to do to take care of it.

Several of the women were informed that they had cancer through phone calls from their physicians. One woman stated: "He told me on the telephone. On the telephone! That to me was a big no-no." The majority of women were informed, in person, by their physicians.

Coping Strategies

Many of the women expressed little confidence in their ability to cope immediately after diagnosis. However, after the diagnostic phase most women used normalization and sought to keep their routines from being disrupted. The majority of women in this study used family, friends, a fighting spirit, and a deep and abiding faith in God to cope with the initial diagnosis and treatment:

I learned to rely on others for help. My sister took me to the doctor. My church family brought us food and my kids helped with the house work.

One woman, diagnosed with cervical cancer, stated that she had "absolutely no support" even though she was temporarily living with her brother.

Knowledge Deficit and Participation in Treatment Decisions

Most of the women were undergoing treatment, relative to type of tumor and stage of disease, at the time of the interview. Women with cervical cancer underwent hysterectomies and those with breast cancer had biopsies, lumpectomies, mastectomies, radiation and/or chemotherapy as deemed necessary by their physicians. Both Caucasian and African-American women listened intently to what their physicians recommended. However, African-American women were less likely to ask questions, ask for additional information, use other resources, e.g. Internet, or challenge decisions made by their physicians regarding treatment. They were also more likely to have had a mastectomy. One African-American woman stated: "I didn't ask questions. I just did what he told me." In contrast, one Caucasian woman with breast cancer refused treatment stating:

I went to an herbal healer. She took me off all sugar and caffeine. I can't have any pork and I'm supposed to eat 6 oz. red meat each day—lots of fruit, eggs, and butter. I've lost five pounds. In three months, if I'm not cured or if I'm not dead I will find another doctor and will probably have the surgery.

Treatment Issues

The majority of women cited being emotionally prepared prior to surgery. "I was as prepared as you could be for a thing like that." The most difficult aspects of treatment were disfigurement after mastectomy, issues related to sexuality and feelings of unattractiveness, accompanying feelings of loss, and the appearance of side-effects related to chemotherapy. Those who had undergone radiation alone complained of fatigue but were generally able to go about their daily routines. They managed their fatigue by enlisting the help of others and by taking frequent rest periods. For those who received chemotherapy, side-effects that were most disturbing were nausea and vomiting, feeling ill, fatigue, pain, and hair loss. The following statements are illustrative of the above concepts: "Every night when I take a bath I'm not prepared for what I'm gonna see. I think about being disfigured and I start to cry. A part of me is gone."

You ask about sex. What sex? I don't feel like having it and I don't want him to see me this way. But I told him, "If you can't handle it then you need to go. Cause I don't need nobody like that."

I have swelling in the upper part of my chest and my arm. And I have trouble doing all kinds of things. Things I used to do. It gives me fits. I try not to let it bother me. I can't even lift a skillet. Putting on my clothes—I have to have help. I can't tie my shoes.

I knew that my hair would probably fall out but I didn't expect it to fall out in big clumps when I washed it. I cried and cried even though they said it would grow back in. I never go out without my turban.

Health Promotion

Participants approached health promotion in several different ways. Some cited engaging in limited exercise, “eating better,” and, being more appreciative of the “little things”. Only a few cited taking vitamins or using herbal remedies. Many stated that they had made no lifestyle changes.

Barriers to Treatment

Five of the women in this study cited financial difficulties in terms of paying for treatment. Those women who were covered under private insurance or Medicare had substantial out of pocket costs. One woman stated: “I had to pay \$5 every time I went to the office. I’m up to \$30 and I can’t even pay that.” Those women on Medicaid had no out-of-pocket costs. “I got sent to the social worker and she got me on Medicaid.”

Women living in rural areas often traveled great distances for treatment. However, they did not complain. “Sometimes I’d be so sick. But that’s just the way it is.”

Spirituality

Spirituality was a dimension that permeated each woman’s experience. Frequent references to God were evident in statements made by participants. “Oh, God, please don’t let it be positive” or “please God help me through this.” One woman’s comments summarized sample sentiment:

God has always bailed me out. I believe He’s there for me and that He loves me. I hope it’s His will that I will live. I ask for help everyday and every night before I go to bed. He’s the first place I’ve always turned.

DISCUSSION

When compared to results of the author’s previous research with women of means (Lyons et al., 2002), findings from this study indicate similarities in the traumatic nature of the experiences of breast and cervical cancer survivors. Fear and anxiety were experienced during diagnosis and treatment regardless of race, urban/rural residence, or differences in socioeconomic status. These women denied fear of dying. They did fear future reoccurrence of their cancers and were concerned about the possibility that their mothers, daughters, and/or siblings would develop cancer. Again, this finding did not differ by race, rural/urban residence, or diagnosis.

All of the women interviewed were determined to be survivors. All had days when they were depressed but they were able to implement strategies that kept them focused on the task of getting well again. Congruent with the findings of Cowley et al. (2000) and Henderson et al. (2003) the women coped with diagnosis and treatment through the use of normalizing strategies, the use of social support, positive reappraisal, seeking and using social support, and relying on spiritual beliefs as a source of strength.

The majority of women said that they had received adequate information prior to surgery and fully understood what type of surgery was to be performed. However,

congruent with the findings of Lackey (2001), rural African-American women were less likely to seek information or ask questions and more likely to accept their physician's decisions. They were also less likely to have access to the Internet for information regarding their illnesses and could have benefited from additional pre-operative education and counseling.

The need to mobilize resources after diagnosis was a universal reaction without regard for race or urban/rural residence but accessing resources was more cumbersome for rural women. Rural residents traveled greater distances for appointments and felt more isolated. They were less likely to know what services were available to them and were less confident about taking the necessary steps to access those that they did know about. Community education or support groups sponsored by local health departments or churches could be useful in meeting the need not only for support but also for education concerning available services in rural areas.

A surprising finding was that the majority of women in this study were receiving Medicaid services after referral by their state's breast and cervical cancer early detection programs. Participation in this program enabled these women to receive health care that they would otherwise be unable to afford. This fact indicates that the system is working and is a major step in the reduction of health disparity.

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