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

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ABSTRACT

Purpose: The goal of this study was to understand the emotional impact of diagnoses of breast or cervical cancer on low-income rural Southern women by exploring depression and cancer-related quality of life in women who have been diagnosed with one of these cancers.

Method: The design for this descriptive study was a one-time cross-sectional telephone survey. This study reports the findings from Phase II of the project. In Phase II, results from Phase I, as well as established measures of depression (CES-D) and cancer-related quality of life (FACT-B) were used to develop a telephone survey instrument that measured the impact of cancer on the lives of an additional 60 women from the designated areas.

Findings: Results from Phase II indicate that both African American and Caucasian women, irregardless of rural or urban residence, who are diagnosed with breast or cervical cancer, experience significant anxiety, rely heavily on support systems that are already in place, are very knowledgeable about their diagnosis and treatment, have difficulty in the management of side-effects during treatment, use spirituality as a mechanism for coping with the illness, would utilize counseling services from a nurse after diagnosis, and generally do not meet criteria for clinical depression.

African American breast cancer patients were found to have a significantly (F=8.11) higher quality of life score than Caucasian breast cancer patients. Breast cancer patients who had a lumpectomy were found to have a significantly (F=5.91) higher quality of life score than those breast cancer patients who had undergone a mastectomy. Living in a rural area, experiencing side-effects such as nausea, vomiting, hair loss, and swelling was predictive of a significantly lower quality of life.

Examination of cancer patients' depression scores found a higher incidence of depressive symptoms if they did not receive adequate information prior to surgery. Patients diagnosed with cervical cancer were significantly more depressed than patients with breast cancer. Limitations: The use of convenience sampling and a small sample size in this study limits generalizability.

Implications: This study provides valuable information for practitioners to use in caring for breast or cervical cancer patients.

INTRODUCTION

Estimates from the American Cancer Society (ACS) for the year 2003 are that 211,300 women will be diagnosed with breast cancer and that 13,000 women will be diagnosed with cervical cancer (American Cancer Society [ACS], 2003). Of those, 3,400 cases will be documented in Alabama and 2,400 cases in Mississippi. In addition, 200 cases of cervical cancer are expected to occur in both Alabama and Mississippi (ACS, 2003). Many of these women will be African American or impoverished and/or live in rural areas (National Cancer Institute, 2003). In order to meet the healthcare needs of low-income women, programs such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) have been instituted, and provide access to lifesaving cancer screening, diagnostic services, and treatment centers to millions of uninsured and underinsured women (CDC, 2003). Additionally, early detection and advances in cancer treatment have decreased mortality rates, raising concern for the well-being and quality of life of breast and cervical cancer survivors.

Data reported here are from Phase II of a larger 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 (Lyons, in press). Results from Phase I indicated that primary issues for women with breast or cervical cancer include: fear and anxiety; coping strategies that were, for the most part, sufficient; and support systems that were adequate. The study revealed that the majority of women voiced a need for more in-depth knowledge about the type of treatment to be received, felt that they were emotionally prepared prior to surgery, managed side-effects during treatment with some difficulty, used health promotion strategies, and consistently utilized spirituality in their quest for healing. Qualitative analysis identified few differences in the cancer experience between rural and urban women, race, ethnicity, or socioeconomic status. The current study examines some of the same concerns, depression, and quality of life in a larger sample of rural and urban low-income Southern women.

BACKGROUND

Quality of Life

There is considerable agreement that quality of life is multifaceted and multidimensional (Ferrell et al. 1997; Ferrell et al. 1998). The World Health Organization Quality of Life Group (1995) recognized that physical/health status, psychological status and social functioning are essential components that must be considered when examining quality of life. However, a number of specific variables such as the meaning of the new diagnosis to the individual, the type of intervention that is required, treatment side-effects, the type of support that is available, body image and sexual functioning, financial resources and socioeconomic status affect outcomes and quality of life in breast and cervical cancer patients (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Nissen, Swenson, Ritz, Farrell, Sladek, & Lally, 2001). Additionally, logistical issues such as taking time off from work, transportation, and childcare, impact quality of life and are possible mediators of positive outcomes for women with breast or cervical cancer (Swanson, 1996).

Other factors impact quality of life. Social support from spouses, family members, and friends, as well as support from health care professionals are important factors in adjustment to breast cancer (Hoskins et al. 1996; Lackey, Gates, & Brown, 2001; Loveys & Klaich, 1991; Street and Voight 1997) found that quality of life was higher for women who perceived greater responsibility and choice for treatment decisions than for those who perceived limited input or control over these decisions. However, information-seeking behaviors that enable women to make informed choices are highly individualistic. Rees and Bath (2001) found that some women actively seek information and others avoid information. Still others vacillate between seeking and avoidance. But, those who sought information used it to cope with their cancers, regain a sense of control and assist in the decision making process. The investigators found that those women who avoided information did so to escape from anxiety, feelings of negativity, and depression.

Spirituality is an important aspect of cancer care (Sephton, Koopman, Schaal, Thoresen, & Spiegel, 2001). Fernsler, Klemm, and Miller (1999) investigated the relationship between spiritual well-being and the demands of illness imposed by a cancer diagnosis. The authors concluded that subjects who reported higher levels of spiritual well-being experienced significantly lower demands of illness related to physical symptoms, monitoring symptoms, and treatment issues.

Disparity

Low-income minority women may face disparity in health care. Some authors contend that disparity in health care is primarily related to race but sufficient evidence exists to suggest that differences in diagnosis, treatment, and survival may be attributable to low socioeconomic status and a lack of insurance coverage rather than to race (Bradley, Given, & Roberts, 2001; Shinagawa, 2000). Low-income women with breast or cervical cancer face problems of inadequate housing, along with fear, anger, and grief that is intensified by negative provider attitudes and stereotypes about socioeconomic status (Levine, Levenberg, Wardlaw, & Moyer, 2001). Depleted financial resources may magnify the impact of a diagnosis of breast cancer or cervical cancer for some low-income women. Out-of-pocket costs such as prescriptions, transportation, co-pays, and lack of paid leave from jobs may result in an insurmountable burden for many women and thereby contribute to healthcare disparity (Levine et al. 2001).

Rural versus Urban Residence

Other factors may contribute to disparity. Living in a rural area may mean that individuals must travel long distances to the nearest hospital or treatment facility. It is known that, on average, women in rural areas travel twice the distance to treatment centers as those in urban areas (Swanson, 1996; Wilson, Anderson, & Meischke, 2000). Consequently, people who become ill and live in rural areas often learn to filter out what symptoms are manageable by the individual, versus what may become problematic if left untreated. Family members, friends, and acquaintances often assume roles of “inside,” albeit informal, diagnosticians and therapists (Long, 1993).

According to Wilson et al. (2000), rural women need more education about breast cancer and more emotional support after diagnosis than urban women. Angell et al. (2003) concluded that women in rural areas need immediate psychosocial intervention that is affordable, accessible despite distance, culturally appropriate, and designed for women with little education.

Depression

Psychological sequelae experienced by the woman with breast or cervical cancer directly affects how she copes with her illness and has been found to include intrusive thoughts, avoidance, anxiety, depression, and impaired relationships (Baider & De-Nour, 1997; Epping-Jordan et al. 1999; Lyons, Jacobson, Prescott, & Oswalt, 2002; Primo et al. 2000; Vickberg, Bovbjerg, & DuHamel, 2000) Women who attribute a negative connotation to the illness experience have been found to have significantly higher levels of depression, anxiety, and poorer quality of life than those with positive attribution (Degner, Hack, O'Neil, & Kristjanson, 2003). Women who are able to transform negative aspects of the breast or cervical cancer experience into ones with positive meaning and who assist in making choices regarding treatment decisions fare better than those who do not (Degner et al. 2003; Koopman et al. 2001; Lyons et al. 2002; Taylor, 2000). Previous research by this author (Lyons et al. 2002) indicated that, after the initial diagnostic trauma and the retraumatization of treatment, many women are able to attribute inherent value to the illness experience and see themselves as stronger for having dealt with the illness.

Pascreta (1997) found that 9% of her sample (n=79) met criteria for major depressive disorder or dysthymia. 24% had elevated depressive symptoms, physical symptom distress, and impaired functioning in daily life. Self-reported depression burden was found to influence severity of side-effects (Badger, Braden, & Mishel, 2001). Depression scores and psychological distress in early stage cervical cancer patients have also been reported to be higher than those in the general population. Cull et al. (1993) reported that patients feared reoccurrence of their cancers, experienced sexual problems, and were unable to communicate their needs to their partners.

Purpose

The goal of this study was to understand the emotional impact of diagnoses of breast or cervical cancer on low-income rural and urban Southern women by exploring depression and cancer-related quality of life in women who have been diagnosed with one of these cancers. 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 obtained from this study will be used to further knowledge about how these women cope with cancer, ultimately leading to interventions that will aid in reducing health disparity in this population.

METHOD

Sample

Sixty 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. Following Institutional Review Board (IRB) approval 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. Participants met inclusion criteria of having been diagnosed with breast or cervical cancer during the previous 6 months, having access to a telephone, and willingness to respond to questions posed by the researcher. Respondents were asked to sign a consent form which described the purpose and confidential nature of the study. They received $50 for their participation. Assurances were given regarding the participant's right to withdraw from the study until such time as all data were analyzed.

Design

The design for this descriptive study was a one-time cross-sectional telephone survey. A telephone survey is a rapid, cost-efficient strategy for data collection from a large sample and geographic area (Lavrakas, 1990). Sixty newly diagnosed women were surveyed about the impact of breast or cervical cancer on their lives, depression, cancer-related quality of life, and other issues identified from the literature and from Phase I of the study.

Instruments

Depression, a common response to a cancer diagnosis, was measured with the Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977). This well-established 20-item scale measures the major symptoms of clinical depression. Alpha coefficients are .84 for the general population and .90 for a patient sample. Test-retest correlations of .48 (n=378) were moderate but appropriate as the CES-D was designed to measure the current level of depression. Cancer-related quality of life was measured by the Functional Assessment of Therapy for Patients with Breast Cancer (FACT-B) which contains the FACT-General plus the Breast Cancer Subscale (BCS) (Cella, 1996). The FACT was developed with an emphasis on patients' values and instrument brevity. It contains 36 items and 5 subscales measuring physical well-being, functional well-being, emotional well-being, social well-being, and additional concerns about breast cancer. Coefficient alpha for the total score was .90, with subscale coefficients ranging from .63 to .86. The FACT-B is considered appropriate for use in oncology clinical trials and clinical practice. Evidence supports high (.88) test-retest reliability for the BCS, as convergent, divergent, and known groups construct validity. All but three BCS items (self-consciousness about dress, shortness of breath, and swollen arms) are also suitable for cervical cancer patients. These three items were deleted for those patients. Additional questions developed from Phase I data were asked of each respondent (Table 1).

Table 1

Cancer Interview Guide Questions

Questions	Number	Percentage
Cancer 1st found		
Mammogram	30	50
Breast self-exam	18	30
Doctor’s exam	12	20
Other	0	0
Told about your cancer		
Call from doctor	5	8.3
Call from nurse	3	5
In person by doctor	51	85
By your spouse or other Family member	1	1.7
Feeling upon notification		
Shock	48	80
Fear	51	85
Anxiety	52	86.7
Calm	8	13.3
Anger	5	8.3
Other	1	1.7 *
Type of cancer treatment		
Lumpectomy	19	31.7
Mastectomy	35	58.3
Hysterectomy	3	5
Radiation	19	31.7
Chemotherapy	33	55
Other Medication	4	6.7
Other	4	6.7
No treatment	0	0 *
Treatment side effects		
Nausea/vomiting	34	57.6
Pain	39	66.1
Weakness	42	71.2
Fatigue	52	88.1
Hair loss	34	57.6
Swelling	2	3.4
Infection	2	3.4
Burns	4	6.8
Numbness	11	18.6
Hot flashes	3	5.1
Other	0	0
No problems	1	1.7*
Quit/take off work		
Yes	14	70
No	6	30
Employer support		
Financial	0	0
Time off without pay	9	64.3

Sick leave	4	28.6
Other	2	14.3
Personal Support		
Spouse	27	45
Children	43	71.7
Friends	35	58.3
Other	7	11.7
No support	1	1.7
Obstacles to treatment		
Yes	57	96.6
No	2	3.4
Types of obstacles		
Transportation	3	5.3
Childcare	0	0
Long waiting times	1	1.8
Financial	57	100
Other	0	0 *
Difficulty paying for Tx		
Yes	51	86.4
No	8	13.6
Emotionally prepared prior to surgery		
Yes	34	57.6
No	25	42.4
Adequate information prior to surgery		
Yes	55	91.7
No	5	8.3
Understand surgery prior		
Yes	58	96.7
No	2	3.3
Participate in Tx decisions		
Yes	53	88.3
No	7	11.7
Used counseling if available		
Yes	60	100
No	0	0
Promote health since Dx		
Eat better	19	32.2
Exercise	5	8.5
Rest	37	62.7
Spend more time w/ family	47	79.7
Appreciate life more	52	88.1
Vitamins	7	11.9
Herbal medicines	0	0
Role of Spirituality since DX		
Strength	47	88.7
Consolation	46	86.8
Closer to God	47	88.7
Go to church more	2	3.8
Pray more	16	30.2
No affect	4	7.5 *

Sample

Fifty-three women who had been diagnosed with breast cancer and seven women diagnosed with cervical cancer comprised the sample for this study. All had been diagnosed within the previous six months and ranged in age from 27-72 years (mean of 49.8). About half of the women resided in Alabama and half in Mississippi; 46% (n= 28) resided in rural areas with the remaining 54% (n=32) residing in urban areas of those states. 57% (n=34) of the women were African American and 43% (n=26) were Caucasian. All had incomes of less than $30,000 with the majority declaring incomes of approximately $10,000 or less. 78% (n=47) received financial assistance from Medicaid, 11.9% (n=7) were Medicare patients, and the remaining 10% (n=6) had some type of private insurance. Complete demographic data is provided in Table 2.

Table 2
Sample Demographics

Items	Count	Percentage
Type of Medical insurance		
Blue Cross/Blue Shield	3	5.1
CHAMPUS	0	0
Medicare	7	11.9
Medicaid	46	78
Other	3	5.1
Marital Status		
Married	30	50
Widowed	2	3.3
Divorced	14	23.3
Separated	5	8.3
Never Married	9	15
Education		
Less than 8th grade	1	1.7
Almost completed HS	19	31.7
Completed HS/GED	27	45
Some college/Trade	13	21.7
Baccalaureate Degree	0	0
Master's Degree	0	0
Post Graduate	0	0
Household Status		
Live alone	9	15
Live with spouse	30	50
Live with children	16	26.7
Live with extended family	4	6.7
Live with friend	1	1.7
Place of Residence		
House	42	70
Apartment	10	16.7
Mobile	8	13.3
Other	0	0

Family Income		
Less than $10,000	21	35.6
$10,000-$20,000	24	40.7
$20,000-$30,000	11	18.6
$30,000-$40,000	3	5.1
$40,000-$50,000	0	0
$50,000-$70,000	0	0
$70,000-$90,000	0	0
$90,000+	0	0
Don't know	0	0
Race		
Caucasian	26	43.3
African American	34	56.7
Religion		
Protestant	55	93.2
Catholic	0	0
Jewish	0	0
Other	4	6.8
Type of Cancer		
Breast	53	88.3
Cervical	7	11.7

Data Analysis

Research questions were divided into two categories. The first category: "Is there a significant difference between breast cancer patients' quality of life and their race, type of surgery, chemotherapy, educational level, patient participation in decision making in treatment, patient treatment side effects, social support systems, rural/urban residence, and emotional preparedness? The second category: "Is there a significant difference between cancer patients' depression scores and their race, type of surgery, chemotherapy, educational level, patient participation in decision making in treatment, patient treatment side effects, social support systems, rural/urban residence, and emotional preparedness?" These questions were tested by means of the chi square statistic (FACT B) and analysis of variance (CES-D).

Findings

Sixty low-income, African American and Caucasian women, who resided in rural and urban areas of the Deep South participated in this study. All had been diagnosed with breast or cervical cancer. The women in this study found out that they had cancer through mammograms (n=30), breast self-exam (n=18), or physician exam (n=12). The majority of women were informed of their cancers in person, by their physicians. However, eight women described finding out during phone calls from their physician or a nurse. The majority of the women expressed shock, fear, and anxiety upon notification. Some experienced anger and still others stated that they were "very calm". The type of cancer treatment varied depending on type and severity of cancer. Three individuals had hysterectomies, the remainder had lumpectomies (n=19), mastectomies (n=35), radiation (n=19), and/or chemotherapy (n=33). Treatment side effects included nausea and vomiting, pain, weakness, fatigue, hair loss, swelling, and numbness. The majority had what they considered to be excellent support from spouses, children, friends, and church family. Participants (n=53) overwhelmingly felt that they had experienced obstacles to treatment particularly in terms of financial difficulty and would not have been able to afford treatment without Medicaid or Medicare. More than half of the women felt that they were emotionally prepared prior to surgery, understood what surgery was to be performed and felt that they had participated in treatment decisions. However, 100% of the women stated that they would take advantage of additional education and counseling by a nurse if it were available. The women in this study engaged in a variety of health promoting behaviors such as "eating better", exercise, rest, spending more time with family, appreciating life more, and taking vitamins. None of the participants admitted to taking herbal medications. When asked about the impact of spirituality on their experiences the most prevalent answers were strength, consolation, and feeling closer to God. Table 2 depicts participant responses to survey questions.

In examining the research questions (n=52) related to quality of life (FACT-B) only race, type of surgery, rural/urban residence, and treatment side effects were found significant ($p< 0.05$). African American breast cancer patients were found to have a significantly ($F=8.11$) higher quality of life score than Caucasian breast cancer patients. Breast cancer patients who had a lumpectomy were found to have a significantly ($F=5.91$) higher quality of life score than those breast cancer patients who did not. Patients who had a mastectomy were found to have a significantly ($F=4.73$) lower quality of life score when compared to those patients who did not. Breast cancer patients living in rural areas were found to have a significantly ($F=5.13$) lower quality of life score as opposed to patients living in urban areas. Patients were found to have a significantly lower quality of life score if they experienced nausea and vomiting ($F=5.51$), hair loss ($F=7.62$), and swelling ($F=16.13$).

Examination of cancer patients' depression questions (CES-D) (n=60) found only two questions (emotional preparedness and type of cancer) to be significant ($p<0.05$). Results indicated that patients who felt that they did not receive adequate information about their surgery prior to surgery were significantly (x 2 = 7.97) more depressed than patients who felt they received adequate information. Those patients with cervical cancer were found to be significantly (x 2 = 11.58) more depressed than patients with breast cancer. However, making any inference based on these findings may be suspect, due to the small number of patients with depressive symptoms for both questions (Emotional preparedness=5, type of cancer=7).

DISCUSSION

The goal of this study was to understand the emotional impact of diagnoses of breast or cervical cancer on low-income rural and urban southern women by exploring depression and cancer-related quality of life in women who have been diagnosed with one of these cancers. Despite differences in race or rural/urban residence and congruent with Phase I of this research (Lyons, 2004) the women in this study experienced similar responses to the diagnosis of breast or cervical cancer. They acknowledged shock, fear, and anxiety related to the diagnosis, surgery, and treatment. They had good support systems in place and relied on family and friends for help in meeting their psychosocial needs pre and post surgery and during treatment. However, 100% of the women indicated that they would welcome the opportunity to discuss their concerns with a nurse counselor.

Inadequate financial resources and lack of insurance were significant barriers to access to care for many of the women. However, all were screened for their cancers by their state's Breast and Cervical Cancer Early Detection Program. Once they received a positive diagnosis they were referred to Medicaid to receive financial assistance, thereby leveling the playing field in some respects with women who have insurance. The women in this study who had insurance were burdened by a limited ability to pay for out-of-pocket expenses such as co-pays, medication, and transportation to treatment facilities. Nursing assessment of financial resources/needs and subsequent referral to appropriate social services could be beneficial to these patients.

Consistent with current literature (Henderson, Fogel, & Edwards, 2003) African American women in this study were found to have a higher quality of life than Caucasian women. Perhaps as other research has shown (Bourjolly, 1998), this difference is related to differences in religious coping. Mastectomy patients were found to have a lower quality of life than those who had undergone lumpectomy. Congruent with other research findings (Rustoen, Moum, Wiklund, & Hanestad, 1999) this difference may be attributed to body image concerns, pain, sexual concerns, and self-esteem issues.

Women with breast cancer who lived in rural areas had poorer quality of life scores than those living in urban areas. Distance to treatment, perceived lack of physician support, and isolation may have been contributing factors to this finding. Lower quality of life scores were apparent in women who experienced treatment side-effects such as nausea and vomiting, hair loss, and swelling.

Contrary to the findings of other researchers (Badger, Braden, & Mishel, 1999; Pascreta, 1997) none of the women in this study met criteria for clinical depression. However, women who felt that they did not receive adequate information prior to surgery had more symptoms of depression. This finding may be attributed to feelings of helplessness, not knowing what to expect, an inability to ask questions, or feeling a lack of control over the outcome. Assessment of depression symptoms by the clinician is key to treatment and successful outcomes. The differences in depression scores related to preoperative preparation and teaching support the findings of the Phase I study (Lyons, 2004) and suggest that a more comprehensive approach to education before surgery would have a positive impact in the reduction of depressive symptoms that these women experience.

This one-time cross sectional telephone survey is limited by several important methodological limitations that restrict confidence in the interpretation of results. The cross-sectional nature of the data prohibits any claims of causality and the small sample size limits generalizability of results. Data were collected through self-report responses to interviews which may lead to methodological shortfalls because validation of subject responses was not performed. However, this study clearly highlights the fact that nurses have unique opportunities to to answer pertinent questions for patients and to intervene as deemed appropriate for breast and cervical cancer patients.

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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