

# Exploring Patient-Physician Communication in Breast Cancer Care for African American Women Following Primary Treatment

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**Purpose/Objectives:** To investigate patient-physician communication from the patient's perspective about guidelines and sources of information used in developing survivorship care and preferred avenues for information delivery to African American breast cancer survivors.

**Design:** Qualitative.

**Setting:** Medical centers in the eastern United States.

**Sample:** 39 African American breast cancer survivors with a mean age of 55.

**Methods:** Each participant contributed to one of four two-hour focus group discussions and completed brief questionnaires regarding sociodemographic characteristics and cancer-specific data. Focus group topics included involvement in discussions and decision making about survivorship care, specific instructions and information that physicians provided regarding follow-up medical care and preventive health actions, concerns about recurrence and ways to prevent it, and sources of information used to develop survivorship care plans.

**Main Research Variables:** Survivorship care, patient-provider communication, information delivery methods, and African American breast cancer survivors.

**Findings:** Participants reported gaps in the information given to them by physicians about their diagnosis, treatments, side effects, and guidelines for follow-up care. Participants expressed strong interest in self-care practices aimed at reducing their risk of recurrence and receiving evidence-based information and guidelines from healthcare providers. The majority (about 90%) reported physician checkups and mammography screening during the prior year, whereas only 54% reported making daily efforts to improve their health and reduce their risk of recurrence. Although evidence-based guidelines are available to healthcare providers delivering follow-up care to breast cancer survivors, more than 90% of participants in the present study reported a lack of specific recommendations regarding diet or physical activity as ways to improve quality of life and health as a cancer survivor.

**Conclusions:** The present study underscores 2006 findings from the Institute of Medicine that strategies for delivering information and guidance to cancer survivors and coordinating their care remain important issues for patients and their healthcare providers.

**Implications for Nursing:** The present study's findings highlight the need expressed by breast cancer survivors for comprehensive guidance from healthcare providers in developing plans of care that improve patients' quality of life and target recurrence risk. Guidelines are available for dissemination and use in medical settings; however, the guidelines have not been incorporated into standard medical practice for patients with cancer. Information about long-term follow-up care after primary treatment should target the specific needs of survivors from diverse ethnic, socioeconomic, and educational backgrounds to promote understanding of surveillance to detect recurrence, long-term effects of cancer treatments, and general health maintenance.

## Key Points . . .

- ▶ African American breast cancer survivors desire comprehensive guidance from healthcare professionals to improve their quality of life and decrease the risk of cancer recurrence.
- ▶ Survivors indicated that gaps exist in the guidelines for surveillance, treatment symptoms, and recurrence prevention provided by physicians.
- ▶ Long-term follow-up care should target cancer survivors from diverse ethnic, socioeconomic, and educational backgrounds.

**R**educing the rates of recurrence and mortality for more than 2.4 million breast cancer survivors in the United States is an important public health goal (Ries et al., 2007). A necessary step toward accomplishing this goal involves providing evidence-based information and guidelines for follow-up care to patients with cancer after their primary treatment is complete. However, the mechanisms and context for delivering this information and guidance to patients while coordinating their care remain important issues for patients and physicians. The present study was designed to investigate patient-physician communication related to the delivery issue from the perspectives of African American breast cancer

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survivors who historically have received less information and fewer opportunities to participate in decision making during medical appointments than Caucasian breast cancer survivors (Cooper-Patrick et al., 1999; Kaplan, Gandek, Greenfield, Rogers, & Ware, 1995; Royak-Schaler et al., 2002).

The gap in scientific understanding about the patient-physician communication process and the limited dissemination of evidence-based guidelines by healthcare providers to cancer survivors was identified by the Institute of Medicine (IOM) in its report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt, Greenfield, & Stovall, 2006). In the report, the IOM presented guidelines for developing plans of follow-up medical care and preventive health practices that should be given to survivors by their physicians. The guidelines are important for breast cancer survivors whose personal histories are a risk factor for disease recurrence and developing breast cancer in the opposite breast (Gill et al., 2004), particularly for African American survivors, who are at greater risk of dying from breast cancer than Caucasian women (American Cancer Society [ACS], 2007).

Few studies have investigated patient understanding of biomedical guidelines for survivorship care that include both follow-up medical care and preventive health practices or patient compliance with their physician's recommendations. The present study was designed to address the gap in the scientific literature and investigate the patient-physician communication process from the perspectives of African American breast cancer survivors. Researchers investigated survivors' discussions with physicians about survivorship plans of care, including follow-up medical care and preventive health actions (e.g., diet, physical activity), participation in decision making about survivorship care, concerns about recurrence and ways to minimize recurrence risk, sources of information used in developing survivorship plans of care, and preferred avenues for receiving information about necessary follow-up medical care after primary treatment for breast cancer.

## Literature Review

### Disparities Among African American and Caucasian Breast Cancer Survivors

Mortality rates for African American breast cancer survivors are 33% higher than for Caucasians (ACS, 2007) despite the higher incidence of the disease in Caucasians (Ries et al., 2007), and African Americans are less likely to survive for five years following diagnosis than Caucasian women (77% versus 90%, respectively) (Smigal et al., 2006). African Americans typically are diagnosed at later stages than Caucasians and have higher mortality rates at every stage of cancer diagnosis (Chu, Lamar, & Freeman, 2003; Edwards, Gamel, Vaughan, & Wrightson, 1998; Shavers, Harlan, & Stevens, 2003). Some studies have found that African American ethnicity is associated with lower socioeconomic status, less usage of medical services, higher occurrence of comorbidities, lower screening rates, and unfavorable tumor biology (Hershman et al., 2005; Jazieh & Buncher, 2002; Royak-Schaler et al., 2002).

Several studies have investigated the disparities to elucidate the differences in breast cancer mortality for African American and Caucasian women (ACS, 2007; Krieger,

1989; Mandelblatt, Andrews, Kerner, Zauber, & Burnett, 1991; Marbella & Layde, 2001; Royak-Schaler & Rose, 2002). African Americans are more likely to be uninsured compared to Caucasians (16.5% versus 9.8%, respectively) (Cohen, Martinez, & Free, 2007) and may face other difficulties that affect their health care (e.g., limited health literacy, perceived discrimination in medical settings, difficulties communicating with physicians). African Americans also reported shorter office visits and lower visit satisfaction with physicians who are of other races (Cooper et al., 2003; Roter et al., 1997). The disparities are a significant issue as minority women often have a greater need for medical care and guidance because of their higher levels of morbidity and comorbidity than Caucasian women (Williams, 2002).

### Information Needs of Breast Cancer Survivors

The desire for cancer-related information and the capacity to obtain it differs greatly among breast cancer survivors. Survivors who report receiving information tended to ask questions, express concerns, and assert their preferences during medical appointments (Gordon, Street, Sharf, & Souček, 2006). Patients with lower literacy levels tended to ask fewer questions and made fewer requests for information or additional services (Katz, Jacobson, Veledar, & Kripalani, 2007), and, therefore, may understand less about their medical conditions and treatments than patients with higher literacy. All patients with breast cancer should receive information about long-term follow-up care after primary treatment is complete to help them understand the importance of surveillance for recurrence, long-term effects of cancer treatments, and general health maintenance (Doubeni et al., 2006; Hurria & Hudis, 2003; Partridge, Winer, & Burstein, 2003).

Many survivors live with ongoing concerns about recurrence for years after initial treatment. Recurrence concerns have been identified in conjunction with medical checkups, body or functional changes, disease recurrence in another survivor, and media events about breast cancer (Ganz et al., 1996, 2004; Gray et al., 1998; Payne, Medina, & Hampton, 2003). Cancer survivors also are at higher risk of developing other malignancies that might be predisposed by cancer treatment, genetic predisposition, or lifestyle behavior (Ganz, 2001). In addition, breast cancer survivors are at higher risk of developing nonmalignant comorbid conditions (e.g., cardiovascular diseases) because of premature menopause after chemotherapy or exposure to radiation therapy (Colditz et al., 1987; Theodoulou & Seidman, 2003; Zambetti et al., 2001).

IOM (Hewitt et al., 2006) reported that after primary treatment, the guidance physicians provide to cancer survivors during follow-up care is too limited. Other studies have found that many healthcare providers underestimate the information needs and desires of patients with breast cancer (Goldberg, Guadagnoli, Silliman, & Glicksman, 1990; Suominen, Leino-Kilpi, & Laippala, 1995). The present study investigated patient reports about types of information provided to them by physicians and opportunities to participate in discussions about follow-up care.

### Coordinating Follow-Up Care: Patient-Physician Communication

The coordination of follow-up care that targets the contexts of health status and lifestyles of patients with breast cancer can be a daunting task as a result of the fragmentation of cancer

care and a lack of coordination between cancer specialists and primary care providers regarding the responsibilities for the ongoing screening and monitoring of patients (Doubeni et al., 2006; Hewitt et al., 2006).

Discussions in the medical setting have been shown to significantly affect patient decisions about healthcare practices and the related health outcomes after completing breast cancer treatment. Providing clear information and emotional support, sharing decision making, and agreeing on the nature of the issue and the need for follow-up can facilitate patient-physician partnerships and promote compliance with plans of follow-up care, including prevention (Greenfield, Kaplan, & Ware, 1985; Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Kaplan, Greenfield, & Ware, 1989; Rost, Flavin, Cole, & McGill, 1991). Conversations about weight management, one of the few modifiable risk factors associated with breast cancer recurrence, are particularly important for African American survivors whose high body mass index may increase their risk of recurrence and mortality (Goodwin & Boyd, 1990; Rockhill, Weinberg, & Newman, 1998; Trentham-Dietz et al., 1997). Patients who received oncologists' recommendations to exercise have been found to significantly increase reports of weekly physical activity compared to patients who did not receive this recommendation ( $p = 0.01$ ) (Jones, Courneya, Fairey, & Mackey, 2004).

The present study investigated participants' preventive health actions along with their understanding and use of prevention information provided by their physicians and other sources. Researchers assessed understanding of cancer risk factors such as poor nutrition, lack of physical activity, and obesity (Ward et al., 2004) that may place African Americans, whose rates of obesity are significantly higher than Caucasians (36.5% versus 21.8%, respectively), at higher risk of breast cancer recurrence (Goodwin & Boyd, 1990).

## Methods

A qualitative study design was used to investigate the patient side of patient-physician communication, particularly survivorship care, sources of information used by survivors in developing plans of care, and preferred mediums for information delivery to breast cancer survivors. Grounded theory (Strauss & Corbin, 1998) guided the development of open-ended questions designed to assess, compare, and categorize survivors' views on their involvement in decision making about follow-up care. Patient concerns about recurrence and sources of information used in developing plans to reduce the risk of recurrence also were investigated.

Participants were recruited from the University of Maryland Greenebaum Cancer Center (UMGCC), the Baltimore Washington Medical Center (BWMC), the Sisters Network Baltimore Chapter, and the ACS Reach to Recovery Program. Eligible participants, self-identified as African American, were aged 30–75 years and had a diagnosis of primary breast cancer. Equal numbers of women recruited were younger than age 50 or age 50 and older and were diagnosed with breast cancer either fewer than five years or more than five years prior to the study. Survivors who had a breast cancer recurrence were excluded from participating in the study; 5% of patients had stage III or IV at diagnosis of their primary cancer. The study was approved by the University of Maryland's institutional review board.

## Procedure

Four two-hour focus group sessions were conducted at UMGCC, BWMC, St. Agnes Hospital, and the ACS offices during the summer of 2005. Upon arrival, each participant signed an informed consent form and completed brief self-administered questionnaires. The focus group leader facilitated the discussions following a moderator guide that was designed to standardize data collection across the four groups. All focus group sessions were audio taped. In addition, two notetakers numerically identified the participants and their comments and kept count of who agreed with the main points of discussion or the perspectives of other participants.

## Measures

Participants completed brief questionnaires that collected sociodemographic data (age, education, income, and marital status) and cancer-specific data (stage at diagnosis, time since diagnosis, and treatments received). The moderator of the focus groups asked participants a series of questions that probed involvement in decision making. Topics included survivorship care, the specific instructions and information received from physicians regarding follow-up medical care and preventive health actions to minimize risk of recurrence, participant concerns about recurrence and prevention, sources of information used in developing survivorship care plans, and preferred avenues for information delivery to survivors. The moderator guide is available from the corresponding author upon request.

## Data Analysis

Questionnaire data were summarized with descriptive statistics and focus group data were transcribed from the audiotapes. Two types of thematic analyses were conducted to inductively identify emergent themes: basic categorical answers to specific inquiries were analyzed and qualitative data analysis addressed the specific research questions and the themes that emerged from participants' perspectives and conclusions. A codebook was constructed and data were coded by theme and area of inquiry using the ATLAS<sup>®</sup> 5.0 data analysis software. The data and codes were checked at several points in the process for consistency and objectivity. Data reduction was accomplished through a coding sort using ATLAS 5.0 to identify the key concepts in the thematic and inquiry categories. Key concepts were derived from the focus group participant responses to questions posed by the moderator, statements made by the participants about other introduced topics, and ongoing dialogue among the participants. Data were analyzed by comparing and contrasting themes within and across the four focus groups.

## Results

### Participant Characteristics

Four focus group sessions were conducted with 39 African American breast cancer survivors, with a mean age of 55. Twenty-five participants (64%) were recruited through the Sisters Network Baltimore Chapter or the Reach to Recovery Program of ACS. Fourteen participants (36%) were recruited through UMGCC and BWMC. Most of the participants (72%) were high school graduates, about 46% were married or living with a partner, 59% were diagnosed with breast cancer when

**Table 1. Sociodemographic and Breast Cancer Data**

Characteristic	n	%
<b>Age (years)<sup>a</sup></b>		
< 55	20	51
≥ 55	19	49
<b>Income (\$)</b>		
< 20,000	13	33
20,000–40,000	13	33
> 40,000	8	21
Unknown	5	13
<b>Education</b>		
Less than high school	11	28
More than high school	28	72
<b>Marital status</b>		
Married or live with partner	18	46
Single	5	13
Divorced or separated	10	26
Widowed	6	15
<b>Age at diagnosis (years)</b>		
< 40	8	21
40–49	14	36
50–59	9	23
≥ 60	8	21
<b>Stage at diagnosis</b>		
0 <sup>b</sup>	3	8
I–II	19	49
III–IV	2	5
Unknown	15	38
<b>Surgical treatment</b>		
Lumpectomy	17	44
Mastectomy	16	41
Lumpectomy followed by mastectomy	4	10
Unknown	2	5
<b>Adjuvant therapy</b>		
Chemotherapy only	6	15
Radiation therapy only	4	10
Chemotherapy and radiation	17	44
None	12	31
<b>Hormonal therapy</b>		
Yes	11	28
No	28	72
<b>Years since end of treatment</b>		
≤ 1	5	13
1–5	16	41
> 5	18	46

N = 39

<sup>a</sup>  $\bar{X}$  = 5 years

<sup>b</sup> Patients with ductal carcinoma in situ

Note. Because of rounding, percentages may not total 100.

age 40–59, 57% were diagnosed at stages 0, I, or II, and 87% had finished their primary cancer treatment more than a year prior to the focus groups (see Table 1).

### Focus Group Themes

Participants shared their communication experiences along the cancer continuum from diagnosis and primary treatment to follow-up medical care. They reported gaps in the information given to them by physicians about guidelines for follow-up care and their diagnoses, treatments, and side effects. Participants expressed concerns about recurrence and confusion regarding specific plans of preventive action.

Participants articulated a need for guidelines that could help them develop plans for follow-up and survivorship self-care. A summary of participant responses organized according to the five areas outlined in the moderator guide follows. The focus group themes are summarized in Figure 1.

**Involvement in medical decision making across the cancer continuum:** Most participants (95%) expressed a desire to play an active or collaborative role in making their medical decisions (see Table 2). Only 5% preferred to leave the final decision to their physicians.

Participants expressed concerns about the quality and quantity of information supplied by healthcare providers to help them through the decision-making process. Some reported being overwhelmed by the amount of information and expressed that this negatively affected their ability to make truly informed decisions.

The doctors overwhelmed me with information; they gave me a lot of literature, books, pamphlets, even a video to watch, and it got to the point where it was so much information that I just sort of shut down and I just didn't want to hear anymore, didn't want to think about it, I just went with my intuition as far as my treatment is concerned.

Others reported not receiving enough information.

When I found out about cancer, there was no discussion about the procedure, what it was all about, he was ready to just chop off my breast and send me out the door without any kind of information about breast cancer. He just simply said, "You got cancer and you have to have a mastectomy." I think we deserve better.

- Overall survivor experience with provider-patient communication and factors affecting it
  - African American survivors want to actively participate and share in medical decision making with physicians.
  - Survivors report difficulties receiving information from providers regarding treatment and developing or managing survivorship plans.
  - Survivors feel the need to do independent research and be assertive in interactions with providers to get information they believe will improve their health outcomes.
  - Age, education, and insurance coverage, more so than race, were perceived to affect the quality of information received from physicians.
- Attitudes toward survivorship care after diagnosis and treatment
  - African American survivors are concerned about the possibility of recurrence.
  - Most survivors have developed some type of survivorship care plan, largely without specific guidelines from physicians.
  - Some are unsure about the efficacy of various plan components (e.g., diet, exercise).
- Information avenues for breast cancer survivors
  - Survivors identified healthcare providers and brochures to be their main sources of information.
  - Information provided by healthcare professionals did not include clear guidelines for follow-up medical care or prevention recurrence.
  - Older survivors do not favor the Internet or computer-based educational programs as sources of information.
  - Other breast cancer survivors were identified as the best information resource for African American women with breast cancer.

**Figure 1. Themes Identified by African Americans Regarding Survivorship Care After Completion of Primary Treatment**

**Table 2. Preferred Role in Medical Decisions**

Response	n	%
I prefer to make the final selection about which treatment I will receive.	4	10
I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.	13	33
I prefer that my doctor and I share responsibility for deciding which treatment is best for me.	19	49
I prefer that my doctor make the final decision about which treatment will be used, but seriously consider my opinion.	1	3
I prefer to leave all decisions regarding treatment to my doctor.	2	5

N = 39

Only about half of participants who reported treatment side effects (n = 25) said that their physicians had discussed the side effects with them. However, many participants did not blame the healthcare providers for their own lack of knowledge. Throughout the course of the discussions, participants stressed the importance of being active knowledge seekers independent of the healthcare providers. Some explained that the doctors were initially resistant to responding to their concerns and emphasized the importance of being assertive in their interactions with healthcare providers.

She was wonderful. I really liked her. But she would make me so mad, because I would tell her different things that were happening, but in her mind she was trying to undermine certain things so I [would] take the medicine. But, I told her and she was better about it.

Only three participants believed that race could affect the relationship between patients and physicians. Most participants did not believe that racial discrimination was a factor that influenced their relationships with medical providers. Instead, they believed that poverty, lack of insurance, and limited education could bias medical providers' perceptions of their patients more so than race.

You go touch base with some of the less educated, less affluent people. . . . You will find out a lot of times that they feel like they're just getting tossed to the side and that's with all ethnic groups.

**Participant concerns about recurrence:** Participants reported ongoing stress and difficulties following treatment. Although not overtly fearful, many reported concerns about recurrence and expressed strong interest in self-care aimed at reducing their risk. Fifty-four percent reported making daily efforts to improve their health and reduce their risk of recurrence, and 95% reported that they had been to their doctor at least once in the previous year. Also, 89% had mammography in the past year. Although most participants agreed about the importance of early detection of recurrence, some complained that mammograms were stressful and painful.

Uncertainties emerged about strategies scientifically determined to reduce the risk of breast cancer recurrence. Diet modification and physical activity were only mentioned by 31% and 21% of the participants, respectively, and not in the context of weight control as an evidence-based strategy for risk reduction (see Table 3).

### Sources of information used in developing survivorship plans of care:

Almost all participants (n = 38 of 39) reported a lack of specific recommendations from healthcare providers regarding diet or physical activity. Participants subscribed to a variety of theories of healthy eating. Some avoided high-fat foods or carbohydrates. Others added healthy foods such as flaxseed, fish oil, and organic fruits and vegetables to their diets. Only two participants mentioned losing weight as a specific goal to decrease their risk of recurrence. Participants pointed to the importance of returning to the healthy traditional diet of their African American heritage, which includes many green vegetables.

Similar to dieting, participants used various approaches to physical activity, and walking was mentioned the most. Whereas some participants took up new exercise programs, others maintained the programs they had before diagnosis. Although almost all women reported some type of survivorship care plan, some feelings of uncertainty existed about the efficacy of self-care. Three participants expressed doubts that any physical efforts could be effective.

### Preferred sources of breast cancer information delivery to survivors:

Fourteen participants identified healthcare providers and brochures as their main sources of information for learning about breast cancer treatment and care (see Table 4). Age was a distinguishing factor in participants' preferences. Older participants ( $\geq 55$  years) identified brochures (13 of 19) to be their main source of information, and younger participants (< 55 years) preferred the information provided by healthcare providers (15 of 20). Books and the Internet were identified as important sources but ranked after information provided in the healthcare setting.

My surgeon's office was really good and so was my oncologist's office. . . . They gave me this really big book on everything about my treatment; all of the [reports] and things that I needed to know I'm gonna have. My oncologist actually gave me a nice calendar of dates of when, after I finished my last radiation, I need to come back for this and when I need to come back for my blood test. So I had this calendar that was on my refrigerator for the next two years.

Age was an important barrier to the use of the Internet. Only 42% (8 of 19) of those aged 55 or older used the Internet compared to 100% (N = 20) of those younger than age 55. Some participants found that the Internet provided

**Table 3. Activities That May Reduce the Risk of Recurrence**

Response <sup>a</sup>	n	%
Change in diet	12	31
Regular mammograms	9	23
Regular exercise	8	21
Regular doctor's appointments	8	21
Medications	4	10
Lose weight	2	5
Other <sup>b</sup>	7	18

N = 39

<sup>a</sup> Participants were able to choose more than one response.

<sup>b</sup> Responses were prayer (2 participants), bone scans (2), self-examination (1), mastectomy (1), and avoiding secondhand smoke (1).

**Table 4. Survivors' Primary Sources of Information About Breast Cancer Follow-Up Care**

Source	Age < 55 Years (N = 20)		Age ≥ 55 Years (N = 19)	
	n	%	n	%
Brochures	12	60	13	68
Scientific articles	4	20	8	42
Medical personnel	15	75	10	53
Internet	11	55	5	26
Books	9	45	10	53
Others	3	15	4	21

general information not targeted to them, which was confusing and misleading.

When researchers asked for the best way to communicate information about breast cancer to African American women, most participants identified personal experiences disclosed by other cancer survivors as the most effective means of receiving information throughout the entire treatment and recovery process. One participant said, "Yes, the computer can give four to five options that you can choose from . . . but it is totally different from actually getting that tangible response from someone else who's actually been through it."

## Discussion

The gaps in information and guidelines identified by cancer survivors in the present study's four focus groups were consistent with those identified by the IOM (Hewitt et al., 2006). The gaps were noted along the continuum of cancer care from diagnosis and primary treatment through survivorship. About 38% of participants in the present study were unaware of their stage of disease at diagnosis, 5% did not know what type of surgery they had undergone, and 31% claimed that they never received either chemotherapy or radiation. Only 50% of the women who reported treatment side effects had discussed the symptoms with their physicians. Although discussions with physicians were viewed as being the primary source of information about survivorship care and the most helpful, participants in this study reported gaps in guidelines for surveillance, symptoms after treatment, and prevention, which raised important questions about who is responsible for having survivorship discussions with patients upon completion of primary treatment. Is it cancer specialists or primary care physicians who are responsible for coordinating the preventive care of patients with cancer? In addition, what is the role of oncology nurses in providing guidance about prevention and health promotion to cancer survivors?

The present study's findings indicate that patients' questions about the coordination of follow-up care as survivors remain largely unanswered. Inattention toward disseminating guidelines to physicians regarding the coordination of care for cancer survivors may be indicated by declining rates of mammography screening and decreasing concerns about the risk of breast cancer over time by breast cancer survivors (Doubeni et al., 2006; Schapira, McAuliffe, & Nattinger, 2000).

To address the "teachable moment" (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005) following breast cancer di-

agnosis and treatment to promote long-term health, a critical need exists for guidance from healthcare professionals that targets the diverse needs of survivors in developing feasible plans of ongoing care. Current estimates indicate that only 20% of oncologists provide lifestyle guidance to their patients (Demark-Wahnefried et al.). For African American women with breast cancer whose rates of obesity place them at higher risk of recurrence (Goodwin & Boyd, 1990), this guidance must target the context of their individual health status and lifestyles for improving breast cancer outcomes. Assessing patient understanding of this information is critical (Lerman et al., 1993) because some patients struggle with applying medical information (Royak-Schaler et al., 2006).

The desire for cancer-related information and the capacity to obtain wanted information differ greatly among breast cancer survivors. Survivors who report receiving information tend to ask questions, express concerns, and assert their preferences during medical appointments (Gordon et al., 2006). However, patients with lower literacy levels tend to ask fewer questions and make fewer requests for information or additional services (Katz et al., 2007), and as a result, may understand less about their medical conditions and treatments than patients with higher literacy. All women with breast cancer should receive information about long-term follow-up care after primary treatment is complete to help them understand the importance of surveillance for recurrence, long-term effects of cancer treatments, and general health maintenance (Doubeni et al., 2006; Hurria & Hudis, 2003; Partridge et al., 2003).

Many participants reported concerns about recurrence following primary treatment. Pervasive uncertainty was expressed about specific ways to reduce the likelihood of cancer recurrence other than routine medical visits and mammography screening. Participants lacked knowledge that moderating weight gain could be an effective risk reduction strategy, and less than 52% mentioned dietary change and physical activity. Also, more than 90% of participants reported a lack of specific recommendations from their healthcare providers regarding diet or physical activity. This gap is important because recent studies have found that weight control, physical activity, and dietary practices (fat, fruit, vegetable, and fiber intakes) among breast cancer survivors are similar to those observed in the rest of the U.S. population (Bellizzi, Rowland, Jeffery, & McNeel, 2005; Caan et al., 2005; Coups & Ostroff, 2005; Stull, Snyder, & Demark-Wahnefried, 2007).

The present study's findings highlight the need expressed by breast cancer survivors for comprehensive guidance from healthcare providers and oncology and primary care teams to develop plans of care that improve quality of life and target the risk of cancer recurrence. Guidelines are available for dissemination and use by healthcare providers but have not been incorporated into standard medical practice with cancer survivors. For example, ACS advised that breast cancer risk can be reduced by engaging in vigorous physical activity for at least four hours a week, avoiding or limiting alcohol intake to no more than one drink a day, and minimizing lifetime weight gain through combining caloric restriction and regular physical activity (Kushi et al., 2006). The IOM (Hewitt et al., 2006) recommended that the following information should be provided by physicians who deliver a survivor's follow-up care: complete information about the stage of disease, treatments

received, and risk of recurrence; screening guidelines that target level of risk; information about long-term symptoms and effects of primary treatment (e.g., lymphedema, depression); information regarding diet and evidence linking good nutrition to health; a specific survivorship plan of care tailored to reduce individual risk of recurrence; and the context of lifestyle and culture. The present study highlights the challenge and need for translating lifestyle guidelines into medical practice to improve the quality and length of life for cancer survivors.

## Study Limitations

The African American breast cancer survivors who agreed to participate in these focus groups may be representative of the Baltimore, MD, metropolitan area, but not of the general population of patients with breast cancer. The participants were recruited from two urban and two suburban centers and their levels of education were somewhat greater than the majority of the U.S. population; about 72% had some college education. However, the present study was one of the first to investigate the domains of information presented to African American cancer survivors by physicians delivering their follow-up care, according to IOM guidelines (Hewitt et al., 2006).

## Implications for Nursing

The present study underscores the finding that strategies for delivering information and guidance to cancer survivors and coordinating their care remain important issues for patients and their healthcare providers. Although patients who are involved in their treatment and care decisions are more successful at self-management and have better health outcomes than those who are not (Cooper-Patrick et al., 1999; Ganz et al., 2004; Kaplan et al., 1995; Royak-Schaler et al., 2002), the study's participants did not report such involvement in their cancer care. Instead, more than 90% reported a lack of specific recommendations from healthcare providers for reducing their risk of cancer recurrence, highlighting a missed opportunity to develop feasible plans of ongoing care and promote long-term health.

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