

Breast Cancer Survivors' Perspectives of Care Practices in Western and Alternative Medicine

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According to the American Cancer Society (ACS), 2009a), an estimated 40,610 breast cancer deaths were expected in 2009. However, as a result of advances in early detection and treatment, many patients with breast cancer can expect survival that is similar to age-matched women without the disease (Rockson, 2002). The five-year relative survival rate for localized breast cancer has increased substantially from 63% in the 1960s to 89% (ACS, 2009a).

Although breast cancer survivors are living longer, they are not necessarily as healthy as the general population (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). Furthermore, they have to face many treatment-related problems that may impact them physically and psychosocially, such as lymphedema, which affects 10%–25% of the nearly 2 million breast cancer survivors in the United States (Loudon & Petrek, 2000). In addition, treatment effects of fatigue, weight gain, sleep disturbance, and osteoporosis have been reported (Mayer et al., 2007). Common psychological and social problems in breast cancer survivors include fears of recurrence; normative mood changes; uncertainty; an increased sense of vulnerability; feeling of loss; concern about body image, self-concept, and sexuality; emotional distress related to role adjustments and family response; and concern about finances and employment (Knobf, 2007).

Breast cancer survivors use health care not only from Western medicine, but also from the alternative medicine sector. According to Buettner et al. (2006), the reported use of complementary and alternative medicine in women with breast cancer ranges from 36%–83%. However, Yeh, Lin, Tsai, Lai, and Ku (1999) pointed out that although application of alternative, generic, or folk care alone or simultaneously with professional healthcare practices may be commonplace in breast cancer survivors, patients are reluctant and afraid to communicate their beliefs or practices to professionals.

Purpose/Objectives: To explore perspectives of breast cancer survivors about their care with Western medicine and alternative medicine.

Research Approach: Qualitative, ethnographic.

Setting: Cancer center in the midwestern region of the United States.

Participants: 9 breast cancer survivors who had experienced health care involving Western medicine and alternative medicine.

Methodologic Approach: Semistructured interviews were conducted to elicit each participant's perspective about care practices. Data were analyzed with an ethnographic qualitative data analysis method.

Main Research Variables: Care practices in Western medicine and care practices in alternative medicine.

Findings: Western medicine was seen as traditional or mainstream treatment, whereas alternative medicine was seen as anything not involving hospitals and doctors or as complementary. Perceived outcomes from alternative therapies were coping with disease and treatment, holistic care, and emotional support, whereas perceived outcomes from Western medicine were negative things that they had to go through and as an instrument of God. Kinship, social, economical, educational, and belief factors influenced care practices.

Conclusions: Care practices from alternative medicine or Western medicine vary for breast cancer survivors. Many factors influence their selection decisions about care practices.

Interpretation: Nurses should be concerned about what care practices mean to breast cancer survivors. Further research should be considered to evaluate the potential contribution of each factor to breast cancer survivors' decision making about care practices.

Exploring patients' perceptions of healthcare practices within a cultural context is helpful. According to Nishimoto and Foley (2001), healthcare professionals who recognize and appreciate cultural diversity can positively impact outcomes. Patients who are more satisfied with their care are less likely to discontinue their treatment, particularly if their cultural beliefs are

taken into account. Thus, the purpose of this study was to explore the care practices used to promote health and well-being of breast cancer survivors. The research questions were as follows.

- What were the breast cancer survivors' perceptions about care practices with regard to both Western medicine and alternative medicine?
- What factors influenced the selection of care practices with regard to Western medicine and alternative medicine?

Methodologic Approach

Design

The researchers used the ethnographic research method design by Leininger and McFarland (2006) because the method uses a unique and essential qualitative method to study caring and healing practices, beliefs, and values in diverse cultural and environmental contexts.

Selection and Recruitment of Participants

The researchers used a purposive sampling strategy to recruit the participants (N = 9). Inclusion criteria were (a) older than 18 years of age, (b) English-speaking, (c) a diagnosis of breast cancer at least one year previously, and (d) experience with healthcare practices in both Western and alternative medicine. After the Health Sciences Institutional Review Board at the University of Missouri approved the study, participants were recruited from a cancer center in the midwestern region of the United States. All participants were informed about standard principles of protection of human subjects, including the right to refuse, withdraw, or stop participating in the study. All participants provided written informed consent under the principle of full disclosure and received a copy of the consent form.

Data Collection and Analysis

The in-depth interviews took an average of 60–90 minutes per session, with at least two weeks between each of the two interviews. All interviews were audiotaped and transcribed verbatim. Observation and reflection during the participants' interviews were used to explore their perspectives regarding the domain of inquiry. Broad, open-ended questions were used to open the interviews by focusing the participants on their care practice experiences. For example, one such opening statement and related broad questions were: "What are the care practice methods you use to promote your health and well-being?" "Would you please tell me what these methods look like?" The interviewer then asked questions to solicit individual thought about care practices with regard to both Western medicine and alternative medicine. Key questions included: "From your perspective, what do the care practices you use mean to you?" "How do

you define Western medicine and alternative medicine?" "Could you please describe your experiences using Western medicine and alternative medicine?" "What factors influence you to decide which care practices you use to promote health and well-being?"

The verbatim data obtained from audiotaped interviews and accompanying field notes taken during and following the participants' interviews were transcribed. Data were analyzed with Leininger and McFarland's (2006) four-phase method. The process began with documentation and analysis of all observation and interview experiences. The second phase focused on analysis of descriptors, and the third phase identified patterns related to the domain of inquiry. The fourth phase included formulation of themes, which were validated by peer review.

Sample

Nine breast cancer survivors were interviewed. The age of participants ranged from 44–61 years. Of the nine women, one had 18 years of education and the rest had 12–16 years of education. Six women reported more than four years since diagnosis of breast cancer; the rest reported diagnosis within four years. Four women were at stage I of disease at diagnosis, whereas five women had stage II disease. Eight of the nine participants stated that they sometimes attended worship services. Four of the participants worked full-time, two participants worked part-time, and the rest did not have jobs.

Findings and Themes

Definitions of Alternative Medicine and Western Medicine

Data saturation was achieved after interviews with nine participants. Two major themes emerged from the data: (a) Western medicine is traditional or mainstream treatment, and (b) alternative medicine is anything not involving hospitals and doctors and should be called complementary.

Participants described Western medicine as traditional or mainstream treatment. As one participant said, "To me, Western medicine is traditional and it means standard treatments. It's mainstream medicine." Another participant said, "Western medicine would be what the doctors recommend. Anything in a hospital, kind of traditional." These definitions are similar to the definition from the National Cancer Institute (2009), which defined Western medicine as a system in which healthcare professionals treat diseases and that can be called conventional or mainstream medicine.

Alternative medicine was defined as anything not involving hospitals and doctors. One participant said, "Alternative medicine would be anything that you do to help your health that doesn't involve a doctor or a

hospital.” Similarly, one participant stated, “Not anything that doctors recommend to me. It’s something natural.” This definition is similar to the definition by the National Center for Complementary and Alternative Medicine (2009), which defined complementary and alternative medicine as a group of diverse medical and healthcare systems, practices, and products that are not generally considered part of conventional medicine.

Interestingly, the participants also defined alternative medicine as complementary. As one participant mentioned, “My definition for alternative medicine would be complementary. It’s not a total departure from the MD route. It’s complement.” Another participant stated, “I see it as a supplement to traditional treatments. Complementary would be the word I would use more than alternative. It’s complementary.” According to ACS (2009b) and the National Institutes of Health (2009), complementary medicine is used along with standard medical care, but alternative medicine is used instead of standard medical care. Thus, as the participants in this study had experienced both Western and alternative medicine, they perceived that alternative medicine should be called complementary.

Perceptions of Care Practices of Alternative Medicine and Western Medicine

From the analysis of transcribed interview data, perceived outcomes of care practices from alternative therapies were seen as (a) coping with disease and treatment, (b) holistic care, and (c) emotional support. Perceived outcomes of care practices from Western medicine were (a) negative things to endure and (b) an instrument of God.

Alternative medicine and coping with disease and treatment: The first perceived outcome of care practices from alternative therapies was identified as coping with disease and treatment. One participant who used dance as her care said,

It became my way of coping with my treatment to have something positive to do, and I learned that no matter how tired I was, no matter how bad I felt, when I went to dance, I felt better and I wouldn’t think about breast cancer for a whole hour during my dance lesson. So, it really became my way of coping with the stress of having illness.

Additionally, one participant stated that praying gave her a sense of humor that helped her go through a bad time. As she said, “God gives you a sense of humor through bad times. I think He does give us a sense of humor. It just feels good to laugh, and to laugh is good for you.” This was consistent with other reports. For example, Hann, Baker, Denniston, and Entekin (2005) found that the benefit of complementary therapies from cancer survivors’ perspectives was to reduce stress or help people cope with cancer. In addition, Humpel and

Jones (2005) reported that one expectation from complementary and alternative medicine for cancer survivors was assisting conventional treatment and recovery.

Alternative medicine and holistic care: The second perceived outcome of care practices from alternative therapies was identified as holistic care. One participant who went to a chiropractor said, “What I like about him was he looked at my tongue. He was looking at my body to see what the body was saying, and then he would ask me questions.” Similarly, another participant who practiced meditation talked about what it meant to her. She said, “I think it’s healing emotionally, and when it healed you emotionally, it healed you physically.” As Canales (2004) suggested, to be healthy, individuals need to have balance among mind, body, and spirit. Accordingly, participants in this study described outcomes of care practices from alternative therapies as holistic care, which covered mind and body.

Alternative medicine and emotional support: The last perceived outcome of care practices from alternative therapies was identified as emotional support. The participants described that with their care practices, they received hope and peace, which could promote their health and well-being.

In terms of hope, the participants who used prayer to promote their health and well-being shared how important God and prayer were. As one participant said, “Having God there with us, it’s like the parents holding the child by the hand. A lot of times it is not physical but more is the emotional.” Interestingly, another participant stated that both healthcare providers and prayer were necessary for patients. She said,

The doctors and the nurses gave me wonderful care, but then the prayer just made it more complete. Just like giving the baby water on top of the food. That is an important part of surviving. You have to have that hope, and that is where prayer becomes important, giving you that hope.

Additionally, peace was described as one outcome of emotional support that participants got from their care practices with alternative therapies. One participant who used tai chi as her care practice to promote her health and well-being also shared about peace gained from performing tai chi. She stated, “It just brings a sense of peace and calm. You can’t really do it well without, kind of giving you a peace as part of it.” Furthermore, one participant who used prayer said,

When I would come over here to get the chemo, I would say “Pray for me,” and that peace would flood over me, and it was like someone had taken velvet material. How soft that is, like I had just been wrapped up in it. I just had that peace.

Similarly, one participant stated that she received peace from God: “He gave me just a sweet sense of

peace through it all. Even though everything goes crazy around you, even though you got cancer facing you, you have a peace.”

From this study, the authors found that participants described outcomes of care practices from alternative therapies as emotional support by receiving hope and peace from God. These findings are somewhat consistent with other reports. Howard, Balneaves, and Bottorff (2007) reported that spirituality was a source of inner peace, comfort, and emotional strength when women were scared, worried, or in pain. Similarly, Canales (2004) also reported that spirituality played an important role for breast cancer survivors during treatment and recovery.

Western medicine and negative things to endure:

The first perceived outcome of care practices from Western medicine was identified as negative things that they had to go through. Although Western medicine was helpful in terms of curing cancer, it also was seen as negative things that patients with breast cancer had to go through. A lot of participants shared their experiences with bad side effects of their treatments. For example, one participant talked about how bad she felt with the treatments: “I’m painful. It’s scary. I mean it’s just something to have to go through.” One participant stated,

When you get lymph nodes taken out, you are not the same anymore like you used to. And with the chemo, the hair falls out. You felt nausea, sick at your stomach. I had bone problems, like aches, pain, and then it felt like flu symptoms. You know you ache everywhere for a day.

One participant compared chemotherapy to a red devil. She said,

That chemo is the awful one called “the red devil.” I had no energy. I really felt like I was going to die. I mean I just got that bad. My sense of smell was so keen, so acute. I was so cold inside. Nothing could warm me up.

Lastly, one participant pointed out an interesting issue. She stated that Western treatment was worse than disease.

I’m sure you heard one time, “The treatment is worse than disease,” you know, before it becomes an advanced disease. All the side effects that you experienced from the Western medicine treatments. Oh, my God, can there be a better way to treat?

This finding is consistent with a study by Kreling, Figueiredo, Sheppard, and Mandelblatt (2006) that found that perceptions of negative side effects of chemotherapy (e.g., hair loss, nausea) were barriers for many women to get such treatment.

Western medicine and an instrument of God: Another perceived outcome of care practices from Western

medicine was identified as an instrument of God. For instance, one participant said, “God is in a great position. So he uses medicine, he uses doctors. He can use diet and supplements.” Likewise, another participant also expressed the idea: “Sometimes the Lord just uses the doctors to fix the problems. The Lord uses the doctors as a tool. He gave them the knowledge, gave them to do some of these things.” Similarly, one participant said, “God provided wonderful doctors and nurses. God is the one that gave the doctors and nurses wisdom.” This is consistent with findings in other studies that God acts through physicians to cure illness, that God’s will is the most important factor in recovery, that spiritual faith is involved in healing, and that doctors are seen as the instrument of God’s will (Johnson, Elbert-Avila, & Tulsy, 2005; Mansfield, Mitchell, & King, 2002; Qidwai & Tayyab, 2004).

Factors Influencing Care Practices of Alternative Medicine and Western Medicine

From the analysis of transcribed interview data, care practices of alternative medicine and Western medicine for breast cancer survivors were influenced by many factors, categorized as kinship and social, economic, educational, and belief. This finding supports the theory of Culture Care Diversity and Universality (Leininger & McFarland, 2006), which stated that many factors such as kinship, economics, belief, or education influenced care in different environmental contexts.

Kinship and social factors: Kinship and social factors could influence breast cancer survivors when they were making decisions about care practices of either alternative medicine or Western medicine. This study found that a family member, especially a husband, was an important person. One participant who decided to get surgery said that she and her husband decided together. She said, “My husband and I decided together. We pretty much knew that it was gonna have to be, but we felt that it’s better for me to lose my breast than to lose my life.” Another participant who received surgery and radiation also stated that she decided with her husband to do the procedures. She said, “We made the decision together. He would read the papers pretty much, too.” Furthermore, one participant who went to an alternative medicine clinic in Mexico said that although she decided to go there by herself, her husband influenced this care practice. She said, “My husband is very much into natural stuff, and he heard about this clinic in Mexico.”

Other family members, especially children, also were important people who could influence care practices for breast cancer survivors. As one participant who had used a variety of alternative therapies said, “It’s not just about me. It’s about my family, and I need to be healthy, to be there for my family, to raise my children.” Another participant, who used dance to fight cancer, stated that she was doing it because of her son. She said,

I have a little boy. I think I was setting an example for him that no matter what you have to deal with in life, you still live your life and you go on and you do everything. You can enjoy your day, enjoy filling your life with the things you love to do. That was a benefit.

These findings are consistent with another study by Kreling et al. (2006), which found that family members are central for women to accept, cope, and recover from breast cancer. In addition, husbands, children, and grandchildren are important in decision making that leads to the use of chemotherapy for older breast cancer survivors.

Furthermore, social factors were influential. One participant said that she used herbs and supplements because of her friend's suggestion.

I had a friend who had been working closely with the naturopath just for her own health and her family health issues. . . . So, she is the one who educated me and got me in touch with lines of information and avenues to proceed in that direction with any possible treatment.

This finding is consistent with another study that examined sources of information about complementary and alternative medicine for patients with lung cancer. Molassiotis et al. (2006) found that friends are a main source of information about complementary and alternative medicine.

Economic factor: The economic factor could influence breast cancer survivors when they were making decisions about their care practices. One participant stated that Western medicine was focused on money: "The medicine is so expensive. When you go to the doctor, you go to the surgeon or whatever. It's so expensive. I think it's all about money-making." However, she said that the cost of alternative therapy was a barrier, too: "I had my experience once in Mexico. There was only one time because you cannot afford it. It's so expensive." Another participant stated that she tried to eat organic food but could not do it completely because it was expensive. This finding is consistent with the finding that the cost of complementary and alternative medicine is the most negative aspect in cancer survivors' perspectives (Humpel & Jones, 2005). However, some participants did not care about money but were concerned more about their lives (Boon, Brown, Gavin, Kennard, & Stewart, 1999). As one participant said, "It's not cheap, but I find I get benefit from it. So, I spend my money for something like this."

Educational factor: The educational factor could influence breast cancer survivors when they were making decisions about their care practices. The educational factor played a role as a key factor in helping participants understand what they were reading, ask questions related to their treatments, and then decide

what they would do. One participant who decided to get surgery and radiation talked about how education helped her make decisions. She said, "I have a degree in biology. I went to medical school for a year. So I'm very well educated and I can read these papers and I can understand them and I can ask questions." One participant who had been working with cancer issues also confirmed how important the educational factor was. She said, "I'm a cancer registrar. We collect data on cancer, and I've done this for quite a number of years. I think the benefit of my knowledge about this disease is that when I told my family, I was able to be pretty sure and they trusted me because they knew that I did know what I'm talking about."

The educational factor also influenced care practices with alternative therapies for breast cancer survivors. One participant stated that research influenced her to be aware of using vitamin D. She said,

There are some discussions and research about women taking vitamin D. They don't have approval, but they think vitamin D could play a role in whether or not you get breast cancer, and so I decided that I would try to take more vitamins.

One participant not only read a book, but also went to seminars and talked with people to find her own care practice method. She said,

I went to seminars where there was a group of people that offered different thought about food as alternative medicine. It was very interesting and very much an education. I also read a lot and talked a lot to herbalists and naturopaths.

This finding is consistent with other reports, which found that the educational factor is associated with decision making in treatment (DiGianni, Garber, & Winer, 2002; Er, Mistik, Ozkan, Ozturk, & Altinbas, 2008).

Belief factor: Belief in God could influence breast cancer survivors when they were making decisions about their care practices. As one participant said,

I believe very sincerely that God made the whole world. He made the plants and the animals and everything. So I believe very strongly in different kinds of things that made the multivitamins and supplements.

One participant who decided to receive surgery and chemotherapy stated that belief in God influenced her. She said, "As he made us, he knows what I need. He knows if I need the surgery, a chemo, or a radiation." This finding is consistent with a study by Johnson et al. (2005) that reported that spiritual beliefs may influence the treatment preferences of patients throughout the course of illness and that patients may believe that God is responsible for physical and spiritual health. Similarly, Silvestri, Knittig, Zoller, and Nietert (2003) found that

faith in God was one important factor in treatment decisions by patients with lung cancer.

Furthermore, some participants decided to use alternative therapies because they thought Western medicine did not work for them. As one participant said, "Chemo made your hair fall out, and surgery put you in all kinds of pain, but when I got a couple capsules a day, it doesn't hurt." One participant decided to go to alternative therapy because she received a variety of opinions from Western doctors about her treatment. She said, "When you go to a doctor, you always got a couple of opinions. Because one doctor said this, the other one said something different. See, they make you wonder what to do, why not on the same level?" This finding is similar to a study by Palinkas and Kabongo (2000), who found that patients attending family practice clinics used complementary and alternative medicine because of failure of conventional treatments.

Implications for Nursing

Care practices either from alternative medicine or Western medicine vary for breast cancer survivors. Many factors influence patients' decisions. Care practices with alternative therapies and Western medicine for breast cancer survivors should be an important focus of practice and research. The most important finding to emerge from the current study is what care practices of alternative therapies and Western medicine mean to breast cancer survivors. Care practices of Western medicine were described as something that they had to go through, whereas care practices of alternative therapies were seen

as a way of coping with disease and treatment, as holistic care, and as emotional support. However, a weakness of this study is that the researchers explored participants' perspectives of care practices with regard to Western medicine and alternative medicine in general. Learning their perspectives toward specific care practice methods would be useful. For instance, in future research, the authors might look at what care practices of alternative therapies such as yoga, meditation, prayer, or supplements mean to breast cancer survivors.

Overall, many factors (kinship and social, economic, educational, and belief) can influence care practices of breast cancer survivors both in Western medicine and alternative therapy. This issue deserves future research to evaluate the potential role of each factor in decision making about care practices by breast cancer survivors. For instance, the authors might study how family members play a role in decisions about care practices.

Finally, a limitation of the study was that participants were primarily Caucasian; thus, generalizability to a broader population of breast cancer survivors is limited. Further work is required to explore perspectives about care practices in other races and other locations.

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