Chemobrain in Underserved African American Breast Cancer Survivors: A Qualitative Study

Connie Rust, PhD, DPh, MSW, and Cindy Davis, PhD

Although research has been conducted to address specific medical and psychosocial needs of breast cancer survivors, little has been done to address needs along the entire trajectory of care. One such need is chemobrain, a phenomenon recognized as an identifiable psychosocial cognitive change in breast cancer survivors. The purpose of this article is to present the findings of a qualitative study conducted with two focus groups of underserved African American breast cancer survivors. Four themes emerged from the transcribed interviews: the concept of chemobrain, variability among individuals, the stigma of chemobrain, and methods of coping.

In addition, findings revealed that health professionals were not used by the participants as a resource to address the issues of chemobrain, which holds significant implications for practice. That fact highlights the implications for oncology nursing with respect to providing education and support for patients experiencing chemobrain. Nursing professionals are in a position to be a frontline resource for breast cancer survivors, providing information, education, and coping methods to help improve their quality of life.

Chemobrain is receiving increased attention as an identifiable psychosocial cognitive change that disrupts the lives of breast cancer survivors (Alfano & Rowland, 2006; Boykoff, Moieni, & Subramanian, 2009; Castellon, Silverman, & Ganz, 2005). Defined as a decline in memory or foginess, chemobrain is recognized in empirical literature, but details about cause and duration are debated (Alfano & Rowland, 2006; Jansen, Cooper, Dodd, & Miaskowski, 2011; Tallibert, Voillery, & Bernard-Marty, 2007). Chemobrain affects 33%–50% of all patients undergoing chemotherapy treatment (Olin, 2001; Staat & Segatore, 2005). Symptoms of chemobrain can be subtle and inconclusive, such as fatigue, mental confusion, forgetfulness, shorter attention span, inability to concentrate, and changes in executive function (Burstein, 2007; Staat & Segatore, 2005; Tallibert et al., 2007). The Oncology Nursing Society (2011) putting Evidence Into Practice resources further define cognitive impairment as a decline in function in single or multiple domains of brain function, such as attention and concentration, executive function, information processing, language, visuospatial skill, psychomotor ability, learning, and memory.

A specific cause has not been determined for chemobrain (Alfano & Rowland, 2006; Jansen et al., 2011; Tallibert et al., 2007). Empirical support exists of chemotherapy-induced impairment of cognitive function in patients with breast cancer (Brezden, Phillips, Abdolell, Bunston, & Tannock, 2000; Schagen et al., 2002; Schagen, Muller, Booger, Mellenbergh, & van Dam, 2006; Tchen et al., 2003; Weinke & Dienst, 1995), in addition to a link to other adjuvant therapies such as tamoxifen (Jenkins, Shilling, Fallowfield, Howell, & Hutton, 2004). Although an association has been found, the mechanisms of impairment require additional study (Falleti, Sanfilippo, Maruff, Weih, & Phillips, 2005; Jansen et al., 2011; Jansen, Miaskowski, Dodd, Dowling, & Kramer, 2005; Raffa et al., 2006). Multiple factors have the possibility of contributing to cognitive dysfunction, such as hormonal changes, supportive medication, psychiatric changes, and biologic vulnerability (Burstein, 2007; Tallibert et al., 2007).
The effect of chemobrain on the quality of life of breast cancer survivors is a relatively new area of research in the literature.

The effect of chemobrain on quality of life of breast cancer survivors is a relatively new area of research in the literature (Boykoff et al., 2009; Jansen et al., 2005; Staat & Segatore, 2005; Tallibert et al., 2007). A decline in cognition can have a monumental impact on quality of life (Jansen et al., 2005; Kibiger, Kirsh, Wall, & Passik, 2003; Tallibert et al., 2007). These women often are caretakers, mothers, grandmothers, sisters, wives, partners, employers, and employees (Abel & Subramanian, 2008; Davis, 2009; Mayer, 2003; Staat & Segatore, 2005). Because of the multiple roles that these women have in their lives, alterations in cognitive function and quality of life affect those around them as well. One of the aims of the current study was to assess the quality of life of the study participants in light of the multiple roles with which breast cancer survivors often are faced.

Research addressing cognitive impairment in patients with breast cancer focused on broad populations, with no focus on disadvantaged or underserved populations (Brezen et al., 2000; Jansen et al., 2008; Kreukels et al., 2006; Schagen et al., 2002; Tchen et al., 2003; Weinke & Dienst, 1995). Underserved populations (e.g., low income, ethnic minorities) of breast cancer survivors are vulnerable and at greater risk for lower quality of health; in fact, ethnic minorities are less likely to receive high-quality care, even after controlling for socioeconomic status (Kressin, 2005; Smedley, Stith, & Nelson, 2003). Because of the unique needs of these populations, both ethnic and socioeconomic, more information is needed regarding specific areas of concern. Therefore, this qualitative study was designed to explore the issues faced among underserved African American breast cancer survivors, their experiences with cognitive impairment from chemobrain, and the impact of chemobrain on their quality of life.

Methods

This exploratory study collected qualitative information from medically underserved African American women with breast cancer. The term underserved is defined in the study as uninsured or receiving TennCare, the government assistance healthcare plan for the state of Tennessee. Participants were recruited from a breast cancer organization that provides supportive services to underserved African American women with breast cancer based on availability and willingness to participate. Institutional review board approval was obtained for the study prior to data collection. Focus groups comprised volunteers who met the criteria of being diagnosed with breast cancer, aged 18 years or older, and having completed chemotherapy and radiation at least one year prior to the study. After obtaining informed consent and demographic information for each volunteer, the focus groups were formed. Each group contained 12 participants and one focus group leader and conducted one session lasting about one hour. The focus groups were conducted simultaneously prior to a scheduled meeting of a breast cancer support group in an urban city in the southern United States. Because of the large response, the researcher assigned to be the notetaker became the leader of the second group. Although the groups were larger than desired, a third group could not be formed because of time and the lack of a third focus group leader. The focus groups were audio recorded and then transcribed.

A total of 24 women participated, all of whom were African American. Seven of the women (29%) were aged 46–60 years, nine (38%) were older than 60 years, and eight women (33%) did not provide their age. Twelve (50%) of those responding had a high school education, three women (13%) reported college-level education, one (4%) had attended graduate school, and eight (33%) did not respond. The mean time since diagnosis was 6.1 years (SD = 5.8 years).

Analysis was based on the qualitative approach of grounded theory, which allows researchers to develop explanations of key social processes grounded in empirical data (Tavakol, Torabi, & Zeinaloo, 2006). Participants were asked open-ended questions to elicit conversation regarding the issues they faced, their experiences with cognitive impairment, and the impact of chemobrain on their lives. Data coding began with the researcher listening to and transcribing the audio tapes. Transcriptions then were sent to the other authors for review. Open coding involved examining the data in discrete parts for differences and similarities, and then identifying themes within the data. The researchers examined the data until consensus was achieved with the emerging themes. The next step was to code the data into categories and develop salient themes (Miles & Huberman, 1994; Rubin & Babbie, 2008).

Results

Four themes were identified: (a) the concept of chemobrain, (b) variability of chemobrain among individuals, (c) the stigma of chemobrain, and (d) methods of coping. The first theme focused on the concept of chemobrain. Those who had experienced a change in cognition certainly believed chemobrain was real for them. Chemobrain was described by participants as “fogginess,” “forgetfulness,” and the tendency to “go blank.” Some older women commented that although memory issues occurred before treatment, the intensity of the fogginess of their memory was greater after chemotherapy. One woman commented that the memory issues were more noticeable after treatment, saying, “You have to think really hard now. You just can’t think and be like you used to be, you know, just livin’.”
Another participant described that when she experienced lapses in memory, she had to “wait and it will come around.” Many anecdotal accounts were given of forgetting the reason for going into a room, misplacing items, forgetting where to turn while driving, and losing money.

For me, if something would come up that I know that I knew well, [that] I could do it quickly before chemo, and after chemo I would say, “Why am I not doing it the way and as quickly as [before]?”—[such as] cooking a recipe, simple and routine.

The second theme focused on the variability in intensity and duration of chemobrain amongst the participants; in other words, they did not all experience chemobrain in the same manner. Although not all of the women experienced chemobrain, the majority of them either had in the past or currently were experiencing it. One participant had not received chemotherapy but was taking tamoxifen and experiencing “fogginess.” A small percentage of the women who had experienced chemobrain stated that it was a short-term issue, whereas the majority of the women reported that chemobrain was an ongoing challenge for them. Intensity of symptoms ranged from insignificant forgetfulness to serious issues with cognition.

I had trouble with being forgetful before chemo. But that is the thing you notice once you’ve had chemo. It’s more noticeable.

When I was taking chemo, the fire department got to know me on a first-name basis because I would try to make tea late at night . . . five times they were out to my house to the point that they would come in the house and say, “What you doing Ms. [W]? ”

Comments about living with chemobrain covered a broad spectrum of emotions. Several women commented on the frustration of having to cope with forgetting. Others described the phenomenon as aggravating. A common thread through all of the comments about chemobrain was the disruption of their daily lives and their ability to multitask. All of the participants were members of an underserved population, with inadequate access to services. Many of these women were caretakers and had family members depending on them. Others lived alone and had no social support. As shown in the earlier quotations, the decrease in cognitive function clearly had an impact on all those who were experiencing chemobrain.

For me, when driving, I couldn’t remember if I am supposed to turn or not. I had to ask myself where I am going. Sometimes it really got on my nerves.

The third theme identified in the focus groups was the stigma associated with the cognitive changes from chemobrain. When asked whether other people recognized the changes in their cognition, participants affirmed that the loss of memory and subsequent behavior, such as a slowing down of accomplishing daily tasks, was acknowledged by family, friends, and coworkers.

When you put something down and you’re looking for it and they say, “What did you do with it, mama, what are you looking for?”

One of the group members expressed concern about being perceived as mentally unstable, saying, “They know it’s something different—I know they are gonna call me schizophrenic.” Others framed the issue as one that can be dealt with by applying more time and energy to remembering.

You backtrack. I forget where I put things—I put it there and next thing I know it ain’t there and I say, “I know I’m not going crazy.”

The fourth theme revolved around coping strategies to deal with the cognitive impact of chemobrain, such as humor, social support, spirituality, and self-efficacy. Humor was a primary means of coping with chemobrain. Several anecdotal accounts were shared that elicited laughter from the members and generated more conversation about coping. One participant shared a particularly memorable anecdote.

The other day I asked my son, “Where is my telephone?”—and I was talking on it! I know I never did anything like that before!

Peer support was another coping strategy used by participants. Participants discussed the importance of social support from other women with breast cancer.

I think it is healthy for us to be able to come together and to share with each other. And that is the way we see it—sisters coming together. We’ve got one common thing.

Participants also discussed the importance of community resources, such as churches.

At my church, we meet once a month. Whatever information I find out, I share with my church and I leave information for other churches, so the other churches know the information as well. This is the way I communicate the information.

Although many community services were available, some participants were not familiar with the resources and expressed concern about how to access them. The consensus of the group members was that a more uniform method of obtaining information and support was needed other than word of mouth.

You know, and maybe two or three other people may know, but the bulk of the people sitting at this table may not know.

The importance of spirituality was apparent through the responses of the participants. The majority of the group members expressed a strong reliance on faith in God as a primary reason for their ability to cope with the changes that had occurred in their lives as a result of breast cancer treatment. That faith gave many of the respondents a perceived sense of well-being and
improved quality of life, with participants saying, “God loved me enough that he gave me another chance” and “I thank God that I am still here testifying.”

Self-efficacy, defined as the confidence people have in their ability to take action and to successfully perform that action (Markland, Ryan, Tobin, & Rollnick, 2005; National Cancer Institute, 2005), also emerged as a coping mechanism for some participants. Although many participants emphasized the limitations that occur with chemobrain, a few respondents described coping skills that allowed them to overcome difficulties that occurred with foggy thinking. Some members described the use of cognitive restructuring to reframe their situations and make positive adaptations to their daily lives to function more effectively.

I had to think harder. And it took me a long time to do simple things . . . but, it’s not like you can’t think. It’s just that you have to realize there’s something in you that’s gonna have you go off, so you get up from the computer and go around and come back and sit down.

Other participants related that these changes had prompted them to say what was on their mind and be more open with people. That openness had given them the courage to speak to people that they may not have otherwise approached. Relationships were improved as a result of this newfound freedom of expression.

I used to kind of hide things about what I thought about people but now I don’t hide it—I just come right out and say it. I’m more open now. I don’t try to hide anything anymore. It seems like ever since, whatever comes up comes out.

Discussion

This qualitative study presented findings regarding the reality of chemobrain, its variability among patients, the perceived stigma that chemobrain may impose on patients, and the methods employed by patients to cope with the effects of this phenomenon. Findings revealed that women in the current study experienced cognitive challenges, which they described as chemobrain resulting from their cancer treatment. The findings of the focus groups corroborate the literature regarding patient recognition of chemobrain (Abel & Subramanian, 2008; Alfano & Rowland, 2006; Boykoff et al., 2009; Castellon et al., 2005; Jansen et al., 2011; Mayer, 2003; Myers, 2012; Tallibert et al., 2007) and variance among participants (Falletti et al., 2005; Jansen et al., 2005; Tallibert et al., 2007). A qualitative study by Boykoff et al. (2009) reported that participants called chemobrain the “most troublesome post treatment symptom” (p. 223). The symptoms described (e.g., memory loss, difficulty concentrating, reduction of organizational skills) are similar to those described in empirical research (Boykoff et al., 2009; Burstein, 2007; Myers, 2012; Staat & Segatore, 2005; Tallibert et al., 2007). As described by Staat and Segatore (2005), participants acknowledged the difficulty of multitasking and maintaining roles at work and as a caretaker at home. Alfano and Rowland (2006) stated that patients often are unprepared to deal with chemobrain after chemotherapy treatment, which was corroborated in the current study. In addition, lack of information given to the women by their healthcare providers was an issue of concern. Self-reported reduction of quality of life from the impact of chemobrain was a common thread throughout both focus groups, which also was found in other studies (Boykoff et al., 2009; Jansen et al., 2005; Kibiger et al., 2003; Staat & Segatore, 2005; Tallibert et al., 2007). That alteration caused the women to rely on various coping skills, such as humor (Abel & Subramanian, 2008; Johnson, 2002), social support (Abel & Subramanian, 2008; Davis, 2009; Filazoglu & Griva, 2008; Wonghongkul, Dechaprom, Plumivichuvate, & Losawatkul, 2006), spirituality (Choumanova, Wanat, Barrett, & Koopman, 2006; Davis, 2009; Filazoglu & Griva, 2008; Fredette, 1995; Johnson, 2002; Mayer, 2003; Morgan, Gaston-Johansson, & Mock, 2006), and self-efficacy (Danhauer, Crawford, Farmer, & Avis, 2009; Davis, 2009; Filazoglu & Griva, 2008). One particular observation made by the researchers was a lack of seeking help from healthcare providers with regard to chemobrain. Unlike previous research, a pertinent topic that emerged from the group of underserved women was their reliance on their spirituality to cope with the side effects of chemotherapy treatment, including chemobrain.

Some issues inherent to underserved populations merit more attention, such as unequal access to medical information, medical care, and psychosocial support. The participants’ conversations rarely mentioned using healthcare providers as a resource for dealing with chemobrain. What was most evident about this issue was the lack of mention of a healthcare professional recognizing the existence of chemobrain, educating the patient on what to expect and how to cope, and providing the patient with resources when needed. Recognition of the phenomenon of chemobrain by healthcare professionals was not apparent to the women in the current study. Patients should be educated properly about the possibility of experiencing cognitive difficulties during and after chemotherapy and during the use of other adjunctive therapies. That information needs to be provided prior to and throughout the course of treatment. Discussion of chemobrain with the patient prior to treatment validates chemobrain as a real issue, prepares the patient for chemobrain if it should occur, and opens up dialogue with the patient in the event that it needs to be addressed in the future. Patients may struggle with choosing whether or not to have treatment because of apprehension about succumbing to chemobrain, thus emphasizing the need for an informative discussion (Raffa et al., 2006). In addition, providing informed consent, identifying treatment toxicities, and administering self-care are areas for concern (Jansen et al., 2005). Information should be offered in a format that is easy for patients to understand and retain (Jansen et al., 2008). Trained professionals can help to guide the patient through these processes, aid the patient in making informed decisions, and direct patients to healthcare providers who can provide supportive measures to alleviate the symptoms of chemobrain and enhance cognition (Myers, 2012; Raffa et al., 2006). That can be facilitated by the assignment of a patient navigator (Davis, Darby, Likes, & Bell, 2009; Dohan & Schrag, 2005; Freeman, Muth, & Kerner, 1995; Till, 2003).

Limitations

Several limitations existed in the study. First, recruiting and sampling were limited to participants of one breast cancer support group. Second, time was constrained because of the
support group meeting that followed the focus group meetings. Third, only one method of data collection was used. Because of the large response, the researcher that was assigned to be the notetaker became the leader of the second group. Finally, no provision existed for a third group to reduce the number of participants per group. In addition, this study has limited generalizability because it was limited to one group of women in one location.

Conclusion

Chemobrain is a phenomenon that affects many patients with cancer. With the growing number of breast cancer survivors, the impact of chemobrain can have long-term effects on health and quality of life. Underserved breast cancer survivors have the added burden of receiving inadequate information and treatment of the symptoms and consequences of chemobrain. Nurses and all healthcare professionals must acknowledge the dilemma that this population faces and address the cognitive as well as psychosocial issues of breast cancer survivors, in addition to providing the support and resources needed to help them navigate this phase of treatment (Boykoff et al., 2009; Jansen et al., 2011; Mulrooney, 2008; Reid-Arndt, Yee, Perry, & Hsieh, 2009; Von Ah, Jansen, Allen, Schiavone, & Wulff, 2011).

References


