Memories of Treatment: The Immediacy of Breast Cancer

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This article represents one facet of the author's research on women's experiences of embodiment after breast cancer. Herein, women's reliance on and rejection of medicalized understandings of this condition are explored via participants' descriptions of memories of treatment. Data collection consisted of 24 in-depth interviews with 12 women, using phenomenological and feminist approaches. Five themes emerged: (a) issues of control, (b) suffering, (c) encountering medicine, (d) visible loss, and (e) leaving active treatment. Participants found the medicalization of breast cancer to be problematic, but they were also reluctant to leave the realm of acute care. Although a large volume of breast cancer research now exists, the women's accounts demonstrate that further research into the experience of breast cancer is necessary.

Keywords: *breast cancer; cancer survivorship; phenomenology; embodiment*

The growing population of breast cancer survivors affirms that research on this condition is imperative (Carter, 1993; Maunsall, Brisson, Dubois, Lauzier, & Fraser, 1999). Diverse studies have included nurses' perceptions of breast cancer patients and treatment decision making (Charles, Redko, Whelan, Gafni, & Reyno, 1998; Crockford, Holloway, & Walker, 1993), yet a recent qualitative metasynthesis (Arman & Rehnsfeldt, 2003) showed that certain dimensions of experience, such as suffering, might have been overlooked in research that depicts breast cancer as a positive force involving transformation and transcendence. My research also questions views of breast cancer as transformative, in that it shows how women both rely on and reject the medicalization of breast cancer via exploration of their memories of treatment. For the women in this study, encountering medicine was problematic, as it involved suffering, yet leaving acute care was also described as difficult. Participants suggest that prior research has neglected the complexity of this condition, thereby limiting medical professionals' abilities to respond to women with breast cancer.

RELEVANT LITERATURE AND PERSPECTIVES

In their review of breast cancer literature, Muraoka and Gotay (1998) highlighted some of the controversies associated with breast cancer, as they indicate that there

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are studies that proclaim no differences in psychosocial indicators in relation to treatment, and there are studies that show significant differences. However, in another review, Glanz and Lerman (1992) concluded that breast conservation yields better results for body image. Simultaneously, other researchers have suggested that clinical breast cancer research is problematic. Qualitative studies of women's experiences with breast cancer have suggested that the psychosocial aspects of topics such as chemically induced menopause and lymphedema have been neglected (Carter, 1997; Davis, Zinkland, & Fitch, 2000). Furthermore, Langellier and Sullivan (1998) asserted that prior research emphases on the effects of a mastectomy replicate sexist power dynamics and that women speaking for themselves about breast cancer suggest that issues other than breast loss are more important.

Much of the research on breast cancer also reifies dichotomies of health and illness through assumptions that once breast cancer treatments have been completed, women have few concerns. Some have demonstrated that there is a wealth of literature showing that breast cancer patients suffer emotionally and psychologically, but few have investigated the effects of treatment from the perspective of women (Crockford et al., 1993; Polinsky, 1994). Although Watson (1988) has argued that medical research is becoming more "phenomenologically inductive," it is not clear that this interpretive movement is being used creatively in the literature on breast cancer (p. 21). In writing of breast cancer, Bredin (1999) stated, "Despite the wealth of literature . . . there have been few studies . . . directly quoting a woman's private perspective; how in her words she experiences her changed body" (p. 1113). Loveys and Klaich (1991) concurred, suggesting that women's concerns ought to be addressed as women describe them, not following more clinical models of research.

Although a few qualitative studies have emerged in response to critiques of biomedical approaches, researchers have tended to focus on singular issues, such as breast loss, lymphedema, and menopause (Bredin, 1999; Carter, 1997; Davis et al., 2000). Furthermore, Dow and Lafferty (2000) have suggested that women experience changes in quality of life and psychosocial adjustment that might not be observed readily in clinical practice. Although Arman, Rehnsfeldt, Lindhom, and Hamrin (2002) were most interested in existential questions about life and death that occur as a result of breast cancer, they, too, suggested that women suffer in relation to health care and that some dimensions of suffering remain unrecognized by health care professionals. As noted earlier, Arman and Rehnsfeldt (2003) indicated that despite recent qualitative research on breast cancer, experiences such as suffering remain unexplored.

Although Arman and Rehnsfeldt (2003) directed attention toward the topic of suffering, their review of the literature does not explore women's direct accounts of this phenomenon. Loveys and Klaich (1991) wrote, "Illness demands are experienced in every aspect of a woman's life, including her identity, daily routines, family and social experiences and her perception of the past, present, and future" (p. 75). Taken together, these findings suggest that women speaking for themselves, about their own experiences, can contribute much to knowledge about the complexity of life after breast cancer. The focus of this article is on the ways in which women both accept and reject the medicalization of breast cancer, as situated within the broader context of a study of embodiment after breast cancer.

RESEARCH QUESTION AND ORIENTATION

Overall, the guiding question for my research was What are women's experiences of embodiment after breast cancer? In asking women open-ended questions about the details of their everyday lives after breast cancer, I hoped to advance understanding of the impact of breast cancer on taken-for-granted routines and experiences. Although my research was conducted within the discipline of sociology, I drew on literature from a variety of disciplines, including philosophy, nursing, social work, and women's studies.

Phenomenology can be considered both a philosophy and a method (Beck, 1994). Phenomenology's "goal is to describe human experience as it is lived" (Merleau-Ponty, in Beck, 1994, p. 500). Particularly helpful in the context of my research was the phenomenological concept of embodiment. In brief, embodiment refers to the idea that body is not simply an object controlled by mind, that we are our bodies and that body and society exist in a dialectical relationship (Barral, 1969; Butler, 1988; Ledermann, 1982; Rehorick, 1986). To date, there have been few studies of embodiment after breast cancer.

Congruent with phenomenology are feminist paradigms that also emphasize the importance of women's words for understanding complex experiences, but feminist research also provides the opportunity to understand encounters with medicine via the concept of medicalization. This refers to an intricate social process involving the dominance of biomedical paradigms and authoritarian models of health care in which illness experiences are understood as biological and individualistic (Walters, 1994). Contemporary researchers have also suggested that women themselves contribute to the perpetuation of social discourse, including the medicalization of their experiences (Miller & Findlay, 1994; Riessman, 1998; Walters, 1994). Qualitative approaches such as phenomenology thus offer the potential for increased understanding of the meaning of breast cancer, whereas feminist approaches provide a critical awareness of the social context of this condition.

Through conceptualizations of embodiment and medicalization, both phenomenology and feminism recognize that for people "to be in less than normative health becomes a determinant of their being treated as less than full subjects" (Shildrick, 1997, p. 169). Health care professionals who attempt to treat the "living, experiencing, suffering person" can find their efforts thwarted by a system that is based on understanding the body as a machine rather than embodiment (Leder, 1992, p. 33).

Orienting to breast cancer outside of the realm of biomedicine permits incorporation of the ideas outlined previously. How do women rely on a medicalized framework to understand their experiences of breast cancer? How do women resist such understandings? Qualitative and feminist approaches allow for the framing of these lines of inquiry and permit a critique of some of the predominant literature on breast cancer for despite various approaches to counseling and treatment, there is no way of predicting how women will respond to breast cancer (Wear, 1993).

RESEARCH DESIGN: GATHERING AND ANALYZING DATA

With regard to research practice, a phenomenological approach has been described as "one of enlargement. It makes us thoughtful of the consequential and the inconsequential, the significant and the taken-for-granted" (Munhall, 1994a, p. xii). The work of van Manen (1984, 1990, 1997) best exemplifies a continuity of thought and reflection from phenomenology's inception to its continued practice today. Phenomenology uses a variety of methods, including etymological analysis, exploration of personal experiences, interviews, observations, and art (van Manen, 1990; Zaner, 1964). Sociologists have also argued that research should be "grounded" in lived experience (Richardson, 1992; Smith, 1987).

Aspects of qualitative research relevant to my study may be summarized as follows: (a) opening up to the phenomenon of breast cancer, (b) attending to the literature, (c) collecting stories, (d) analysis and reflection, and (e) dissemination. This process of research has been described in greater depth by Munhall (1994b) and van Manen (1990). These works also provided guidance for data collection, as did Ellis (1995), Holstein and Gubrium (1995), and Seidman (1991).

Data for this study were collected via discussions (one focus group and in-depth interviews) with women who had experienced breast cancer. Prior to the discussion and interviews, my project proposal was reviewed and approved by a university research ethics board. Five women participated in the focus group discussion, the purpose of which was to facilitate the creation of interview guides. Subsequently, I interviewed 12 women on two occasions each. The majority of the participants were recruited through a snowball sampling technique and learned of this study from friends or acquaintances, or through the distribution of letters of invitation to breast cancer support groups located in a Maritime province in Canada. All participants signed consent forms before contributing to the focus group discussion or participating in the interviews.

My analysis of the focus group transcript assisted with the development of two interview guides. The focus group discussion began with topics surrounding diagnosis and treatment. Although I was interested specifically in embodiment after breast cancer, I realized, from prior research, that it would be difficult for women to share their current experiences without first addressing diagnosis and treatment. Next, I asked what changes the women had experienced following breast cancer and how they felt about the changes. These topics raised by the focus group participants (e.g., weight gain, menopause) provided direction for issues to be raised in the interviews.

In total, 12 women participated in two in-depth interviews each, for a total of 24 interviews. I interviewed the women in their homes, with the exception of two women, one of whom wished to be interviewed in her office and another who wanted to meet me at a restaurant. Interview participants ranged in age from 42 to 77. Only 2 of the participants were working outside of the home at the time of our interviews, and 5 of the women described themselves as being retired. One woman stated that she had been a teacher and did not categorize leaving the profession as retirement. Ten of the 12 women were married, whereas 2 were widowed. The number of years that had passed since their breast cancer diagnoses ranged from 1 to 24. Treatments included mastectomy, radiation, chemotherapy, and combinations of these three modalities. Seven women were also prescribed tamoxifen following the conclusion of acute treatments. Seven could be categorized as long-term breast cancer survivors at the time of the interviews, using a 5-year marker.

As is congruent with a phenomenological approach, and consistent with the focus group discussion, the use of only a few open-ended questions in the first interview allowed me to follow each woman's interests and concerns. As I began each interview with a request for each participant's breast cancer story, most women followed a narrative format, moving from diagnosis through treatment to the present. As noted earlier, I sensed that it would be difficult for women to speak to me about changes to their bodies without first framing their experiences as stories, and I discuss the women's breast cancer narratives in greater depth elsewhere (Thomas-MacLean, in press).

Each participant's second interview began with a review of information provided in the first interview, thereby supporting emerging themes. Also, I developed follow-up questions particular to each participant through the use of direct quotations from the initial interviews. Departing slightly from a phenomenological tradition, which suggests the use of only a few open-ended questions, I then continued with approximately 30 questions that asked about topics such as sleep patterns, clothing, use of breast prostheses, and diet. Although my questions had specific foci, they were open ended and phrased in ways that invited evocative descriptions. For instance, I asked each participant to describe the appearance of her chest, what her chest felt like, and to compare her feelings about her body after breast cancer to the time prior to becoming ill. Furthermore, the questions were in keeping with phenomenological guidelines, in that I asked women to consider elements of everyday life that are often taken for granted. For example, I asked women whether they had changed the type of clothing they wore and if there were changes to their sleep patterns. Simply asking the women to reflect broadly on changes to embodiment might not have facilitated reflection on everyday life. However, I concluded all of the interviews by encouraging participants to discuss anything they wished in relation to breast cancer and its aftermath.

I completed data analysis following established phenomenological guidelines (e.g., Munhall, 1994a, 1994b; van Manen, 1984). I read transcripts both holistically and line by line. A holistic reading provided, for example, an understanding of the women's stories of breast cancer, whereas reading line by line facilitated understanding of issues surrounding embodiment. Throughout several readings of the transcripts, I sought quotations that best captured a particular experience and studied transcripts for their similarities as well as their differences. Consistent with phenomenology, writing and rewriting formed part of the analytical process (van Manen, 1984), as did conversations with colleagues in sociology and nursing. As I wrote about participants' experiences of life after breast cancer, several works also provided guidelines for positively evaluating the credibility of my work (Ellis, 1999; Leininger, 1994; Riessman, 1993; Thorne, 1997). Finally, I sent participants reports on this research and invited their feedback. Those who provided feedback responded positively to my work.

MEDICINE REMEMBERED

Participants' accounts of life after breast cancer illustrate the idea that just because women have completed acute treatments for breast cancer, it does not mean that experiences of breast cancer have ended. Survivorship is a "dynamic, life-long process" (Pelusi, 1997, p. 24). What does it mean to recognize that concepts such as health, illness, and cure do not adequately address the scope of breast cancer experiences? How do women experience the process of medicalization as both positive and negative? How might researchers understand breast cancer's immediacy through memories of treatment?

Here, five key themes concerning breast cancer's immediate presence in the women's lives are explored. These themes have been distilled from the second interviews I completed with the participants. Although some of the topics discussed were introduced in our first interviews, women returned to them in the follow-up interviews, thereby demonstrating their importance. Although I originally wished to focus on the period of time following acute treatments, I have shown in this article that separating treatments from the time when they have concluded might be an artificial distinction. The five key themes that are constitutive of participants' memories of treatments are (a) issues of control, (b) suffering, (c) encountering medicine, (d) visible loss, and (e) leaving active treatment.

The women in this study showed that they remained puzzled about various aspects of breast cancer treatments, even years after they have occurred, and that participants needed to make sense of this part of their stories. Also, memories of treatment were articulated strongly, even though the women were between 1 and 24 years past their breast cancer diagnoses. Through articulations of feelings and memories of treatment, participants conveyed much emotion, demonstrating that past events can still be felt or experienced in the present. Although cancer discourse might convey the idea that once treatments are completed, a patient is cured and no longer thinks about the effects of illness, the women in this study demonstrated that this is highly inaccurate, and although some support for this idea is found in the psychosocial literature, it is not thoroughly explored (Carter, 1993; Ferrans, 1994; Polinsky, 1994).

Issues of Control

Even before treatments begin, one must deal with the shock of a cancer diagnosis. Unlike other illnesses, which can be experienced gradually, a diagnosis of breast cancer can be jarring in its rapidity, as it can occur in a matter of days. One participant illustrated some of the impact. On learning that she had cancer and would require treatment, she says she needed some time "to get used to the idea" that she had cancer and would require a mastectomy. Another participant demonstrates that even prior to the beginning of treatments, medical professionals must continue to work to understand the meaning of a cancer diagnosis:

> I was just at a good point in my life. My career was right at its peak and then on the 10th of January, that was completely taken away from me. I had no warning. I certainly didn't want to leave my work and all the time I was sick, I kept thinking, "When can I go back?" And I kept in touch with part of my work as much as I could and then when I took so sick, I just lost all control. And I miss it. And when something is taken from you without your permission, it's just like a little kid with a toy. You tell your daughter to go to bed and she's playing with her dolls and you take the dolls away [laughs].

For this woman, cancer has meant a loss of control. Her identity was very much connected to her work, and it was taken from her. Decisions about various treatments were also described as "difficult," as they are not without controversy, nor are they prescribed universally. Participants illustrated the connections between physical and emotional dimensions of diagnosis and treatment, both before and after treatments are completed. Breast cancer and its treatments can result in an unwanted loss of control as one's body succumbs to illness and medicine. Conversely, breast cancer treatments can also result in a granting of autonomy that is not necessarily welcome.

Although researchers on treatment decisions have argued that such decisions are best made by the patient, some women find making such decisions difficult and the opportunity somewhat unwelcome. Feminist analyses of women's experiences show that women specifically have not witnessed egalitarian approaches to treatment. Can women be expected to assume much responsibility for treatment decisions if unaccustomed to occupying an authoritative role? Furthermore, given the uncertainty of many cancer treatments, one must ask what choices are really being presented. These questions and participants' experiences add to the complexity of understanding medicalization.

For example, one participant did not describe the treatments as arduous but stated that having some autonomy in the decision-making process (i.e., lumpectomy vs. mastectomy, chemotherapy or not) was unexpected and perplexing. She said she was "really taken aback" by the choices she had to make. Another participant also spoke of choosing between a mastectomy and a lumpectomy but indicated that the decision was facilitated through contact with a second specialist. For a third participant, reflection on the type of surgery she had was the most notable feature of her treatments. She said that she now wishes she had a radical mastectomy rather than the modified radical mastectomy that she did have as she now would not be as worried about a recurrence. A fourth participant also questioned her choice of treatments as she was offered a choice between a lumpectomy and a mastectomy but feared the effects of chemotherapy and radiation if she opted for the former:

> I knew if I went for the mastectomy I wouldn't have to go further for the treatments, I wouldn't have to have chemotherapy or the radiation as long as it hadn't advanced to the glands so I took a chance that it hadn't gone further and therefore I wouldn't need any more treatment so for me that was important . . . I think no matter what decision you make you always have regrets as to did you do the right thing. So I still feel it probably is the right thing I did, but there are still times you do question it.

Questions about treatments lingered long past their completion, as the women cited above demonstrate. For other women, however, the treatments were the strongest memories or sites of reflection. Body's experiences are paramount. Diagnosis, decision making, and the treatments, therefore, illustrate the ambiguity of body and medicalization, which means that "body is most intimately 'me' and 'mine' " but might also be an experience of alienation, as being-for-the-Other, and that encountering a physician might be an experience of objectivity and alienation (Toombs, 1992, p. 59). Nowhere is this more evident than during the expression of pain and suffering.

On Suffering

Two participants' experiences with the installation of ports for the administration of chemotherapy concretize these assertions and illustrate the ways in which the body can become objectified through treatments and the process of medicalization. For these participants, the installation of the port was one of the most difficult aspects of breast cancer. One woman expected to have the port installed in her arm, but the physician was unable to install the port there. Instead, it was inserted in her chest. She said,

> It took two hours and it was pretty stressful. The whole experience was stressful. You're on this tiny little table and they are sort of sticking your shoulder up so they can get access and they've got covers over you, your neck is twisted and there is this television thing that you can actually see and they finally got it and they were checking to see it was going to the right places and I sort of came out of there feeling—it was just a lot to take in . . . They left the needle in the port because I was going to start chemo the next day . . . so I came out with this huge bandage over the top and I think it was just emotionally, way more than I was expecting. I wasn't anticipating that so it was distressing . . . it was the most unpleasant part in some respects and mostly I guess because it wasn't anticipated.

Treatments can involve suffering. This participant searched for ways to describe her experience. It was unanticipated and unexpected. It was a lot to take in. Are her words an attempt to understand, or cover, pain that is incomprehensible? Another participant also spoke of difficulties with the port that was installed in her chest. Her repeated use of the words "rubbing," "painful," and "hurt" depicted the physical and ceaseless nature of suffering and pain:

> I mean the hole was only about an inch. It was a little one, but when I turned over, I can remember how bad it hurt. It was unbelievable and I thought, I was kind of scared to look to see how big the incision was but when I looked, something so tiny, but it hurt so bad. Like am I being a wimp here? But when the nurse came in and explained, there's a foreign substance in there so like it wasn't just the incision I was feeling, it was the foreign substance in there rubbing on everything on the inside . . . It was really painful. So after that I got thinking, "Oh boy, should I have did this?" because it was really, really painful. And I thought, "I've been through a mastectomy, I was cut from here to here and it wasn't as painful as just this little inch."

This participant described pain, but she also questioned herself, her identity, because of the procedure, wondering if she was weak or a wimp. The first participant cited did not anticipate what the procedure might involve, and no one explained the possibilities to her. In retrospect, vocalizing the desire to receive such information might be expressive of an attempt to shape a new or alternate story, one that might make more sense.

In addition, both participants just quoted show that the body was a site of uncomfortable manipulation, with little attention paid to embodiment, or the intersection of self and body. Their accounts are similar, but perhaps the latter conveys more clearly the experience of medicalization, as this woman referred to her body as an object, using the phrases "grow in the body" and "the body adapted to it" rather than referring to herself in the first person. Objectification means that one's body is no longer one's self or one's own, body is experienced as other, or not harmonious with self, a means by which one is seized and caught by the present (Leder, 1985).

This is further reflected in both participants' descriptions of the anticipation of chemotherapy. The first participant cited felt much apprehension about chemotherapy, although she stated that she did not experience significant side effects from the treatments. Would her apprehension result from her experience with the port? In retrospect, this participant's anticipatory feelings remained distressing:

> Maybe it was just because I really wasn't sure what to expect and I can remember driving to the hospital on the Friday with my husband and sitting in the car and starting to hyperventilate because I was just getting anxious and was anxious because I guess I just didn't know and the reality, well you're going to have chemotherapy, well that's fine but what does it mean?

She wondered what it means to have chemotherapy. Was she querying only the physical experiences and routines of chemotherapy? Was she wondering only about the procedure, or is her question bigger than that? Might she have been asking about the risks of this treatment or its impact on her life, about further pain and suffering?

Encountering Medicine

One author wrote that the "cancer patient . . . is at the bottom of a status hierarchy" (Bricker-Jenkins, 1994, p. 27). One woman's experiences with chemotherapy show that perhaps the concerns outlined above were not without foundation, as she was provided with an "experimental drug," which her husband had to administer with a needle 3 times per day. This participant says, "I just kept getting sicker and sicker" during chemotherapy. Finally, she was admitted to the hospital and underwent several blood transfusions. Another participant also found dealing with the medical system and, more specifically, one doctor's orientation to practice quite upsetting, and at this point, her narrative became fractured:

> He really wasn't very personal. You think of doctors, I know my doctor anyway—you walk in and he starts talking statistics and things you'd read in a book almost. Of course maybe that was his way of dealing with it, it could have been. You can't get personal with every cancer patient you see because they're emotional so you probably have to be hard for them. Like he was the one who told me, even when he told me like if you get pregnant you know we'll have to abort it because we'll have to do treatments and all this. And even when I started crying, he just kept right on talking.

Is such detachment necessary? Coulehan (1995) wrote of the detachment of physicians. It has been justified as necessary for the preservation of the physician (as the participant above perceived) as well as the patient who must believe in the objectivity of medicine, or that medicine and doctors must be "hard." Although such detachment seemed plausible to Coulehan early in his career, he has stated that he now considers emotions "the energy and life" of his practice, characterizing detachment as a "risk or failure of medical education" (pp. 222-223).

For three participants, then, a lack of attention to, or detachment from, the meaning of cancer and treatments, and its implications for their lives, was the most disturbing aspect of medicalization. This detachment contrasts markedly with feminist and some nursing perspectives of caring and curing as ethical responsibilities (Gadow, 1989; Holmes, 1989; Watson, 1990). However, although hearing that she should not become pregnant was initially very upsetting to one participant, in retrospect, she described the situation somewhat differently:

> It's funny because all of these emotions went through my mind but then in the end, I was glad the decision was taken out of my hands. That sounds terrible I think but because I really agonized over the decision and maybe it was the fact that being human, you always want what you can't have. That's probably it in a nutshell. I really didn't want any more kids but when they told me you can't have them, you think, "Well it would have been nice to have another one." And you go through all this but then in the very end you think, "Boy am I glad we couldn't" [laughs].

Although some treatment issues might, then, appear to be resolved with reflection and the passage of time, others were not. One woman questioned why she was confined to her bed for such a long period after her mastectomy, as she noted that women do not stay in bed that long today, whereas a second participant had difficulties with a reaction to an injection designed to bolster the immune system during chemotherapy. She had to inject herself with the medication because of a preexisting blood condition 3 days after each chemotherapy treatment for 10 days each time. She stated,

> It does sort of make you feel like a pincushion after a while, the first three or four times aren't so bad, but by the end of it, you're like, thank God this is the last one. I don't know if I can find another place to stick the needle in . . . and the reaction I had was pretty severe. . . . It was scary and having got through the first one, then when I had my second round of chemo and I had to do this again, I was really apprehensive. . . . Maybe the cure is worse than the disease, I don't know. That is what I found upsetting.

Participants' comments about treatment, and this participant's puzzlement, direct attention to the importance of understanding the meaning of cancer and treatments. The participant just quoted found herself mired in uncertainty, as did the women who were faced with making decisions about their treatments. Another woman found herself enveloped in the moral uncertainty associated with possible pregnancy. Four participants described another troubling aspect of treatment, hair loss, or the body's visible and immediate signal "to the external world that one is a cancer patient" (Mathieson & Barrie, 1998).

Visible Loss

Although breast loss has received much attention in the psychosocial literature on breast cancer, Schover (1991) has written that alopecia is more visible than the results of a mastectomy. Hair loss is difficult to hide, but Schover does not write about it in any sort of comprehensive fashion. It is worth brief consideration in this research context as it provides a comparison to breast loss, as one participant showed when she spoke of dreading hair loss:

> I'm not sure why, I know that sounds really vain after all I'd been through, to have the breast removed and think that okay there's this woman, she's losing a part of her body, that didn't bother her but what's really going to bother her is losing her hair! Maybe it's the outward appearance like not having a breast, that's fine people don't know, it's underneath you can wear a prosthesis, or with me in the wintertime I don't bother wearing my prosthesis, I wear a sweater and you can't tell anyway. But with your hair, people see you every day and I guess it's just, I don't know how to explain it because I'm not a person who's really, really vain I didn't think. But it was just the fact of losing my hair.

Although she did not lose all of her hair, and later repeated that it did not bother her to lose some of it, she still devoted a great deal of attention to her hair loss. Perhaps it was more troublesome than she would have liked to admit. In contrast, another participant explicitly described hair loss as "the most devastating aspect" of treatment:

> I wish that they would have told me how to buy a wig. I was never told, all they said was "You know you're gonna lose your hair." I was never told what to look for in a wig, they have beautiful scarves out now and hats and things, I never did get any of those. I wore a terry cloth hat and it was so disgusting looking . . . I looked horrible. I wish they'd told me how to put on make-up, to replace your eyebrows. I think I would have even gone and got false eyelashes. I would have liked to see more help in that area and then I don't know if a person should be told of the side effects of chemo but I think they should be prepared for them.

Another participant reported being fascinated by hair at a time when she had none and says that she eagerly waited for her hair to grow back. In contrast, one woman said hair loss did not really bother her, and she was lauded as courageous for going without a wig. She said that she perceived this not as a courageous act but, rather, as an act of attention to her own comfort. To wear a wig would have made this participant feel hot, itchy, and uncomfortable.

There is, then, no one way to respond to breast cancer, its treatments, and their side effects. In this respect, it is a unique illness. Beyond uncertainty and side effects, breast cancer can also carry with it other long-term effects. For one participant, the physical effects of chemotherapy continued well past completion. The ramifications of breast cancer and treatments affect all spheres of life, including appearance, family relationships, moral dilemmas, and interactions with medical professionals. What is perhaps most intriguing, however, is that despite the difficulties inherent to cancer treatments, finally completing acute treatments, and thereby ending a process in which body was medicalized, was not described as entirely positive.

Leaving Active Treatment

Bury (1982) has argued that one must not only be critical of medicine and medicalization but also recognize that medical knowledge, although often "ambiguous and limited," provides a legitimate source for patients to understand or know illness (p. 179). Two women both stated that they felt "lost" after acute care was completed. One said she felt she was "on [her] own." Another woman returned to this idea in our second interview and stated that she felt "let down":

> While you are actually doing something, with the acute care, you're going through your chemo, you're going down every day for your radiation and you are really feeling like you're doing something and then all of a sudden it's over and you don't really have the attention that you're getting and the doctors or the nurses and the technicians all paying attention, isn't quite the right word, but being there and doing things for you and all of a sudden you're saying, "Okay, is this all there is? Like, oh my God, had this worked? How do I know if this has worked and what's happening?"

Pelusi (1997) stated that existing "literature provides little information regarding the survivor's feelings of being abandoned by health-care professionals after cancer therapy" (p. 1350). Despite difficulties with treatment, the participant just cited still found leaving the medical system difficult. Another participant described similar feelings as she anticipated the end of her 5-year prescription of tamoxifen. She said she had "a very bad feeling" about it. The words of these two participants can be read as indicative of a feeling of alienation. The women were leaving a medical system that is powerfully supported as the only socially sanctioned recourse to health and healing that currently exists in our culture. Perhaps leaving this system also involves a loss of the potential for knowing illness, understanding its meaning, or understanding oneself.

For both those who experience breast cancer and those who witness the illness, then, "the overwhelming physical, psychological, social, or economic changes that often accompany chronic illness can make it appear that nothing of the former self remains" (Barnard, 1990, p. 544). One can feel objectified or distressed at the loss of objectivity that is presumed to be a part of medical care, yet participants also talked of returning to self, as one participant did:

> It was just about 5 years to the day, well within a couple months that I woke up one morning. And you know you get better all the time and you're not always sick, it's just you have some bad days but they get fewer and fewer. And I got better and better and then all of a sudden I woke up and I thought, "Gee I think I feel like my old self." It just kind of hit me you know, but it was just a very gradual thing and I think it took about 3 years until everything healed.

Despite articulation of a return to self, these women's lives were still overshadowed by breast cancer. Memories of treatment remained strong and were clearly articulated. Memories portrayed the indivisibility of body and self. They propel us to new understandings of the complexity of healing.

DISCUSSION

The women in this study show that long after breast cancer treatments have been completed, there remains some degree of uncertainty and questions about acute care. Memories of suffering remain vivid and powerful, as recollecting the mere anticipation of chemotherapy evoked strong emotions. As noted earlier, there is little in the literature on breast cancer that explores suffering in this context (Arman & Rehnsfeldt, 2003). However, for the women in this study, memories of treatment remained connected to suffering, even many years after the conclusion of acute care.

Through articulation of their memories of breast cancer and its treatment, women in this study also illustrate the ways in which the body becomes medicalized as an object through routine practice. Although the medicalization of the body has been illustrated within the domain of sociology, the tension that women experience as they leave the biomedical context has not been examined in current literature. Despite problems with medicine and the limits of medicalized understandings of breast cancer, women were reluctant to sever ties with the institution of medicine. Participants show that despite their negative experiences of medicalization, there were few other ways of framing or understanding their experiences, thereby illustrating ideas conveyed by Miller and Findlay (1994), who have argued that we are held "hostage to modern medicine . . . [which] limits our ability to conceive of 'alternative frameworks' and definitions of problems" (p. 302).

Furthermore, autonomy in the decision-making process, or a departure from an authoritarian model of care congruent with medicalization, was not experienced as empowering because the women were not accustomed to or prepared for this process. This finding is congruent with a study conducted by Hack, Degner, and Dyck (1994), which, in turn, points to the complexity of understanding women and medicalization.

A move toward greater patient autonomy through participation in the decision-making process might also serve to illustrate women's compliance with medicalization. The fact that being a decision maker was not experienced as positive can be considered illustrative of medicalization and the way in which powerlessness translates into complicity with a particular relationship. Perhaps women should be provided with the opportunity to review their treatment decisions as a routine part of follow-up care. To this end, Allen (2002) concluded that current follow-up care practices might need to be revised following a qualitative study of women's emotions while attending a follow-up clinic. Although this might be undertaken by some health care professionals, it did not constitute part of the follow-up care that these participants received.

However, the body is not simply a locus for the manifestation of medicalization. It can also be regarded as "a vessel of meaning, memory, and intention" (Zegans, 1987, p. 30). Memory can be regarded as the "making-present of a past-present" (Brockelman, 1975, p. 19), and, as Cull-Wilby (1993) has written, "We keep our past before us. Our past experiences provide us with our present perceptions" (p. 42). However, memories of treatment have received little, if any, attention in breast cancer research. Raingruber and Kent (2003) showed that the relationship between embodiment and memory has not been articulated clearly. Starting with the standpoint of women shows that memories remain a significant part of breast cancer experiences, even 10 years later, as one participant demonstrated. This research also illustrates that further attention to the topic of memory and embodiment more generally is also needed.

CONCLUSION

Central to contemporary conceptualizations of medicalization is the idea that some sort of tension exists between the acceptance of biomedical approaches, on one hand, and the critique of such approaches on the other. Participants in this study illustrate that encountering medicine involved the objectification of their bodies, a loss of autonomy (or the inability to respond to an offer of autonomy through decision making) and suffering. However, the women also expressed a reluctance to sever their ties with biomedical practitioners. Through attention to embodiment, phenomenology offers an opportunity to understand the meaning of medicalization and suffering, as they are experienced, both immediately and through memories. Charmaz (1999) wrote that suffering is not experienced only physically, nor is it simply psychological; rather, "suffering calls for attempts to control one's life as well as to cope with it. It gives rise to actions as well as feelings. . . . Suffering poses existential problems of identity and continuity of self" (p. 3). Nursing scholars have suggested that there is an ethical dimension to caring (Gadow, 1989; Watson, 1990), one that might involve efforts to understand suffering, that can be overlooked in the context of breast cancer (Arman & Rehnsfeldt, 2003).

Women experienced the medicalization of breast cancer as both positive and negative. This study suggests that further research into women's experiences of medicalization is needed and that biomedical knowledge about breast cancer and its aftermath require enhancement. Clearly, medicine as an institution and as practice would benefit if breast cancer narratives and memories of treatment were honored and women's lingering questions were addressed. Phenomenology, medicine, and nursing might share certain phenomena: "observing, interviewing, and interacting with clients so that a deeper understanding of the client's experience can be grasped" (Beck, 1994, p. 501). Emphasizing these aspects of care during breast cancer follow-up could mitigate some of the long-term effects of medicalization.

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