

Managing the Impact of Posttreatment Fatigue on the Family: Breast Cancer Survivors Share Their Experiences

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With improvements in both early detection and treatments for breast cancer, the number of survivors has increased dramatically in recent decades. One of the most common lingering symptoms posttreatment for cancer survivors is chronic fatigue. Based on family stress theory and Rolland's typology of illness, this qualitative study extends our understanding of the impact of persistent posttreatment fatigue on families and how breast cancer survivors manage the family issues that arise because of this chronic stressor. Participants included 35 female survivors of breast cancer (mean age = 54 years) who experienced fatigue after the completion of active cancer treatment, with the exception of long-term hormonal ther-

apy. Data were generated from (a) observations of group sessions from a randomized controlled fatigue intervention designed to reduce fatigue in breast cancer survivors, (b) individual in-depth interviews, and (c) family sessions. Qualitative analysis revealed two broad themes that illustrate how the survivors manage the impact of fatigue on their families: Interpreting the meaning of the fatigue and Dealing with the inability to perform family roles. Study findings describe the difficulties in family adaptation when the family is not able to assign a clear meaning to a chronic symptom posttreatment and build upon family stress theory by highlighting interrelationships among communication patterns and role shifts in the family system.

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It is often stated that cancer is a family disease (Baider et al., 1996; Kissane et al., 1994; Lederberg, 1998; Lewis, 1996; Sherman & Simonton, 1999), but medical care in oncology, including breast cancer, is still focused primarily on the patient and often ignores the context of the family environment. Likewise, although there is a growing recognition of the need to support

the approximately two million breast cancer survivors as they adapt to life after treatment (Institute of Medicine, 2005; President's Cancer Panel, 2004; Rowland, 2004), the family aspects of the challenges they encounter during this period of transition have not received adequate attention in either research or clinical practice (Institute of Medicine [IOM], 2005; Lebel, Rosberger, Edgar, & Devins, 2007; President's Cancer Panel, 2004). Survivorship issues such as ongoing physical symptoms, psychosocial stress, financial concerns, and poor family functioning, may interfere with the ability to perform family roles. A report by the IOM poignantly states that "Caregivers and family members often require, but do not receive, the respite, health care, psychosocial, and financial assistance they need in meeting the many needs of cancer survivors in their lives" (Institute of Medicine, 2005, p. 67), and underscores the importance of using a family centered approach to service provision for this population.

PERSISTENT FATIGUE IN BREAST CANCER SURVIVORS

Approximately one third of breast cancer patients develop persistent, severe fatigue after treatment (Andrykowski, 1998; Bower, 2000; Lindley, 1998; Meeske et al., 2007; Servaes, 2002). Contributing factors for chronic posttreatment fatigue in breast cancer survivors include sleep disturbances, menopausal symptoms, pain, depression, reduced activity levels, emotional stress, family problems, and other life stressors that interact with and compound each other (Bower et al., 2000; Servaes, 2002). The type of fatigue experienced by cancer survivors is much more severe than "every-day" tiredness; survivors are exhausted and unable to function, even after long rest periods. Some also experience symptoms such as weakness, exhaustion, inability to concentrate, and little drive to do anything (Ng, Alt, & Gore, 2006).

Fatigue can prevent breast cancer survivors from performing family roles, which

commonly increases stress for both survivor and family. Changing roles within the family during the cancer survivor's recovery may exacerbate the survivor's emotional stress (Coggin & Shaw-Perry, 2006; Mallinger, Griggs, & Shields, 2006; Oktay & Walter, 1991). In other words, there may be a reciprocal relationship between the negative impact of the survivor's fatigue on family dynamics and the family's maladaptive response to these hardships that may, in turn, create additional stress for the survivor (Maly et al., 2005; Radina & Armer, 2001).

Although the defining characteristics of posttreatment fatigue are well known, how breast cancer survivors manage the impact of their fatigue on the surrounding family is not well understood. The twofold purpose of this paper is (a) to describe how survivors with persistent posttreatment fatigue experience and respond to family issues, and (b) to build theoretical understanding of how they manage these family issues. The results have the potential to guide practice and future research, including family based intervention research.

THEORETICAL FRAMEWORK

The theoretical framework anchoring this study is family stress theory (McCubbin & Patterson, 1982, 1983). The underlying premise of this theory suggests that when a family member is threatened by a serious illness, the family typically reacts with an appraisal of the threat, followed by developing and applying coping strategies and marshalling social support. If the family unit is able to adapt to the illness successfully, it maintains its equilibrium and continues to fulfill its primary functions (e.g., child-care, financial stability, household maintenance), which in turn fosters a better adaptation in the individual with the chronic illness. Healthy adaptation is more likely when families are able to (a) acquire new resources or coping behaviors, (b) reduce the demands they must deal with, and/or (c) change the meanings about

their situation, about themselves as a family, or their view of the world (Patterson & Garwick, 1994, p. 132). In the context of breast cancer, this model suggests that after the cancer diagnosis, the family must first interpret the meaning of the illness (appraisal) and cope with the demands of the treatment phase (e.g., surgery, chemotherapy, radiation, and/or hormonal treatments) and any long term effects. Family adaptation is achieved when the family copes using open communication, mutual support, and role shifts made necessary by the illness.

Rolland (1984, 2005) expanded the family stress model to include a typology of illness characteristics that may differentially impact families. In this typology, the critical characteristics of breast cancer include its potential for a life-threatening outcome, and the uncertainty surrounding this outcome. Although only about a third of women diagnosed with breast cancer eventually die of the disease (American Cancer Society, 2010), it is impossible to know with certainty that the cancer will not return, even when the disease is diagnosed at a very early stage. Managing this uncertainty can be extremely difficult for survivors and their families.

In Rolland's model, posttreatment fatigue in breast cancer survivors can be viewed as a secondary stressor that also requires family adaptation. Characteristics most salient to "fatigue" are that (a) it is unexpected insofar as survivors and families anticipate that the survivor will return to "normal" after successful treatment, (b) it results in incapacitation that can prevent women from returning to former activities and family roles and (c) it exacerbates uncertainty concerning possible recurrence of cancer. Taken together, this integrated theoretical framework provided a context for our research in which we aimed to further explore and extend our understanding of how breast cancer survivors with persistent posttreatment fatigue ex-

perience and manage the impact on their families.

METHOD

Sample

The research reported here is based on qualitative data gathered as part of a larger mixed-methods evaluation of a family focused randomized controlled fatigue intervention designed to reduce fatigue in breast cancer survivors (Authors, 2007a, 2007b). Participants for the larger study were recruited from two large urban hospital centers in the Mid-Atlantic region and were screened against the following eligibility criteria: (a) diagnosis of nonmetastatic breast cancer; (b) at least 3 months postadjuvant chemotherapy or radiation therapy; (c) persistent moderate to severe fatigue, as measured by the Vitality subscale of the SF-36 (Ware & Sherbourne, 1992); and (d) having a family member who could attend two group sessions and 1–2 family sessions if randomized into the experimental arm. Family was broadly defined to extend to close friends in cases where relatives were not available.

The results are based on (a) field notes from observations of 35 women who participated in group sessions, (b) notes from debriefing the social worker following 18 family sessions with the survivors and family members, and (c) two in-depth interviews that were conducted with 24 of the 35 study participants. All participants in the family arm ($n = 13$) were interviewed. We also interviewed 11 members of the control arm who were selected using purposive sampling techniques (Maxwell, 2005). Specifically, we included women who reflected diversity of racial or ethnic background, socioeconomic status, marital status, and family developmental stage and whose participation in the groups suggested that they had family experiences to share that were relevant to our research question. The interviews were audio-recorded, transcribed, and independently cross-checked

by the first two authors. Participants' names have been changed to protect confidentiality.

Techniques to increase the trustworthiness of findings included prolonged engagement (the data gathering and analysis phases took place over 2.5 years), journaling, triangulation (members of the research team were from three professional disciplines), member checking (tentative findings were shared with research participants who evaluated them for authenticity), and peer debriefing through presentations at national and international conferences.

Data Analysis

All data were entered into the N-Vivo7 software program for analysis using grounded theory coding techniques (Charmaz, 2006; Corbin & Strauss, 2008; Strauss & Corbin, 1998). First, open coding of the data was independently performed by the first two authors to identify concepts and categories. Subsequently, the concepts were developed into tentative themes and subthemes. After the principal concepts and themes were identified, they were compared to the family stress theories, and theoretical implications were developed. The themes were used both to explore the applicability of family stress theory to the experience of breast cancer survivors with persistent fatigue and their families, and to extend the theory to the condition of post-treatment fatigue in breast cancer survivors and their families (Gilgun, 1999).

RESULTS

The average age of the 35 survivors who participated in the study was 54 years ($SD = 13.0$). Approximately two thirds were White, and one third African American. Sixty-three percent were married, and the others were either single (14%) or divorced (23%). They averaged 15 years of education ($SD = 1.5$). The average time since diagnosis was 3.8 years ($SD = 3.5$). While family members were not interviewed, they were observed in group ses-

sions and were included in data from family sessions with the social worker. These family members included 5 husbands, 3 sisters, 3 children, 3 friends, and 1 father.

Our data analysis identified two broad themes related to how breast cancer survivors with fatigue experience and manage family issues: (a) *Interpreting the meaning of the fatigue in the family*, and (b) *Dealing with the inability to perform family roles*. This second theme has two subthemes: (a) *Protecting children from the impact of fatigue*, and (b) *Experiencing guilt and anger over the loss of family roles*.

Theme 1: Interpreting the Meaning of the Fatigue in the Family

"Why Aren't Things Normal Yet?"

When the survivor completes treatment, survivors and family members often anticipate a return to "normal" role and family functioning. However, persistent fatigue precludes a return to preillness functioning. Survivors struggle with how to interpret this discrepancy, to themselves and to family members. In some cases, the lack of return to previous levels of activity and role functioning leads to suspicion the survivor is malingering. Esther, speaking about her husband's response to her fatigue, says, "*He doesn't really buy it, but he has given up fighting it . . . He is not quite convinced.*" At a group meeting her husband confirmed her perception, "*You see the lingering effects of the cancer. You're wondering, 'When are you going to snap out of it?'*"

Leslie also spoke about how the fatigue intervention helped to validate the fatigue for her husband. "*Kind of like I said about the essential validation of coming [to program]. I think there's something, a message that gets through to him as well, like: [in husband's voice] 'Oh this must be a real problem if you have to go to some group about it.'*" Phyllis, an older African American, woman brought her daughter to the program, and later reflected, "*I'm so happy*

that [daughter] was able to participate. Now she understands that there is something called 'fatigue' and that I'm not just making excuses."

Leslie also suspects that her children question the legitimacy of her fatigue. When her daughter came home from school one day and saw her in a nightgown, she said, [in daughter's voice] "Can't you get over this? Why are you still in bed?" Leslie comments, "They hate it. They hate that I nap. It reminds them that I was sick, and I'm still not better yet, and frankly, I think they think I'm lazy."

In addition to expressions of doubt or anger, many of our respondents report that family members try to push them to overcome the fatigue. Roberta, a married woman whose sister accompanied her to the program, provides an example: "Cause I know she used to kinda like push it, like if I would say 'No I don't feel like it,' she'd [sister] say, 'Oh come on. You'll feel like it. Let me call you back later on.'" For Bonnie, a married woman with teenaged children, it was her father who tried to push her. "Because he was always saying, 'Why don't you walk more? Why don't you do this more? You know it's always more, more.'" When family members are struggling with the meaning of the fatigue, they may be unsure what their role(s) should be in helping to resolving it. If family members conclude that the fatigue indicates laziness, malingering, or the lack of an appropriately "positive" attitude, they may think that the best way to help the survivor is to push her to be more active and work through the fatigue.

Another interpretation of the meaning of the fatigue is related to the uncertainty concerning the outcome of breast cancer. Some survivors may fear that family members are interpreting the fatigue as a signal of a return of the cancer. Nancy watches her 11 year-old daughter struggle with the interpretation of the fatigue. "I think when things were happening and there was treatment going on and she [daughter] knew I

was doing something to get better, that I was gonna get better. And now that there's nothing going on and no treatment going on and I don't have a reason to be tired, then [in daughter's voice] 'Why are you tired? Why are you not doing anything? Why aren't you working? Why aren't things normal yet? Where is her regular mom? . . . Other people don't, but she notices that I can't . . . And she thinks I should be getting normal.'"

Nancy's daughter's confusion stems from her worry about Nancy's future health, not from suspicion that she is lazy. Another example is provided by Susan, a divorced woman with two daughters who were teenagers at the time of her breast cancer diagnosis. Susan didn't want to "scare the kids," so she never discussed her cancer openly with them. Now, years after treatment, she continues to experience fatigue, and her daughters continue to worry about her. The older daughter reacts with anger, while the younger daughter has developed an anxiety disorder. "I worry about her all the time," the younger daughter says in the family group.

Breast cancer survivors with fatigue are aware that family members are watching them closely as they try to interpret the meaning of the fatigue. Some survivors seek to frame the family member's interpretation through direct explanation. For example, Nancy tells her daughter that she is tired from the cancer treatments. "So a couple of Times I've had to say, 'I'm sorry I'm not normal yet; I'm still tired. The medicine is still in my system.' And I have to remind her that, . . . that I am still sick. That the cancer's gone; but the medicine was so strong that I'm still tired, and I'm still weak. And she forgets; because she sees me not doing things, and she doesn't, she just wonders where her old mom was [is]."

In summary, this theme illustrates how survivors see their family members struggling to account for the fatigue and attribute meaning to it. Some survivors describe having family members who see

fatigue as “malingering” and try to push them to do more, while others worry that it may mean a return of the cancer and respond with anger or concern. Survivors may seek to provide an explanation (normalizing fatigue) to family members, or to try to hide the fatigue as much as possible. It is possible that the fears of recurrence in the family may exacerbate these fears in the cancer survivor as well. The fact that it is very difficult to attribute a clear meaning to the fatigue makes adaptation problematic for survivors and families.

Theme 2: Dealing With the Inability to Perform Family Roles

Our participants’ stories suggest that a primary impact of fatigue in breast cancer survivors is their inability to carry out previous family roles. Before being diagnosed, most of the women in our study held heavy responsibilities, including care and support of children (or grandchildren), spouses/partner, parents and other family members and friends, household maintenance, and in many cases, paid and/or volunteer work. We found two sub themes that represent how survivors deal with the impact of their inability to perform previous family roles: *Protecting the Children* and *Experiencing Guilt and Anger over the Loss of Family Roles*.

Subtheme A: Protecting Children From the Impact of Fatigue: “I Try To Do All I Can So the Kids Are Not Affected”

A common experience described by the participants who had young children was to try to protect them from any negative impact. This commonly took the form of trying to ensure that the children’s lives were kept as close to their preillness lives as possible. Leslie, for example, states “. . . the timing’s a little unfortunate ‘cause I really do get tired at 2:00 and that’s the best time to take a nap, but they come home between 3:00 and 4:00, and so I’ve tried to be awake by the time they get home. And it’s very very discouraging for them to come

home and I’m asleep, I mean that’s exactly what they don’t want.”

Nancy also tries to maintain life routines for her daughter despite her fatigue. In her case, this means maintaining extended family traditions. Before her illness, Nancy routinely hosted large family parties around holidays and family milestones. While she was exhausted doing all of these activities, she did not consider curtailing any of them because she feels strongly that she needs to keep her daughter’s life from changing.

Like other survivors with young children, Kathy endeavors to shield her children from the negative effects of her lingering fatigue. *“I really try to do all I can so my kids aren’t affected. I mean I know that probably sounds terrible, like my husband is second rate or something, but I don’t want them [children] to feel any of this. I don’t want . . . if at all possible [pause] so I try to do the day as I normally would do and by the time dinner comes, you know, that’s it.”*

Although her children are adults, Carol tries to keep her fatigue from them and extended family. She takes care of her grandchild when asked to help, even though she is too fatigued. Consequently, Carol reveals that she does not have the energy to do the things that she enjoys. *“I mean pretty much I tried to keep it to myself. I mean obviously I live with my husband so he was aware of it; but with the boys it was, ‘Oh no no; I can do that.’ . . . And I think they’ve been aware of it probably more than I realized that they are. But it’s still not something we talk about as far as, ‘Mom can’t do that,’ because I don’t want to admit that to myself.”*

Women who have children try to preserve their energy to keep their children’s lives as normal as possible, despite their fatigue. This applies (as in Carol’s case) even when the children are grown. This may involve some deception, or hiding of the fatigue. Women find it easier to deceive children, but this strategy is not possible in

interactions with husbands. In some cases, husbands are partners in the task of protecting the children, but this may come at some expense to the marital relationship (as highlighted in the following section).

Subtheme B: Experiencing Guilt and Anger Over the Loss of Family Roles and Relationships: "I'm Not Keeping Up My End"

For some couples, the postcancer treatment fatigue resulted in a loss of the opportunity to share time and activities that had been the basis of the relationship in the past. For example, Esther and her husband complained in the family meeting that the fatigue was interfering with their relationship, because they cannot do the "fun things" that they used to do. Kathy shared the impact of fatigue with the social worker in the following way: "[Before the breast cancer] *We would spend two or three hours together either talking, playing a game, or just watching TV together. That happens, you know once every few weeks now. . . . I know my husband feels, and he's also a night owl, so you know, for him, that's four or five hours being alone . . . Yeah, he's kind of lonely. Right.*" Participants also shared that the fatigue, in combination with the breast cancer treatment side effects (e.g., hot flashes), have interfered with their sex lives. "*I would say mainly it affects my husband and our relationship you know the time we spend together.*"

Carol and her husband of 38 years, described their marriage as "very traditional" insofar as she took responsibility for all household tasks, such as cleaning, cooking, and gardening. Now with the posttreatment fatigue, Carol says, "*I'm not keeping up my end. I don't have the energy. I feel guilty about not being able to do what I used to do.*" She feels that her husband has been supportive, but has not picked up these tasks. "*He was supportive in that it's,* [in husband's voice] *'Oh don't worry about that.' Oh the house isn't getting clean.* [in

husband's voice] *'Oh, don't worry about that,' not 'Let me do it.'* [in husband's voice] *'Doesn't matter to me whether the bathrooms get done.'* So that added a different level of frustration for me as far as I would like, I can't stand. I think I wanted him to say, [in husband's voice] *'Oh, let me do that for you.'* But of course that's not his nature; he wasn't gonna do that. So a lot of Times I was very resentful. I got irritated because I'm thinking, *'Why doesn't he know that I can't rest because the floors are dirty; but I don't have the energy to clean the floors.'* So there was [sic] a lot of arguments that way. And, yes, he will help if asked, and the problem is, I don't understand why I have to ask." Carol feels guilty about her failure to perform previous family tasks and explains, ". . . I constantly feel that if I'm not producing something—either a clean house or a beautiful garden or, you know, making something—that there's something, I should be doing something."

Some survivors feel guilty that they are not fulfilling all past family roles. Relationships with husbands seem to be particularly prone to stress. This may be exacerbated because when unable to fulfill all previous roles, they use their limited energy in other areas (e.g., as discussed above, keeping things the same for the children).

DISCUSSION

Our study explored how breast cancer survivors with posttreatment fatigue experience and manage family issues. Our first theme, "*Interpreting the meaning of the fatigue,*" suggests that it is difficult for survivors and families to attach meaning to the fatigue. However, family stress theory posits that in encountering a stressor, the family must appraise the meaning of the stressor to successfully adapt to it (Patterson, 1989; Patterson & Garwick, 1994). We learn from our participants' voices that interpretation of the meaning of fatigue is especially difficult as it cannot be divorced from the family's prior experience with

breast cancer. The process of assigning meaning to fatigue is further complicated because it is unexpected, it comes after treatment for a life-threatening disease that can recur at any time, and its outcome is uncertain. The family stress model also suggests that the lack of clarity about the meaning of the fatigue, combined with the emotional response to family interpretations (e.g., malingering or recurrence) makes open communication in the family problematic. Furthermore, role shifts that are central to healthy adaptation to illness in the family may not occur if family members feel that the fatigue is not legitimate.

The second theme to emerge in the analysis, *"Dealing with the inability to perform family roles,"* can be understood within the framework of Rolland's typology of chronic illness (Rolland, 1984) that delineates how family responsibilities and reactions differ according to the type and phase of the illness (e.g., tasks of the diagnostic phase differ from those in the "chronic" phase). Families often rally to offer support during the crisis phase of an illness (e.g., peri-diagnostic period and active treatment), providing help with caregiving needs and household responsibilities. However, following the resolution of an acute illness, these informal caregivers expect the survivor to return to normal levels of activity and resume their "assigned" roles in the family system.

In contrast, in the context of a chronic illness, families must shift from an acute response to more prolonged or even permanent changes in role responsibilities, including reconfiguring work patterns, having extended family or adult children moving back home, and hiring additional household help. In early stage breast cancer, affected individuals and families expect to experience a "crisis" or acute illness model, and adjust their familial roles accordingly. However, persistent fatigue prevents the breast cancer survivor from quickly returning to preillness functioning, and necessitates the type of long-term role

shifts that are needed in a chronic illness. The survivor and her family are often left in an unclear situation, with potential for role confusion and unclear communication in the family as different family members develop different meanings about the persistent fatigue. The lack of a clear meaning can create a barrier that interferes with the family's ability to shift from an "acute" illness response to a more "chronic" set of role shifts.

If the survivor feels that her fatigue is not perceived as a legitimate illness by her family members, this may exacerbate the experience of fatigue and spur feelings of guilt among survivors. We also learn from the survivors' stories that if the fatigue is perceived as a possible return of the cancer, in the absence of open communication about this, family members may not accept role shifts because this may seem like an admission of the feared outcome.

Our findings also suggest that survivors with children try to protect them by keeping their lives the same, a process that often reflected restricted communication in the family system. In some cases, the survivor tries to explain the fatigue directly, while others may try to hide it. In addition to leaving the survivor exhausted and exacerbating her fatigue, restricted communication is not necessarily helpful for the children in the family unit. Previous research has shown that when a parent is threatened with a serious illness, children are often aware of the threat, and in the absence of open communication, they often fear that their parent is dying (Authors, 1991, 2005).

Limitations

A major limitation of study findings relates to the fact that we did not conduct direct interviews with the family members. Future research should further explore these results with family members to identify points of consistency, as well as divergence in perspectives and experiences as the family system responds to the survi-

vor's fatigue. In addition, because the design of the larger study precluded the use of theoretical sampling and an inductive analytical model we do not know if our study would have identified new concepts that were not part of family stress theories, had we started with no preconceived categories. In addition, it is possible that the women in our sample, and their families, differed in some systematic way from other breast cancer survivors with persistent posttreatment fatigue. For these reasons, the themes and conclusions drawn from this analysis should be confirmed in other populations.

Conclusions and Implications

This qualitative analysis contributes to the limited literature on family aspects of breast cancer by providing a description of the process of adaptation when the family is not able to assign a clear meaning to chronic symptoms posttreatment. It also builds upon family stress theory by highlighting interrelationships among communication patterns (e.g., restricted communication) and role shifts in the family system. Our results underscore the value in normalizing the experience of fatigue for survivors and their family members and highlight the importance of a family centered approach to service provision with this population in which both the survivor's needs and concerns and those of family members are addressed and supported. This research can also be used to guide future family based intervention research for breast cancer survivors with fatigue and their families.

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