

# Parenting Experiences With Adolescent Daughters When Mothers Have Breast Cancer

Deborah Stiffler, PhD, RN, CNM, Joan Haase, PhD, RN,  
Barbara Hosei, RN, MSN, WHNP, and Brooke Barada, RN, MSN, PNP

**Purpose/Objectives:** To examine maternal parenting during the time when a mother is diagnosed with and treated for breast cancer from the mothers' and adolescent daughters' perspectives.

**Research Approach:** Empirical phenomenologic.

**Setting:** Sites in Indiana and Arizona.

**Participants:** 8 mothers and 1 of their adolescent daughters. The mothers were aged 37–46 years at the time of diagnosis, had stage 0–IV cancer, and had completed treatment 1–12 years earlier. Participants had one to four children ranging in age from 13–24 years at the time of the interview. Ages of the adolescent daughters at the time of diagnosis ranged from 10–15 years with an average of 13.5 years.

**Methodologic Approach:** An open-ended, audiotaped interview was conducted with each participant.

**Findings:** Six major theme categories were found: (a) a battle to be fought on many fronts—what is at stake if the battle is lost, (b) I tried to tell her, (c) standout moments in our family's cancer journey, (d) mobilizing to protect self while preserving parenting, (e) voices of fear, and (f) after treatment is over, you are not done.

**Conclusions:** Mothers set a high priority on parenting and experienced difficulty in setting priorities to meet their own needs and those of their families, including those of their adolescent daughters. Mothers need assistance learning ways to help their daughters through the breast cancer experience, particularly related to maintaining their relationship and communicating.

**Interpretation:** Mothers should be given assistance with strategies for realizing their own needs and finding positive ways to deal with the needs of their families. Nurses can play an integral part of this development.

## Key Points . . .

- ▶ Scant research has focused on mothers who have adolescent daughters and the concerns they face when the mother is diagnosed with and treated for breast cancer.
- ▶ Mothers with breast cancer frequently try to protect their adolescent daughters by keeping their lives as normal as possible, often at the expense of the mother.
- ▶ Mothers with cancer need assistance early in diagnosis and treatment to help them understand what family members are dealing with and ways to assist communication.
- ▶ Further research is recommended on how mothers can resume effective parenting once treatment is completed and on potential interventions to help mothers and daughters regain a sense of normalcy in survivorship.

or school-age children. Little is known about parenting an adolescent during a mother's breast cancer diagnosis. In this article, findings related to mothers' experiences of parenting adolescent daughters are reported. The data are part of a larger study of mothers' experiences of parenting and adolescents' experiences of being parented during the mother's diagnosis and treatment for breast cancer.

## Background

Being diagnosed with and treated for breast cancer can affect a woman's family in many ways, particularly during the childbearing and child-rearing years. Chemotherapy-related

In 2007, an estimated 178,500 women were diagnosed with invasive breast cancer and an additional 62,000 women were diagnosed with breast cancer in situ (American Cancer Society [ACS], 2007). Because approximately half of the women were 61 years or younger (ACS), many would still be bearing or raising children. If each of the women had one to two children, about 100,000 children could have a mother newly diagnosed with breast cancer at any given time.

Research indicates that these mothers experience treatment-related symptoms that can impair their ability to parent and that children of mothers with breast cancer are more likely to have behavioral issues, emotional distress, and negative self-perceptions than children whose mothers are healthy (Cummings & Davies, 1994; Goodman & Brumley, 1990; Panacione & Wahler, 1986). Parenting needs, as well as responses to having a mother with breast cancer, likely differ based on a child's developmental phase. Most research on parenting for mothers with breast cancer has focused on preschool

*Deborah Stiffler, PhD, RN, CNM, is an assistant professor and the coordinator of the women's health nurse practitioner major, Joan Haase, PhD, RN, is the Holmquist professor in pediatric oncology nursing, Barbara Hosei, RN, MSN, WHNP, is a former master's student, and Brooke Barada, RN, MSN, PNP, is a former master's student, all in the Family Health Department in the School of Nursing at Indiana University in Indianapolis. This research was supported by a nursing research grant funded by the ONS Foundation through an unrestricted grant from Amgen Inc. (Submitted May 2007. Accepted for publication June 21, 2007.)*

Digital Object Identifier: 10.1188/08.ONF.113-120

fatigue may interfere with the mother's ability to provide day-to-day care for her children, and partners often are unprepared to deal with the increased home management responsibilities (Elmberger, Bolund, & Lutzen, 2000; Lewis, Zahlis, Shands, Sinsheimer, & Hammond, 1996; Rayson, 2001). Depressed mood may impair a mother's ability to parent. She may be less emotionally available and communicative, provide less supervision and consistency of discipline, take less initiative, or experience increased feelings of hostility, irritability, and coerciveness (Cummings & Davies, 1994; Goodman & Brumley, 1990; Lewis & Hammond, 1992, 1996; Lewis, Hammond, & Woods, 1993; Lewis, Woods, Hough, & Bensely, 1989; Panaccione & Wahler, 1986).

Breast cancer diagnosis, treatment, and symptom-related consequences may result in increased overall marital and family tension (Lewis et al., 1993; Lewis & Hammond, 1992, 1996). The mother may lack the ability and strength to continue her role and feel extreme guilt in relation to the family (Elmberger et al., 2000; Ohlen & Holm, 2006). Yet the mother often will try to maintain her usual routine to make things seem ordinary even while she feels completely out of the ordinary with breast cancer (Ohlen & Holm). Researchers have found that mothers frequently try to hide their feelings and are reluctant to ask for help because they do not want to appear weak (Elmberger et al.).

The long-term effects on the mother-child relationship of maternal depressed mood and other symptoms related to having breast cancer still are unclear, although the child's view of the quality of the relationship is a significant predictor of the coping behavior for boys and girls (Kliwer, Fearnow, & Miller, 1996). Few studies have specifically examined how adolescents are affected when their mothers are diagnosed with and treated for breast cancer, but research has shown that adolescents often feel burdened by additional responsibilities because of the illness (Davey, Gulish, Askew, Godett, & Childs, 2005). One of the developmental tasks of adolescence is establishing an individual identity, and adolescents often look at their parents as role models. Changes in the parenting ability of the mother battling breast cancer may negatively affect that development (Elmberger et al., 2000).

Adolescent daughters of mothers with breast cancer show higher levels of stress, anxiety, and depression (Davey et al., 2005). They also have conflicting emotions when their mothers are ill, wanting to be supportive and helpful, yet feeling anger and resentment toward their mothers for the increased demands placed on them. In addition, they may fear being diagnosed with cancer in the future (Davey et al.). Those conflicting emotions can cause the tumultuous time of adolescence to become even more difficult. The purpose of this article is to describe maternal experiences of parenting adolescent daughters when the mother is diagnosed with and treated for breast cancer.

## Methods

### Approach

An empirical phenomenologic research approach was used for the current study. Phenomenology describes the meanings of experiences from the perspective of the person experiencing them (Oiler, 1982).

## Participants

The purposive sample, obtained from clinical and community sites in Arizona and Indiana, included women who had been diagnosed with stage 0–IV breast cancer, had completed treatment, and had an adolescent daughter aged 13–18 during the time of diagnosis and treatment. For the larger study, both mother and daughter needed to be willing to participate to be included.

Because phenomenology identifies the commonalities of experiences, even among diverse samples, the researchers did not attempt to control variables such as education, religious preference, socioeconomic status, marital status, or cultural background. In addition, a sample size was not predetermined; instead, participant interviews continued until redundancy occurred in identification of theme categories. To provide descriptions of the acute phase and immediately after treatment and still have the experiences close enough in time to have adequate recall, participants initially were recruited who had completed treatment within the previous two years. However, participants' memories of their experiences clearly remained vivid, so recruitment was expanded to include two participants whose initial diagnosis and treatment were more than two years before. The additional women provided data rich in meaning, particularly relating the consequences of parenting when battling breast cancer.

After obtaining institutional review board approval for the study, members of the research team worked with oncologists who specialized in breast cancer treatment and their staff to identify potential participants who met the study criteria.

After the women agreed to participate, an interview, including the location, was scheduled. The data-generating questions were provided at least three days before the interview so that the mothers and daughters could reflect on their experiences. The purpose of the study was reviewed and the informed consents were signed at the time of the interview.

### Data Collection

An open-ended, audiotaped interview was conducted with each participant. The goal of each interview was to obtain as clear and rich a description of the experience as possible and to ensure that the participant, rather than the interviewer, determined the specific content discussed. As a result, a minimum number of broad, data-generating questions were asked, beginning with, "Please tell me about your experience of parenting [adolescent daughter's name] when you were diagnosed and treated for cancer." Probes, such as "tell me more about that," were used to facilitate the participant's description of her experience. Each participant was encouraged to continue talking until she felt that the experience had been fully described. Interviews lasted 45–60 minutes.

### Data Analysis

The audiotaped interviews were transcribed and checked for accuracy by members of the research team, and then further analysis was done collaboratively within the research team. The data from the first six mothers were analyzed using a procedure adapted from Colaizzi (1978). Common themes were identified and organized into clusters and categories. The themes, clusters, and categories, as well as the essential structure, were validated by comparison of the last two participant interviews with the findings to ensure that the themes were reflected in the participants' experiences.

# Results

## Sample

The sample consisted of eight mothers recruited from sites in Indiana and Arizona. At the time of diagnosis, ages ranged from 37–46 ( $\bar{X} = 32.875$ ), and at the time of the interview, ages ranged from 42–54 years ( $\bar{X} = 36.25$ ). The participants' stage of cancer at diagnosis ranged from 0–IV. Six of the mothers had completed treatments 1–2 years prior to the interview; two had completed treatments 11–12 years prior. Participants had one to four children ranging in age from 13–24 years at the time of the interview. Ages of the adolescent daughters at the time of diagnosis ranged from 10–15 years, with an average of 13.5 years.

Significant statements were extracted from the data and analyzed to produce six major theme categories. Figure 1 summarizes the theme categories with related theme clusters.

### A Battle to Be Fought on Many Fronts—What Is at Stake if the Battle Is Lost?

In many ways, the mothers' cancer experience was analogous to a battle occurring on several fronts. However, as mothers, the usual cancer-related battles—the devastating and debilitating treatments, side effects, and the accompanying emotional battles with uncertainty, fear of dying, and being alone—were overshadowed by the daunting concerns for family.

**Reviewing what is at stake, win or lose:** The mothers had a strong sense of the consequences to their families if they lost the physical battle to live. One woman stated, “Most important was living and being there for [my adolescent daughter]. . . . I cry when I talk about it. . . . It was just so scary.” The battle for family was broader than the battle to live and also meant keeping family together, minimizing disruption as much as possible during the treatments, helping the children escape long-term consequences from the experience, and ensuring that everyone would be okay in the event that the physical battle with cancer was lost.

If I die, who's going to take care of the kids . . . if I have metastases and die? That will probably happen in about five years. I have five years to get these girls ready and convey to them everything that I want them to know to become whole people.

Efforts to win the overall battle—to beat the disease and to persevere in making things right for self, the adolescent daughter, and the whole family—were accompanied by consequences. One consequence was mothers' inability to be present for their adolescent daughters in their usual ways. They experienced sadness and guilt as they realized the treatments or symptoms prohibited them from being consistently and fully available.

Not being able to be there for every single game because you're not well or be there to help her with homework or her problems because I didn't have the energy like I wanted to. . . . Not being the parent that you want to be.

Each of the mothers felt the desire to be present for and normalize their daughters' experiences throughout their adolescent years. They wanted to have the comfort of seeing their daughters develop into well-adjusted young adults. The cumulative illness-related difficulties that prevented mothers

### A Battle to Be Fought on Many Fronts—What Is at Stake if the Battle Is Lost?

- Reviewing what is at stake, win or lose
- Battling emotions and emotional battles

### I Tried to Tell Her

- Unrelenting communication decision making: who, how, when, and how much to tell
- Prioritizing the parenting role in managing communication responses
- Whatever else is communicated, hope must be communicated.

### Standout Moments in Our Family's Cancer Journey

#### Mobilizing to Protect Self While Preserving Parenting

- Managing life while acknowledging one cannot control it
- Tailor making mom to meet adolescent daughter's needs

#### Voices of Fear

- Fear of the consequences on parenting from enduring cancer
- Fearful to plan

#### After Treatment Is Over, You Are Not Done

- Still not done
- I wish I had known during treatment.

## Figure 1. Theme Categories and Related Clusters

from being truly present for their daughters were seen as ominous for their daughters' future well-being. Most other aspects of dealing with the cancer were placed in the context of wanting to be present now and in the future for the adolescent daughters and other children: “Part of the pain of the whole thing was not being able to do as much as I wanted to do for her. Guilt, just terrible parent guilt.”

**Battling emotions and emotional battles:** In the midst of fighting the cancer and trying to be present for their daughters, mothers fought to emotionally hold on when the daughters' responses to their mothers' situation often seemed insensitive, unhelpful, or uncaring. Mothers experienced annoyance, disappointment, abandonment, and anger when daughters' behaviors were perceived as avoiding them, being selfish, or lacking understanding and compassion. At times, mothers were not prepared for such reactions and were puzzled, hurt, and even astounded at such behaviors.

She wasn't as loving as I thought, in my mind, she should be, and that's the part—that she was most withdrawn during my main sickness. . . . I thought she would be the one who would be very open . . . she was the one that I wanted to be there the most, but she couldn't be.

The mothers clearly struggled to find ways to deal with their daughters' reactions while working to understand how and why their own cancer-related concerns might generate such negative responses. Although feeling hurt and helpless to change their daughters' behaviors, mothers attributed the behaviors to normal adolescent developmental needs of separating from parents, being with friends, or attending school activities.

Mothers sensed that emotional battles with their daughters and attempts to deal with their own reactions could cause lasting harm to their relationships unless addressed. The following quotation exemplifies the sense of helplessness and fears about what was at stake in the mother-daughter relationship.

My worst fear about having cancer wasn't that I would die or that the house wouldn't be clean, but that, in the course of my illness, I would not be a good mother. I think the cancer catapulted [the adolescent daughter]

into being rebellious and withdrawn from me, and what really makes me angry is that the cancer took my daughter on a different course, a separate road from the one I was on, and by the time she left home at 18 years old, I had been robbed of those years in between. . . . I felt like the damage in my relationship with [my adolescent daughter] was one of the highest prices I paid, and the way she responded cost her as well . . . and I couldn't do anything about it.

## I Tried to Tell Her

Communication was a particularly important component of the mothers' experiences of parenting when diagnosed with and being treated for breast cancer. The mothers thought about and struggled with how to talk—or not talk—about the cancer, treatments, and related concerns. So much of the communication seemed laden with potentially harmful meanings. Communication with family, particularly with adolescent daughters, required a lot of decision making with many factors weighed.

**Unrelenting communication decision making: Who, how, when, and how much to tell:** From the mothers' perspective, each of their children had different needs that had to be met individually. They found differences in what information each child needed to adjust to the mother's breast cancer. Those decisions were ongoing as mothers navigated through their cancer journey. Ultimately, communication decisions related to adolescent daughters were based on several factors, including the mothers' desires to (a) protect and shield their daughters from distress, (b) keep adolescent life as normal as possible, and (c) help the daughters gain some level of understanding appropriate for their coping, age, and previous responses to communication efforts. Although mothers' ultimate decisions about communication varied regarding the degree of openness and the content of communication, each wanted to make good mother-daughter communication decisions and carefully weighed and frequently evaluated their decisions. Most communication occurred with a desire to have greater openness.

We were very open with our kids and very open with [adolescent daughter] about what was going on, so that they understood how important each step was. . . . We didn't hide anything, because I think when you hide things, it makes it scarier. . . . The most important thing that we did as parents was to communicate exactly what was going on.

Regardless of whether open or limited communication was decided on, mothers often second-guessed their communication decisions.

**Prioritizing the parenting role in managing communication responses:** Open communication did not always foster open dialogue. From the mothers' perspectives, after receiving the information, some daughters became very concerned about even the smallest details of their mothers' illness, whereas others acted as though nothing had changed and withdrew or acted out. Mothers felt a responsibility to address unexpected reactions.

I wasn't getting from her what I thought I would get because she was always . . . so open and sweet and all of a sudden, she just clammed up. . . . She was short with me . . . she was angry.

The mothers tried to tune in and adjust their parenting to meet whatever they perceived as their daughters' needs for communication. One mother said, "Since [my adolescent daughter] wouldn't answer any questions, I just gave her information in a very nonchalant way and just told her how I felt."

**Whatever else is communicated, hope must be communicated:** Regardless of the level of openness or the content of communication with their daughters, mothers strove to convey a positive and hopeful perspective about the cancer. One mother was determined to convey a positive perspective by "acting normal," even when facing a stem cell transplantation.

[The stem cell transplantation] was not like a big traumatic thing. I was just going to go figure this out and do it because I had too much on my plate. I was very positive and upbeat all the time.

Some drew on their faith in God to communicate their hopefulness for dealing with the breast cancer: "I knew that God was there for me, one way or another." Another mother said, "There was no one else. It was God who gave me my strength."

Despite efforts to be very positive and hopeful in their communications, the mothers had expectations that their daughters would be concerned. They were surprised when daughters responded with casual acceptance or avoidance or even acted out.

It really kind of put this whole thing on a different level for [the adolescent daughter]. "If there is something for me to worry about, Mom, let me know and if not, I'll see you." It surprised me because I would have thought she would have been more [upset] by it.

## Standout Moments in Our Family's Cancer Journey

Standout moments in the course of cancer diagnosis and treatment, such as getting the diagnosis or losing hair, are not unusual for women with breast cancer. Such standout moments for the participants often were experienced within the context of family as a whole and, in particular, in relation to their adolescent daughters. Telling their families of the breast cancer diagnosis is one example of a standout moment. "I brought my oldest daughter home and the girls came home from school and I told them I have cancer. . . . We all sat and cried for awhile."

When specific dates and times related to important family events or holidays stood out, often it was as though those events were seared into the fabric of their family memory.

We found out on [our adolescent daughter's] birthday.

I had the biopsy the day before Thanksgiving, and then the day after Thanksgiving the tissue came up positive and the radiologist called.

[The hair loss] happened to be three days before Christmas, so that was not good.

All of the mothers discussed losing their hair as a significant moment for themselves and their daughters. Some mothers chose to acknowledge the hair loss with their families by attempting to make happy memories of shaving heads and having fun.

When my hair fell out, we had bought these clippers, and so [my daughters] actually helped shave my head bald.

[My older daughter] actually styled my hair first; she cut it and made it all punk. We shaved [my husband's hair], too. We had black sunglasses and black leather jackets and they took pictures outdoors looking all punk and everything, and then she buzzed me all the way. It was kind of like a family thing.

Others viewed the experience of hair loss as symbolic of the whole distressing experience.

When I lost my hair on Christmas Eve, [my daughter] was nuts, even though I had forewarned her and had cut my hair short, she was just a mess. I mean hysterically. Hysterical. It was awful.

## Mobilizing to Protect Self While Preserving Parenting

In the midst of dealing with cancer, the mothers did many things to maintain their role as parent while mobilizing their families to actively deal with the cancer.

**Managing life while acknowledging one cannot control it:** Mothers were determined to protect the rhythms of their lives and their family routines. "I was going up for [a promotion] and I was [an officer in] my national association, so I had to travel. I didn't want to give that up because it was a national role." They also worked hard to keep up their parenting role and responsibilities so that family life would change very little. However, as they experienced increasing intensity in their treatment-related symptoms, which were impossible to ignore—particularly the fatigue, the mothers eventually came to realize that they simply could not do everything they were used to doing for their families. "I remember being angry because I would try to do things and I just couldn't do them." Mothers needed to conserve their energy and protect themselves from complications to survive for their family. Recognizing the need to let go of some parenting responsibilities was seen as a great loss of control, and determining what they would relinquish was difficult. "A lot that happened was outside of my control, and as a woman and a mom, control was a big thing that I had to learn to let go of, which I didn't do very easily."

The mothers came to understand that they needed to deal with their sense of self as a parent and their symptoms. They gradually mobilized themselves, their families, and their social networks to find numerous strategies to keep the household functioning at some level, get any work-related needs met, and help their daughters have normal adolescent experiences. After her adolescent daughter had an unusually negative response to the way the family was managing, one mother said,

All five of us sat in bed together . . . I will never forget . . . we took turns [talking about ways to manage things better] and it was the most empowering thing and it was a turning point for our family because there were several areas of need the kids addressed that they could take part in to ease my frustration and theirs.

**Tailor making mom to meet adolescent daughter's needs:** Mothers were very aware that the need to adjust how the family functioned increased the possibility of placing too much responsibility on each member. This was particularly a concern when mothers had to rely on their adolescent daughters to manage their responsibilities. In response to that concern, mothers sometimes ignored or diminished their own

health needs and put on a "no worries" facade to avoid placing additional expectations on their daughters.

A lot of people put pressure on [the adolescent daughter] to take good care of her mother. I would tell people, "I am the adult, and her responsibility is to be a child. She doesn't need to worry about taking care of me."

Mothers set a high priority on minimizing their own symptoms to avoid seeing their daughters lose normal adolescent experiences. They attempted to monitor how well their daughters were managing in the midst of the mothers' cancer.

I don't think we had any behavioral or adjustment problems. . . . She was so busy with school and sports that she was kept busy enough; she didn't have time to really dwell on any of this.

While wanting their daughters to experience a normal adolescence, mothers, sometimes reluctantly, relinquished aspects of their parent role to others: "Her [older sister] has always been like a second mom. When I was sick, if something was really bothering her, she'd go to [her older sister]."

Mothers monitored their daughters' needs to process the experience of having a mother with cancer. Mothers sought ways to help daughters work through cancer-related concerns, such as fostering daughters' connections with others who had experienced cancer in their families or having them spend time with friends and their parents to create a sense of normalcy.

One of the things that helped was my daughter's friend's mom had breast cancer and was in remission and doing fine. They spent time together and they did a lot of soul searching, talking, and she came away from that better.

Finding outlets for their daughters' concerns was sometimes perceived as missed moments of intimacy by the mothers. Participants had difficulty accepting that their daughters needed to seek help from substitute mothers and sometimes saw this as failure to fulfill their role as parent.

You know, when I was sick, I didn't feel like messing with it . . . [and now I ask] "Why did I let them do it?" You know, "Why did I let it get this far?" And I kind of feel out of control now. I don't know how I'm going to get that back without being a total bad guy.

## Voices of Fear

The mothers' fears for their own survival were compounded and often overshadowed by their fears of lasting, devastating effects on their daughters' present and future lives because of their having cancer.

**Fear of the consequences on parenting from enduring cancer:** After relinquishing important aspects of the parenting role, mothers feared the consequences to their daughters' well-being. They questioned the extent to which emotional upheavals might leave permanent emotional scars.

Did I scar my kids for life? Did I mentally scar them? Because you sit back and let somebody else parent. I am afraid I am going to find out I did something to them that's going to last the rest of their lives.

Mothers' fears for their daughters' well-being were fueled by their fears of failure as a parent.

I think I was really hard on [my adolescent daughter]. She overreacted to my illness by acting out, and I overreacted

to her acting out by being more afraid. Most of my parenting mistakes were fueled by fear, feeling so completely responsible for the outcome.

Other fears were fueled by mothers feeling responsible for increasing their daughters' risks for breast cancer in the future. "It's bad enough I had cancer, now it raises their risk of getting it, and are they going to blame me because I got it?"

**Fearful to plan:** Mothers had difficulty thinking about and planning the future for themselves and their families. Moving on, taking on the role of a survivor, did not come easily because any security they felt before the diagnosis and treatment was shaken.

As long as I was taking the treatments, I was pretty sure that there was no cancer left. You know, but now that I'm not doing anything, I'm afraid it'll come back. Do I go on being scared for the rest of my life waiting for the other shoe to drop? Am I going to stay cured?

### After Treatment Is Over, You Are Not Done

Although cancer treatments were completed, the mothers soon realized their cancer journey was not done and that life would not return to a previous normal.

**Still not done:** The mothers experienced a sense of relief when the cancer treatments were finished, but also a sense of uncertainty about how to move forward.

You wait and you do all the treatments and you do everything the doctor tells you and then, all of the sudden, it's all over and you're not doing anything, so it kind of takes away the power. . . . I'm totally powerless at this point. I'm not doing anything to prevent the cancer from coming back. I want somebody to tell me what to do. You know, for six months people have been telling me what to do and now all of the sudden they're like, "Go home," and nobody's telling me what to do or what I should be doing.

Ending treatment was not the end of the mothers' work.

After treatment is over, you are not done. It's much tougher than during treatment. . . . You're a different person . . . the kids walking very gingerly around, [wondering] who is mom now? . . . Mom's afraid now. It was hard for me to admit those nine months after everything was finished, I was still struggling.

The losses were sensed as irreparable in some ways.

It was just really hard because . . . she didn't want anything to do with me. . . . This is the only way she could adapt to what was going on was to pull away. I didn't know what to do. . . . Kids do different things in order to adapt, and that's her way of adapting. I don't think we are as close as what we were. Because we were real, real close.

For women who . . . have bought the line that we can be everything to everyone and it isn't going to cost a thing, it does. It costs us emotionally, spiritually, and physically, and we wonder why there is nothing left when we get through.

**I wish I had known during treatment:** Participants identified many things they needed throughout their experiences, primarily information for themselves and their daughters.

I needed information that said, you know, it's okay, you have cancer and it's okay to punish your child . . . more information to tell you how to deal with the cancer, somebody to talk to who has already been through it. Someone to tell how they dealt with it and how things turn out, what happens afterwards. I can't find anything that tells what happens after cancer is over.

For her adolescent daughter, one mother wished for

A book or information or a teen group to tell [my daughter] how it was, something that tells her it's okay for you to be mad [at the cancer], but don't scream at mom about the cancer. Don't blame mom for the cancer. It is okay that you're mad. You're mad because of the cancer.

## Interpretation

The results of this study demonstrate that women battling breast cancer who are mothers of adolescents have multiple needs and responsibilities. Their lives are complicated. Some of the findings already have been discovered within the research literature, but some have yet to be discussed.

### A Battle to Be Fought on Many Fronts

The mothers in this study demonstrated how their parenting concerns outweighed the concerns for their own self-care, despite the severity of the symptoms, which is supported by previous researchers. As in the current study, several studies identified the ways in which family concerns were intertwined with other cancer-related concerns (Elmberger et al., 2000; Fitch, Bunston, & Elliot, 1999; Ohlen & Holm, 2006). Those concerns included worrying about how the family would cope, feelings of loss of control over their lives, the sense that they were unable to do things for their families, the need to keep things as normal as possible, difficulty relinquishing control to others, and feelings of guilt when they needed to ask for help (Elmberger et al.; Fitch et al.; Ohlen & Holm). Women battling breast cancer had to make changes in their lives. What was surprising in the current study, and not specifically identified in other studies, was the extent to which the mothers rose above their own needs to meet those of their adolescent daughters. The mothers' determination to keep fighting in the midst of the fatigue and other symptoms was remarkable.

### I Tried to Tell Her

Communication issues were a high priority with the mothers; knowing what to discuss with their adolescent daughters was extremely difficult. Other researchers reported similar findings. Mothers have difficulty finding a balance regarding what children need to know—making them feel included yet not wanting to needlessly worry them (Fitch et al., 1999; Forrest, Plumb, Ziebland, & Stein, 2006). They also found that children tended to pick up on conversations and moods around the house. Similar to the present study's findings, the research indicates that some parents tried to protect their children from the cancer by not talking about it, but this tended to cause other concerns (Forrest et al.; Harpham, 1999). Mothers in the current study needed help in developing strategies for communication with their adolescent daughters and other family members. Communication with adolescents often is difficult for parents, and the strains of discussing cancer-related issues clearly complicated the communication. Billhult and Segesten

(2003) described the difficulty of mothers wanting to tell their children everything so that they had good information rather than allowing the children's imaginations to form ideas about the cancer. Fears of worrying children or causing fantasies that were worse than reality were reasons for not giving children accurate and adequate information (Fitch et al.). However, giving children age-appropriate information regarding breast cancer has been found to decrease their anxiety (Forrest et al.).

Studies regarding the specific information needs of adolescents during their mothers' illness revealed that, first and foremost, they needed to know whether their mothers were going to survive (Kristjanson, Chalmers, & Woodgate, 2004). Next, they wanted to know the facts about the illness and how they could help their mothers. They also appreciated information regarding how other adolescents felt in similar situations (Kristjanson et al.). Mothers needed help engaging their daughters in communication about these and other cancer topics. The mothers seemed to long for open communication but were not sure how to achieve it. Walsh, Manuel, and Avis (2005) indicated the need for open communication regarding the cancer to maintain a child's trust. Mothers who avoided discussing their experiences tended to have adolescents who felt isolated and unsupported (Kristjanson et al.).

As in the current study, Billhult and Segesten (2003) reported that mothers tried to put away negative thoughts and only think about positive things. The mothers in the present study believed that, in all circumstances, they should communicate hope to their daughters. However, by focusing on the positive, whether the mothers actually fostered communication or whether they gave messages that fears or concerns were not acceptable topics is unclear.

### **Standout Moments in Our Family's Cancer Journey**

The two major standout moments for mothers were related to hair loss and holidays. Distress related to hair loss has been described in several studies (Boehmke & Dickerson, 2005; Forrest et al., 2006; Kiebert, Hanneke, de Haes, Kievit, & van de Velde, 1990; Longman, Braden, & Mishel, 1999; Love, Leventhal, Easterling, & Nerenz, 1989), although how the mothers experienced the loss in terms of their relationships with their daughters was not described. For the mothers in the current study, their daughters' reactions to and involvement in hair loss decisions were very important. Many of the mothers also described diagnoses or surgeries as standout moments, which often were tied to significant dates such as birthdays or holidays. They discussed how that took the joy out of those dates. No similar concepts have been discussed in previous research.

### **Mobilizing to Protect Self While Preserving Parenting**

The mothers struggled to reconcile their need to parent with the realization that the cancer prevented them from being in control of everything. As they came to realize that they needed to pay attention to their own physical and emotional needs, they worried about placing too many expectations on their daughters, which is evidenced in the literature. The mothers in a study by Fitch et al. (1999) talked about the tension involved when they asked their children to assume more responsibility at home. They needed the help, but they wanted to keep their adolescents' lives as normal as possible. To ask them to assume more responsibility meant that they were causing them to "grow up too early" (Fitch et al.).

## **Voices of Fear**

The consequences of parenting during the time of diagnosis and treatment continued into survivorship for the participants. The sense of completion that the mothers expected when the cancer treatments ended was not there. The journey was far from over. The fear of recurrence was accompanied by a sense of "What has the cancer done to my family?" They wondered how, or even if, they would be able to return to some level of normalcy, particularly in their relationships with their daughters. Walsh et al. (2005) described some of those fears. The mothers in that study related feelings of grief and loss in their lives as well as the lives of their children. They lost a portion of child rearing and had no way to recoup the lost time. The mothers also feared for their children, many of whom showed signs of emotional distress and coping difficulties. Those difficulties were manifested by withdrawing emotionally, acting out, denying feelings, or avoiding conversations (Lewis & Darby, 2003; Walsh et al.).

## **After Treatment Is Over, You Are Not Done**

After their treatments were completed, the mothers described a sense of abandonment by their healthcare providers. No one told them what to do anymore. Those survivorship issues have not been well studied. The mothers in this study needed to know how to resume parenting and regain the roles they relinquished during the cancer experience. They sensed a need to reestablish a fulfilling parenting role and relationships with their adolescent daughters.

## **Nursing Implications**

The current study identified several areas in which nurses can help mothers with breast cancer cope. Mothers need help setting appropriate priorities. They should be supported with strategies for realizing their own needs and positive ways to deal with their families' needs. Having others depending on them helped to keep them going (Billhult & Segesten, 2003); however, mothers with breast cancer need help deciding which battles to fight and which to delegate or relinquish. Nurses can help mothers organize a list of needs and responsibilities and develop strategic plans to accomplish them.

Communicating with adolescents about cancer is another area in which nurses can help. Parents often have little information about what their adolescents are dealing with, thinking about, or feeling when a mother has breast cancer (Lewis & Darby, 2003). That lack of information makes communication difficult. Using information extracted from the research, nurses can help mothers understand their adolescent daughters and develop appropriate communication techniques.

Nurses should be aware of and discuss the difficulty in transitioning to survivorship. Acknowledging the possibility of ongoing concerns even after treatments and letting the mothers know that they may contact the nurse with questions or concerns may aid in that transition.

## **Conclusions**

Although some research studies have examined mothers with breast cancer and their school-age children, little research has focused on mothers who have adolescent daughters. Even though some of the experiences are similar, the mothers in this

study voiced many different concerns. This study contributes a basic understanding of the difficulties that are unique to mothers with breast cancer and their adolescent daughters.

The mothers in this study tried to protect their adolescent daughters, shielding them from the harsh realities of cancer and keeping their lives as normal as possible; however, that shielding was done at a cost to the mothers' own well-being.

A few mothers in this study had never really talked to their daughters about their cancer or what either was feeling. After participating in the interview process, a member of the research team followed up on one of those cases. The mother and daughter talked about how they had subsequently initiated deep conversations about the cancer that actually started a healing process between them. Clearly mothers could benefit from having help with communication to open and maintain dialogue about sensitive issues with their daughters. The Enhancing Connections Program, an evidence-based educational counseling intervention developed for school-age children by Lewis, Casey, Brandt, Shands, and Zahlis (2006), can be adapted so that it is developmentally appropriate for mothers

with adolescent daughters. The adapted interventions can address specific issues for mothers with adolescent daughters, but women with cancer need that information early in cancer diagnosis and treatment.

The current research study identified other areas in which continued research is needed. This study focused only on adolescent daughters. Research needs identify sons' needs. Further research also is recommended on communication content and how communication influences the mother-daughter relationship. Further research is recommended on how mothers resume parenting when treatment is complete and potential interventions that can help mothers and daughters regain a sense of normalcy.

*The authors gratefully acknowledge Francis M. Lewis, RN, FAAN, PhD, the co-principal investigator of the grant awarded by the ONS Foundation, for her inspiration and guidance to do this study, and Terri Farmer, RN, for her assistance with data collection and preliminary analysis.*

**Author Contact:** Deborah Stiffler, PhD, RN, CNM, can be reached at [dstiffle@iupui.edu](mailto:dstiffle@iupui.edu), with copy to editor at [ONFEditor@ons.org](mailto:ONFEditor@ons.org).

## References

- American Cancer Society. (2007). *Breast cancer facts and figures: 2007–2008*. Atlanta, GA: Author.
- Billhult, A., & Segesten, K. (2003). Strength of motherhood: Nonrecurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Sciences, 17*(2), 122–128.
- Boehmke, M.M., & Dickerson, S.S. (2005). Symptoms, symptom experiences, and symptom distress encountered by women with breast cancer undergoing current treatment modalities. *Cancer Nursing, 28*(5), 382–389.
- Colaizzi, P.F. (1978). Psychological research as the phenomenologist views it. In R.S. Valle & M. King (Eds.), *Existential-phenomenological alternatives for psychology* (pp. 48–71). New York: Oxford University Press.
- Cummings, E.M., & Davies, P.T. (1994). Maternal depression and child development. *Journal of Child Psychology and Psychiatry, 35*(1), 73–112.
- Davey, M., Gulish, L., Askew, J., Godett, K., & Childs, N. (2005). Adolescents coping with mom's breast cancer: Developing family intervention programs. *Journal of Marital and Family Therapy, 31*(2), 247–258.
- Elmberger, E., Bolund, C., & Lutzen, K. (2000). Transforming the exhausting to energizing process of being a good parent in the face of cancer. *Health Care for Women International, 21*(6), 485–499.
- Fitch, M.I., Bunston, T., & Elliot, M. (1999). When mom's sick: Changes in a mother's role and in the family after her diagnosis of cancer. *Cancer Nursing, 22*(1), 58–63.
- Forrest, G., Plumb, C., Ziebland, S., & Stein, A. (2006). Breast cancer in the family—Children's perceptions of their mother's cancer and its initial treatment: Qualitative study. *BMJ, 332*(7548), 998–1003.
- Goodman, S.H., & Brumley, H.E. (1990). Schizophrenic and depressed mothers: Relational deficits in parenting. *Developmental Psychology, 26*(1), 31–39.
- Harpham, W.S. (1999). Resources for helping children whose parent (or other loved one) has cancer. *Cancer Practice, 7*(2), 96–99.
- Kiebert, G.M., Hanneke, J., de Haes, C.J., Kievit, J., & van de Velde, C.J. (1990). Effect of perioperative chemotherapy on the quality of life of patients with early breast cancer. *European Journal of Cancer, 26*(10), 1038–1042.
- Kliewer, W., Fearnow, M.D., & Miller, P.A. (1996). Coping socialization in middle childhood: Tests of maternal and paternal influences. *Child Development, 67*(5), 2339–2357.
- Kristjanson, L.J., Chalmers, K.I., & Woodgate, R. (2004). Information and support needs of adolescent children of women with breast cancer. *Oncology Nursing Forum, 31*(1), 111–119.
- Lewis, F.M., Casey, S.M., Brandt, P.A., Shands, M.E., & Zahlis, E.H. (2006). The Enhancing Connections Program: Pilot study of a cognitive-behavioral intervention for mothers and children affected by breast cancer. *Psycho-Oncology, 15*(6), 486–497.
- Lewis, F.M., & Darby, E.L. (2003). Adolescent adjustment and maternal breast cancer: A test of the "facet hypothesis." *Journal of Psychosocial Oncology, 21*(4), 81–104.
- Lewis, F.M., & Hammond, M.A. (1992). Psychosocial adjustment of the family to breast cancer: A longitudinal analysis. *Journal of the American Medical Women's Association, 47*(5), 194–200.
- Lewis, F.M., & Hammond, M.A. (1996). The father's, mother's, and adolescent's functioning with breast cancer. *Family Relations, 45*(4), 456–465.
- Lewis, F.M., Hammond, M.A., & Woods, N.F. (1993). The family's functioning with newly diagnosed breast cancer in the mother: The development of an exploratory model. *Journal of Behavioral Medicine, 16*(4), 351–370.
- Lewis, F.M., Woods, N.F., Hough, E.H., & Bensely, L.S. (1989). The family's functioning with chronic illness in the mother: The spouse's perspective. *Social Science and Medicine, 29*(11), 1261–1269.
- Lewis, F.M., Zahlis, E.H., Shands, M.E., Sinsheimer, J.A., & Hammond, M.A. (1996). The functioning of single women with breast cancer and their school-aged children. *Cancer Practice, 4*(1), 15–24.
- Longman, A.J., Braden, C.J., & Mishel, M.H. (1999). Side-effects burden, psychological adjustment, and life quality in women with breast cancer: Pattern of association over time. *Oncology Nursing Forum, 26*(5), 909–915.
- Love, R.R., Leventhal, H., Easterling, D.V., & Nerenz, D.R. (1989). Side effects and emotional distress during cancer chemotherapy. *Cancer, 63*(3), 604–612.
- Ohlen, J., & Holm, A.K. (2006). Transforming desolation into consolation: Being a mother with life-threatening breast cancer. *Health Care for Women International, 27*(1), 18–44.
- Oiler, C. (1982). The phenomenological approach in nursing research. *Nursing Research, 31*(3), 178–181.
- Panaccione, V.F., & Wahler, R.G. (1986). Child behavior, maternal depression, and social coercion as factors in the quality of child care. *Journal of Abnormal Child Psychology, 14*(2), 263–278.
- Rayson, D. (2001). Adjuvant chemotherapy for women with young children: Our patients as parents. *Journal of Clinical Oncology, 19*(1), 279–281.
- Walsh, S.R., Manuel, J.C., & Avis, N.E. (2005). The impact of breast cancer on younger women's relationships with their partner and children. *Families, Systems, and Health, 23*(1), 80–93.