# The Significance of Motherhood for Adolescents Whose Mothers Have Breast Cancer

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f the almost 200,000 women newly diagnosed with breast cancer each year (Jemal et al., 2009), many have adolescent children. Although the effect of breast cancer on women and their spouses has been well researched (Hoskins & Haber, 2000; Lewis, Hammond, & Woods, 1993; Northouse, Templin, Mood, & Oberst, 1998; Pasacreta, McCorkle, & Margolis, 1990), research that focuses on how adolescent children cope with maternal disease is just starting to emerge (Edwards et al., 2008; Kristjanson, Chalmers, & Woodgate, 2004; Lewis, 2004).

The potential burden of living with a mother's cancer diagnosis and treatments (Behar, 1999; Compas et al., 1994; Compas, Worsham, Ey, & Howell, 1996; Lewis & Hammond, 1996), her potential loss (Conway, 1995), and the need to assume caregiver responsibilities for the family (Gates & Lackey, 1998; Hilton & Elfert, 1996) may be stressful and potentially devastating for adolescents. Many question their own and their mothers' mortality (Barnes et al., 2002; Issel, Ersek, & Lewis, 1990; Kristjanson et al., 2004; Rauch, Muriel, & Cassem, 2002). Although most women speak to their spouses about their disease, they may have difficulty communicating with their children (Barnes et al.; Behar; Shands, Lewis, & Zahlis, 2000). Worries about their mother and, for girls, about getting the disease themselves (Issel et al.; Lichtman et al., 1984), have been identified. Although adolescent sons report anxiety about their mothers' diagnosis of breast cancer (Hilton & Elfert), adolescent daughters report a higher level of stress-response symptoms, including anxiety and depression (Compas et al., 1996). Adolescent children generally feel torn between their own needs and those of their mother at a time when they are striving for individuation and separation (Armsden & Lewis, 1993; Nelson, Sloper, Charlton, & While, 1994). A limited knowledge base is available regarding the experiences of adolescents from their perspectives in comprehending how their lives are affected (Lewis, 1996; Quinn-Beers, 2001; Zahlis, 2001). Lewis (1998, 2004), in reviewing more than 25 years of research on the effect of breast cancer on families, has concluded that additional research from an interpretive

**Purpose/Objectives:** To describe adolescents' experiences of living with mothers with breast cancer.

Research Approach: Qualitative.

**Setting:** Northeastern United States.

**Participants:** 11 adolescents aged 13–19 years whose mothers were diagnosed with breast cancer within a year prior to the study.

**Methodologic Approach:** With Van Manen's phenomenologic interpretive paradigm, multiple levels of analysis of transcribed semistructured interviews yielded common themes and a unique account and understanding of adolescents' lives when their mothers have breast cancer.

**Main Research Variables:** Adolescent coping and maternal breast cancer.

**Findings:** Five distinct themes were identified: life changed, turning to self, learning to be with my mother, needing to normalize, and speaking openly—the importance of communication. Study findings uncovered the powerful role mothers held in the adolescents' lives.

**Conclusions:** The depth of the feelings and conflicts expressed by the adolescent participants, who appeared to be coping with their mothers' breast cancer, emphasizes the need to explore coping responses used in adolescent adjustment to maternal breast cancer. Given that all the adolescents reported some level of anxiety and conflict in their lives, further research should address factors that underlie their coping mechanisms.

**Interpretation:** Study findings and insights underscore the significance of the maternal-adolescent relationship. Healthcare professionals need to ask more directed questions and develop interviewing and counseling skills to support mothers through this difficult illness. Adolescent children require support and guidance in coping with their mothers' breast cancer journey.

paradigm is needed to better understand how adolescents' lives are affected. The purpose of the current study was to describe the experience of adolescents living with and communicating about their mothers' breast cancer.

#### **Methods**

This qualitative study was guided by Van Manen's (1990) phenomenologic interpretive paradigm, which is

aimed at the study of "the meaning and significance of lived human experience" (p. 57). Van Manen's method helps to uncover the richness of the phenomenon being studied through repeated analysis and interpretation. It includes thematic analysis of each interview transcript being read as a whole multiple times to identify the essential themes and intensity of experience described by each participant. A second level of analysis involves the identification of common themes across all interview transcripts. The final level of analysis focuses on deeper reflections of what Van Manen refers to as the four "life worlds" of time, space, body, and relations. The researchers pose analytic questions for themselves and the participants in writing and rewriting the final phenomenologic text. Rewriting challenges the researcher to deeply reflect on participants' articulated experiences by reviewing them with content experts, checking back with participants, and exploring emerging descriptions with relevant literary and artistic sources. The resulting phenomenologic text provides a unique account and understanding of adolescents' lives when their mothers have breast cancer.

#### **Participants**

Following approval from human subjects committees, a purposive sample of 11 adolescents was recruited from several cancer clinics in northeastern U.S. cities through referrals from nurses and physicians at participating research centers. After the researcher received consent from the mothers, she called the adolescents to describe the study to them and ask for their verbal consent before proceeding. The step provided adolescents with an opportunity to consider their participation in the study without potential added maternal pressure. Criteria for inclusion in the study included adolescent children aged 13–19 years who were English speaking and had mothers diagnosed with breast cancer within the prior year. Participants were provided with a \$20 gift certificate to a music store in consideration of their involvement in the study. The participants identified themselves as being Caucasian, African American, or Hispanic; five boys and six girls composed the sample. The participants came from a variety of socioeconomic backgrounds, and two participants were from single-parent homes. Participants attended junior or senior high school or college. They all reported having supportive relationships with their parents and identified one or two supportive friends or school personnel with whom they had shared the experience of their mothers' diagnosis of breast cancer. The mothers were diagnosed with stage I or II disease and treated with a combination of lumpectomy and chemotherapy or radiation. All but two of the mothers worked outside of the home. Everyone approached agreed to participate in the study.

#### Setting

When informed consent was obtained from the mothers and assent obtained from the adolescents, the interviews were scheduled at a time and place requested by the mothers and adolescents, which ranged from clinic office space to their homes.

#### **Data Collection and Analysis**

In-depth, semistructured interviews were carried out face-to-face or over the phone (as requested by two participants), audio taped, and transcribed. Participants responded to the fundamental research question: In your own words, can you describe what it has been like for you since your mother's breast cancer diagnosis? Four additional categories of questions, consistent with Van Manen's (1990) methodology, were used as probes to uncover a deeper and broader level of description (see Figure 1). As the interviews proceeded, participants were asked to reflect on the emerging themes identified from preceding interviews. The researcher kept observational notes throughout data collection related to the interview process and setting, participants' ease of recall, and insights about their experiences. Following the completion of the 11 interviews, the researcher interviewed three of the participants a second time and discussed the development of the meaning that was becoming apparent in the analysis, writing, and rewriting. Literature that further explored the emerging phenomenologic narrative was reviewed.

The study rigor in establishing trustworthiness of the findings was ensured by using the qualitative evaluation criteria of credibility, fittingness, and auditability (Beck, 1993). Credibility, the confidence one can have in the truth of the findings, was established by listening openly to participants' descriptions of their experiences. The researcher reviewed the emerging themes throughout the process and during writing and rewriting the final narrative. The final description of the participants

- Can you describe how your mother's breast cancer illness and treatments might have affected you in school, sports, work, or other activities? Have you seen any changes in the activities since your mother's diagnosis and treatments?
- Can you describe to me one day in particular where you were talking to your mother about her disease, or when you wished you could have talked about it, and what that felt like? Is there a song, piece of art, or literature that reflects those feelings?
- How have you handled living with your mother's disease and treatments? Is there anything in particular that has helped you through this time?
- What would you recommend to help other teenagers faced with the same experience?

# Figure 1. Interview Probes Using Van Manen's Methodology

Note. Based on information from Van Manen, 1990.

experiences was provided to them to ensure that the meaning was accurate. Auditability, the ability to follow the decision trail of the researcher with data analysis, was established with intersubject agreement by the researcher, a methodologic expert, and a content expert who reviewed transcripts, emerging themes, and the final text. Fittingness refers to how well the emerging themes and phenomenologic text fit into the context of the effect of breast cancer on families and children. Clinic and content experts supported the fittingness of the final text in describing the experience of adolescents whose mothers have breast cancer.

### **Findings**

Participants were told of their mothers' diagnoses by their mothers alone, mothers and fathers, or in one instance, their father alone. Participants expressed feelings of shock, sadness, and surprise at hearing the cancer diagnosis. Some cried and were fearful for themselves or their mothers, and all expressed distress. The intensity of the experiences became apparent in the themes that emerged from the analysis of each transcript: life changed, turning to self, learning to be with my mother, needing to normalize, and speaking openly—the importance of communication.

### **Life Changed**

The first powerful image that came through was of the adolescents' lives being unraveled by their mothers' breast cancer diagnoses and treatments. They felt worn down and unprepared. Most stated that their lives had been changed because their mothers were sick. They felt nervous at times, with a diminished ability to focus or concentrate, whether at school or in playing sports.

It came as quite a shock . . . I started to think about it more and realized that it was something that would be going on for a long time and would affect her life and the way she felt and affect everything . . . me. . . . It started sinking in and I got more upset and stressed out . . . I just lost most of my mental strength that I had before.

As the interviews progressed and the researcher and adolescents spoke about the emerging descriptions of living with their mothers' breast cancer, participants started to articulate just how it had changed their day-to-day existence. Their normal patterns of life as a teenager were changing. They did not want to complain but did reflect on and stated that they were home more. They realized they had more household responsibilities because their mothers were sick. One participant, when asked if and how life had changed, said, "Just being around the house helping out . . . there was so much to do around the house that I just stayed around the

house." As the interviews continued and participants were asked to reflect on the emerging theme, they said they felt as if their teenage lives were tipped slightly off balance. They suddenly were thinking about their mothers' breast cancer and not just about school, friends, and activities.

#### **Turning to Self**

Participants found solace in listening to music, participating in activities with their peers, or being by themselves. Their goal was to be able to focus on something that would take them away from their new reality of their mothers having breast cancer. Several spoke about the importance of sports, whereas others turned to music as a means of reflecting, finding hope and inspiration through the words of songs. No common favorite songs or musical groups were identified. A strong faith and affiliation with a church group provided solace for several teens, as did a sense of family unity. Despite receiving support, participants spoke of a need to turn inward. They felt awkward going to their mothers for comfort if they were sad and crying, particularly when their mothers were so ill. The adolescents began to rely more on themselves to not burden their mothers and often did not share as much with their mothers. They focused on their schoolwork and activities, trying not to do anything that would worry their mothers and relied on themselves to solve problems, make decisions, and, at times, to escape.

I was in a hard situation because I had school to concentrate on . . . so I had to work it out somehow myself, and I couldn't call my Mom to talk to her (like I normally would) because I'll get emotional. . . . It started to hurt her because I would talk to my brother, but I couldn't talk to her. . . . I talked to one of the counselors at school so that I wouldn't get overwhelmed.

Surprisingly, the mothers were unaware of the intent of the behavior. As the researcher walked into the homes of several participants, the mothers commented that they did not think their breast cancer diagnosis had really affected their children. To them, the daughters and sons were going about their business as usual. Yet comments such as the following, particularly from three younger participants, clearly conveyed that their lives were affected by turning to more solitary activities.

So most of the time I'd spend either in my room or in the basement just by myself so I had to escape somewhere . . . I'd watch *Star Trek* or something like that . . . it was just different from here; just like a different place to be like absorbed into.

When the researcher asked participants if they usually engaged in activities with their friends, they said, "Normally, yes—but not now." Three participants used the phrase "to escape to."

#### **Learning to Be With My Mother**

Participants recognized that the time spent with their mothers had changed. Instead of being driven to and from activities or sitting around the kitchen table at dinner, their mothers were noticeably absent. They were concerned as they watched the increased fatigue, illness, and, in some instances hair loss, take their toll. Being with their mothers at those times was a challenge as it drew attention to the severity of the illness and her potential loss. The adolescents all expressed an intense desire to be close to their mothers, particularly when they were apart. Adolescents who had finished high school or were applying to colleges did not want to attend a college far from home. Suddenly, they were less concerned that their mothers' cancer had drawn them away from their usual daily activities. A participant said, "It's really hard, but I don't want to be anywhere else." When in school, participants often would go to the nurse's office and ask if they could go home. They reported calling their mothers to check on them, especially during chemotherapy treatments.

The hardest time was in chemotherapy. It was pretty tough 'cause she was like sick and . . . my mother was just lying there. I would ask her if she needed anything and she was like no it's OK . . . so we just laid there and watched TV together . . . just spent time together.

Participants spoke about needing to find a new way of being with their mothers and seemed to gain strength and purpose when they did.

So I just tried to develop a relationship and tried to get to know what's hurting her and how she's feeling and just reach out to her. 'Cause I mean if you reach out to your mom when she's going through something like this, she's going to reach back.

#### **Needing to Normalize**

Participants spoke about times when their mothers were back to "normal" and more engaged in their lives and those of their families. When their mothers had good days, participants went out with friends, played sports, and did "normal stuff." Participants had a noticeable lightness in their voices as they described their activities and accomplishments. When treatments had finished, participants had hope that life would get back to "normal."

It was like I needed some space right now to do normal things . . . and like I'm a . . . [sports] player and I guess that is like my kinda release and just playing constantly felt good to do.

I was hoping that once the radiation was finished things would get back to normal around here.

## Speaking Openly—The Importance of Communication

Open communication was important to participants. They reported feeling worried and imagining the worst before their mothers or parents explained the cancer diagnosis, treatments, and prognosis to them. Participants felt secure with the knowledge. Not being afraid to talk about cancer was essential. When the fifth theme was emerging, the researcher asked participants to review it.

And they told me exactly what it was all about, and I felt better because I thought it was worse than it was and so I found out all of the details . . . and it was good to know everything they knew.

But now we just talk about everything and being open about the cancer and stuff. I can ask about anything and you know . . . that is so important.

Another participant stated that he did not feel like he needed to "walk on pins and needles." He could say and, more importantly, ask what he needed to know.

As the researcher reread and rewrote the analysis, spoke to participants, and read the literature, related books, and lyrics from popular music, an overall meaning emerged. The reason the experience was unique and powerful for participants became clear: because their mothers were sick. The researcher reflected further on what motherhood means in American society. Images of "soccer mom" and "super mom" underscored the effect of maternal breast cancer on adolescent children.

#### The Phenomenologic Text and the Significance of Motherhood When Mothers Have Breast Cancer

Participants in the study described the effect of their mothers' breast cancer as a powerful experience. As they reflected on the increased chores and time spent at home, they realized the significant role their mothers play in their lives. The conceptualization of motherhood as central to a child's world and development is common in American society and provides a context for the uniqueness of the experience for adolescent children. Popular magazines, plays, and literature depict the child's psychological well-being as dependant on the mother and her accessibility to them. The American "soccer mom" is expected to shepherd her children everywhere and be reachable any time they might need her. Breast cancer changes that reality at a time when adolescents need her to be available, even as they strive for more independence. The maternaladolescent relationship takes on a new meaning in the context of maternal breast cancer, one that ultimately can provide adolescents and mothers with an important cathartic experience and a new conceptualization of

what it means to be a mother (Mendell & Turrini, 2003). Open communication and creating new ways of being together help the transition to what some call a "new normal" (Harpham, 1997). Adolescents become aware that they can be strong for their mothers by handling their own worries or by reaching out to their mothers rather than waiting for them to reach out.

#### **Discussion**

Adolescents who came forward to take part in the current study had supportive relationships and wanted to share their concerns and experiences. The strength of their feelings and conflicts revealed the depth of the effect maternal breast cancer had for them. Findings from a growing body of quantitative and qualitative research (Gates & Lackey, 1998; Hilton & Elfert, 1996; Kristjanson et al., 2004; Lewis, 2004; Nelson et al., 1994; Welch, Wadsworth, & Compas, 1996) recognize the changes adolescents perceive in their lives as a result of parental cancer. The reported changes range from increased household responsibilities (Gates & Lackey; Nelson et al.), to feeling torn between their own lives and the needs of their mothers (Lewis, Ellison, & Woods, 1985), to general feelings of anxiety and uncertainty (Kristjanson et al.; Welch et al.). Adolescents in the study had a sudden recognition that the normal pattern of their lives and activities was disrupted. They also reported having more household chores as well as turning to more solitary activities, relying on themselves rather than on their mothers.

Several studies have identified how adolescents cope with parental cancer by internalizing their anxiety or avoiding thoughts about their parents (Armsden & Lewis, 1993; Nelson et al., 1994; Worsham, Compas, & Ey, 1997). Although Davis Kirsch, Brandt, and Lewis (2003) recognized a need by parents to make the most of the moment with a younger cohort of children whose mothers had breast cancer, the adolescents in the current study recognized their need to create new ways of spending time with their mothers. Adolescents across studies (Chalmers et al., 2000; Issel et al., 1990; Worsham et al.) have acknowledged a need to normalize the experience of maternal breast cancer at times by getting back to "business as usual" and school and sports activities. A final common theme from other studies was the importance of open communication in helping children cope with parental cancer within the family (Grabiak, Bender, & Puskar, 2007).

Major findings and insights provided by the current study that further an understanding of adolescents' living with maternal breast cancer underscore the significance of the maternal-adolescent relationship. Regardless of the ages, races, or socioeconomic backgrounds of the participants, the findings highlighted the role that mothers play in adolescents' lives, even at a time when, developmentally, adolescents are striving for their own identity. Popular magazines, literature, and music have depicted

mothers as the backbone of families and societies, crediting them with powers to keep families together and their children out of trouble. If mothers are suddenly ill and unavailable, adolescents are challenged to ask some significant questions: What will I do without my mother? What will happen to me if my mother does not get better? What is important to me now?

When mothers are further affected with depression related to cancer, their ability to be fully present in the relationship is compromised (Lewis, 2004). Although psychological theories of separation-individuation abound, attachment theory (Salter Ainsworth, Blehar, Waters, & Wall, 1978) and the development of attachment security in adolescents can provide further insights. Attachment security is demonstrated in a secure-base phenomenon where adolescents can explore their emotional and cognitive independence from parents (Allen et al., 2003). The event requires parents, and, in relation to the current study, mothers, who are supportive and sensitive to the lives of their adolescent children. Mothers who are attuned respond and provide their adolescents with homes as safe havens at times of emotional distress. Adolescents who have a high degree of relatedness with their mothers can explore their own emotions and responses from a secure attachment base. In the case of breast cancer, when mothers are suffering from fatigue and their own anxiety, they often are not aware of the internal states of their adolescent children. Many participants felt misunderstood by their mothers when they tried to cope with the stress alone or to normalize their everyday activities. Yet they also felt secure within their open family communication system to explore new strategies for coping with an unfamiliar and stressful experience in their lives.

#### **Study Limitations**

Although the findings of the current study are limited to the group of participants, they do illuminate the experience of adolescents whose mothers have breast cancer. Few studies to date have asked adolescents to explore their thoughts about this phenomenon from their perspective.

# Conclusions and Implications for Practice and Research

The depth of the feelings and conflicts expressed by a study group of adolescent participants who appeared to be coping with their mothers' breast cancer emphasizes the need to explore the responses and coping mechanisms used in adolescent adjustment to maternal breast cancer. Given that all participants reported some level of anxiety and conflict in their lives because of their mothers' breast cancer, healthcare professionals need to provide anticipatory guidance to mothers and supportive

services for mothers and their adolescents. Although many mothers may report that their children are coping well with their disease, professionals need to ask more directed questions and develop interviewing and counseling skills to support mothers through this difficult illness. For many healthcare professionals, the mother is the identified patient to whom they feel a primary loyalty. They may find challenging her assumptions and encouraging a more active and open communication style with her adolescent difficult, particularly if she has some misunderstandings about the child's behavior. A strong mother-child relationship has been linked with healthy psychological development and well-being of children and adolescents (Cicchetti & Toth, 1998). An adolescent's ability to cope with new and stressful events is enhanced when a secure-base relationship with the mother from which to explore and navigate life is present (Allen et al., 2003). However, the quality of the mother-adolescent relationship can suffer when mothers have breast cancer, resulting in further adjustment problems for their adolescent children. Women with a diagnosis of breast cancer may be struggling to accept and understand their diagnosis and making decisions regarding their treatment options. Their ability to be fully present and engaged in their adolescents' lives at this time may be hindered (Elmberger, Bolund, & Lutzen, 2000; Lewis & Darby, 2003). Further research

should address the relationship between mothers and adolescents in developing effective strategies to cope with maternal breast cancer.

Several questions emerged from this study. What coping responses and strategies do adolescents use to deal with maternal breast cancer? What factors separate adolescents who are coping with the stress of their mother's breast cancer from those who will develop psychological problems? What is it about the motheradolescent relationship that appears to act as a mediator for adolescents' developing problems? Can a positive relationship and open communication system with adolescents improve mothers' experience of their breast cancer? What roles can oncology healthcare professionals play in addressing the needs of adolescent children and their mothers who have breast cancer? Research that addresses those questions will further enhance the body of knowledge available to practitioners in working with this population.

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