

A Young Woman Looks Back: Losing Her Mother to Breast Cancer

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In August 1997, the wonderful life my mother had worked so hard to make for us came to an abrupt halt. I distinctly remember the hot summer day when we were watching television and the telephone rang. It was the gynecologist my mom had worked with for 20 years asking her to come into the office to discuss the results of her mammogram. I can still recall the frightened look on my mother's face and the suffocating feelings. I accompanied my mother and grandmother to see the physician and sat in the waiting room unable to focus on anything but the peach-colored walls, anxiously waiting for my mother, grandmother, and the doctor to come out of his office. I do not remember what I was thinking at only 11 years of age, but I know that what I was told shortly after was something I could never have imagined: My mom had breast cancer. I remember hearing "cancer" and feeling as though every bit of life within me was drained out.

I always felt as though the bond my mother and I shared was deeper than the average mother and daughter. My father and my mother separated before I was born. My mom welcomed me, her only child, into the world without anyone else by her side. As a single mom, she worked very hard to provide what she felt was needed, always making time for us to spend together. She was always there for me. I could have never imagined my life without her. We lived with my grandmother, who looked after me while my mom went to work, and the three of us were inseparable.

I remember, even as a young child, thinking about how lucky I was to have two strong and exemplary women in my life. I always looked up to my mother and admired the strength she possessed. She was a young adolescent when her parents immigrated to the United States from Costa Rica and she had to deal with coming to a new country, learning a new language, and adjusting to a new culture. She met this challenge and made all other obstacles she faced seem effortless.

Although the improvement in breast cancer survival statistics is a move in the right direction, it creates mixed emotions for me. Why was my mother one of the ones who had to die? Was she given the appropriate treatment? Was her breast cancer detected too late to be cured? Then I wonder about myself. Will I have breast cancer one day and, if I do, will I have the good fortune to be treated with the latest developments? Will I be a survivor or will I, too, die from this dreadful disease?

Everything seemed to move quickly after my mother received the diagnosis. She underwent surgery and had a radical mastectomy. I remember feeling so helpless; I couldn't do anything to make her breast come back, to help her incision heal faster, or relieve the horrific nausea and vomiting and fatigue after chemotherapy. I could only sit and watch as chemotherapy infused into the Port-a-Cath® on the left side of her chest, knowing that the side effects got worse with each cycle of chemotherapy. I never heard a word of complaint from my mother. I was amazed by her strength and courage. I am not sure if she internalized her fears and pain, but she appeared positive and confident that she would win the struggle.

Once my mother's treatments were over, life seemed to return to normal. The prosthesis and special bras had not gotten in the way of her normal activities. I also returned to being a normal adolescent girl. My mother, my best friend, was back! Once again, I enjoyed shopping, watching movies, and sharing stories with my mother. Two years went by and the cancer experience my family endured seemed long in the past. We began to plan a party for my 15th birthday and I was very excited for the big day. It was then that we received another dreadful phone call—the cancer had recurred. Our lives were torn and shaken to the core.

Impact of a Mother's Breast Cancer on Children

As many as 43,000–86,000 children younger than age 18 are potentially af-

fected when a woman is diagnosed with breast cancer. An estimated 30% of diagnosed women have at least one school-aged or adolescent child at home (Faulkner & Davey, 2002). Research has been conducted to bring to light the experiences, feelings, and fears of adolescents whose mothers are diagnosed with breast cancer (Clemmons, 2009; Mosher, Danoff-Burg, & Brunker, 2006; Stiffler, Barada, Hosei, & Haase, 2008). Common themes repeat throughout the literature. The emotional effect is riveting and lifelong.

Research has confirmed that adolescent girls whose mothers have breast cancer report more stress symptoms and higher anxiety and depression scores than other groups of children, adolescents, or young adults (Compas, Worsham, Ey, & Howell, 1996; Davey, Gulish, Askew, Godette, & Childs, 2005). Additional distress from the norm may arise from the developmental struggle for independence and self-identity conflicting with the knowledge that the adolescent is needed at home to fulfill the household responsibilities of the mother (Faulkner & Davey, 2002). In addition, adolescent daughters of mothers with cancer may be more distressed than adolescent sons because they tend to identify more with mothers and feel the need to support them emotionally while, at the same time, having the additional concern of their own mortality related to the disease (Faulkner & Davey, 2002; Lichtman et al., 1985).

Stiffler, Barada, et al. (2008) interviewed adolescent girls about their experiences with their mother's breast cancer. A common theme was the struggle of wanting to remain close to their mothers while, at other times, wanting to escape, ignore the situation, and participate in activities outside the home. Adolescent girls also expressed a sense of responsibility not only to fulfill household responsibilities but also the need to take on the role of a nurse in caring for their mothers. The study also investigated the emotions experienced by adolescent girls after treatment was completed. The adolescent girls expressed

feelings of relief and happiness as a sense of normalcy returned to their homes; however, the fear of recurrence loomed.

A child's reaction to the mother's experience will vary according to developmental age, but Kristjanson, Chalmers, and Woodgate (2004) highlighted common behaviors found in the literature—avoiding the illness, maintaining normalcy, and spending more time together as a family. Adolescents may experience difficulty because of their developmental need to assert their independence and, at the same time, being drawn closer to the family because of illness (Azizi, 2009; Kristjanson et al., 2004). Stiffler, Barada, et al. (2008) identified eight major themes that described the emotional turbulence of daughters in the studied population (see Figure 1). The daughters' emotional reactions were on a continuum of disbelief regarding what their mothers were having to experience, dealing with their own needs and added responsibilities related to their mothers' illness, and guarded relief once their mothers successfully completed treatment. Kristjanson et al. (2004) pointed out the importance of the adolescent to be able to create a balance of attending to the illness and maintaining the normalcy of adolescent life. In a qualitative study, Clemmons (2009) found that when a mother's treatment ends, the adolescent hopes that life will get back to normal.

Impact of Recurrent Disease

A critical time for adolescents is when the disease recurs. The possibility of death is reinforced at this point (Krist-

- World turned upside down
- Stop the intrusion—need to get away—reluctant to leave.
- Mom can't die.
- A hole where mom used to be
- Filling in the hole where mom used to be
- Being there for mom—managing mom
- Managing my reactions—being selfish or difficult
- Guarded relief

Figure 1. Adolescent Daughter Theme Categories When Mom Has Breast Cancer

Note. From "When Mom Has Breast Cancer: Adolescent Daughters' Experiences of Being Parented," by D. Stiffler, B. Barada, B. Hosei, and J. Haase, 2008, *Oncology Nursing Forum*, 35, p. 936. Copyright 2008 by the Oncology Nursing Society. Adapted with permission.

janson et al., 2004). The information and support needs of adolescents are greatest at this time because knowing whether or not the mother was going to survive was found to be the most important piece of information received, regardless of age (Kristjanson et al., 2004). Lichtman et al. (1985) found that a poor prognosis, aggressive surgery, and difficult treatment contributed to a difficult adjustment for both mothers and children; negatively affecting the mother-child relationship.

Personal Reflections

My mother's recurrent disease felt like the ultimate test of our faith and hope. Everything seemed more complicated than the first time, perhaps because we knew what awaited us, and there was no hope for cure. The oncologist said the chemotherapy would be stronger than before because the cancer had returned. That was difficult to imagine because my memories from the first time around had been agonizing enough. The effect of the second chemotherapy experience seemed more intense for all of us.

I remember going into the bathroom one morning and finding clumps of my mother's hair falling out as she brushed it. Alopecia had not happened the first time. Although I knew from movies and television that this was a possible side effect of chemotherapy, I began to wonder if this meant that her condition was getting worse. What was going to happen next? I was afraid. But my mother was strong in character—the hair loss and intense chemotherapy did not stop her. The family attended a school play that same night like nothing abnormal was happening.

My mother became weak, neutropenic, short of breath, and developed lymphedema as the disease progressed. As an adolescent with limited medical knowledge, I did not understand what was happening. Events seemed to change quickly—oxygen was delivered to our home and my mother lost her energy and became less independent. She had always been such a strong, self-sufficient woman. I could see and feel her frustration. We tried our best to keep a sense of normalcy in our relationship. My mother and I still went shopping to the mall, but now I was pushing her in a wheelchair. I look back and think that perhaps I had tried to believe that this was the new normal, and I believed it, too. The stage of recurrence is a critical time for adolescents (Kristjanson et al., 2004). Adolescents' fears increase, however, an

attempt is made by adolescents to remain hopeful even when the severity of illness increases (Kristjanson et al., 2004).

Even at her worst, I did not, and could not, contemplate life without my mother. I wanted to believe she would always be there for me as she always had been. School became a form of escape. I did not want teachers or counselors or too many friends to know what was happening. I did not want pity. I did not want to be questioned and constantly reminded of what was happening at home. My friends never asked, or maybe I did not allow them the opportunity. It was as if they knew I did not want to talk about my mother; perhaps it was that friends and teachers did not know what to say. I was struggling with being a normal high school student and being present for my mother. At that time, I didn't realize that all the feelings I was experiencing were normal for an adolescent girl whose mother was dying of breast cancer. I felt very isolated and very lonely. Stiffler, Barada, et al. (2008) normalized what I experienced. Adolescents in the study did not want to be constantly asked how they were doing because this reinforced the reality of the cancer. Adolescents use school and outside activities to help them cope with the illness demands at home (Azizi, 2009; Stiffler, Barada, et al., 2008). "Although a mother's breast cancer illness creates special needs and concerns that require attention, the importance of continuity of the adolescent's life (e.g., normal school relations, friendship) was valued" (Kristjanson et al., 2004, p. 117). Clemmons (2009) pointed out that adolescents turn inward and focus on their schoolwork and activities to prevent doing anything that would cause increased stress for their mothers.

Fear and Loss

I remember my withdrawal. I felt that no one could possibly understand what I was going through. I was not simply an adolescent whose mother had cancer, I was an adolescent whose only parent was going to die and I did not want to face it. I felt that if I spoke about it or if I verbalized my fears, "it" would become reality. The possibility of losing my mother was too much to handle at the same time as trying to carry on with my own life. I imagined that my mother felt the same way because she never spoke about the possibility of her death to me. How is a mother supposed to tell her only daughter that she is going to die? How does she tell her that their

struggles during the last five years were in vain and that none of the sacrifice had paid off? How does she say goodbye? Stiffler, Haase, Hosei, and Barada (2008) noted that communication for mothers and adolescent daughters are based on the following factors: to protect and shield daughters from distress, attempts to keep the daughter's life as normal as possible, and to help the daughter understand the illness appropriate to her coping resources and age. Decisions about who, how, when, and how much to tell is a continual challenge (Stiffler, Haase, et al., 2008).

Looking back, I remember feeling that my mother did not have to tell me she was dying. I felt that I knew what she was thinking and feeling and I could only hope she knew what I was thinking and feeling, too. If I could have spoken the words that were on my mind and in my heart, I would have told her that it was alright, that I understood that she had done all that she could, that it was not her fault, that I would remember all the good times we shared, all the wonderful things she did for me and, above all, that she was and would always be my hero. On April 22, 2002, heaven received my mother. I was by her side when she took her last breath.

Long-Term Repercussions

My life has been greatly affected by my loss. Losing my mother has contributed to the development of the woman I have become in my personal and professional life. My mother passed away during a crucial point in my life: close to graduating from high school and while I was making decisions as to what career path I would pursue. I feel that my decision to become a nurse was significantly influenced by my mother's disease and death. Although at times apprehensive with fear and disconcertment toward pursuing a nursing career, I began to realize that the life experience I had lived prepared me to be a unique and compassionate individual. I am not a stranger to emotional pain, grief, and loss. My experience prepared me to be gentle, yet determined; strong and unwavering when faced with obstacles and challenges.

Genetic Testing in Daughters of Women With Breast Cancer

As a young woman now, I worry about my own health. I have concerns about my own future and wonder if I, too, will someday have to battle this disease. I

wonder if knowing and being aware of my risk would be an advantage? However, I also battle with how much I really *want* to know from genetic testing. If I test positive, will I live the rest of my life in fear? This goes against how I have decided to live my life. In spite and, perhaps, in many ways, because of this pain and loss I experienced at a young age, I have learned to enjoy each day and not sweat the little things—to really appreciate the beauty of this world. Will my outlook on life change if I were to find out that I have the gene for breast cancer? Or is it simply irresponsible and naïve of me to not want to be tested? It is a dilemma that I and many other women face.

Adolescent daughters of mothers with breast cancer do express fears that they also will develop the disease (Azizi, 2009; Kristjanson et al., 2004; Mosher et al., 2006). Conto and Meyers (2002) pointed out that some women have misconceptions about developing breast cancer or their abilities to influence this risk through preventive strategies. Research has shown that "although knowing mutation status may provide a sense of control in life plans, it may alternatively create high levels of anxiety" (Hutson, 2003, p. 241). The decision to receive genetic testing is highly individualized and counseling must always accompany genetic testing as a supportive psychological measure.

Nursing Implications

Nurses can play an important role in monitoring adolescent daughters who accompany their mothers to medical appointments (Mosher et al., 2006). Stiffler, Haase, et al. (2008) asserted that parents often have little information on what their adolescents are dealing with, thinking about, or feeling when a mother has breast cancer. Information shared with adolescent girls should be directed toward their ability to verbalize their needs for information, their developmental age, and education levels. In Stiffler, Barada, et al. (2008), not one of the adolescent participants reported discussions taking place between themselves and healthcare providers. Adolescents have said that most of their information needs have not been met (Kristjanson et al., 2004). Nurses should practice family-focused care and assess the information and emotional needs of adolescents of mothers with breast cancer; including the effect of the illness, demands in the home setting, the transition to survivorship, fears of recurrent disease, the adolescent's needs during the terminal phase

of illness, and concerns about genetic counseling (Mosher et al., 2006; Stiffler, Barada, et al., 2008; Stiffler, Haase, et al., 2008). Research has demonstrated that effective coping by adolescents comes from a secure mother-child bond and open communication (Clemmons, 2009; Kristjanson et al., 2004), both of which nurses can influence with intervention and support.

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Clinical Highlights: Factors Influencing a Child's Inability to Cope With a Parent's Cancer Diagnosis

Coping and Adaptation

Research has identified factors that influence a child's inability to cope with a parent's cancer. An identified risk factor is when the parent of the same sex is ill. A child's age, gender, and cognitive maturity also has been found to affect the way a child responds to such a stressful situation (Compas et al., 1994). Lewis, Ellison, and Woods (1985) found that adolescents aged 14–19 years experienced conflicting feelings related to an increased amount of responsibilities, a decreased amount of social activities, and a desire to care for their mothers. Clemmons (2009) found that adolescent girls had a greater appreciation of the role that mothers play in the household when being faced with additional chores and taking some of their mother's responsibilities. Specifically, daughters of patients with breast cancer may experience additional stress related to increased psychological distress because of the thought that they have a two-to-threefold risk of developing breast cancer themselves (Offit & Brown, 1994).

Not all children will react the same way to a parent's illness and death—both positive and negative behaviors can arise. Mosher, Danoff-Burg, and Brunker (2006) assessed post-traumatic growth and found that the daughters of women who are breast cancer survivors can experience positive changes in their lives. Coping strategies such as planning, active coping, seeking social support, and processing emotions were found to be positive in contributing to growth; coping through denial was not. Another important factor to consider is whether the daughter of a woman with a breast cancer diagnosis is the caregiver. Mosher et al. (2006) found the effects of providing care to be beneficial provided that adequate coping strategies also were in place. Looking at each patient and the family's situation on an

individual basis can assist intervening in an appropriate and unique way.

Clinical Presentation

Children with a parent with cancer must be assessed closely to identify potential negative behaviors and consequences in the growth and development of the child. Affected children may demonstrate adjustment difficulties such as anxiety, depressed mood, low self-esteem, somatic complaints, and behavioral difficulties (Beardslee & Hoke, 1997; Hoke, 1996). Hoke (1996) identified four types of negative reactions to a parent's cancer—mood and self-esteem changes, academic performance changes, somatic symptoms, and social and interpersonal changes. Evidence of these negative reactions can be anger, fearfulness, anxiety, stomach aches, appetite and sleep disturbances, and loss of interest in social activities.

Implications for Nursing

Nurses possess the knowledge and psychosocial skills to assess and work with patients and their families. Northouse et al. (2002) suggested that nurses have the ability to monitor the psychological adjustment of daughters when they accompany their mothers to appointments and provide them with information regarding supportive services. Family-based programs that focus on coping can benefit mothers and their daughters. Nurses can direct daughters of women with breast cancer to high-risk clinics. Research has shown that genetic counseling yields higher rates of mammography, clinical breast examination, and breast self-examination in women with family histories of breast cancer (Watson et al., 2005). Therefore, nurses can give the patients and their daughters valuable tools to get through the immediate and long-term stressors of living through breast cancer.

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