When a woman is diagnosed with breast cancer, the diagnosis affects the entire family. More than 180,000 women are diagnosed with breast cancer each year (American Cancer Society [ACS], 2007) and half of these women are younger than age 60. Between 43,000–86,000 children younger than age 18 potentially are affected by this diagnosis, with as many as 30% of women who are diagnosed with breast cancer having at least one school-age or adolescent child in the home (Faulkner & Davey, 2002).

Adolescents who have mothers diagnosed with breast cancer experience many changes and threats to their way of life. These changes can result in anxiety and depression that cause difficulties in their home, school, and social lives (Solvi & Ulsæt, 2003). Negative changes can be, in part, because mothers who have breast cancer have high rates of depression and treatment-related symptoms for up to or longer than two years after being diagnosed (Goldberg et al., 1992). When mothers have depression, it can impair their ability to parent, leaving adolescents to try to cope with their day-to-day stressors and increased burdens placed on them when their mothers are ill (Solvi & Ulsæt). Mothers with breast cancer may have less emotional availability, communicativeness, energy for supervision, consistency of discipline, and initiative and may have increased hostility, irritability, and coerciveness (Cummings & Davies, 2004; Faulkner & Davey, 2002; Stiffler, Haase, Hosei, & Barada, 2008). Adolescents find that when their mothers are depressed, they are less accessible or emotionally available. The normal routines in the home are disrupted and frequently the home and marriage experience increased tension (Elmberger, Bolund, & Lutzen, 2000; Lewis & Darby, 2003; Lewis & Hammond, 1996; Rayson, 2001; Solvi & Ulfås). Researchers also indicate that for men and women, adolescents’ views of the quality of the mother-adolescent relationship are a significant predictor of adolescents’ coping behaviors (Kliwier, Fearnow, & Miller, 1996). Adolescents tend to have lower self-esteem when they rate parenting quality as low (Lewis & Hammond). This article reports findings related to adolescent daughters’ experiences of being parented when their mothers have breast cancer. The data are part of a larger study of mothers’ experiences of parenting and adolescents’ experiences of being parented during the acute course of their mothers’ illness.

Purpose/Objectives: To examine the experiences of being parented when mothers are diagnosed and treated for breast cancer from the perspectives of adolescent daughters.


Setting: Participants were recruited from sites in Indiana and Arizona.

Participants: Eight adolescent daughters whose mothers had been diagnosed with and treated for breast cancer. Ages of the adolescent daughters at the time of diagnosis ranged from 10–15, with an average age of 13.5 years. Ages at the time of the interview ranged from 13–24 years.

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

Findings: 8 major themes were found: A 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, and Guarded Relief.

Conclusions: The daughters were struggling with changes going on in their lives. They found themselves in reversed roles with their mothers and felt conflicted between meeting their mothers’ needs and their own. Daughters required help in communicating their needs to their mothers and others.

Interpretation: Nurses can assist adolescent daughters of mothers with breast cancer to find useful information, discuss effective ways of communicating, and facilitate the use of positive coping mechanisms.

Key Points...

- Little research has focused on adolescents and their experiences when their mothers are diagnosed and treated for breast cancer.
- Adolescent daughters whose mothers have breast cancer clearly struggle with many issues during their mothers’ illnesses, including conflicting emotions of wanting to help their mothers and wanting to remain normal.
- Adolescent daughters need assistance to find developmentally appropriate information, communicate their needs, and develop appropriate coping mechanisms.
- Further research is recommended on facilitating open communication on sensitive issues and the development of interventions that might help daughters and their mothers regain a sense of normalcy.
Background

Adolescence is a particularly vulnerable time. When a parent is diagnosed with cancer, adolescents can experience increased depression and anxiety and decreased self-esteem (Miereau & Compas, 1996; Solvi & Ulfsaet, 2003). Researchers have examined the perception of the stressfulness of cancer, anxiety and depression, and stress response symptoms in children, preadolescents, adolescent children, and young adults who had a parent with cancer. They found that adolescent girls whose mothers had breast cancer reported more stress symptoms and their anxiety and depression scores were higher than all the other groups of adolescents, children, or young adults. The finding is consistent across studies (Davey, Gulish, Askew, Godette & Childs, 2005; Solvi & Ulfsaet). Across all types of cancer, adolescents scored higher for anxiety and depression symptoms than children or young adults. The more serious the illness, the higher the anxiety and depression and stress response scores (Solvi & Ulfsaet).

How the adolescent copes influences his or her ability to adjust to the experience (Compas, Worsham, Ey, & Howell, 1996; Yates, 1999). However, the coping mechanisms that adolescents and other family members use during the diagnosis and treatment process are not well identified (Compas et al.). For the most part, children and adolescents do have an accurate appraisal of their parents’ cancer. If adolescents perceive their parents’ cancer as life-threatening, they are more likely to use potentially maladaptive coping strategies (Compas et al.; Davey et al., 2005).

A child’s self-esteem and behavior occur within the context of a family (Faulkner & Davey, 2002). When a parent has cancer, and as illness-related demands increase, the parent-child relationship can be negatively affected, which in turn can affect the child’s adjustment and self-esteem (Hoke, 2001; Lewis & Hammond, 1996). Adolescent daughters of mothers with cancer often are significantly more distressed than adolescent sons because they tend to identify more with their mothers (Davey et al., 2005; Faulkner & Davey). The daughters want to support their mothers during their illness, yet may resent the intrusion and increased responsibilities (Davey et al.; Faulkner & Davey; Hoke). Daughters and sons are struggling at this stage of their development to form a separate identity. They may have feelings of guilt for trying to break away from the family at a time when they know that they are needed at home, emotionally and physically (Faulkner & Davey). Adolescents also may experience more distress than children because of their greater cognitive development, which makes them more aware of the implications of cancer for their parents and family (Compas et al., 1996; Davey et al.). Considering where adolescents are in their cognitive development at the time of their mothers’ diagnosis also is important (Davey et al.).

Few qualitative studies examine how adolescents cope and adjust to maternal breast cancer. Isel, Ersek, and Lewis (1990) found in semistructured interviews that the ways younger children and adolescents coped were different. Adolescents tended to downplay their mothers’ breast cancer, and when carrying on with “business as usual,” they became more involved in their homework and suffered from altered sleep patterns (Faulkner & Davey, 2002; Isel et al.). These coping strategies may be forms of avoidant coping mechanisms (Hoke, 2001; Isel, et al.). For the most part, quantitative measures and semistructured interviews with adolescents whose parents had cancer have been used to describe the coping efforts of adolescents. Qualitative perspectives on how adolescents adapt to the stress of parental cancer are lacking (Lewis & Hammond, 1996). Therefore, the purpose of the present study was to describe adolescent daughters’ experiences of beingparented when their mothers were diagnosed and treated for breast cancer.

Methods

Approach

An empirical phenomenologic research approach was used for the study. Phenomenology seeks to describe the meanings of experiences from the perspective of the person experiencing them (Oliver, 1982). In empirical phenomenology, the researcher brackets preconceived ideas about the phenomenon of interest during data collection and analysis to discover the meanings underlying the statements with narrative stories of experiences provided by participants (Giorgi, 1997). Phenomenology is useful to describe the commonality of a phenomenon across participants; in this case, parenting experiences of mothers with breast cancer. This commonality is referred to as the essential structure of the experience, whereby the key factors common across caregivers are elucidated (Giorgi).

Participants

The purposive sample, obtained from clinical and community sites in Arizona and Indiana, included the daughters of women who had been diagnosed with stage 0–III breast cancer and had completed their treatment. The daughters were ages 10–15 during the time of their mothers’ diagnosis and treatment for breast cancer.

Because phenomenology seeks to identify the commonalities of experiences even among diverse samples, no attempt was made to control for variables such as education, religious preference, socioeconomic status, marital status, or cultural background. A sample size was not predetermined and participants continued to be interviewed until a redundancy was reached in identification of theme categories, that is, determined that no new themes were being added. To obtain participants’ descriptions across the continuum of the acute phase and immediately after treatment and still have the experience close enough in time to provide adequate recall, participants initially were recruited whose mothers had completed their treatment within the previous two years of being interviewed. Participants’ memories of their experiences were very vivid, so recruitment was expanded to include two additional participants whose mothers were further out from their initial diagnosis and treatment. These daughters also provided data rich in meaning and expanded the data base to include perspectives of the longer-term consequences of being parented when their mothers were dealing with breast cancer.

After obtaining institutional review board approval of the study, members of the research team worked with oncologists who specialize in breast cancer treatment and their staff members to identify women with breast cancer who had adolescent daughters who met the criteria for participation. Staff members obtained permission for someone on the research team to contact the mothers. Both mothers and
daughters needed to be willing to participate to be included in the larger study.

Once the agreement to participate was obtained, a time and place for an interview that was convenient to participants was established. Most interviews were accomplished in the participants’ homes; however, one interview was conducted in a room at the university library and another was performed in the office of one of the authors. To allow her to reflect on the experience, the data-generating questions were provided to daughters at least three days ahead of the scheduled interview. At the time of the interview, the purpose of the study was reviewed, informed assent and consent were given by participants, with the consents signed by mothers if daughters were younger than 18.

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. To do this, a minimum number of broad data-generating questions were asked, beginning with, “Please tell me about your experience of being parented when your mother was diagnosed and treated for cancer.” Probes such as “Tell me more about that” were used to facilitate a full description of the participant’s 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 research team or professional transcriptionists transcribed the audiotapes and checked for accuracy by members of the research team. The research team collaborated on further analysis. The data from the first six participants were analyzed using a procedure adapted from Colaizzi (1978). Significant statements were extracted and restated in a more general language of science; meanings then were formulated. Common meaning themes across the participants’ data were identified and organized into clusters and categories. The themes, clusters, and categories were developed into a full narrative description from which the conceptual structure was developed. Trustworthiness and credibility were enhanced in several ways: (a) using a systematic, step-by-step process to reduce the likelihood of premature closure to analysis; (b) maintenance of an audit trail of the analysis whereby each theme could be traced back to the original statement in context; (c) training of the research team by one of the authors, who has extensive experience in the method; (d) collaborative analysis among all members of the research team; and (e) comparing the findings from the first six participants with the additional two participant interviews. These participants’ experiences reflected the identified themes as well.

Results

Sample

The sample consisted of eight adolescents. Ages at the time of their mothers’ breast cancer diagnosis ranged from 10–15 years ($\bar{X} = 13.5$) with age at the time of the interview of 13–24 years. The mothers’ stage of cancer at time of diagnosis ranged from 0–III. Six of the mothers had completed treatments 1–2 years prior to the interview; two mothers had completed treatments 11–12 years prior. Participants had 1–4 siblings ranging in age from 2–24 years at the time of the interview. Ages of the mothers at the time of diagnosis ranged from 37–46, with an average of 38.2 years, and their ages at the time of the interview were 42–54.

Approximately 800 significant statements were extracted from the data and analyzed. They were organized into 78 themes and 36 theme clusters. Theme clusters then were organized in the following eight major theme categories: A 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, and Guarded Relief. Figure 1 shows the theme categories with related theme clusters.

A World Turned Upside Down

The daughters could vividly describe the experiences surrounding their initial finding out about the cancer, and they often linked their experience of finding out to a significant date, such as Christmas, Thanksgiving, or a birthday. Daughters’ responses to finding out about the cancer were tempered by whether or not they knew others with cancer and the nature of the previous experiences (e.g., whether someone they knew had done well or had died from cancer).

As the daughters came to an awareness of the reality of their mother’s cancer, they had a jumble of thoughts and emotions. They initially reacted with a sense of unbelief that such a horrible thing could happen to their mothers. They then began to experience the fears of potentially losing their mothers to death, “It just happened so fast, and it just felt like this couldn’t happen to me, not my family, why my family?”

The initial reactions of denial and then fear that their mothers would die were accompanied by or grew into a realization that their mothers’ illness not only affected their mother but profoundly affected them as well. They pondered what the actual implications of the illness would be for their mothers and how the cancer would affect them, their life goals, and activities, “I was mad at first, but then realized it was happening to her, not me. But we were all going through it with her.” The daughters had a profound sense of impending change in how life was to be—a loss of childhood innocence—everything seemed different.

The daughters had a realization that now nothing could be taken for granted. Routines became unpredictable. The daughters felt a sense of obligation yet also experienced a desire to help out by taking on additional responsibilities. Regardless of how they felt, the participants’ normal social lives were in danger of being interrupted in very significant ways.

I was in eighth grade, getting ready for high school. I had all this stress with friends, relationships, and school. I can’t deal with this now.

I just needed her to be normal. I needed her to be like all the other moms. I had to help out a lot more around the house. It made me mad. I would just do it so I could go out and play.

Stop the Intrusion—Need to Get Away—Reluctant to Leave

Participants felt both a pulling toward and a need to push away from the situation. Cancer was intruding on their lives and they tried to ignore it or tried to get away or escape from
A World Turned Upside Down
- Time stands still
- It was happening to her, but we were all going through it.
- Linking with significant date
- An awakening about the seriousness of cancer
- The surface of the reality was not the true situation
- Losing hair was traumatic
- Surgery was scary
- Emotions running the gamut

Stop the Intrusion—Need to Get Away—Reluctant to Leave
- Trying to ignore the cancer
- Avoiding the cancer’s intrusion on my life
- Not wanting others to know
- It is not okay to be sick
- Defiance
- Losing the hub of my life

Mom Can’t Die
- Treatments will save her
- Fear of the unknown
- What happens if she does die?

A Hole Where Mom Used to Be
- Pretending there is not a hole
- Mom trying to hang on
- Mom trying to reassure adolescent
- Some days are almost normal.
- Mom has dropped out.
- Mourning who mom used to be
- Mom is no longer the one to rely on.
- Helplessly watching

Filling in the Hole Where Mom Used to Be
- Collective effort
- Trying to be the hub of the household
- Managing mom
- Filling in the hole with outside activities

Being There for Mom—Managing Mom
- Getting closer to mom
- Sometimes I can not be there for her.

Managing My Reactions—Being Selfish or Difficult
- Desire to be normal
- Finding guideposts
- Expressing all shapes and sizes of anger
- Seeking reassurance
- Educating self about cancer

Guarded Relief
- Mom feeling better
- Finishing treatment
- Mom persevered
- Finding a meaning
- Watching mom return
- Keeping some things different

Figure 1. Daughter Theme Categories and Clusters

the unpleasantness of home, their mothers’ illness, the added responsibilities, and missing out on activities.

I had other things to do. I did stuff with my friends. I had a job. I just did stuff that a normal teenager would do. Not a teenager with a mom with breast cancer. I didn’t want to be involved in it. I just stepped aside and let everything continue on the rest of my life and let everyone else live their lives and not have to constantly be thinking about how it was going to affect me every day.

Mom Can’t Die

The daughters faced the possibility of their mothers dying in an approach-avoidance way. As they watched the treatments and side effects, they were hopeful that the treatments would keep their mothers from dying, while feeling that the treatments were too awful for their mothers to endure. The daughters came to realize that their mothers could die in several ways: from the cancer spreading, from the side effects, or from having a car accident from being too tired from the treatments to drive safely.

The daughters also thought about what would happen if their mothers did die. These thoughts ran a gamut of considerations, including financial ones and how they would pick up where their mothers left off in terms of responsibilities such as housekeeping, siblings, and other ways the mothers cared for their families. The primary conclusion of this internal dialogue was a hopeful denial—I do not think, cannot think that she will die.

When she wasn’t around, if she wouldn’t survive, I’d just have to live with my dad and brother, and she is the only one who shops with me. She always knows the sale items. Well, I was scared.

A Hole Where Mom Used to Be

The daughters spoke of how their mothers tried to proceed through their days as though the cancer and its treatment did not affect them by keeping their usual schedules and routines at work, around the house, and with the family. Some days this “covering” worked and the mothers seemed almost normal; the daughters felt reassurance that things would be okay. At other times, the daughters stood helplessly by, watching their mothers slip away into the grueling treatments and devastating side effects.

As the mothers became sicker from their cancer treatments, they had to relinquish some, and at times all, of their maternal duties. The daughters mourned the loss of their mothers as they had known them. They felt profound loss related to not being able to rely on their mothers, loss of their mothers’ companionship, and loss of their mothers’ involvement in their everyday activities.

I think I just needed attention from my mom. Others can give you as much attention, but it is not the same. When you are 14 years old, they can give you attention but they don’t understand the kind of attention that you need.

Filling the Hole Where Mom Used to Be

The daughters experienced a sense of responsibility placed on themselves or by others to fill in the hole where mom used to be. They felt they had assumed a great many of the household responsibilities. Examples included household chores, cooking, cleaning, childcare for younger siblings, and driving themselves to activities. The daughters felt the heaviness of these responsibilities to the point that often they felt they were responsible to hold everything together. Frequently, the daughters did not appreciate this added burden on their lives.

My sister and I did a lot of cooking because [mom] couldn’t stand the smell of food, and we did a lot of cleaning. Mom would just sit down and go to sleep. She’d just quit. When she did that it made all of us angry because she wasn’t stickin’ around for us.
Being There for Mom—Managing Mom

As well as managing the household, some of the daughters felt the responsibility of managing their mothers and their care. These daughters acted almost as home health nurses for their mothers, managing their mothers’ medications and appointments. They were very protective of their mothers, trying to shield them from emotional upset, keeping their schedules clear, making sure that they rested, and running interference with friends. They would check in on their mothers frequently throughout the day to make sure they were doing well. By taking care of their mothers, the daughters learned to put others ahead of themselves. They were trying to keep their mothers alive.

When she started losing her hair that was just the worst because she kept saying how she felt really ugly, and I just felt really bad, and I just kept saying, “Mom you are beautiful.”

At times, the daughters had to protect themselves. When they just couldn’t take being so close to the illness experience with their mothers any longer, the daughters found ways to keep themselves busy with other activities. By going out with friends and working, they tried to keep their outside life as normal as possible. Their home life seemed to be completely upside down. Their outside activities kept them grounded in normalcy.

Just like take your mind off things. Not having to be at home. Like having fun so you don’t have to worry about it, think about it. If you have nothing to do you are just thinking about it, but if you are off with friends having fun you don’t think about it at all.

Managing My Reactions—Being Difficult or Selfish

The daughters struggled to find reactions that were acceptable to themselves and others. They vacillated between positive reactions and less-than-positive ones and often withdrew completely when they couldn’t manage their reactions. Sometimes emotions would just get the better of them.

I had been thinking about myself the whole time. If I was having a bad day, I would displace my anger on everything. She would ask me a simple question and I just couldn’t handle it—I’d just start yelling.

They also looked for guideposts, seeking stories of positive outcomes wherever they could. Guideposts were found in discussions with peers and adults with similar experiences who could help them make sense of the chaos or in God.

Knowing that everything was going to be okay, God was in control of the situation, and I didn’t need to worry about it. I kind of had that mindset. I just decided to be strong and let it happen.

Guarded Relief

Once the mothers successfully completed treatment, the daughters felt a sense of guarded relief. They celebrated the fact that their mothers had survived the cancer. They looked forward to returning to a more normal way of life.

I feel just glad everything is over. I feel a lot happier now. I can be back to my old self, and I missed that. I kept pushing people away and now I can just be happy . . . and not have to worry about this and put it behind me and know that it did happen and be proud of my whole family for getting through it.

Yet, the daughters also knew that their mothers were not completely safe; recurrence of the cancer could happen. As relieved as they were that the cancer was gone, in the back of their minds, they worried about the possibility of the cancer returning.

The daughters watched a renewal in their mothers after their cancer experiences. As their mothers’ health returned, the daughters watched the emergence of their “old” mom. They could return to doing “normal stuff.” Their energy, discipline, and companionship returned. Some of the daughters talked about a new respect for their mothers. They had watched their mothers fight the toughest fight of their lives and be victorious. They felt a sense of awe in what their mothers’ had accomplished.

Overall the daughters noticed a new twist on the “old” mother. Although their mother had returned to normal, there were some notable differences. The mothers enjoyed the little things again like driving their daughters to their activities. They celebrated life. The daughters hoped that these new attitudes would continue long after the cancer was just a distant memory.

Now that the immediacy of the cancer and cancer treatments was over, the daughters sought to find meaning in the experiences they had during their mothers’ illnesses. Some of the daughters described finding a voice for breast cancer survivorship by becoming activists, teaching others about breast cancer, and preventive measures. Breast cancer became the focus of numerous school papers. The daughters wanted to prevent others from having to go through what they experienced. Many of the daughters voiced a concern for keeping themselves healthy and were aware of the genetic component of breast cancer. They were interested in screening and detection for breast cancer, seemingly preparing themselves for the future.

Discussion

Findings from the study indicated that adolescent daughters whose mothers had been diagnosed with and treated for breast cancer were dealing with numerous issues.

A World Turned Upside Down

The daughters in the study clearly were struggling with the dramatic changes that were going on in their lives. The findings support those of previous researchers. As in the present study, other researchers found that children who experience changes in their lives related to cancer or sudden illness frequently show signs of anxiety and depression (Solvi & Ulfisaet, 2003). They struggle with symptoms such as depressed mood, anger, lower self-esteem, somatic and behavioral problems (Hoke, 2001), and increased family conflicts (Faulkner & Davey, 2002). These symptoms are even worse when the child is an adolescent (Davey et al., 2005; Solvi & Ulfisaet), and adolescent daughters have a more difficult time dealing with the stressors than adolescent sons (Chalmers et al., 2000; Davey et al., 2005; Faulkner & Davey, 2002; Kristjanson, Chalmers, & Woodgate, 2004). Consistent with the literature, the adolescent daughters in the study had many
demands on their lives from family, school, social, and developmental stressors. They had to cope with the added stressors and demands of a parental illness and their lives were thrown completely out of balance (Davey et al.; Solvi & Ulfsaet).

Researchers have shown that the family’s ability to adapt to the stressors related to the mother having breast cancer is correlated with the level of family adaptation (Melton & Northouse, 2001). A family with fewer available resources perceives the mother’s diagnosis of cancer as more threatening (Melton & Northouse). When the adolescent daughter is older and closer to leaving home, research indicates that she is better able to adapt than younger adolescents (Wellisch, Schain, Gritz, & Wang, 1996). Parents often underestimate their adolescent daughters’ ability to adapt to the cancer diagnosis (Forrest, Plumb, Zieblick, & Stein, 2006). Frequently, adolescents deal with stressful situations by becoming detached or by isolating themselves, which can lead the parents to believe that their adolescent is unaffected (Forrest et al.). Similarly, the adolescent daughters in the study often chose, at least briefly, to escape from the cancer by ignoring it or getting out of the house.

Stop the Intrusion—Need to Get Away—Reluctant to Leave

The daughters in the study were frequently conflicted between anger and guilt. They knew that they needed to help their mothers around the house, yet they had a need to protect themselves. They frequently needed to get out of the house, yet felt guilty that they were not there to help out. As with the subjects of the present study, other researchers found that adolescent daughters frequently feel torn between what they want and need to do as adolescents and the demands of their mothers’ illness (Davey et al., 2005; Faulkner & Davey, 2002). This conflict makes the adolescent more vulnerable to emotional distress (Faulkner & Davey). Adolescent daughters especially are prone to this distress because they want to support their mothers during their illness, yet they feel anger and resentment for the interference with their normal activities. This could cause the daughters to withdraw from their mothers (Davey et al.; Faulkner & Davey). Mothers also are more likely to make demands for support on their daughters than on their sons. Because of this, mothers may report more dramatic and rejecting responses from their adolescent daughters (Faulkner & Davey; Stiffler et al., 2008). Similar to findings in the present study, adolescents of both sexes looked to outside activities to help them cope with the situation at home (Hoke, 2001).

Adolescents have a developmental need to begin separating from their families, yet when their mothers have breast cancer, completing this developmental task is difficult. As in the present study, many adolescents report feelings of guilt because their normal lives are continuing outside of the home while their mothers are left to suffer (Kristjanson et al., 2004).

The adolescent daughters in the study coped in many ways, by using faith, humor, talking things out with others, distraction, positive thinking, and keeping busy with outside activities. Davey et al. (2005) documented similar ways of coping. Solvi and Ulfsaet (2003) discussed a common strategy used by adolescents when dealing with the increased demand. They labeled this process “going in and out.” In “going in and out,” adolescents can leave the situation, emotionally and literally. They can get away from what is going on at home, gain a respite and, when feeling renewed, can return better able to deal with their responsibilities again (Solvi & Ulfsaet).

Mom Can’t Die

The daughters in the study struggled to find someone with whom they could talk about their mothers’ breast cancer and their fears that she might not make it. They did not want to burden or distress their mothers with their needs. They needed help making sense of the chaos that was now controlling their lives. The daughters’ needs were very similar to those found in other research studies. The adolescents in the studies reviewed wanted to be able to talk about their mothers’ cancer when they wanted or needed to, but they did not want to be constantly asked how their mother was doing. They avoid talking with school counselors or teachers because they did not want to be asked on a regular basis, thus being constantly reminded of their mothers’ cancer (Davey et al., 2005). At the same time, they wanted their teachers to know about their struggles so that if they were particularly quiet or moody, the teachers would understand (Kristjanson et al., 2004). Researchers also indicated that adolescents have a need to talk to other adolescents who have had similar experiences to know what to expect (Davey et al.). They want access to a therapist to talk and to help them develop positive coping skills but not necessarily to receive advice from them (Davey et al.).

Being There for Mom—Managing Mom

The daughters in the study related how frequently they had to take on some of the responsibilities and roles that their mothers had relinquished because of their cancer illnesses and treatment. They mourned the loss of their mothers in this capacity, and often felt anger over having to take on more responsibilities. With the anger also came guilt for feeling this way. These feelings of adolescent daughters when a parent has cancer also have been reported in the literature. For example, several authors discussed how frequently older children, out of necessity, take on the roles of caregiver to younger siblings, housekeeper, cook, and other household roles (Davey et al., 2005; Faulkner & Davey, 2002; Stein, Riedel, & Rotheram-Borus, 1999; Yates, 1999). Stein et al. called this phenomenon the “parentification” of adolescents. The authors warned that although the role of caregiver often is necessary, the adolescent does experience some disadvantages. “Parentification” may be very demanding, causing the adolescents to become overburdened with their responsibilities and keeping them from achieving their own developmental tasks, possibly leading to negative mental and health consequences (Faulkner & Davey; Stein et al.).

Managing My Reactions—Being Difficult or Selfish

The daughters in the present study struggled to find reactions that were acceptable to themselves and to others. They wanted to do right by their mothers and by themselves, but frequently, their reactions were not positive. This often led to them withdrawing from the situation. In the literature, adolescents described their mothers’ breast cancer experiences as extremely negative. The cancer disrupted their family lives and major changes took place within their families (Solvi & Ulfsaet, 2003). Yet, the adolescents perceived that they were supposed to cope in a positive manner with everything that was happening around them. Faulkner and Davey (2002) described these events within the context of family systems theory. The condition of one family member influences every other family member. All members are interdependent with the others and what affects one family member, affects all. Hence, an adolescent daughter’s life is complicated by her mother’s breast cancer. As an
adolescent developmental task, daughters should be struggling for independence and forming a separate identity; however, in the context of a parent with cancer, daughters feel conflicted between desires to break away from the family and knowing that they are needed desperately at home (Faulkner & Davey). If they are not able to pull away, their self-concept might be negatively affected and also cause ambivalence and resentment (Faulkner & Davey). Similar feelings were discussed by the daughters in the present study.

Nursing Implications

Clearly, a need exists for developmentally appropriate communication interventions focused on the adolescent daughters, their mothers, and on healthcare providers. The developmental levels of the adolescents need to be assessed and communication and health-related information should take these levels into consideration. No “one size fits all” approach exists for communicating with adolescents (Faulkner & Davey, 2002; Forrest et al., 2006; Kristjanson et al., 2004; Stein et al., 1999). Adolescents need specific information regarding the cancer. They want to know that not all people with cancer die. They want to know about the treatments and the seriousness of the disease and they do not want to feel excluded from cancer-related conversations (Chalmers et al., 2000; Forrest et al.; Kristjanson et al.). Discussion about healthcare providers was markedly absent by the daughters in the study. Not one daughter mentioned that she had been helped or had talked with her mother’s healthcare provider. Several authors have asserted a need for assistance from providers, but none specifically discussed what providers are doing to help the adolescent children of the mother with breast cancer. Researchers indicated that adolescents do not feel they were supported by the medical team, which they feel is very important (Chalmers et al.; Forrest et al.; Kristjanson et al.). Finally, adolescents want to know that what they are feeling and thinking is normal and other adolescents are dealing with similar concerns and feelings (Davey et al., 2005; Chalmers et al.; Forrest et al.; Kristjanson et al.).

The study identified several areas of concern for adolescent daughters of mothers who have been diagnosed and treated for breast cancer and nurses are well positioned to assist adolescents through this difficult time. Adolescent daughters clearly struggled with many developmental, psychological, physical, and social issues within their families, with their friends, and at school. Nurses, whether in the school or in the oncology office, who have contact with adolescents whose mothers have breast cancer can help the adolescents locate information they identify as important, including ways to communicate effectively with their families and friends. The intervention developed by Lewis, Casey, Brandt, Shands, and Zalhis (2006) may be a starting point for a developmentally appropriate communication intervention for mothers with adolescent daughters. The current program is an evidence-based educational counseling intervention developed for the school-aged child. The intervention could be adapted to address the specific issues of adolescent daughters that are discussed in the study. Nurses also can identify and actively address problems that arise when an adolescent’s coping mechanisms are more negative than positive. Finally, by fostering a connectedness with the adolescent, nurses may be able to enhance an adolescent’s ability to seek answers to questions and ask for help when needed.

Conclusions

Most research studies that have examined children of mothers with breast cancer have focused on school-aged children. Although the amount of research that focuses on the adolescent child is growing, much can still be learned. The present study contributes to a beginning understanding of the difficulties experienced by adolescent daughters when their mothers are diagnosed and treated for breast cancer. Although qualitative research is not generalizable, these findings also could apply to adolescents whose mothers have other types of cancer.

Daughters of mothers with breast cancer clearly would benefit from having assistance in communicating with their mothers and others in an open manner about the sensitive issues they are facing. The study identified other areas in which continued research is needed. The study focused on adolescent daughters and their mothers. Research needs to focus on the fathers in these families and adolescent sons who may have similar yet unique needs. Also, further research is recommended on communication content and how communication influences the mother-daughter relationship in the context of mothers with breast cancer.

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References