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Losing Her: Children's Reported Concerns in the First Six Months of Their Mother's Breast Cancer Diagnosis

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Abstract

Background: Maternal breast cancer has a significant impact on the well being of school-aged children but we know very little about the concerns these children attribute to their mother's illness.

Objective: To describe child-reported illness-related concerns experienced in the initial 6 months of their mother's diagnosis and to identify any differences by age and gender of the child.

Methods: Data were obtained from 140 school-aged children (7-12 years) within 6 months of their mother diagnosis with Stage 0-III breast cancer. Children's written responses to an open-ended question were analyzed, "Think about a situation that has bothered you during the last month that had to do with your mom's breast cancer." Inductive content analysis was used to analyze the data using methods adapted from grounded theory. Trustworthiness of results was protected by coding to consensus, formal peer debriefing, and maintaining an audit trail.

Results: Losing Her, the core construct, was identified and organized the children's concerns in 4 domains: (1) her being away from me; (2) worrying about her; (3) seeing my mother be different; and (4) changing how things work.

Conclusion: All children reported illness-related concerns about which they were bothered. Even seemingly short-term treatment-related absences from the child were interpreted as difficult.

Implication for Practice: Findings from the current study add to nurses' awareness and knowledge about the concerns of school-aged children during their mother's initial treatment for breast cancer. Nurses are in a key position to provide services directly to the child or through the mother.

BACKGROUND

Breast cancer is the leading type of cancer among women in the United States in terms of both new cancer cases and deaths.¹ In 2018, an estimated 330,100 women will be diagnosed with invasive or *in situ* breast cancer and 22 percent of them will be mothers of minor

children.^{1, 2} Having a mother diagnosed with breast cancer places children at heightened risk for emotional problems such as depression, anxiety, withdrawal and behavioral avoidance, fear, and worrying.^{3–5} To best support children, it is essential to identify and understand their illness-related concerns when their mother is diagnosed with breast cancer. In the absence of that understanding, it becomes more difficult to identify and deliver the appropriate programs or services.

An illness-related concern is defined as the actual and potential issues, thoughts, or feelings that the child explicitly attributes to the mother's illness. There are only 5 known qualitative studies to have documented school-aged children's illness-related concerns about their mother's breast cancer.^{6–10} Only 2 of these 5 studies focus explicitly on concerns of children aged 7–12.^{7,10} Instead, the majority of studies contain data obtained on adolescents or include aggregated data from both adolescents and school-aged children, making it impossible to extract information about the specific concerns of school-aged children.⁴

If we overlook the issue of age and include results from all 5 studies, children's reported concerns can be organized into seven main areas: the mother dying from the cancer^{6–10}, disruption to family routines^{6–10}, the mother's medical treatment and hospitalization^{6–10}, the effect of the cancer on the mother's well-being^{6,7,10}, the mother's illness getting worse¹⁰, the child's uncertainty and confusion^{6–10}, and fears of getting the cancer themselves.^{6,10}

There are no studies that have examined the relationship between the child's age and gender and their attributed illness-related concerns to their mother's breast cancer. Some evidence suggests that the child's age and gender may influence their well-being and psychosocial adjustment.^{5,11} For example, higher levels of anxiety and adjustment difficulties were reported in older daughters of mothers with breast cancer.¹² Similarly, female children reported a greater frequency of depressive symptoms compared to male children in both mothers with breast cancer and a healthy control group.¹² However, in a systematic review of predictors of child psychosocial adjustment, neither age nor gender was a significant predictor.¹³

The current study has 2 purposes: (1) to describe, in the children's own words, the illness-related concerns they attribute to their mothers' breast cancer within the first 6 months of the mother's diagnosis; and (2) to explore the relationship between the child's reported illness-related concerns and the child's age and gender.

METHODS

Study Eligibility

Data for the current study were obtained from baseline data collected from 140 school-aged children aged 7 to 12 years who were enrolled in a Phase III randomized control trial that tested the efficacy of a cancer parenting program (reference withheld to de-identify authors). Children were eligible for inclusion if they had a mother who was diagnosed with early-stage breast cancer (Stages 0–III) within the past 6 months, read and wrote English among their languages of choice, and had a mother who was in a committed intimate relationship

with a partner. Study participants were enrolled from 6 US states: Washington (WA), California (CA), Pennsylvania (PA), Minnesota (MN), Arizona (AZ), and Indiana (IN).

Study Procedure

After approval from the Institutional Review Board (IRB), members of the study team contacted eligible mothers by phone; mothers were read an IRB-approved enrollment script and were invited to ask any questions about the study they wished. If the diagnosed mother agreed to participate, she was asked to obtain her school-aged child's agreement to participate in the study. Pending the child's indication of willingness to participate, members of the research team obtained signed informed consent and assent documents in participants' homes and provided baseline questionnaires. Specially trained data collectors were instructed on a standard way to administer the children's study measures. The children were unaccompanied by their mothers while they completed the questionnaires privately. The children independently wrote about their illness-related concerns regarding their mother's breast cancer with one exception. A research assistant was trained to assist children who were unable to read or write by acting as the child's secretary, writing down the child's exact words as the child dictated them. Data analyzed in the current study were limited to the child's written response to an open-ended question: "Think about a situation that has bothered you during the last month that had to do with your mom's breast cancer." After that question, the child was asked to write his or her response in the space provided.

Data Analysis

Data analysis involved 6 phases. First, each child's written text was transcribed verbatim from their respective questionnaires and verified for accuracy. These texts were read through several times by the senior author to become immersed in the data. Next, inductive content analysis was used to code these data using methods adapted from Glaser and Strauss and extended by Lewis and Deal and others.¹⁵⁻²¹ See Figure for details of the analysis process.

Data were initially unitized: a complete idea from the child's transcribed text was identified as a unit. After unitizing the data, all units were organized inductively through open coding and categorizing. Categorizing involved placing the units into groups in which the units shared a common property and labeling each category with the participant's own words. The third phase, constant comparative analysis, extended throughout the entire coding process. This involved a comparison of each unit within a category in terms of its fit with that category compared to its fit with all the other categories. This process refined the categories and protected the unique and non-overlapping quality of each category. Next, the refined categories were grouped into higher-order conceptual domains, each of which was defined. Constant comparative analysis was again carried out to protect the unique and non-overlapping qualities of each domain. Before identifying the final set of domains and definitions, the domains were reexamined to further increase parsimony. The core construct represented the main overarching construct that further organized and explained all the domains and categories, adding to the parsimony of the coding.¹⁷ In the last step of the analysis, domains and categories were organized into groups by age and gender of child.

The trustworthiness of study results were protected through every phase of the coding process by coding to consensus, peer debriefing, and maintaining an audit trail.^{17,19,21,22} The authors worked to obtain 100% consensus between the primary coder and peer debriefer.^{18,19,23} Peer debriefing involved: (1) examining the fit of each unit of data with its category; (2) verifying that all categories were unique and non-overlapping; (3) assessing the accuracy of each domain's definition; (4) comparing each unit with all other categories in order to verify the accuracy of its placement within the chosen category; and (5) verifying the fit of each category with its designated domain.

RESULTS

Sample Characteristics

Children in the study sample averaged 9.85 (*SD* 1.52) years of age and were almost equally distributed by gender: 74 (52.9%) females and 66 (47.1%) males in second through seventh grade in school. The majority of the diagnosed mothers were Caucasian (*n* = 177, 83.6%) and all mothers except one had completed some college education or higher (*n* = 139, 99.3%). Mothers averaged 43 years of age (*SD* 4.93) and had been married for an average of 16.4 (5.82%) years. Mothers had been diagnosed for an average of 3.90 (*SD* 2.10) months at entry into study; the majority (*n* = 85, 60.7%) had Stage II or III breast cancer while 55 (39.3%) had Stage 0-I breast cancer. Most of the mothers (*n* = 107, 76.4%) were receiving chemotherapy and 59 (42.1%) were receiving radiation therapy at the time of the children's participation in the study.

Losing Her was the core construct that explained the children's reported illness concerns about their mother's breast cancer during her first 6 months of diagnosis and treatment. Although children expressed a number of concerns related to their mother's cancer, the content of those concerns centered on the children's view that they were losing her in some way. Children used different words to express their negative feelings about what they were experiencing because of their mother's breast cancer such as worried, scared, and sad. Losing her was sometimes temporary when she was away at the hospital, sick in bed after chemotherapy, or having surgery. Some children were bothered by the possibility of losing their mother permanently; thinking she might die or that something might go wrong after surgery or treatment. Changes in their daily routines, family activities, and their time with her were all additional aspects of "losing her" which were featured in the children's writing.

The core construct of *Losing Her* encompassed 4 domains: (1) her being away from me; (2) worrying about her; (3) seeing my mother be different; and (4) changing how things work. See Table for a summary of domains, categories, and the distribution by gender of child. A detailed description of each of the domains follows, including categories, and illustrative verbatim written text from the children. Participant's code number, gender, age, and the state from which each participant was enrolled follow each child's quote.

Her Being Away from Me

Children felt extremely worried when the illness caused their mother to be physically separated from them. They were also concerned about the possibility she might die from the

cancer and that they would lose her permanently. Three categories were included in this domain: (1) going to her doctor's appointments or the hospital; (2) waiting for her; and (3) worrying she might die.

When asked what bothered them about their mother's cancer, one child wrote, "I didn't like my mom leaving home overnight at the hospital" (MN1024, F, 7 yr.). Others indicated, "When my mom is in the hospital, I feel different" (WA 1036, F, 11 yr.) or "She had to go to the hospital for a couple of days" (MN1026, F, 11 yr.). Needing to wait for their mothers was a source of distress. Two children described how this bothered them: "The waiting is what bothered me the most" (CA1002, F, 11 yr.); "One day my mom left; I was very scared that she would die" (WA1032, M, 8 yr.). Many children struggled with the possibility of their mothers dying from cancer: "Sometimes I worry because I think that she might die" (WA1008, F, 10 yr.). Another child wrote, "The situation that has bothered me is that I think about how we are going to live without her if she dies" (AZ1003, F, 10 yr.).

Worrying about Her

The majority of children feared for their mother's well-being. These concerns extended beyond the cancer to the impact of the disease and its treatment on their mother. They explicitly described the consequences the cancer and its treatments had on their mothers. This domain included 4 categories: (1) getting her chemotherapy and becoming sicker; (2) thinking about her surgery; (3) seeing her sick and staying in bed; and (4) worrying about something going wrong.

Children were concerned about their mother's chemotherapy: "Seeing her get chemotherapy bothered me" (CA1032, M, 9 yr.) and were bothered when their mothers felt worse after treatment. They wrote, "It makes me mad that she's already feeling sick and the shots and pills make her feel even more sick" (WA1025, F, 10 yr.) and "My mom had chemo and because of the chemo her legs and hips hurt a lot and that scared me" (MN1009, F, 8 yr.).

Most male participants worried about their mother's surgery; one child said he was concerned about her surgery and thought about it every night. In his words, he was "Thinking every night about the surgery" (PA1006, M, 11 yr.). Another boy wrote that he was concerned about the outcome of his mother's surgery: "What would happen when she was done with surgery, like if they did something wrong, then I was worried" (MN1018, M, 11 yr.).

Witnessing their mother sick, not feeling well, or being sleepy in bed disturbed many children; as one wrote, "It makes me mad that she's already feeling sick" (WA1025, F, 10 yr.). Another girl offered, "Mom sleeps more because of breast cancer" (PA1028, F, 8 yr.). Other children worried that doctors were going to do something bad to their mothers or that the cancer might spread. One boy wrote this about what bothered him the most: "That one cancer cell will be left after surgery and will sneak and multiply" (WA 1003, M, 11 yr.). Another wrote: "I am afraid if the people working with her permanently damage her body" (WA 1027, M, 11 yr.).

Seeing My Mother Be Different

Children were concerned when their mother appeared physically and emotionally different compared to how they knew her before the illness. Two categories made up this domain: (1) looking different to me and (2) seeing her afraid, crying, and irritable

Children were scared when their mother seemed different to them. One girl described her mother after surgery in this way: “After my mom’s surgery we went to visit her in the hospital—she was so pale and helpless-looking in the bed, that scared me”(MN1011, F, 12 yr.). Observing the mother losing her hair was a concern for many children, especially boys. One wrote, “When my mother lost her hair due to chemotherapy I was sad” (AZ1010, M, 8 yr.). Another stated, “My mom’s hair loss bothered me” (WA1038, M, 11 yr.).

In addition to the physical symptoms they observed, children, mostly girls, were concerned about their mother’s feelings. One child said, “I’m also worried about her feelings” (PA1002, M, 8 yr.); one girl raised the question, “What if my mom will not be happy?” (CA1006, F, 12 yr.). Other children noticed how their mothers became irritable. One girl wrote, “She becomes irritable, grouchy more now as compared to when she didn’t have breast cancer” (MN1005, F, 12 yr.).

Changing How Things Work

Several children were bothered by changes in their everyday life as a family, their daily routines, their care, and when their mother was unable to do what she usually did before the illness. This domain consisted of 2 categories: (1) being unable to do things like before, and (2) not taking care of our family or me.

When the cancer prevented the mother from joining the family in activities, more girls than boys were bothered. One girl wrote, “She can’t come to California for vacation with the rest of family as planned” (AZ1007, F, 9 yr.). A boy wrote, “We couldn’t go to the beach on the weekends anymore” (CA1013, M, 12 yr.). When things changed at home, children were concerned: “Sometimes my mom had to stop doing the dishes” (AZ1011, M, 7 yr.). Another child wrote that he was “bothered by how the house is going to get clean due to this cancer” (MN1003, M, 11 yr.). Some children were upset when they had to help in the house. One child said she was concerned about her “mother not doing what she usually does. She can’t do what she used to do; the rest of the family has to help” (CA1007, F, 7 yr.).

Children described the changes that affected their time and activities together with their mother, comparing this to before the mother’s illness. Children listed some of the changes that bothered them: “Mom can’t play with me as much as she could when she wasn’t sick” (WA1001, M, 8 yr.); “I feel different because usually she reads me stories, watches movies with me” (WA1036, F, 11 yr.); and “She could not ride bikes with me; it made me sad” (IN1009, M, 10 yr.). Other children wrote no one was there to take care of them: “I had to go to my grandma’s house a lot because there was no one at home to watch me” (WA1040, F, 10 yr.).

Analysis by age revealed that all children, regardless of age, held the same illness-related concerns with two exceptions. Older children (11–12 years) were concerned or bothered by

observing emotional changes in their mother, including seeing her afraid, crying and irritable. School-aged children (7–10 years), more than older children, were concerned about how things changed at home. Results by child's gender revealed a higher proportion of female children reported concerns in two domains and two categories: "her being away from me", "changing how things work", "seeing her sick and staying in bed", and "seeing her afraid, crying, and irritable." However, male children reported a higher proportion of concerns in three categories: "thinking about her surgery", "worrying about something going wrong", and "looking different to me," (See Table).

DISCUSSION

This study is the first to obtain child-reported data on their attributed illness concerns from a large sample of children ages 7 to 12 years whose mothers were diagnosed with Stage 0-III breast cancer in the past 6 months. Written text from the children was transcribed verbatim and systematically coded, enabling us to identify concerns from the child's viewpoint. Study results revealed that most every aspect of the children's lives was affected by their mother's illness.

The core construct, *Losing Her*, depicted the real and symbolic loss of their mother in the children's own words, a process that was evident across domains and categories. Initially, when they were first made aware of the cancer, the children tried to hide it from others, including their peers. Being physically distanced from their mother during the mother's hospitalization bothered many children. Rather than viewing the hospital as a place to which their mother could get medical care, children worried about her during hospitalization. Would she be harmed? Would she die or not return home, adding to their worry about permanently losing her to death. In fact, the highest frequency illness-related concerns of the total sample were reflected in the domain "worrying about her" and its categories: getting her chemotherapy and becoming sicker, thinking about her surgery, seeing her sick and staying in bed, and worrying about something going wrong (Table). Once their mother returned from hospitalization, children saw her sick, tired, and staying in bed, all behaviors that were atypical compared to how they knew their mother before the cancer. Witnessing the side effects from chemotherapy made children wonder if the doctors were doing something wrong or if they were going to lose their mother due to the treatment. When the children saw their mother looking different, for example losing her hair or getting very ill, they became additionally concerned.

Children were observers of their mother's behavior, not just her overt physical changes. Both physical and behavioral changes led the children to believe they were going to lose her. Children worried about their mother's feelings and felt sorry for her when they saw her afraid or crying (IN1009, M, 10 yr.). They often associated her nervousness with the chemotherapy (CA1009, F, 9 yr.).

The children's fear of losing her physically and emotionally was reflected in their description of how the cancer intruded into their daily routines and family activities. Children "lost" the mother they knew before the cancer when the mother did not attend outdoor activities, stopped reading them stories, or did not clean the house. Their mother's

altered presence or participation in their care and routines made the children feel that they were left with no one to take care of them or their family. Some children wished their mother never had the cancer.

Study results can be further understood by examining their fit with two theories: Piaget's cognitive-developmental theory²⁴ and attachment theory.²⁵ At a manifest, rather than symbolic level, the children's written concern is their perception of what is affecting them that they explicitly attribute to the mother's disease. The developmental stage of the child is a filter and lens through which the child perceives and labels that concern. School-aged children under the age of 9, for example, are concrete thinkers who are focused on observables or behavioral cues;²⁶ they may be unable to comprehend treatment side effects and wonder why treatment is making their mothers worse.²⁷ Results from the current study corroborate this concrete thinking. For example, an 8-year-old boy wrote, "because of the chemo her legs and hips hurt a lot" (MN1009, F, 8 yr.). The ability of children to understand the illness and its consequences increases, as they grow older. Older school-aged children (i.e., from 10–12 years) frame the illness-related concerns in terms of their abstract thinking ability and generate potential causes for their mother's breast cancer.^{26–28} This more abstract thinking was reflected in our data, as when a 12-year-old girl was bothered when her mother's "white blood count is too low for her to take the treatment" (MN1017, F, 12 yr.).

The child-reported concerns in the current study tightly articulate with attachment theory; when a child is confident about the physical and emotional availability of the attachment caregiver, he or she develops a sense of security.²⁵ From this perspective, changes in the family environment and the child–mother relationship from the cancer threaten the child's security. The core construct of *Losing Her* clearly indicated that children's security was threatened by the mother's cancer regardless of the child's age and gender. Notably, when data were inspected by age of the child, there were no differences except in 2 domains: behavioral changes and changes to the status quo. In all other cases, the mother's real or symbolic changes or loss from the cancer affected children across all ages in the study sample.

When the child experienced the mother as physically or symbolically absent, the child called this out as a concern. Symbolic absence was reflected in the data on altered routines or the child's worry that there was no one to take care of them or their family. Physical absence was represented in the data by children who cued on the mother's symptoms, altered mood, or changed behavior. In short, the mother they knew before the cancer was not the same mother they saw or experienced after the cancer.

Study results corroborate previous findings^{6–10} in which school-aged children are mobilized by changes in the family routines, their mother's well-being, her chemotherapy, her hospitalization, and her dying from cancer. However, our study adds further insight into those concerns, indicating that they reflect the real or symbolic loss of the mother to the cancer rather than being isolated issues for the child. Study results also create a map of the child's reported concerns as a larger process in which the disruption of routines or the mother's symptoms becomes much greater than a list of concerns children reported.

The assumptive world of the child was challenged by the mother's illness. This was represented under the domain, "being unable to do things like before." Every detail of mother-child time or activity together was changed, including telling bedtime stories or riding bikes. Children were not merely bothered by changes caused by the cancer; their own emotional response to their mother's cancer was a concern for them. In the words of this child, "I am bothered because I feel sad, scared, or afraid."

Finally, results from the current study provide further insight into children's concerns by reporting on their immediate concerns within the first 6 months of the mother's diagnosis. In contrast, the two prior studies of school-aged children^{9,10} were likely affected by recall error; mothers in those studies were, on average, diagnosed 2 to 5 years previously.

Limitations

Study results are limited to the current study sample of school-aged children whose mothers were primarily Caucasian, highly educated, and married. Moreover, findings were based on self-reported written information that was obtained directly from the children through a single open-ended question. A single question cannot begin to capture the richness of the child's experience with his or her mother's cancer. Finally, responses may be confounded by the child's verbal or written skill at communication.

Implications for Practice

Study results provide two directions for practice: provide services directly to the child or provide services directly to the mother. Services to the child could include generating a child-friendly booklet that describes the normality of a child being impacted by their mother's illness; that concerns about the mother are common and are "normal," and do not reflect something bad or negative. Such a booklet could honor the children's diversity of concerns and feelings. At minimum, such a booklet should be read first by the diagnosed mother before the booklet is given to the child so that the mother could decide in what ways she would want to engage with the child about the booklet. Given the magnitude and scope of illness-related concerns that children wrote in the current study, nurses developing such a booklet would want to carefully consider how to introduce the booklet to the mother in order to not overwhelm her with its content. The structure and format of the booklet is beyond data obtained in the current study.

Nurses are in a prime position to augment the mother's skills and confidence to elicit and appropriately respond to their child's concerns. This recommendation is consistent with interventions by Lewis et al., Davey et al., and John et al.^{14,29,30}, all of which emphasized ways to enhance mother-child attachment through communication and interaction. Lewis et al.'s work offered detailed approaches by which a nurse could teach the mother to elicit and support a child's reported illness-related concerns.¹⁴ Davey et al.'s intervention involved bi-monthly support groups to encourage communication and attachment between school-aged children and their ill parents.²⁹ John et al. developed a family-centered inpatient program to improve the mother's and child's quality of life and psychological functioning.³⁰

Future work is needed by nurses to include the mother-child dyad in nurses' framework for practice. The current study's findings add to nurses' awareness and knowledge about the

concerns of school-aged children during their mother's initial treatment for breast cancer. Our hope is that study results illustrate that nothing in the course of diagnosis or treatment for breast cancer can be assumed to be neutral or positive in the eyes of the school-aged child.

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Figure.
Data Analysis Process

Table.

Summary of Domains, Categories, and Distribution by Gender of the Child

Domains and Categories	Number of Units	Frequency of Units by Gender	
		Male	Female
1. Her being away from me	34	11 (32.4%)	23 (67.6%)
Going to her doctor's appointments or the hospital	14	5 (35.7%)	9 (64.3%)
Waiting for her	6	1 (16.7%)	5 (83.3%)
Worrying she might die	14	5 (35.7%)	9 (64.3%)
2. Worrying about her	73	42 (57.5%)	31(42.5%)
Getting her chemotherapy and becoming sicker	27	15(55.6%)	12(44.4%)
Thinking about her surgery	12	9 (75%)	3 (25%)
Seeing her sick and staying in bed	21	8 (38%)	13 (62%)
Worrying about something going wrong	13	10 (77%)	3 (23 %)
3. Seeing my mother be different	33	16 (48.5%)	17 (51.5%)
Looking different to me	15	11(73.3%)	4(26.7%)
Seeing her afraid, crying, and irritable	18	5(27.8%)	13(72.2%)
4. Changing how things work	36	13 (34.6%)	23 (65.4%)
Being unable to do things like before	29	10 (34.5%)	19 (65.5%)
Not taking care of our family or me	7	3 (42.9%)	4 (57.1%)