Describing, Measuring, and Testing a Model of Illness-Related Concerns Among Children Experiencing Maternal Breast Cancer

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Abstract

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Background: Maternal cancer is a substantial source of stress for children. Children of diagnosed mothers are at heightened risk for depression, anxiety, withdrawal, and worrying. To best support these children, it is essential to identify, understand, and be able to measure the children's illness-related concerns. However, to date, very little is known about what concerns children and how those concerns might exacerbate adjustment problems. Furthermore, the field lacks a valid measurement of the child's reported concerns about the mother's cancer. In the absence of such understanding, it becomes difficult to design and deliver programs for children.

Purpose: The overall purpose of the dissertation was to address the gap in the literature about illness-related concerns from the perspective of school-age children experiencing maternal cancer. This dissertation comprises three studies, all of which include a sample of children (7–12 years) of mothers diagnosed with early stage breast cancer. *Study 1* described the experienced illness-related concerns reported by children in the first six months of their mother's diagnosis and identified differences by age and gender of the child. *Study 2* evaluated the content and construct validity of illness-related concerns children attribute to their mother's breast cancer and derived a brief version of a standardized scale to measure these illness-related concerns. *Study 3* tested a theoretical model examining the process through which the children's concerns about the mother's breast cancer influenced their anxiety three months later.

Methods: These studies are based on secondary analysis of data from a longitudinal randomized control trial of a cancer parenting program, the Enhancing Connections Program. Baseline data prior to randomization were used in all three studies; in addition *Study 3* used data from participants 3 months later. *Study 1* utilized inductive content analysis to analyze 140 children's written responses to an open-ended question asking the child, "Think about a situation that has bothered you during the last month that had to do with your mom's breast cancer". *Study 2* utilized confirmatory factor analyses to test and compare three hypothesized factor models of illness-related concerns in children of mothers with cancer guided by a preliminary literature analysis. Models were specified using data from 203 children who completed a 93-item self-report previously untested questionnaire (About My Mother's Illness Scale, AMMI). Based on conceptually informed decision rules, 18 items from the AMMI were selected as indicators to the factors for the three tested models. *Study 3* utilized structural equation modeling and bootstrapping to test the model. Mothers (N= 177) completed a standardized measure of depressed mood and children (N= 177) were assessed on their illness-related concerns, desire for psychological proximity, and anxiety after three months.

Results: *Study 1*: Losing Her, the core construct, was identified and organized the children's concerns in seven domains: (a) knowing about the cancer, (b) her being away from me, (c) worrying about her, (d) being unable to do things together, (e) seeing my mother be different, (f) losing her ability to do what she usually does, and (g) wishing she did not have cancer. *Study 2*: the multidimensional five-factor model revealed the best fit to the data. The five-factor model included five related yet distinct dimensions of illness-related concerns that the child attributed to the mother's cancer: (a) changes in family routines and resources, (b) uncertainty, (c) illness contagion, (d) mother's death, and (e) mother's well-being. *Study 3*: children's concerns were significantly associated with maternal depressed mood and the child's desire for psychological proximity. However, as the mother's depressed mood increased, the child's desire for psychological proximity decreased toward the ill mother. Children's unmet desire for psychological proximity significantly mediated the relationship between their reported concerns and their anxiety three months later.

Conclusions: This dissertation adds to our understating of illness-related concerns in school-age children of mothers with breast cancer and addresses the conceptual and operational limitations in the literature. The derived 18-item Child's Illness-Related Concerns Scale can benefit services and programs and assist in assessing and targeting specific dimensions of children's concerns. Consistent with attachment theory, findings revealed crucial pathways to be targeted by clinicians and future interventions for the adjustment of children experiencing maternal cancer. Alleviating the child illness-related concerns, minimizing the mother's depressed mood, and attaining the children's desire for proximity can prevent or reduce the risk of anxiety in children.

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Chapter 1. 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-age 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 six 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-age children (7-12 years) within 6 months of their mothers diagnosed with Stage 0-III breast cancer. Children written responses to an open-ended question were analyzed using inductive content analysis methods adapted from grounded theory. Trustworthiness of results was protected by coding to consensus, formal peer debriefing, and by maintaining an audit trail. **Results:** *Losing Her*, the core construct, was identified and organized the children’s concerns in seven domains: (a) knowing about the cancer, (b) her being away from me, (c) worrying about her, (d) being unable to do things together; (e) seeing my mother be different; (f) losing the ability to do what she usually does; and (g) wishing she did not have the cancer. **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:** The findings of the current study add to nurses' awareness and knowledge about the concerns of school age 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.

Introduction

Breast cancer is the leading type of cancer among women in the United States in terms of both new cancer cases and deaths (American Cancer Society, 2018). In 2018, an estimated 330,100 women will be diagnosed with invasive or *in situ* breast cancer and 22% of them will be mothers of minor children (American Cancer Society, 2018; Weaver, Rowland, Alfano, & McNeel, 2010). 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 (Ellis, Wakefield, Antill, Burns, & Patterson, 2017; Huang, O'Connor, & Lee, 2014; Purc-Stephenson & Lyseng, 2016). 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 issue, thought, or feeling that the child explicitly attributes to the mother's illness. There are only five known qualitative studies to have documented school-aged children's illness-related concerns about their mother's breast cancer (Forrest, Plumb, Ziebland, & Stein, 2006; Furlong, 2017; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Zahlis, 2001). Only two of these five studies focus explicitly on concerns of children aged 7–12 (Furlong, 2017; Zahlis, 2001). 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 younger children (Huang, O'Connor, & Lee, 2014).

If we overlook the issue of age and include results from all five studies, children's reported concerns can be organized into seven main areas: the mother dying from the cancer (Forrest et al., 2006; Furlong, 2017; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Zahlis, 2001), disruption to family routines (Forrest et al., 2006; Furlong, 2017; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Zahlis, 2001), the mother's medical treatment and hospitalization (Forrest et al., 2006; Furlong, 2017; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Zahlis, 2001), the effect of the cancer on the mother's well-being (Forrest et al., 2006; Furlong, 2017; Zahlis, 2001), the mother's illness getting worse (Zahlis, 2001), the child's uncertainty and confusion (Forrest et al., 2006; Furlong, 2017; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Zahlis, 2001), and fears of getting the cancer themselves (Forrest et al., 2006; Furlong, 2017; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Zahlis, 2001).

The effect of the gender or age of children on their attributed illness-related concerns is essentially unknown when investigating school-aged children of mothers with cancer. Some evidence suggests that children's age and gender may influence their well-being and psychosocial adjustment (Forrest et al., 2006; Furlong, 2017; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Morris, Martini, & Preen, 2016; Purc-Stephenson & Lyseng, 2016; Zahlis, 2001). For example, higher levels of anxiety and adjustment difficulties were reported in older daughters of mothers with breast cancer (Brown et al., 2007). 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 (Brown et al., 2007). However, in a systematic review of predictors of child psychosocial adjustment, neither age nor gender was a significant predictor (Table 1.1) (Krattenmacher et al., 2012).

[Table 1.1 here]

The current study has two purposes: to describe, in the children's own words, the illness-related concerns they attribute to their mothers' breast cancer within the first six months of the mother's diagnosis; and 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 7–12 years who were enrolled in a Phase III randomized control trial that tested the efficacy of a cancer parenting education program (Lewis et al., 2015). Children were eligible for inclusion if they had a mother who was diagnosed with early-stage breast cancer (Stages 0–III) within the past six 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 six U.S. 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 dictate or write his or her response in the space provided.

Data Analysis

Data analysis involved six phases. First, each child's written text from respective questionnaires was transcribed verbatim 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 (Corbin., Strauss, & Anselm, 2008; Elo & Kyngäs, 2008; Glaser & Strauss, 1967; Guba & Lincoln, 1985; Hsieh & Shannon, 2005; Lewis & Deal, 1995; Thomas, 2006). See Figure 1.1 for details of the analysis process.

[Figure 1.1 here]

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. After identifying the final set of domains and definitions, the core construct was inductively identified from the coded data. 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 (Lewis & Deal, 1995). In the last step of analysis, domains and categories were organized into groups by age and gender of child.

The trustworthiness of study results was protected through every phase of the coding process by coding to consensus, peer debriefing, and maintaining an audit trail (Grbich, 2007; Guba & Lincoln, 1985; Lewis & Deal, 1995; Thomas, 2006). The authors worked to obtain 100% consensus between the primary coder and peer debriefer (Elo et al., 2014; Hsieh & Shannon, 2005; Thomas, 2006). 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.

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 White (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 six 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 that 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 seven domains:

1. Knowing about the cancer.
2. Her being away from me.
3. Worrying about her.
4. Being unable to do things together.
5. Seeing my mother be different.
6. Losing her ability to do what she usually does.
7. Wishing she did not have cancer.

See Table 1.2 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 children. Participant's code number, gender, age, and the state from which each participant was enrolled follow each child's quote.

Knowing about the Cancer

Children were bothered when they were told about their mother's breast cancer or when they found out about it themselves. They also wished that other people, including friends, would not find out about their mother's cancer or even talk about it. The two categories in this domain were (a) being told she had cancer and (b) worrying about people finding out or talking about it. . One child said, "I felt sad when she first told me she had cancer" (MN1023, F, 10 yrs.). Children were concerned that other people would know or talk about the cancer; as one child offered, "I'm worried my friends will find out and I don't want them to" (PA1031, F, 12 yrs.). Another child stated, “I kind of wish people would not talk about it because it’s annoying and disturbing” (IN1012, F, 11 yrs.).

Her Being Away from Me

Children felt extremely worried when the illness caused their mother to be physically apart from them. They were also concerned about the possibility she might die from the cancer and that they would lose her permanently. Three categories included in this domain were (a) going to her doctor’s appointments or the hospital, (b) waiting for her, and (c) worrying she might die. When asked what bothered her about her mother’s cancer, one child wrote, “I didn’t like my mom leaving home overnight at the hospital” (MN1024, F, 7 yrs.). Others indicated, “When my mom is in the hospital, I feel different” (WA 1036, F, 11 yrs.) or “She had to go to the hospital for a couple of days” (MN1026, F, 11 yrs.). 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 yrs.); “One day my mom left; I was very scared that she would die” (WA1032, M, 8 yrs.).

Worrying about Her

The majority of children feared for their mother’s well-being. These concerns extended beyond the cancer to the negative impact of the disease and its treatment on their mothers. They explicitly described the consequences the cancer and its treatments had on their mothers. The four categories in this domain included (a) getting her chemotherapy and becoming sicker, (b) thinking about her surgery, (c) seeing her sick and staying in bed, and (d) worrying about something going wrong.

Children were concerned about their mother's chemotherapy: "Seeing her get chemotherapy bothered me" (CA1032, M, 9 yrs.) 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 yrs.) and "My mom had chemo and because of the chemo her legs and hips hurt a lot and that scared me" (MN1009, F, 8 yrs.).

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 yrs.). 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 yrs.).

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 yrs.). Another girl offered, "Mom sleeps more because of breast cancer" (PA1028, F, 8 yrs.). 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 yrs.). Another wrote: "I am afraid if the people working with her permanently damage her body" (WA 1027, M, 11 yrs.).

Being Unable to Do Things Together

Children described the changes that affected their time and activities together with their mother, comparing this to before the mother's illness. Such changes bothered boys and girls similarly. 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 yrs.); "I feel different because usually she reads me stories, watches movies with me" (WA1036, F, 11 yrs.); and "She could not ride bikes with me; it made me sad" (IN1009, M, 10 yrs.).

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. The two categories comprising this domain were (a) looking different to me, and (b) 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, mostly female children were concerned about their mother's feelings. One child said, "I'm also worried about her feelings" (PA1002, M, 8 yrs.); one girl raised the question, "What if my mom will not be happy?" (CA1006, F, 12 yrs.). 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 yrs.).

Losing the Ability to Do What She Usually Does

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 comprised the three categories of (a) not doing things with the rest of the family, (b) changing how things work at home, and (c) not taking care of our family or me.

When the cancer prevented the mother from joining the rest of 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 yrs.). A boy wrote, “We couldn’t go to the beach on the weekends anymore” (CA1013, M, 12 yrs.).

When things changed at home, children were concerned: “Sometimes my mom had to stop doing the dishes” (AZ1011, M, 7 yrs.). Another child wrote that he was “bothered by how the house is going to get clean due to this cancer” (MN1003, M, 11 yrs.). 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 yrs.). Others wrote that 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 yrs.).

Wishing She Did Not Have Cancer

Children wished their mothers did not have the cancer. Some children wondered why their mothers got cancer and wished that it had never happened, saying, “I just wish she didn’t have cancer” (IN1006, M, 8 yrs.). Another wrote, “Why did this have to happen to my mom and no one else?” (CA1038, F, 11 yrs.).

Discussion

This study is the first to obtain child-reported data from a large sample of children ages 7–12 years whose mothers were diagnosed within the past six months with Stage 0–III breast cancer. Written text from the children was transcribed verbatim and systematically coded, enabling us to identify the 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 the domains and categories. Initially, when they first were made aware of the cancer, the children tried to hide it from others, including their peers. Being physically distanced from their mother during her hospitalization bothered many children. Rather than viewing the hospital as a place to which their mother could go to 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 1.2).

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 and/or if they were going to lose their mother due to the treatment. When the children noticed their mothers looking different for example, losing their hair, or getting very ill they became additionally concerned.

Children were observers of their mother's behavior, not just her overt physical changes. Both her 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 yrs.). They associated her nervousness with the chemotherapy (CA1009, F, 9 yrs.). 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 before the cancer when the mother did not attend outdoor activities, stopped reading stories, or did not clean the house. The altered presence of their mothers, or their mothers' participation in care and routines, made the children feel that they were left with no one to take care of them or their family. Finally, some children wished their mother never had the cancer.

[Table 1.2 here]

Analysis by age revealed that all children, regardless of age, had the same illness-related concerns with two exceptions. Older children (11–12 years) were concerned or bothered by observing behavioral changes in their mother, including her being different. Younger children (7–10 years), more than older children, were concerned about how things changed at home. Results by child's age and gender revealed a higher proportion of female children reported concerns in these three domains " knowing about the cancer", "her being away from me", and "losing the ability to do what she usually does". 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" (Table 1.2).

Study results can be further understood by examining their fit with two theories: Piaget's cognitive-developmental theory (Piaget & Inhelder, 1969) and attachment theory (Bowlby, 1969). 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. Younger children under the age of 9 years, for example, are concrete thinkers who are focused on observables or behavioral cues (Wong, Hockenberry, & Wilson, 2007); they are unable to comprehend treatment side effects and wonder why treatment is making their mothers worse (Armsden & Lewis, 1993). 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 yrs.). 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 of the mother’s breast cancer (Armsden & Lewis, 1993; Su & Ryan-Wenger, 2007; Wong et al., 2007). This more abstract thinking was also demonstrated 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 yrs.)

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 (Bowlby, 1969). 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 two 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 study sample ages in the study sample.

When the child experienced the mother as physically or symbolically absent from the child, the child called this out as a concern. Symbolic absence was represented in the data by children's altered routines or their 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 pervious findings (Forrest et al., 2006; Furlong, 2017; Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Zahlis, 2001) 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 just 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 of "being unable to do things together." Every detail of mother–child time or activity together was changed, such as telling bedtime stories or riding bikes. Children were not merely bothered by changes caused by the cancer. The children's own emotional response to their mother's cancer was a concern for them. In the words of one 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 six months of the mother's diagnosis. In contrast, the two prior studies of school-aged children (Hilton & Gustavson, 2002; Zahlis, 2001) were likely affected by recall error; mothers in those studies were, on average, diagnosed two to five years previously.

Limitations

Study results are limited to the current study sample of school-aged children whose mothers were primarily White, highly educated, and married. Moreover, findings were based on self-reported dictated and written information from the children; data obtained through a single open-ended question cannot begin to capture the richness of a child's experience with his or her mother's cancer. Finally, the descriptions of the female and male 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 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 with the booklet. The structure and format of the booklet is beyond data obtained in the current study. 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.

Nurses are in a prime position to augment the mother’s skills and confidence to elicit their children’s concerns. This recommendation is consistent with interventions by Davey et al., John et al., and Lewis et al. (Davey, Kissil, Lynch, Harmon, & Hodgson, 2013; John, Becker, & Mattejat, 2013; Lewis et al., 2015), all of which emphasized ways to enhance mother–child attachment through communication and interaction. Davey et al.’s intervention involved bi-monthly support groups to encourage communication and attachment between school age children and their ill parents. John et al, developed a family-centered inpatient program to improve the mother’s and child’s quality of life and psychological functioning. Lewis et al.’s (2015) work offered detailed approaches by which a nurse could teach the mother to elicit and support a child’s reported illness-related concerns.

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 age 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 age child.

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Table 1.1

Summary of Qualitative Data-Based Studies of School-Age Children's Reported Concerns of Their Mother's Cancer Diagnosis

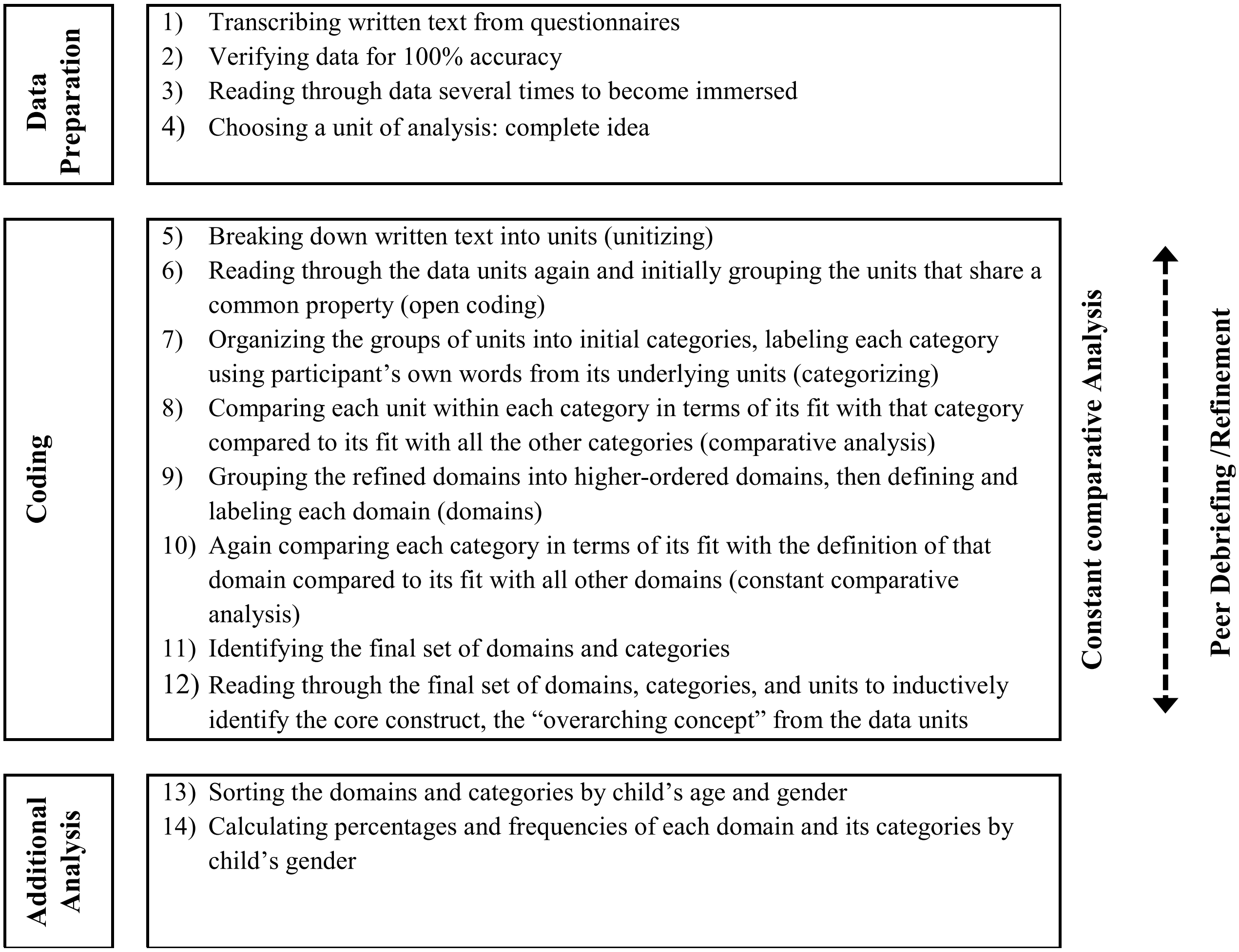
Study	**Sample**	**Methodology and Methods**	**Results**
Furlong (2016) ***Purpose***: To develop a grounded theory of children's day-to-day experience of living with their mothers who have been recently diagnosed with breast cancer and are receiving treatment.	Children (*n* = 28) 7–11 years old whose mothers had been diagnosed within 4 months with breast cancer and are receiving treatment	Grounded theory Semi-structured interviews with the children	*Protecting* was the main concern of children during their mothers' diagnosis and treatment. The children addressed this concern through 3 cyclic and iterative processes: shifting normality, shielding, and transitioning.
Forrest et al. (2006) ***Purpose***: To explore how children of mothers newly diagnosed with breast cancer perceive their mother's illness and initial treatment and compare it with the mothers' perception of their children's knowledge.	Children (*n* = 31) 6–18 years old Mothers (*n* = 37) with early-stage breast cancer (I–III)	Thematic analysis Semi-structured interviews conducted with mothers and children separately	Awareness of cancer as a life-threatening illness, aspects of mother's treatment (hair loss, chemotherapy, post-operative care) were stressful for children. Mothers sometimes underestimated and misunderstood the emotional impact on the child.
Hilton & Gustavson (2002) **Purpose:** To describe children's experiences when the mother required chemotherapy for breast cancer.	Children (*n* = 11) 7–21 years Mothers (*n* = 37) with breast cancer who had chemotherapy within	Qualitative–naturalistic Semi-focused interviews	*Shielding and being shielded* was the major emerging theme. Shielding refers to how children protected themselves from their thoughts and feelings.
Zahlis (2001) ***Purpose***: To gain a better understanding of school-aged children's worries regarding mothers newly diagnosed with breast cancer	Children (*n* = 16) (11–18 years) at the time of interview (8–12 years) at the time of their mothers' diagnosis with early-stage breast cancer	Content analysis Semi-structured interviews with children	Children voiced 9 categories of worries: worrying that the mother was going to die, feeling confused, worrying something bad would happen, worrying about the family and others, worrying when she did not look good, worrying she would be changed, worrying whether the family would have to cut back financially, worrying about talking to others, and wondering whether the child would get cancer.

Hilton & Elfert (1996) ***Purpose***: To describe the children's experiences with their mothers' early stage breast cancer	12 families with children (2–21 years) 3 families with preschoolers (2–5 years) 7 families with school-aged children (6–14 years) 4 families with older adolescents and young adults (15–21 years)	Content analysis Semi-structured interviews of children together with their parents	*Awareness* and *dependence* were main themes emerged in the 3 developmental stages. The developmental level of the children influenced their understanding and illness demands. School-aged children were concerned with the mother's illness and thought of it as a serious situation.

Table 1.2

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. Knowing about the cancer	**13**	**1 (7.7%)**	**12 (92.3%)**
Being told she had cancer	6	0 (0%)	6 (100%)
Worrying about people finding out or talking about it	7	1 (14%)	6 (86%)
2. Her being away from me	**34**	**11 (32.4%)**	**23 (67.6%)**
Waiting for her	6	1 (16.7%)	5 (83.3%)
Going to her doctor's appointments or the hospital	14	5 (35.7%)	9 (64.3%)
Worrying she might die	14	5 (35.7%)	9 (64.3%)
3. 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 %)
4. Being unable to do things together	**10**	**4 (40%)**	**6 (60%)**
5. Seeing my mother be different	**33**	**15 (45.5%)**	**18 (54.5%)**
Looking different to me	15	11(73.3%)	4(26.7%)
Seeing her afraid, crying, and irritable	18	5(27.8%)	13(72.2%)
6. Losing her ability to do what she usually does	**26**	**9 (34.6%)**	**17 (65.4%)**
Not doing things with the rest of the family	7	2 (28.6%)	5 (71.4%)
Changing how things work at home	12	4 (33.3%)	8 (66.7%)
Not taking care of me or our family	7	3 (42.9%)	4 (57.1%)
7. Wishing she did not have cancer	**6**	**3 (50%)**	**3 (50%)**



Data Preparation

1) Transcribing written text from questionnaires
2) Verifying data for 100% accuracy
3) Reading through data several times to become immersed
4) Choosing a unit of analysis: complete idea

Coding

5) Breaking down written text into units (unitizing)
6) Reading through the data units again and initially grouping the units that share a common property (open coding)
7) Organizing the groups of units into initial categories, labeling each category using participant's own words from its underlying units (categorizing)
8) Comparing each unit within each category in terms of its fit with that category compared to its fit with all the other categories (comparative analysis)
9) Grouping the refined domains into higher-ordered domains, then defining and labeling each domain (domains)
10) Again comparing each category in terms of its fit with the definition of that domain compared to its fit with all other domains (constant comparative analysis)
11) Identifying the final set of domains and categories
12) Reading through the final set of domains, categories, and units to inductively identify the core construct, the "overarching concept" from the data units

Constant comparative Analysis

Peer Debriefing /Refinement

Additional Analysis

13) Sorting the domains and categories by child's age and gender
14) Calculating percentages and frequencies of each domain and its categories by child's gender

Figure 1.1. Data analysis process

Chapter 2. Initial Validation of Illness-Related Concerns in Children Experiencing Maternal Cancer

Presented at the 43rd Annual Oncology Nursing Society Congress in Washington D.C., USA, May 17-20, 2018. Almulla H, Oxford M, Lewis F. The Structure of Illness-Related Concerns In Children Facing Maternal Cancer: A confirmatory Factor Analysis of a Child-reported Measure. Abstract # 2790.

Target Journal: Journal of Psycho-Oncology

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Abstract

Objective: To evaluate the content and construct validity of illness-related concerns (IRC) that school-age children attribute to their mother's breast cancer and derive a brief version of a standardized scale to measure these illness-related concerns. **Methods:** We conducted a literature analysis of IRC in children of mothers with cancer that informed three proposed factor models of children's IRC. Models were specified using data from 203 school-age children whose mothers were diagnosed with early stage breast cancer and who completed a 93-item self-report previously untested questionnaire, the About My Mother's Illness Scale (AMMI). Eighteen items from the AMMI were selected as indicators to the factors for the three models. Confirmatory factor analyses were conducted to test and compare the fit of each model to the data. **Results:** The multidimensional five-factor model revealed the best fit to the data (CFI = 0.974, TLI = 0.968, RMSEA = 0.044, SRMR = 0.037, χ^2 (125) = 173.112, $p < .001$, and χ^2/df = 1.38). The five-factor model included five related yet distinct dimensions of illness-related concerns that the child attributed to the mother's cancer: (a) changes in family routine and resources, (b) uncertainty, (c) illness contagion, (d) mother's death, and (e) mother's well-being. **Conclusions:** Study results suggest that we can no longer rely on an overall concept called IRC when studying or clinically assisting children dealing with maternal cancer. The derived 18-item Child's Illness-Related Concerns Scale can benefit services and programs and assist in assessing and targeting specific dimensions of children's concerns.

Introduction

In the United States, approximately 193,375 children were affected by the diagnosis and treatment of maternal cancer in 2018 (American Cancer Society, 2018; Weaver, Rowland, Alfando, & McNeel, 2010). Children of mothers diagnosed with cancer are known to be at increased risk for adjustment problems, including elevated rates of depression, anxiety, concerns, fear, withdrawal, and avoidance behavior (Lewis et al., 2015; Osborn, 2007; Purc-Stephenson & Lyseng, 2016). Despite the documentation of adjustment problems in children, however, it is unclear how children's internal state of concerns might exacerbate adjustment problems, in part because the field lacks a measurement of the child's view of the mother's cancer diagnosis or the impact it has on the child's life. The utilized measures in the current literature of children affected by maternal cancer are not designed to detect concerns of children that were pointed to in interview studies (Huang, O'Connor, & Lee, 2014; Lewis, 2007; Osborn, 2007; Purc-Stephenson & Lyseng, 2016; Romer, Barkmann, Schulte-Markwort, Thomalla, & Riedesser, 2002; Visser, Huizinga, Hoekstra-Weebers, Van der Graaf, & Hoekstra, 2004). Moreover, there is an overreliance on mother-reported measures of the children's behavior and child psychopathology that is not sensitive or specific to the concerns of children experiencing maternal cancer (Huang et al., 2014; Lewis, 2007; Osborn, 2007; Romer et al., 2002; Visser et al., 2004). Relying on mother-reported measures does not solve the problem. Diagnosed mothers may not be the best reporters of concerns their children attribute to their mother's illness. When a mother is focused on survival and managing the demands of her own cancer, she may not notice her child's struggles; similarly, children are more likely to protect their mother and withhold their concerns from their mother (Armsden & Lewis, 1993; Lewis et al., 2015;

Osborn, 2007). To date, however, there has been no known reliable and valid measure of the child's reported concerns about the mother's cancer. In the absence of such a measure, programs and services for children are unable to target children's specific worries.

Despite the growing number of studies demonstrating the impact of a mother's cancer on her child, the concept of a child's illness-related concern has been left undeveloped in the literature. Clinicians and scientists assume "illness-related concerns" is a well understood term when, in fact, it is not well understood; nor has it been examined with data obtained from children. What is needed is an examination of the content validity of a child-reported measure of illness concerns (Holmbeck & Devine, 2009). Second, an empirical test is necessary to rigorously evaluate the theoretical dimensions of the construct as part of construct validation (Holmbeck & Devine, 2009). The current study had three aims: (a) to clarify the content validity of illness-related concerns (IRCs) in children whose mothers have cancer from the published literature, (b) to evaluate the construct validity of IRC by testing and comparing three proposed alternative models of IRC in children of mothers with breast cancer, and (c) to develop a brief tested version of a child-reported measure of IRC that the children have explicitly attributed to their mothers' cancer.

Content Validity of IRC in Children of Mothers With Cancer

There is no conceptual definition of IRC in the published literature. Authors interchangeably and inconsistently use a wide range of concepts to study a child's concerns, including concerns, demands, pressures, thoughts and feelings, perceptions, cognitive appraisal, and coping (Armsden & Lewis, 1993; Forrest, Plumb, Ziebland, & Stein, 2006; Furlong, 2016;

Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Semple & McCaughan, 2013 Su & Ryan-Wenger, 2007; Zahlis, 2001; Zahlis & Lewis, 1999).

To clarify the content validity of IRC, a critical review of the literature was carried out in order to map all aspects of the IRC construct. Analysis yielded five domains of concerns school-age children attributed to their mother's cancer: (a) changes in family routines and resources (Armsden & Lewis, 1993; Furlong, 2016; Hilton & Gustavson, 2002; Semple & McCaughan, 2013; Zahlis, 2001); (b) uncertainty (Armsden & Lewis, 1993; Furlong, 2016; Hilton & Gustavson, 2002; Semple & McCaughan, 2013; Zahlis, 2001); (c) illness-contagion (Forrest et al., 2006; Semple & McCaughan, 2013; Zahlis, 2001; Zahlis & Lewis, 1999); (d) their mother's death (Armsden & Lewis, 1993; Furlong, 2016; Hilton & Gustavson, 2002; Zahlis, 2001; Zahlis & Lewis, 1999); and (e) their mother's well-being (Hilton & Gustavson, 2002; Zahlis, 2001; Zahlis & Lewis, 1999). Each domain of concern is described in the following sections.

Changes in family routines and resources. Children are concerned when their mothers' cancer disrupts or changes their routines and family resources (Armsden & Lewis, 1993; Furlong, 2016; Hilton & Gustavson, 2002; Semple & McCaughan, 2013; Zahlis, 2001). In a recently completed study, several children explained that the changes in home routines and their assumption of new chores and extra responsibilities limited their activities and schedules (Furlong, 2016). In another interview study of 11 children, the children viewed changes in routines and schedules as stressful (Hilton & Gustavson, 2002). Children are also known to have worries about the financial impact of their mother's illness on the family (Zahlis, 2001).

Uncertainty. School-age children have concerns about the uncertainty of what will happen to their mothers and how her cancer would impact their own lives (Armsden & Lewis, 1993; Furlong, 2016; Hilton & Gustavson, 2002; Semple & McCaughan, 2013; Zahlis, 2001). Some children wondered why cancer happened to their mother but not to someone else (Hilton & Gustavson, 2002). In an interview with 8- to 12-year-old children of mothers with breast cancer, more than 50% of the children expressed uncertainty or confusion in not knowing what would happen in the future (Zahlis, 2001)

Illness contagion. School-age children worry about the possibility of having cancer themselves (Forrest et al., 2006; Semple & McCaughan, 2013; Zahlis, 2001; Zahlis & Lewis, 1999). In a study exploring how children perceive their mother's cancer diagnoses, interviewed school-age children reported that they were concerned about catching cancer from their mothers (Forrest et al., 2006).

Mother's death. Children fear long-term separation from their mothers and the possibility that their mother could die from breast cancer (Armsden & Lewis, 1993; Furlong, 2016; Hilton & Gustavson, 2002; Zahlis, 2001; Zahlis & Lewis, 1999). In an interview study with 16 school-age children of mothers with breast cancer, 81% of children feared their mother would die from the disease (Zahlis, 2001). In another study of children's coping with their mothers' cancer, the majority of children had concerns about their mother's death (Furlong, 2016).

Mother's well-being. Children worry about their mother's well-being and the effect the cancer has on her, including after surgery and chemotherapy (Hilton & Gustavson, 2002; Zahlis, 2001; Zahlis & Lewis, 1999). Medical appointments and hospitalizations are events of concern for the school-age child (Zahlis, 2001; Zahlis & Lewis, 1999). Rather than viewing the hospital as a place to treat the mother's breast cancer, school-age children reported that they were worried their mother would never return from the hospital (Zahlis, 2001).

Conceptual Definition and Theoretical Dimensions of IRC

Based on a content analysis of these studies, we defined IRC as the troubling actual and potential thoughts and feelings that the child attributes to the mother's cancer. We hypothesized that IRC is a multidimensional construct that consists of five distinct dimensions: (a) changes in family routines and resources, (b) uncertainty, (c) illness-contagion, (d) mother's death, and (e) mother's well-being. We also proposed that those five dimensions of concerns might be clustered under three main domains: (a) the child's concerns about the family, (b) the child's concerns about himself/herself, and (c) the child's concerns about the mother (see Figure 2.1).

[Figure 2.1 here]

Three plausible factor models were hypothesized: a five-factor model, a three-factor model, and a one-factor model. The five-factor model is a test of the five hypothesized dimensions of the construct (see Figure 2.1). To add further analytic and theoretic parsimony, we also proposed that those five dimensions of concerns might be clustered under three main domains. The three-factor model is hypothesized to consist of three main domains: (a) the child's concerns about the family, (b) the child's concerns about himself /herself, and (c) the child's concerns about the mother. The one-factor model directly tests the assumption that children's illness concerns are unidimensional, not multidimensional.

To evaluate the construct validity of IRC, confirmatory factor analysis (CFA) was used to test and compare these distinct factor models of IRC using data obtained from children. CFA is the most robust statistical approach to evaluate the construct validity of a measure or latent factor, such as IRC (Prudon, 2015) and allows researchers to test a priori proposed structural models against observed data while accounting for measurement error (Prudon, 2015).

Methods

Study Protocol

In the parent study, mothers and their children were recruited from community-based comprehensive cancer centers, community cancer centers, private medical practices, and self-referrals across six states in the United States. Eligible mothers were those diagnosed within the past six months with stage 0 to III breast cancer, were married, had a child between the ages of 7 and 12 years, and read and wrote in English. After obtaining Institutional Review Board (IRB) approval (application number # 16636), members of the study team contacted eligible mothers by phone, read to them an IRB-approved enrollment script, and invited them to ask questions about the study. If the diagnosed mother agreed to participate, we asked her to obtain her school-age child's agreement to participate. Pending the child's indication of willingness to participate, members of the research team obtained informed consent and assent in participants' homes and administered baseline questionnaires. Specially trained data collectors were instructed in a standard way to administer children's measures and complete them independently, away from the children's mothers.

Study Sample

Data were obtained from 202 school-age children (*M* age= 9.8 years, range: 7–12 years, *SD* =1.52, 51.5% males and 48.8% females) who completed the About My Mother's Illness scale (AMMI), a child-report measure administered at baseline as a part of a battery of instruments in a completed Phase III randomized control trial that tested the efficacy of a cancer parenting education program (Lewis et al., 2015). Data to be analyzed in the study were obtained from participants prior to randomization. Mothers were diagnosed within the recent six months (*M* = 3.7, *SD* = 1.9) with stage 0-III breast cancer (39.2 % stage 0–I, 49.4% stage II, and 11.4% stage III), and were mainly White (74.8%) and had completed some college education or higher (87%). The remainder were (6.4%) Hispanic; (3%) Asian; (2.5%) African American; and (1.5%) other ethnicities, including Native American and Pacific Islander. The majority of mothers were receiving chemotherapy or radiation therapy (78%) when their children participated in the study.

Measures

About My Mother's Illness (AMMI). The AMMI is a child-reported measure that was developed by the study team with the long-range goal of documenting the pressures, worries, or issues of concern of school-age children as a broad-brush child-reported measure (Lewis et al., 2015). The original AMMI measure consisted of 93 items reflecting an array of children-reported pressures relevant to the mother's cancer. The items were designed to apply to other maternal illnesses in addition to breast cancer. The 93 items covered theoretical domains extracted from previous studies, including interview studies. Items were written as a list of thoughts, feelings, and behaviors that some children could potentially have when their mother has an illness. Each item was rated on a 5-point ordinal scale (1= never to 5 = all of the time) and children were asked to identify the frequency with which they had the thought or feeling.

A total of six decision rules were applied to reduce the 93-item measure to the 18-item measure (see Table 2.1). First, items were excluded that reflected a change in the child's behavior since the mother's illness (e.g., "I have new chores at home"; "I am nicer to others in my family"). Second, items were deleted that reflected an actual change in the family because of the cancer (e.g., “the house work doesn’t get done”; “we eat different foods”). Third, redundant items were removed (e.g., “I worry I will get sick, too” and “I worry I might get the same thing.”) Fourth, items were removed if they were too abstract or unclear (e.g., “I think about my future” or about “how important life is”). Fifth, we retained items representing a child’s thoughts or feelings (total of 26 items). Finally, eight items were excluded because they did not correspond to one of the five identified dimensions of concerns (e.g., “I wonder if my friends think I am weird”; “ I wonder if my friends are afraid they will catch it”). The 18-item child-reported measure was next tested.

[Table 2.1 here]

Analytic Strategy

Using the selected 18 items, three models were tested and compared for fit to the data (see Table 2.1 and Figure 2.1). For Model 1, all 18 items were specified to inform one factor of IRC and represent the null hypothesis (i.e., that these indicators do not inform multiple latent constructs). For Model 2, the 18 items were specified to load onto three correlated domains of concern: four items indicating family-based concerns, six items indicating concerns about self (the child’s concerns about self), and six items related to concerns about the mother. For Model 3, the 18 items were specified to load onto five correlated dimensions of concerns: Four items indicated concern about family’s routine and resources, three items measured uncertainty, three items measured the child’s concern about becoming ill, three items measured concerns about mother’s death, and three items focused on maternal well-being.

IBM Statistical for Social Sciences (SPSS) version 24 was used to compute descriptive statistics SPSS (IBM, 2017). Missing data were examined to identify patterns of missing data for each of the 18 items of IRC. Mplus (version 8.0) was then used to run CFAs for the three specified models (Muthén & Muthén, 2017). Indicators were treated as continuous, and full information maximum likelihood (FIML) was used to estimate the models. FIML is recommended for handling missing data and is suitable when there are five categories or more and a small sample size (Rhemtulla, Brosseau-Liard, & Savalei, 2012). Modification indices were examined in each model (Kline, 2015). Latent factors were standardized; means and variances were set to zero and one. An overall model fit was indicated by jointly examining comparative fit index (CFI) > 0.95; Tucker-Lewis index (TLI) > 0.95, root-mean-square error of approximation (RMSEA) ≤ .05; the standardized root mean square residual (SRMR) ≤ .08; and chi-square by degree of freedom (χ^2/df) ≤ 3 (Brown, 2006; Hu & Bentler, 1999; Kline, 2015).

Following the determination of model fit, a chi-square difference test was computed to compare nested models, such as the IRC models in the current study (Kline, 2015). A significant chi-square difference (alpha of .05, 2-tailed) indicates that the fit of one model is statistically better than that of the other, especially when both models being compared have acceptable fit, such as Models 2 and 3 in our study (Kline, 2015). Additionally, factor correlations and standardized path coefficients were examined in each model. After we determined the best-fitting model, we computed the internal consistency reliabilities (Cronbach's alphas) using SPSS (IBM, 2017). A Cronbach's alpha of 0.70 or above is considered acceptably reliable because the square of 0.7 yields the percentage of the shared variance, which is 49% (Nunnally & Bernstein, 1994).

Results

Table 2.2 summarizes results for the three models' fit indices. Model 1, the one-factor model, had a poor fit to the data: CFI = 0.799, TLI = 0.772, RMSEA = 0.116, SRMR = 0.075, $\chi^2(135) = 505.01$, $p < .001$, and $\chi^2/df = 3.74$. Model 2, the three-factor model, had adequate fit to the data: CFI = 0.859, TLI = 0.837, RMSEA = 0.098, SRMR = 0.068, $\chi^2\,(132) = 391.30$, $p < .001$, and $\chi^2/df = 2.96$. Finally, Model 3, the five-factor model, indicated a very good fit: CFI = 0.974, TLI = 0.968, RMSEA = 0.044, SRMR = 0.037, $\chi^2\,(125) = 173.112$, $p < .001$, and $\chi^2/df = 1.38$.

[Table 2.2 here]

Because both the three- and five-factor models had an acceptable fit, we compared these two models using a chi-square difference test: $\chi^2\,\Delta\,(7) = 218.19$, $p < 0.001$. There was a significant difference between the three-factor model (Model 2) and the five-factor model (Model 3), indicating that the five-factor model was a better fit to the data. Modification indices were also examined for Models 2 and 3. Post-hoc modifications were not indicated for the five-factor model because of the good-fit indices. In contrast, the three-factor model had cross loadings and correlated residuals. For the IRC five-factor model (Model 3), the factor correlations, standardized path coefficients (factor loadings), and standardized residuals are presented in Figure 2.2.

[Figure 2.2 here]

Factor correlations and standardized path coefficients were all significant *($P > 0.001$)*. The internal consistency reliability of each of the five factors in the IRC five-factor model (Model 3) was ≥ 0.80 (See Table 2.3).

[Table 2.3 here]

Discussion

This is the first known study that has systematically examined the content and construct validity of IRC in a sample of a school-age children facing maternal breast cancer. Based on the published literature, we provided a conceptual definition and identified the theoretical dimensions of IRC and then used that definition to select 18 items from an existing self-report measure that had not been previously evaluated. To assess the dimensionality of IRC, we tested and compared three hypothesized factor models. Our study findings supported a five-factor model of IRC, indicating that IRC is a multidimensional construct that includes five related, yet distinct, latent factors of concerns children attribute to their mothers' cancer: changes in family's routine and resources, uncertainty, illness-contagion, mother's death, and mother's well-being. Our results did not support the one-factor model fit to the data when all 18 items were loaded onto a single factor. The three-factor model provided adequate fit to the data, but the five-factor model had a significantly better fit to the data when compared with the three-factor model.

The five-factor model of the 18-item questionnaire provides both a valid and reliable brief measure of IRC in school-age children experiencing maternal cancer, which we named the Child's Illness-Related Concerns Scale. Each of the five factors can be independently scored as a subscale, given its adequate internal consistency reliability and demonstrated good item-total correlations and factor loadings. Furthermore, the Child's Illness-Related Concerns Scale offers a plausible alternative to pathology-dominated measures of children's behavior. As a child-reported measure, it avoids maternal bias in reporting a child's IRC (Huang et al., 2014; Lewis, 2007; Osborn, 2007; Visser et al., 2004; Romer et al., 2002).

Clinicians and scientists can benefit greatly from IRC's multidimensional structure. The five correlated areas of concerns of IRC offer a theoretical framework to guide the design of interventions targeting the identified areas of concerns and to intervene directly with the child or indirectly with the ill or non-ill parent. To be more sensitive to the child's needs when experiencing maternal cancer, clinicians and scientists designing programs must consider that each child has his or her own profile of concerns that could predict different outcomes. For example, children fearful that their mother's cancer is contagious may develop behavioral problems. Concerns about illness contagion might be addressed through education. Another child who fears his or her mother might die from the cancer may be more prone to anxiety or depression than a child adjusting to a new or unusual family routine. Another area for future research is to evaluate the ability of each of the five dimensions of concerns to predict internalizing and externalizing problems in children; it may be that one domain is more potent at provoking behavioral problems. Further, patterns of concerns may differ among different types of cancer and across different stages of the mother's illness. For example, if a mother is undergoing active treatment, her child may be more concerned about her well-being. This could be addressed by education designed to prepare children in advance in developmentally appropriate ways for hospital visits and questions about their mothers' treatment. However, if a mother is in the terminal stage of the illness, children may be mostly concerned about losing their mothers. Another important utility of the scale is to identify patterns of concerns unique to the child's gender that may determine different coping styles. Finally, because of the significant correlation between the five dimensions of concerns, we can infer that addressing one concern can indirectly help reduce another concern. For example, addressing the child's concerns about the mother's well-being through education can reduce the child's uncertainty and confusion and concerns about losing her.

Future research is needed to test and refine the Child's Illness-Related Concerns Scale, including generating and testing additional items to include concerns that are not part of the current version of the measure (e.g., concerns about peers' responses to the child or the effect of the mother's cancer on the child's school performance) and evaluating predictive validity. Despite needed future research, the Child's Illness-Related Concerns Scale is ready for use in descriptive and intervention studies. Each of the five dimensions of concerns can be computed as a separate score in studying a child's view of the mother's cancer.

Study Limitations

Analyses of the three proposed factor models of IRC were limited to the questionnaire items of the original AMMI. Although the existing pool of 18 items in the Child's Illness-Related Concerns Scale is responsive to the published literature, it is plausible that additional IRCs exist that these items do not reflect. Future studies are needed to examine tests of the construct validity of the measure with different populations of children.

The study sample on which the models were tested consisted of children from primarily White, highly educated two-parent households. Future studies need to test the Child's Illness-Related Concerns Scale with a more diverse population. Additionally, the study sample was limited to children of mothers with early-stage breast cancer. Testing of the five dimensions of IRCs is still needed for other types of cancers and during different stages of parental disease.

Clinical Implications

The Child's Illness-Related Concerns Scale has promise as a practical screening tool for clinicians to assess children's concerns enabling clinicians to provide resources to assist the child and diagnosed parent. The Child's Illness-Related Concerns Scale is ready for additional testing, including testing of its discriminant and predictive validity. Longer range, the identification of a child's IRC can help clinicians efficiently target areas that could reduce the burden of a mother's cancer on her children.

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Table 2.1

The Three Hypothesized Models of Children's IRC

	Selected AMMI Items	**5 Factors** (*Model 3*)	**3 Factors** *(Model 2)*	**1 Factor** *(Model 1)*
Item 1:	I wonder how my family will manage.	**Changes in family's routines and resources**	**Family**	**Illness-related concerns**
Item 2:	I think about how it will affect our everyday life.			
Item 3:	I wonder if our family will have to cut back on what we can buy.			
Item 4:	I worry that our family will have to change the way we live.			
Item 5:	I think why this is happening to me.	**Uncertainty**	**Child**	
Item 6:	I feel mixed up.			
Item 7:	I have lots of questions.			
Item 8:	I wonder why this is happening.			
Item 9:	I wonder if her illness is passed on to me.	**Illness-contagion**		
Item 10:	I worry I might get the same thing.			
Item 11:	I worry that I might have to have surgery too.			
Item 12:	I think about what it would be like to grow up without a mom	**Mother's death**	**Mother**	
Item 13:	I worry that she might die			
Item 14:	I worry that I will be left alone if she dies			
Item 15:	I wonder if the doctors are doing everything that is right	**Mother's well-being**		
Item 16:	I worry when she doesn't act the way she usually does			
Item 17:	I worry when she goes to the doctor			
Item 18:	I wonder if she will be the same again			

Note: AMMI, About My Mother's Illness Scale

Table 2.2

Means (*SD*s) and Internal Consistency Reliabilities of IRC Items/Factors in the Five-Factor Model (Model3)

IRC Factors/Items	**Mean (*SD*)**	**α**
Changes in family's routines	-	0.81
Item 1	2.23(1.37)	-
Item 2	2.28(1.25)	-
Item 3	2.06(1.32)	-
Item 4	2.01(1.28)	-
Uncertainty	-	0.80
Item 5	2.28(1.34)	-
Item 6	2.02(1.24)	-
Item 7	2.56(1.39)	-
Item 8	2.91(1.48)	-
Illness-contagion	-	0.86
Item 9	2.09(1.42)	-
Item 10	1.94(1.33)	-
Item 11	1.97(1.35)	-
Mother's death	-	0.88
Item 12	2.83(1.60)	-
Item 13	2.62(1.61)	-
Item 14	2.21(1.58)	-
Mother's well-being	-	0.82
Item 15	3.08(1.52)	-
Item 16	2.39(1.38)	-
Item 17	2.46(1.48)	-
Item 18	2.68(1.51)	-

Note: **α,** internal consistency reliability

Table 2.3

Model Fit Summary

Models	χ^2	***Df***	χ^2/df	***P*-value**	**CFI**	**TLI**	**RMSEA**	**SRMR**
1 Factor *(Model 1)*	505	135	3.74	< .001	0.799	0.772	0.116	0.075
3 Factors *(Model 2)*	391.3	132	2.96	< .001	0.859	0.837	0.098	0.068
5 Factors (*Model 3*)	173.1	125	1.38	< .001	0.974	0.968	0.044	0.037

Note: χ^2–chi-square; *df*–degree of freedom; CFI–comparative fit index; TLI–Tucker-Lewis index; RMSEA–root-mean-square error of approximation; SRMR–standardized root mean square residual.

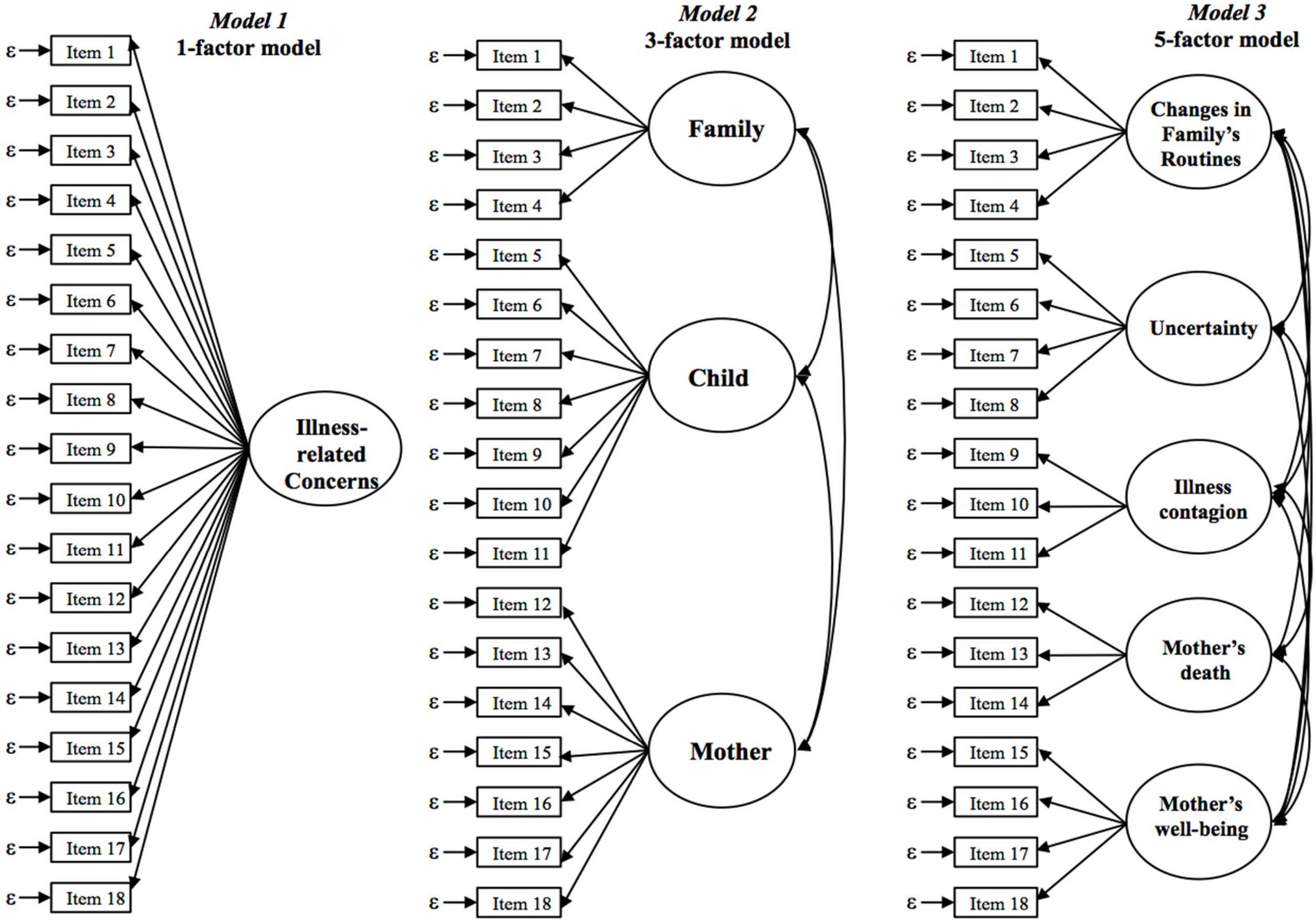

Figure 2.1. Path diagrams of tested models

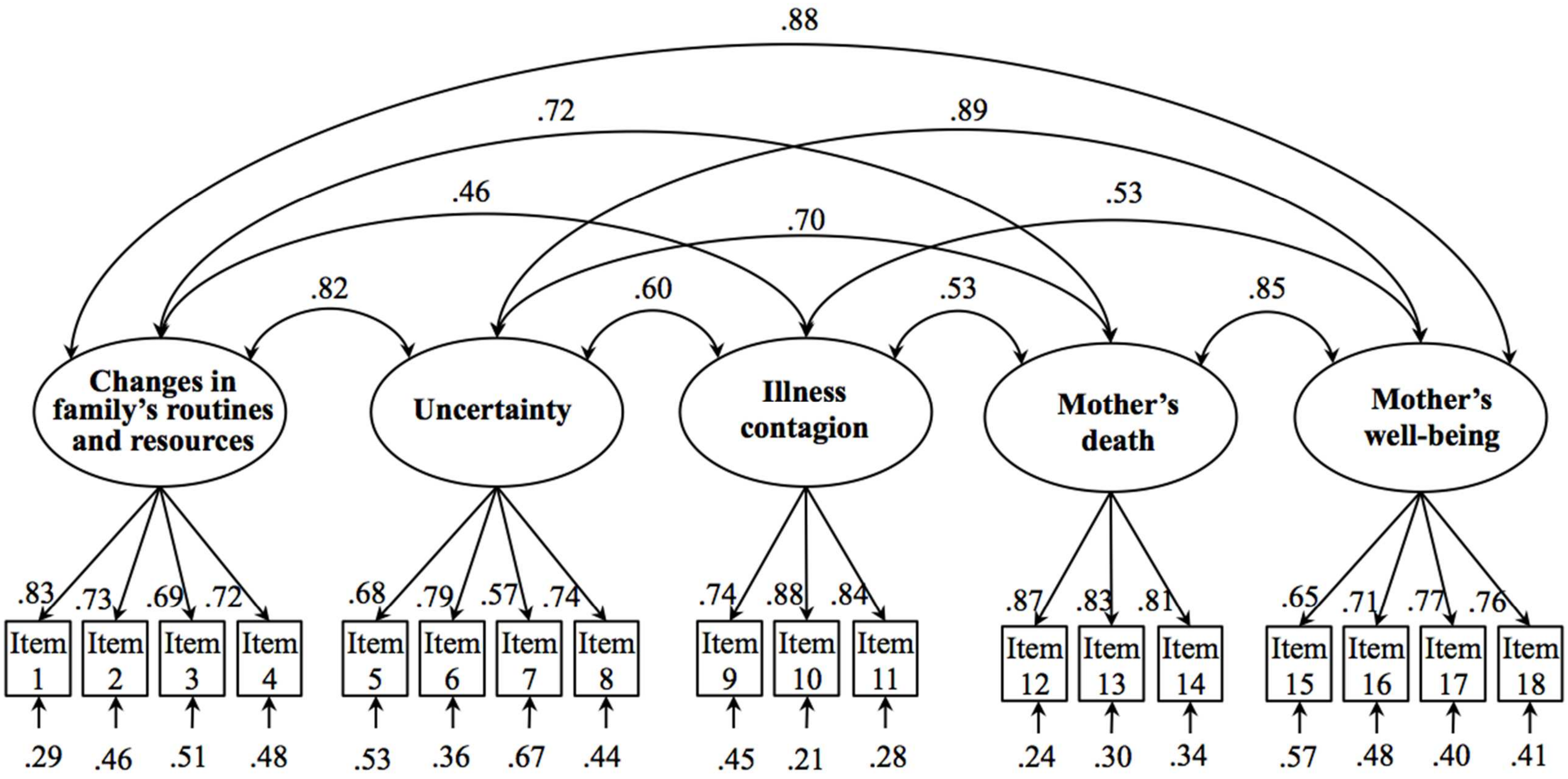

Figure 2.2. Confirmatory factor analysis of five-factor model of IRC significant correlations and standardized path coefficients (*P* <. 05) are presented in the figure.

Chapter 3. Longitudinal Impact of Children's Concerns About Mothers' Breast Cancer on Their Anxiety: Test of a Structural Equation Model

Presented at the 44th Annual Oncology Nursing Society Congress in Anaheim, CA, April 11-14, 2019. Almulla, H. & Lewis, F. The Impact of the Child's Concerns about their Mother's Breast Cancer on The Child's Anxiety Over Time: Test of A structural Equation Modeling. Abstract # 5751.

Target Journal: Journal of Psycho-Oncology

Abstract

Objective: To test a model of school age children's adjustment to maternal breast cancer that was derived from Attachment Theory. We first examined the relationship between the children's illness-related concerns, children's desire for psychological proximity, children's anxiety, and the mother's depressed mood. Second, we tested whether the children's desire for psychological proximity, or, said differently, their wish to be emotionally closer to their mother, mediated the influence of the child's illness-related concerns and mother's depressed mood on the child's anxiety after three months. **Methods:** A total of 177 children (7–12 years) and mothers newly diagnosed with early stage breast cancer were enrolled. Mothers completed a standardized measure of depressed mood and children were assessed on their illness-related concerns, desire for proximity, and anxiety. The model was tested using structural equation modeling and bootstrapping was used to test for mediation effects. **Results:** The model provided a good fit to the data. Results of the direct relationships indicated that children's illness related concerns were significantly associated with maternal depressed mood and they significantly predicted their desire for proximity and their anxiety. However, as the mother's depressed mood increased, the child's desire for proximity decreased. Furthermore, children's desire for psychological proximity significantly mediated the relationship between their concerns and anxiety three months later. **Conclusions:** Consistent with attachment theory, findings revealed crucial pathways to be targeted by clinicians and future interventions for the adjustment of children experiencing maternal cancer. Alleviating the child illness-related concerns, minimizing the mother's depressed mood, and enhancing the mother–child emotional closeness can prevent or reduce the risk of anxiety in children.

Introduction

In 2019, an estimated 300,000 women will be diagnosed with breast cancer in addition to those who are already living with the illness (American Cancer Society, 2019). One third of them are likely to be parents of dependent children (National Cancer Institute, 2019). Cancer is known to affect the entire family, especially children, because they rely mostly on their mothers for care and support (Krattenmacher et al., 2012). Children of such mothers are known to face emotional problems such as anxiety, depression, withdrawal, and worry (Birenbaum, Yancey, Philips, Chand, & Huster, 1999; John, Becker, & Matteiat, 2013; Lewis et al., 2015; Sigal, Perry, Robbins, Gagné, & Nassif, 2003; Visser et al., 2005). However, other studies have found no significant difference in anxiety scores between children of mothers with cancer and control groups of children whose mothers had benign breast biopsies (Hoke, 2001). Some children were found to be resilient to their mother's illness, and the children experience of their mother's illness actually improved family functioning (Osborn 2007; Schmitt et al. 2008).

Despite maternal cancer being a known significant stressor for the affected child, research to date has focused on family systems theory and the transactional model of stress and coping (Lewis & Hammond, 1996; Lewis, Hammond, & Woods, 1993; Lewis, Fugate, Hough, & Bensley, 1989). Although they have contributed to our understanding of the household's functioning with maternal breast cancer, both theories failed to examine the more intimate relational processes between the ill parent and the child's adjustment (Huizinga, 2004; Osborn, 2007). Furthermore, prior models placed children in a passive position in their environment, instead of in the position of creating or managing the impact of the mother's cancer on their own adjustment. Finally, prior papers have limited most of their analysis to cross-sectional designs

(Purc-Stephenson & Lyseng, 2016), leaving unanswered the question of what affects children's adjustment over time to their mother's breast cancer diagnosis.

Available reviews of children's adjustment to maternal cancer are limited to the occurrence of adjustment problems through a range of emotional and behavioral outcomes, as well as to the identification of the factors that contribute to child adjustment (Krattenmacher et al., 2012; Osborn 2007; Purc-Stephenson & Lyseng, 2016). Although identifying risk factors is important to detect children and families who are in need of support, an understanding of how adjustment problems occur or the possible mechanisms by which maternal cancer affects children is still lacking. Elucidating antecedents of adjustment problems or resilience can guide clinicians and scientists in designing evidence-based interventions to alleviate or prevent the negative impact of maternal cancer on children.

The purpose of the current study is to test a theoretically driven model (Figure 3.1) that examines the process through which a breast cancer diagnosis affects children's anxiety three months later. Unlike prior research that derived from family systems theory and the transactional model of coping, the theoretical framework derives from attachment theory (Bowlby, 1969).

[Figure 3.1 here]

The proposed model to be tested includes three concepts that can predict and explain the child's anxiety: a child's illness-related concerns, their desire for psychological proximity or emotional closeness, and maternal depressed mood.

Attachment Theory

Several researchers have emphasized the importance of utilizing attachment theory (Bowlby, 1969) to develop an understanding of how maternal cancer threatens children's security (Armsden & Lewis, 1993; Lewandowski, 1996; Osborn, 2007; Su & Ryan-Wenger, 2007), and yet no studies have applied attachment theory in studying children's adjustment to maternal cancer.

According to Bowlby (1969), children's attachment to their caregivers continues to be significant in their development (Bosmans & Kerns, 2015; Dujardin et al., 2016). In middle childhood, a caring and responsive relationship with a caregiver enhances the child's emotion regulation and social emotional development (Bosmans & Kerns, 2015). In times of distress, the attachment system activates and functions as the child's security regulation system. The caregiver's proximity and the child's support-seeking are two manifested strategies of emotion regulation when children encounter negative and intense emotions that exceed their self-regulation capacities (Dujardin et al., 2016). Expectations about the availability and responsiveness of the caregiver are influenced by the child's repeated experiences with the caregiver. Over time, these expectations become mentally internalized as working models of attachment that are activated during stress to control and guide the child's emotions and behaviors (Bowlby, 1969). The working models of securely attached children represent the caregiver as their safe haven, whom they can approach for emotional support when needed (Heylen et al., 2017). In contrast, the working models of insecurely attached children represent the emotional unavailability of the caregiver as a source of comfort and protection and the children are less likely to seek caregivers' proximity and support to regulate their stress (Bosmans & Kerns, 2015). Insecurity is manifested in different patterns such as avoidant, ambivalent, or disorganized attachment.

Children's desire for psychological proximity. There is evidence in the literature of children's attachment behaviors in regard to seeking their mother's proximity and closeness to control their concerns about cancer. In an interview of 26 mothers with breast cancer about their 8- to 12-year-old children's illness-related experiences, a number of mothers stated that needing closeness and reassurance was a new behavior they observed in their children after diagnosis. One mother described her eight-year-old daughter as "magnetically attached" (Zahlis & Lewis, 1999, p. 34). Another mother said, "She needs hugs, lots of hugs" (p. 34). However, mothers did not assume that the child's behavioral changes in terms of proximity seeking were a signal that the child perceived illness-related pressures.

From the children's perspective, some children explained how comfortable and reassuring it felt when their mothers came back from the hospital (Hilton & Gustavson, 2002). Closeness emerged as a main theme in a narrative interview study about the experience of parental cancer. Children revealed how they felt reassured and secure when they were close to the sick parent and found physical closeness to be a major source of comfort (Karlsson, Andersson, & Ahlström, 2013). The responsiveness of the ill mother to the child's attributed need for psychological proximity and emotional closeness may buffer the negative impact of cancer on the child's adjustment. Additionally, her unavailability when the child demonstrates a need for psychological proximity and support to control distress from the cancer may serve as a link between experiencing cancer-related concerns and the development of anxiety.

In the attachment literature, the association between insecure parent–child attachment and the occurrence of anxiety, depression, or internalizing problems in children has been well documented (Kerns & Brumariu, 2014). This is because insecurely attached children have difficulty regulating their emotions and are not able to access their caregivers to help them regulate their distress and provide comfort. These experiences in turn increase their risk of anxiety. Furthermore, a reciprocal effect between anxiety and insecurity may exist. For example, when children are anxious, emotion regulation becomes more challenging; and, at the same time, their parents may reject or try to control their anxiety, causing children to feel more insecure (Kerns & Brumariu, 2014).

Illness-related concerns. Children who encounter stress have a heightened risk for developing psychopathology, especially when it is not adequately regulated (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). Maternal cancer diagnosis is a substantial source of stress for children. It leads to significant changes in the family environment and mother–child relationship, threatening children's sense of security (Almulla & Lewis, 2019 under review). In our earlier qualitative study on child worries (Almulla & Lewis, 2019, under review), we found that children express their fear of losing their mother from cancer when she is physically or symbolically absent from their lives or losing what they had been used to before the illness. We also found that altered routines, changes in parental roles, and uncertainty about survival affect every aspect of the child's life (Almulla & Lewis, 2019, under review; Semple & McCaughan, 2013; Zahlis, 2001). Children describe these types of changes as stressful. For example, taking on new chores or witnessing changes in the roles between fathers and mothers can contribute to child stress (Furlong, 2016; Hilton & Gustavson, 2002). The mother's hospitalization and treatment are another source of distress for children. Children think about their mother undergoing chemotherapy and surgery and worry whether the doctors are going to do something bad to the mother (Almulla & Lewis, 2019, under review; Zahlis, 2001). Similarly, when children observe the side effects of treatment on their mothers and witness their mother's fears or anxiety, they experience intense worry (Almulla & Lewis, 2019, under review). A major concern for the children was also the notion that their mothers would die from breast cancer (Almulla & Lewis, 2019, under review; Furlong, 2016; Hilton & Gustavson, 2002; Zahlis, 2001). Given the nature of cancer and its prolonged treatments, the level of distress that children may experience because of their mother's illness is understandable. What is less clear is how these concerns increase the children's desire for psychological proximity and, in turn, if this desire was unmet it predicts their anxiety.

Maternal depressed mood. Substantial evidence exists regarding the relationship between maternal depression and elevated levels of internalizing problems in children of mothers with cancer (Lewis & Darby, 2004; Lewis et al., 2015; Purc-Stephenson & Lyseng, 2016; Watson et al. 2005; Zahlis & Lewis, 1999). Maternal depressed mood was found to be a significant predictor of emotional problems in children with mothers who had cancer (Krattenmacher et al., 2012). In interview studies, mothers claimed to be in survival mode and trying to deal with their own struggles with the illness's demands and the treatment's side effects, all of which hindered their parenting and kept them from attending to their children's concerns (Lewis & Darby, 2004; Lewis et al., 2015; Lewis et al., 2017; Zahlis & Lewis, 1999).

Even when mothers are aware of their children's concerns and needs, they are not confident or well equipped to help their children (Lewis, 2011; Semple & McCaughan, 2013). Furthermore, mothers have stated that their preoccupation with their illness prevents them from helping their children. As one mother noted, "I was depleted, so I felt I had no resources to give my nine-year-old son" (Zahlis & Lewis, 1999, p. 39). In another qualitative study about family life when a parent has cancer, mothers reported that their significant distress and fear kept them from being available for their children. As one mothers summarized, "There were a lot of closed doors" (Semple & McCaughan, 2013, p. 223).

In the general literature on maternal depression, maternal psychosocial functioning and the quality of mother–child attachment are two risk factors that are known to influence the development of internalizing and externalizing problems in middle childhood (DeKlyen & Greenberg, 2008). Elevated levels of maternal psychosocial distress significantly predicted later internalizing and externalizing problems in school-age children through the mediation of mother–child interactions (Dubois-Comtois, Moss, Cyr, & Pascuzzo, 2013). Although there is enough evidence of this link, some argue that it might be confounded by rater's bias, in which a more depressed mother might perceive more distress in her child (Osborn, 2007). Additionally, Garmezy (1991) suggested that children's perception of the illness is mirrored by the mother's own perception of the illness. In other words, if children observe that their mother concerned and distressed about her illness, they may become more anxious and worried.

Current study. Although studies have begun to investigate associations among some of the variables children face in regard to maternal cancer, these variables have yet to be studied within one unified model. Thus, in the current study, we used attachment theory to examine the utility of a model of children's adjustment to maternal cancer (Figure 1.1). We first examined the relationship among children's illness-related concerns that were attributed to their mother's illness, their desire for proximity, their anxiety, and maternal depressed mood. Second, we tested whether children's unmet desire for proximity mediated the influence of their illness-related concerns and maternal depressed mood on their anxiety three months later.

Methods

Participants

The study sample was obtained from a larger longitudinal randomized clinical trial that tested the efficacy of parenting programs for mothers with breast cancer (Lewis et al., 2015). In the parent study, mother–child dyads (*N* = 177) were eligible for inclusion if the mother was diagnosed with breast cancer (stages 0–III) within the past six months, read and wrote English among her languages of choice, and had school-aged child between 7 and 12 years of age. After approval from an institutional review board (IRB), study team obtained consent and age-appropriate assent from the mothers and their children.

The study team contacted eligible mothers by phone and read them an IRB-approved enrollment script; if they were interested, the team asked them to obtain their school-aged children's agreement to participate in the study. Pending the child's willingness to participate, members of the study team visited participants' homes to obtain signed informed consent, the child's assent/consent, and demographic and baseline questionnaire data. The specially trained data collectors were instructed on the standard way to administer the children's study measures. The children were unaccompanied by their mothers while they completed the questionnaires privately. Families who completed the study questionnaires at baseline (T1) were approached three months later (T2) and one year later (T3) to complete the study measures.

The current study utilized and analyzed a subset of data from the mother–child dyads at baseline and after three months. Children ranged in age from 7 to 12 years (*M* age = 9.8 years, *SD* = 1.52). Children's gender was equal (51%, *N* = 203). Mothers averaged 43 years of age (*SD* = 4.93) and were diagnosed within six months (*M* = 3.4 months, *SD* = 1.9) with breast cancer (39.2 % stage 0–I, 49.4% stage II, and 11.4% stage III). The majority of mothers (78%) received chemotherapy, radiation therapy, or a combination of both during the course of the study. Mothers' ethnic distribution was mainly Caucasian (74.8%); the remaining mothers were Hispanic (6.4%), Asian (3%), and African American (2.5%); 1.5% consisted of other ethnicities such as Native American and Pacific Islander. Of the mothers, 87% had completed college education or higher.

Variables and Measures

Children's illness-related concerns. We used the Child's Illness-Related Concerns Scale to measure children's concerns attributed to the mother's breast cancer diagnosis (Almulla, Lewis, & Oxford, 2019, unpublished). This child self-report measure is composed of 18 items intended to capture five dimensions of concerns: changes in the family's routine and resources, uncertainty, illness-contagion, mother's death, and mother's well-being. The scale asks children to rate the frequency of each concern on a 5-point scale (1 = "Never" to 5 = "All of the time"). Higher scores denote a higher frequency of concerns. In our sample, internal consistency reliability was acceptable across domains (0.8 and above). We established construct validity for this scale in a prior study (Almulla et al., 2019, unpublished). For the current study, we calculated domain scores by averaging the scores of items in each specific domain. Then, each domain served as an indicator to estimate the latent variable of illness-related concerns (see Table 3.1).

[Table 3.1 here]

Children's desire for proximity. We utilized the Relatedness Scale (Lynch & Cicchetti, 1991, 2002) to measure the child's desire for proximity to the mother. Psychological proximity seeking is a six-item child-reported subscale that measures the degree to which children wish they were closer to their mother (e.g., "I wish my mother understood me better"). Response options range from 1 to 4 (1 = "Not at all true" to 4 = "Very true"). High scores indicate a desire for greater closeness to the mother, whereas low scores imply that the child is satisfied with the degree of closeness to the mother (Lynch & Cicchetti, 1991, 2002). For the current study, we used all items except item 5 ("I enjoy the time I spend with my mother") to estimate the latent variable of "the child's desire for psychological proximity to the mother" When we examined the measurement model of the latent variable by including all six items, item 5 was not a good estimate in our sample, and the model showed a better fit when we excluded it. Internal consistency reliability for the study sample was 0.80 (Table 3.1).

Children's anxiety. We used the Revised Child Manifest Anxiety Scale (RCMAS) to assess children's anxiety (Reynolds & Richmond, 1985). This 28-item self-report scale asks children to rate specific aspects of anxiety brought on by their feelings or actions as "yes" or "no" (e.g., "It's hard for me to get to sleep at night" or "Often I feel sick in the stomach"). Higher scores indicate higher levels of anxiety. Convergent validity was established with the State–Trait Anxiety Inventory for Children (Compas et al., 1996), and internal consistency reliability for the current study sample was 0.90. Item scores were summed, with a possible range of scores from 0 to 28. We utilized the total score as an observed variable in the structural model.

Maternal depressed mood. We used the Center for Epidemiologic Studies-Depression Scale (CES-D) to assess maternal depressed mood (Conerly, Baker, Dye, Douglas, & Zabora, 2002; Radloff, 1977). In this 20-item scale, the mother rates the recent occurrence of symptoms of depression in the past week on a 5-point scale (1 = "Rarely or none" to 5 = "Most or all of the time"). Higher scores indicate higher depressed mood levels. The validity is well established and the internal consistency reliability was 0.90 for the current study sample. Item scores were summed, with a possible range of scores from 20 to 100, and were used as an observed variable in the structural model.

Statistical Methods

Structural equation modeling (SEM) using Mplus Version 8.0 (Muthén & Muthén, 1998-2017) was performed to test the hypothesized model. Prior to testing the theoretical predictions, the measurement model was identified to ensure an adequate fit using confirmatory factor analysis (Byrne, 2012; Kline, 2015). To provide metric latent constructs, one factor loading in each construct was scaled to 1.00. We selected full information maximum likelihood estimation to handle missing data, which assumes data were missing at random (Kline, 2015). We assessed model fit using the associated chi-square, comparative fit index (CFI), Tucker-Lewis index (TLI), root-mean-square error of approximation (RMSEA), and standardized root mean square residual (SRMR). Nonsignificant $\chi^2(df)$, CFI and TLI values > 0.95, RMSEA ≤ .05, and SRMR ≤ .08 jointly indicate a good model fit (Brown, 2006; Hu & Bentler, 1999; Kline, 2015).

In this sample some of the children at T2 (after 3 months) were part of intervention group and it is possible that the intervention group impacted the relationship among the variables. We compared a multiple group analysis between a constrained model and unconstrained model using Intervention as the comparing variable between the intervention (N= 91) and control (N= 85) groups (Bentler, 1999). Both constrained and unconstrained models fit the data well (unconstrained: χ^2 (120) = 198, RMSEA= 0.077, CFI= 0.91, TLI= 0.90, SRMR= 0.075; constrained: χ^2 (136)= 207, RMSEA= 0.086, CFI= 0.92, TLI= 0.92, SRMR= 0.075). A chi-square difference test was computed and showed no significant difference between the constrained and unconstrained models suggesting that the covariance structures were equivalent at T2 ($\chi^2 \Delta$ (16) = 9, $p < 0.001$). Thus, we used to full sample to report results (Kline, 2015).

We examined the structural model after determining whether the measurement model was an adequate fit to determine the significant direct and indirect paths. Direct structural paths were interpreted as standardized regression coefficients. We used the bootstrapping confidence interval (CI) approach with 1,000 iterations to test the hypothesized mediations (indirect paths). The use of bootstrapping CI is recommended over other limited techniques and is considered the gold standard for testing the most accurate indirect effects (Karazsia, Berlin, Armstrong, Janicke,

& Darling, 2014; Preacher & Hayes, 2008). The mediation effect is considered significant if there is no zero in the 95% CI (Preacher & Hayes, 2008).

Results

Means, *SD*s, and correlations among all observed study variables are reported in Table 3.1. The model in Figure 3.1 was found to have a good fit with the sample data: $\chi^2(50) = 81.6$, CFI = 0.96, TLI = 0.95, RMSEA = 0.06 (90% CI = 0.035–0.079), and SRMR = 0.04. Because the chi-square test statistic is highly sensitive to small samples, we attributed the significant χ^2 to our small sample size. To adjust for the small sample size, we divided the chi-square test statistic by the degrees of freedom ($\chi^2/df \leq 3$; Kline, 2015): 1.63. The standardized factor loadings and structural results are presented in Figure 3.1.

As noted in Figure 3.1, a higher frequency of children's illness-related concerns was associated with higher levels of maternal depressed mood (.23, $p < .05$). Maternal depression inversely predicted children's higher desire for psychological proximity to their mothers (-.15, $p < .05$). In other words, when the mother was depressed, children's desire for proximity and support seeking toward their mother was reduced. However, maternal depressed mood did not predict children's anxiety (T2) after three months (-.06, $p > .05$).

The higher frequency of children's illness-related concerns was significantly associated with children's desire for proximity (.72, $p < .001$) and anxiety (T2) after three months 0.31, $p > .05$). In other words, when children were more concerned about their mother's illness, they wished for greater psychological proximity toward their mothers. Moreover, higher degrees of children's desire for psychological proximity predicted higher levels of anxiety in children after three months (.30, $p <. 05$).

The indirect effect of children's illness-related concerns on children's anxiety after three months (T2) was significant (total indirect estimate = 0.21; 95% CI = 0.02 to 0.46), suggesting that the link between children's illness-related concerns and anxiety was significantly mediated by the children's unmet desire for proximity. However, the unmet desire for proximity did not mediate the relationship between maternal depressed mood and children's anxiety (T2) after three months (total indirect estimate = - 0.19; 95% CI = -0.13 to 0.002).

Discussion

This study sheds light on the importance and utility of attachment theory in our understanding of children's adjustment to maternal cancer. To our knowledge, it is the first study to incorporate attachment theory in examining the processes by which children develop anxiety when encountering a significant stressor such as maternal cancer. We investigated the link between the child's reported illness-related concerns and the mother's depressed mood as well as how these two factors influence the child's desire for proximity and the future development of his or her anxiety. The study also examined whether the unmet desire for proximity mediates the influence of the illness-related concerns and the mother's depressed mood on the child's anxiety after three months.

With regards to the tested model in this study (see Figure 3.1), the results demonstrate that (a) a significant link was found between self-reported depressed mood in mothers with breast cancer and their children's self-reported illness-related concerns, (b) elevated levels of maternal depressed mood were significantly associated with child's diminished desire for proximity to the ill mother, (c) children with greater reported illness-related concerns desired more proximity toward their ill mother and the unmet desire for proximity induced higher levels of anxiety in children three months later, (d) the children's unmet desire for proximity mediated the impact of their reported illness-related concerns on their anxiety but did not mediate the impact of maternal depressed mood on their anxiety, and (e) children's concerns also directly influenced their anxiety (however, maternal depressed mood failed to directly influence the development of anxiety three months later. These results support the significance of attachment theory to our understanding of the impact of maternal cancer on children and are discussed in greater detail in the following sections.

Maternal Depressed Mood and Children's Illness-Related Concerns

The significant association between maternal depressed mood and children's illness-related concerns confirms what has been documented in the literature about maternal depression being a risk factor for emotional problems in children experiencing their mothers' cancer (DeKlyen & Grenberg, 2008; Lewis & Darby, 2004; Lewis et al., 2015; Krattenmacher et al., 2012; Purc -Stephenson & Lyseng, 2016; Watson et al., 2005; Zahlis & Lewis, 1999). However, in the current study, we failed to find a direct association between the mother's depressed mood and the later development of the child's anxiety, unlike in previous studies (DeKlyen & Grenberg, 2008; Krattenmacher et al., 2012). Our study was the first to document more specifically the significant association between maternal depression and children's illness-related concerns that may antecede their anxiety. Several explanations can be offered for this significant correlation. One is that stressed mothers who are struggling with their illness are less likely to notice their children's concerns (Lewis & Darby, 2004; Lewis et al., 2015; Lewis et al., 2017; Zahlis & Lewis, 1999). Another explanation could be related to the altered mother–child interaction and communication when the mother is depressed. Others argue that the child's distress is reflected by mother distress in that when the child observes his or her mother's distress; he or she also becomes distressed (Garmezy, 1991). With regard to the idea that the association might be confounded by the rater's bias (Osborn, 2007), in our study children rated their own concerns and mothers rated their depressed mood.

Maternal Depressed Mood and Children's Desire for Proximity

Our results revealed that when ill mothers are highly depressed, children are less likely to desire proximity and closeness from them. This result confirms a previous finding in the attachment literature that maternal depression leads to a prolonged waiting time before seeking proximity or support (Dujardin et al., 2016). Consistent with what would be predicted by attachment theory (Bowlby, 1969), there are two possible reasons for this result. First, the mother's depression diminishes or interrupts the child's expectations of the mother's responsiveness to his or her needs, which, in turn, reduces the child's tendency or desire to seek her support. A second possibility is that some children may have had an existing avoidant attachment strategy before the cancer and are trying not to add to the mother's distress. Instead, they inhibit their desire for proximity simply to protect the relationship with the mother (Bosmans & Kerns, 2015). However, different attachment strategies, prior or during their mother's illness, were not examined in this study. Further research is required to understand how different attachment strategies prior to or during the illness may impact the children's experience of their mother's illness.

Children's Illness-Related Concerns, Desire for Proximity, and Anxiety

The link between children's elevated illness-related concerns and greater desire for their mothers' proximity is a significant result of our study. This result is heavily rooted in attachment theory, indicating that at a time of distress that exceeds the child's capacity for self-control, such as the experience of maternal cancer, the attachment system is activated to regulate the child's emotions though seeking support and proximity from the mother (Bosmans & Kerns, 2015; Dujardin et al., 2016).

The significant impact of this elevated desire for proximity on the children's anxiety after three months is another key contribution of this study. One interpretation could be that the increased desire for the mother's proximity is an indication that the children are threatened; when the children cannot rely on the mother to relieve their intense negative emotions, their risk for anxiety increases. Although this is a new finding in children struggling with maternal cancer, the association is well documented in the attachment literature and implies several explanations (Kerns & Brumariu, 2014). One is that children have difficulty regulating their emotions when they are insecurely attached, which in turn increases their risk of anxiety. Another explanation is that because the cancer is a sudden stressor to the child's security, even secure children may go into a temporary ambivalent or preoccupied attachment because of their uncertainty about their mothers' availability. They also may experience inconsistent contact and support when the mother is physically away for treatment or emotionally removed because of the illness. These children are at higher risk for anxiety because they are consistently worried and unsure about their mothers' availability. In this study, attachment security was not directly measured; however, we measured the desire for closeness and proximity as an indicator of the child's desire to gain access to their attachment figure. Although children with both an avoidant and ambivalent attachment strategy have adapted to the unavailability of their caregivers, the ways in which they deal with their concerns over their mothers' cancer vary, which in turn may predict various later adjustment problems. Future studies are needed to help clarify how different patterns of insecurity might predict the later development of psychopathology.

The significant direct relationship between the children's reported concerns and their anxiety three months later is an important part of understanding children's experiences in the context of maternal cancer and extends the general literature on the risk of developing psychopathology when children face stressors beyond their self-regulatory capacities (Compas et al., 2001). Meeting the child's need for psychological closeness or proximity can reduce the risk of anxiety in children dealing with maternal cancer. This might explain why children have different trajectories when facing maternal cancer, with some developing adjustment problems and others displaying resilience (Birenbaum et al., 1999; John et al., 2013; Lewis et al., 2015;

Osborn, 2007; Schmitt et al., 2008; Sigal et al., 2003; Visser et al., 2005). This result suggests that meeting the child's need for psychological proximity and support from the ill mother can buffer the effect of maternal cancer on children's adjustment. In contrast, the unmet child's desire for proximity can provoke their anxiety.

Study limitations

Several limitations of this study should be mentioned. First, children's illness-related concerns, desire for proximity, and anxiety were all measured using child-reported data. Using the same informant may have resulted in shared variance. Future investigators should consider multiple data informants to gain a deeper understanding of the child's experience.

Second, our study results may not be generalizable to the overall population of children facing maternal cancer, because data were obtained from mother-and-child dyads in the early stage of illness diagnosis and two months later; as such, the results may not apply to dyads in advanced stages of the illness. At the same time, we revealed the specific impact of cancer diagnosis on children in the early stage of their mothers' diagnosis and treatment. Third, the mediator was measured at T1 along with other variables; it would have been preferable to have them at different points of time.

Finally, bearing in mind that mothers in our study were mainly White and highly educated, it is always possible that the results would be different with mother–child pairs from a more diverse or less educated sample.

Clinical implications

The findings of our study reveal factors and pathways that are important to fostering clinical implications and future intervention programs to enhance adjustment and minimize the risk of anxiety in children experiencing maternal cancer. Alleviating the child's illness-related concerns, minimizing the mother’s depressed mood, and meeting the child’s need for proximity may present ideal targets to reduce children’s anxiety and improve their adjustment to their mothers’ illness. Moreover, supporting the child emotionally can buffer the impact of cancer on the child’s anxiety, as evidenced by the children’s unmet desire for proximity as a significant mediator in our study. This may be achieved by designing attachment-based interventions to provide mothers with the knowledge and skills that would increase their responsiveness and availability to their children at times of distress. For example, mothers could be provided with the skills to alleviate children’s concerns about the cancer while maintaining or demonstrating an attitude of responsiveness and closeness to the child. Furthermore, ill mothers could be assisted with their depressed moods without further adding to their burdens.

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Table 3.1

Descriptive Statistics and Correlations Among Study Variables

Observed Variables	N	M (SD)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
1. Changes in family's routines and resources	177	2.35(1.01)	1.00											
2. Uncertainty	177	2.38(1.10)	.58**	1.00										
3. Illness-contagion	177	1.98(1.22)	.40**	.49**	1.00									
4. Mother's death	177	2.52(1.40)	.59**	.52**	.43**	1.00								
5. Mother's well-being	177	2.71(1.24)	.62**	.61**	.42**	.71**	1.00							
6. I wish my mother knew me better (Rel1)	175	1.50(0.90)	.32**	.32**	.19*	.26**	.24**	1.00						
7. I wish I could talk about more things with my mother (Rel2)	175	2.17(1.10)	.32**	.36**	.19*	.34**	.36**	.39**	1.00					
8. I wish I was closer to my mother (Rel3)	175	2.21(1.20)	.41**	.29**	.12	.41**	.45**	.43**	.48**	1.00				
9. I wish my mother knew more about how I feel (Rel5)	175	2.37(1.31)	.45**	.41**	.33**	.40**	.55**	.41**	.51**	.56**	1.00			
10. I wish my mother could spend more time with me (Rel6)	175	2.70(1.12)	.33**	.31**	.22*	.38**	.36**	.38**	.30**	.52**	.41**	1.00		
11. Mother's depressed mood	174	14.4(9.95)	.26*	.14*	.12	.18*	.18*	-.02	-.07	-.09	-.02	.01	1.00	
12. Child's anxiety	153	6.78(6.40)	.38**	.44**	.26*	.35**	.44**	.42*	.29**	.27*	.35**	.46**	-.03	1.00

Note. *$p < .05$, **$p <. 001$.

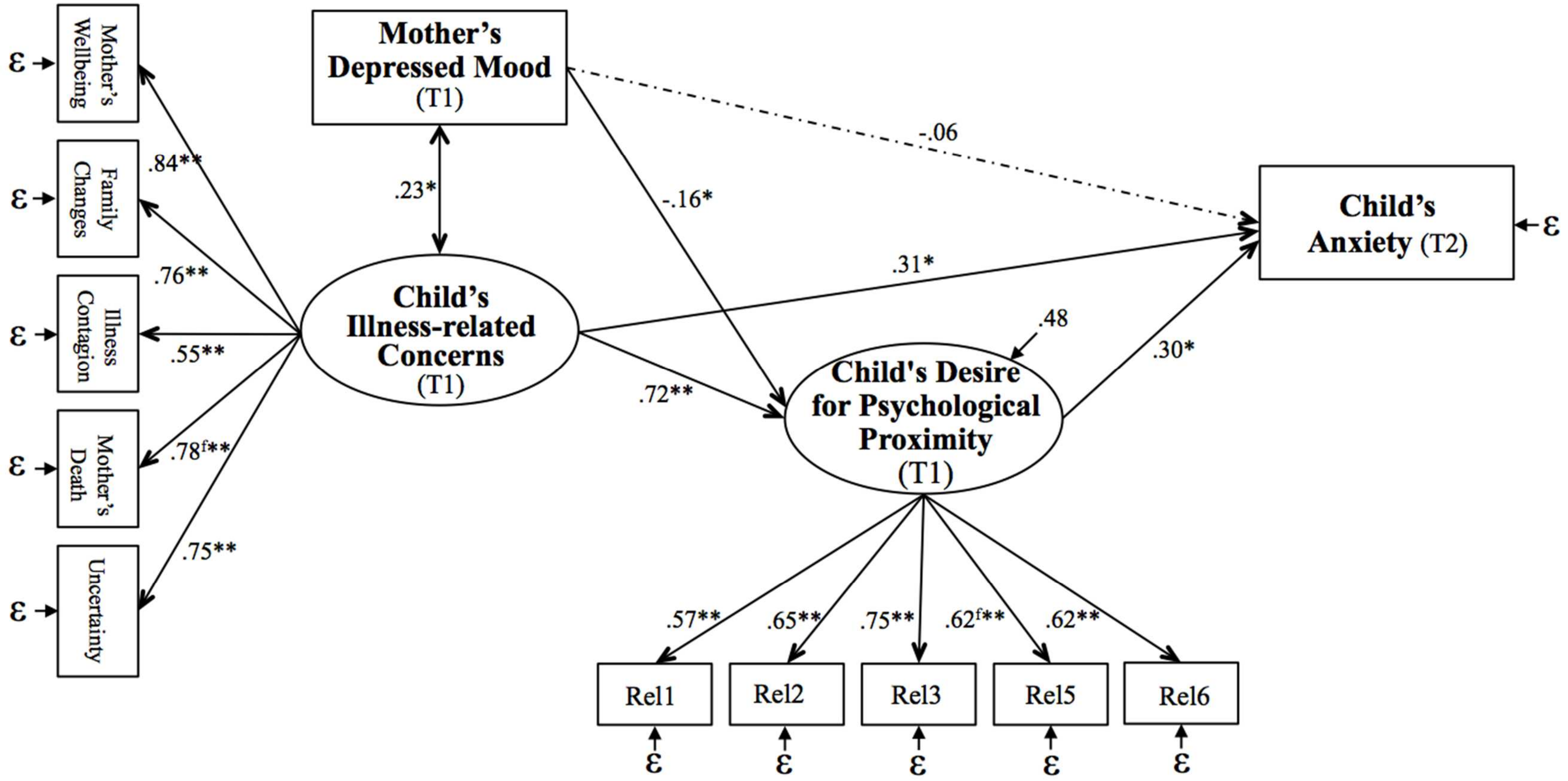

Figure 3.1. Standardized results of structural equation model predicting child's anxiety. T1 denotes baseline; T2 denotes 3-month follow up. Solid lines represent significant effects; dashed lines represent non-significant paths. Latent constructs are shown in ovals and observed variables are shown in rectangles. A superscript f indicates a parameter scaled to 1.0 in the unstandardized solution. $*p < .05$, $**p < .001$.