

Safeguarding the Children: The Cancer Journey of Young Mothers

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Among women worldwide, the two most common types of cancer are cancers of the breast and cervix (World Health Organization, 2015). In young women, breast cancer tends to be sinister, has a less than favorable prognosis, and requires more aggressive treatment (Anders et al., 2008; Lee & Han, 2014). Despite organized cervical cancer screening programs and the introduction of vaccines to prevent strains of cancer-causing human papillomavirus, invasive cervical cancer requiring aggressive treatment is prevalent among younger and older women (Spayne et al., 2008).

Being told that one has cancer produces psychological distress (Carlson, Groff, Maciejewski, & Bultz, 2010; Stadelmaier, Duguey-Cachet, Saada, & Quintard, 2014). Young women experiencing breast or gynecologic cancers are at a higher risk for psychological distress than older women (Gómez-Campelo, Bragado-Álvarez, & Hernández-Lloreda, 2014), particularly during the phases of diagnosis and treatment (Manuel et al., 2007). Many young women diagnosed with cancer are mothers, but little is known about how they manage their maternal roles and responsibilities during each phase of the cancer journey.

Background

A cancer diagnosis triggers fears of death. For many young women, cancer forces them to face their mortality for the first time. After this initial fear, they face threats to their femininity, including concerns about body image and sexual functioning (Ussher, Perz, & Gilbert, 2012). Systemic treatment can affect young women's sexual well-being and overall quality of life because it can induce premature and sudden menopause with symptoms of hot flashes, reduced libido, vaginal and vulvar dryness, and atrophy (Baucom, Porter, Kirby, Gremore, & Keefe, 2005; Katz, 2007). Young women's reproductive-related concerns are diverse. They include fertility, missed opportunities for childbearing, the

Purpose/Objectives: To investigate how young mothers manage their maternal roles and responsibilities during their journey as patients with cancer.

Research Approach: Semistructured face-to-face interviews and analysis.

Setting: Rural and urban communities in eastern Canada.

Participants: 18 mothers aged 27–45 years when diagnosed and who were concluding or had concluded treatment for breast or non-ovarian reproductive cancer.

Methodologic Approach: Glaserian Grounded Theory.

Findings: During the various phases of the cancer journey, mothers focus their efforts on protecting their children from psychological harm. Safeguarding the Children is the explanatory model generated from the interview data that consists of four strategies—customizing exposure, reducing disruption to family life, finding new ways to be close, and increasing vigilance—which mothers implement to protect their children.

Conclusions: Young mothers with cancer manage their maternal roles and responsibilities by strategizing how they can mitigate threats to their children's psychological well-being.

Interpretation: Nurses are ideally suited to address holistic needs and concerns of women with cancer who are mothers. Safeguarding the Children, as an explanatory model for practice, may equip oncology nurses with requisite knowledge and understanding to better anticipate resource, counseling, support, and referral needs of young mothers during their cancer journey.

Key Words: mothers with cancer; grounded theory; psychological coping skills

ONF, 42(5), 534–541. doi: 10.1188/15.ONF.534-541

safety of contraception, whether to pursue pregnancy after breast cancer, their ability to breastfeed (Connell, Patterson, & Newman, 2006; Corney & Swinglehurst, 2014; Lambertini, Pinto, & Del Mastro, 2014), and the possibility of cancer recurrence (Thewes et al., 2013).

Treatment for breast cancer includes surgery, chemotherapy, and radiotherapy (used alone or in combination), as well as other modalities, such as endocrine

therapy (Crozier, Swaika, & Moreno-Aspitia, 2014). Surgical treatment for breast cancer is indicated in almost all cases and involves mastectomy or breast-conserving surgery, such as lumpectomy or partial mastectomy, followed by radiotherapy (Hamelinck et al., 2014). Side effects of treatment can be disturbing even in the short-term. Chemotherapy side effects include nausea, vomiting, hair loss, constipation, neutropenia, anemia, and fatigue. Effects from surgery include postoperative pain, discomfort from drains, and, potentially, with lymphedema, worry about infection and body image issues.

Treatments for reproductive cancers generally include surgery, radiotherapy, and/or chemotherapy. Radiation therapy can impair functional status and quality of life because of radiation pneumonitis, fatigue, difficulty concentrating, and localized skin damage (Arnett, Henry, & Fankell, 2014). In addition, women complain of difficulty sleeping, fatigue, diarrhea, anorexia and nausea, urinary symptoms, and vaginal discharge (Clemmens, Knafl, Lev, & McCorkle, 2008).

Research about young women with cancer is growing, but little investigation has been conducted regarding young women with cancer who are mothers. Research suggests that the cancer experience for this subpopulation is distressing on many levels and that considerable support is required from healthcare professionals (Elmberger, Bolund, Magnusson, Lützén, & Andershed, 2008). Oncology nurses must learn how to assist young mothers with cancer through each phase of the cancer journey. The current study was conducted to begin addressing the significant gaps in practice knowledge and understanding.

Research Approach

Glaserian grounded theory (GT) methodology (Glaser, 1998) was used to investigate how young mothers manage their mothering roles and responsibilities while being treated for cancer. Francis-Connolly (2000) discussed mothering as a social construct imbued with variables, such as culture, of mothers caring for and nurturing their children “learned through social interactions rather than implied through biological links” (p. 282). GT is an inductive research approach that was developed by social science researchers Glaser and Strauss in the 1960s. GT combines Glaser’s conjectural research training from Columbia University with Strauss’ immersion in pragmatist philosophy and premises of symbolic interactionism from the Chicago School of Sociology. Rather than deductively test theories, Glaser and Strauss wanted to find a systematic process to generate a theoretical explanation about how people manage, cope, or adapt to problematic situations that was grounded in everyday, real-life data (Glaser & Strauss, 1967). In fact, GT methodology was

created as the co-originators were investigating how patients and nurses deal with the everyday realities of terminal care in California hospitals (Stern & Porr, 2011). For decades, nurse researchers have adopted GT as the methodologic research tool to better inform and advance nursing practice, particularly when few or no theories exist in the case of caring for young mothers who must endure the cancer journey.

Participants

The participants were 18 mothers recruited from rural and urban communities in eastern Canada who had been diagnosed with cancer and had undergone treatment. Participants were informed about the study by oncology nurses and oncologists. Packets of information about the study were handed to potential participants. In addition, posters were placed in clinics and waiting room areas of each of the cancer centers in the province. Mothers who were interested in the study used the toll-free phone number to contact the researcher for more information or to arrange an interview.

Participants were aged 27–45 years at the time of diagnosis. All participants were actively mothering at least one child aged 17 years or younger. All mothers had undergone surgery, and 17 of the 18 mothers had adjuvant treatment after surgery (see Table 1). Demographic information is reported in ranges to protect the anonymity of the participants.

Data Collection

Following ethics approval and permission from the Health Research Ethics Authority for the province of Newfoundland and Labrador, and the provincial health authorities covering urban and rural centers, data collection commenced with face-to-face interviews. Mothers were provided information and the opportunity to pose questions about the study before they signed consent to participate. Participants responded to semi structured interview questions, including the following.

- Being a young mother, tell me about your cancer experience.
- Were you separated from your children because of treatment or complications?
- If so, what was that experience like?
- What advice would you have for other young mothers experiencing cancer?

Interviews were audio recorded, lasted from 40–70 minutes, and were conducted in mothers’ homes, a hotel room, or an office setting. Some mothers became slightly tearful during the interview, but none opted to stop the interview or reschedule the interview. They were offered the name of a healthcare professional if they wanted emotional support or counseling. Immediately after the

Table 1. Sample Characteristics (N = 18)

Characteristic	\bar{X}	SD	Range
Age at diagnosis (years)	39	5.18	27–45
Age at interview (years)	41	5.19	30–49

Characteristic	n
Type of cancer	
Breast	16
Reproductive	2
Type of treatment (after surgery)	
Chemotherapy	15
Radiotherapy	11
Chemotherapy and radiotherapy	9
Marital status	
Married	16
Separated	1
Divorced	1
Age of children (years)^a	
0 (newborn)–5	10
6–11	11
12–17	11
Older than 17	5
Gender of children	
Male	20
Female	17

^aChildren were at least one year older at the time of the mothers' interviews.
Note. Participants could choose more than one response.

interview, observational data regarding participants' facial expressions, body language, and home setting were recorded as field notes.

Data Analysis

Data analysis, in keeping with GT, involved two steps: building substantive codes and advancing abstraction to theoretical codes (Glaser, 1978; Stern & Porr, 2011). Coding transcribed interview data enabled the researchers to identify what mothers think, feel, and do while living with cancer, and to explain how mothers manage. Building substantive codes brought to the researchers' attention several key participant statements, including, "I didn't want anyone knowing this; I didn't want the kids singled out having a sick mom," and, "All I told them was that I am having a bad cell count. They had no idea of what I had done. They don't need to know; they are too young." These quotes lead to the substantive code "telling the children." Later, this code was abstracted to the theoretical code "verbal disclosure."

The following quote was coded as "hiding drains" and later as "selectively shielding."

Yes, I used to put them [bilateral drainage containers] in the pocket of my shorts, and I had a vest on, and it was summertime. I had a vest and used to

hide it [the drains] that way. They never saw my drains, first or last.

Verbal disclosure and selectively shielding lead to the major conceptual category "customizing exposure." Three additional major conceptual categories also were identified, including "reducing disruption to family life," "finding new ways to be close," and "increasing vigilance."

The core issue among participants was identified; repeatedly in the transcribed data, the researchers discovered that the mothers' concern was not so much for themselves but rather for the psychological well-being of their children. Several conceptual categories were selected to elucidate how mothers addressed this concern. Through the second step (advancing abstraction to theoretical codes), the researchers determined how conceptual categories related to one another. The conceptual categories were, in fact, strategies, and, after much deliberation and consulting the literature, the researchers confirmed four major strategies that finally emerged as the explanatory model that they labeled "Safeguarding the Children."

Findings

During the various phases of the cancer journey, mothers focus their efforts on protecting their children from psychological harm. Safeguarding the Children is the explanatory model generated comprising four strategies: customizing exposure, reducing disruption to family life, finding new ways to be close, and increasing vigilance, which the researchers discovered mothers implement to protect their children (see Figure 1).

Customizing Exposure

Customizing exposure is the strategy whereby mothers decide what should be revealed to their children. Customizing exposure commences with diagnosis and continues throughout all phases of the cancer journey. Mothers consider their children's age, gender, developmental stage, and personality traits before verbally disclosing information about their cancer and determining to what extent they have to shield their children from treatment-related effects (e.g., hair loss). Customizing exposure involves two dimensions: verbal disclosure and selectively shielding.

Verbal disclosure: Mothers verbally disclosed their cancer diagnosis using age-appropriate language. For example, mothers used phrases such as, "Mommy is sick inside," or "Mommy has some bad cells" when speaking with their children aged 4 years or younger, and used the word "cancer" with their older children.

Mothers were respectful of their children's right to know that something was wrong, knowing that their

children might inadvertently overhear or notice things. Most prepared a conversation in their mind as to how to tell their children. One mother described the following situation. "My husband was going to go in and talk to him first, but I said, 'No, you can't. He has to see my reaction.'" She explained that if her son saw her reaction, then he would gauge his reaction accordingly (i.e., upset versus calm).

Mothers chose not only how, but also when to disclose, and this was contingent on what was happening in their children's lives. One mother chose to delay telling her children for 10 days because her oldest child was writing school examinations. "There is no sense letting the kids know about this until he finishes exams," she said.

Selectively shielding: Selectively shielding is the second dimension of customizing exposure. Although receiving the diagnosis of cancer was frightening, mothers controlled their emotions and concealed their expressions of fear from their children. One mother stated, "You know, I had my moments at first when I would have a few outbursts. I would never do it in front of the kids." Another mother said,

I have two little girls, and when I walk into that house, they have to see that mommy is still mommy. And if I went in, you know, with swollen eyes and, you know, running off to my room, I can't.

Several mothers indicated that they also shielded their children from the physical signs of diagnostic testing and treatment. One mother described how shielding her children was important during the very early postoperative period. "I wanted all the tubes out of me before they came up. So when they came up, I was cleaned up, and I had a bit of makeup on, and I was sat in the chair." Daughters and younger children of both genders were exposed to healed surgical incisions because they saw their mother dress and undress or take a bath. Some mothers said that their children referred to their bare chest as "broken" and asked when their "boobie" was going to grow back.

Hair loss was a major concern. One mother said, "When I lost my breast, I did not cry. When I shaved my head, I did." Hair loss was a visible sign of cancer, and the children seemed to be comfortable with their mother's hair loss in the privacy of the home but sought reassurance that their friends would not see their mother without hair. "When we were around the house, she was OK with it. When we went outside, though, she was very keen to remind me . . . 'Don't forget your hair,' . . . because she wanted me to be a normal mom." One mother

told the interviewer that the family locked the front door to give her time to put on her wig before anyone came into the home.

Reducing Disruption to Family Life

Reducing disruption to family life is the second strategy of Safeguarding the Children and was manifested through maintaining routines and selflessly redirecting support.

Maintaining routines: Mothers attempted to maintain the everyday activities of their children. They dressed and drove their children to school or day care, even if they had to return to bed after the children left the house. One of the mothers alluded to the effort required. She said, "There would be days when I couldn't think that it was possible to get up, and I got up and took care of them." Mothers continued to bathe their children at night and tuck them into bed despite experiencing nausea, weakness, fatigue, and other chemotherapy side effects. Maintaining routines also involved special activities, such as birthday parties, Christmas concerts, and school award ceremonies. When physically unable, mothers sought assistance from the children's father, grandparents, and aunts.

Selflessly redirecting support: Selflessly redirecting support is the second way reducing disruption to family life is manifested. Mothers denied offers for help throughout their cancer experience, preferring instead that those offering support turned their attention toward their children. Mothers also wanted support redirected toward the children's father to promote their efforts to care for the children and to maintain a secure, loving home environment.

Similarly, mothers selflessly declined their husband's offers to accompany them during radiation therapy because they thought their children needed their father to stay at home with them. Mothers who lived a distance

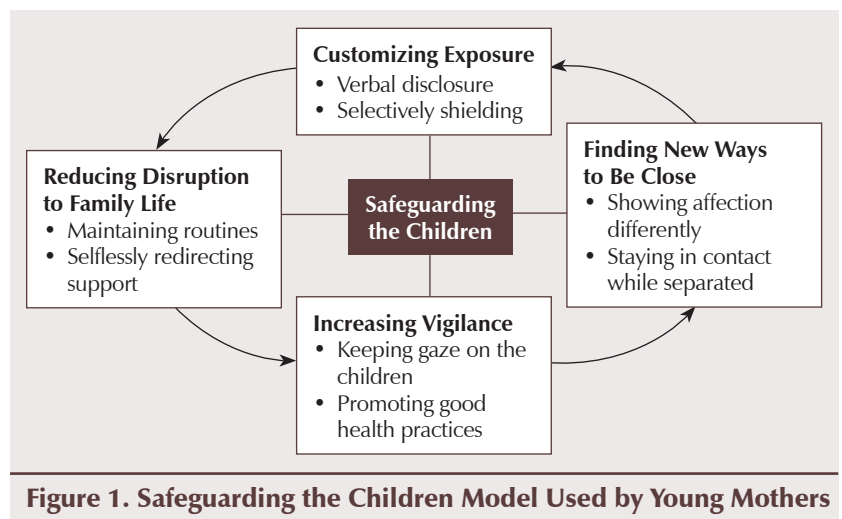


Figure 1. Safeguarding the Children Model Used by Young Mothers

from the cancer center traveled on Monday morning and returned home on Friday whenever possible so that they would be home by the weekend to be with their children. Some mothers received radiation treatment over three weeks versus six weeks, as appropriate. The shorter period meant more time at home, even though it entailed having to increase the dose of radiation. One mother said, "So the radiologist said OK, then we will do it in three weeks and double up the dosage. So I was happy."

Finding New Ways to Be Close

Chemotherapy is commonly associated with episodes of neutropenia, and most of the mothers discussed how they had to take special precautions against the risk of infection. For example, mothers shared how they had to remind their children to wash their hands. If their children were in day care or school, they were particularly susceptible to childhood illnesses and viruses, such as the common cold. Mothers found new ways to be close to their children, including showing affection differently and staying in contact while separated.

Showing affection differently: Showing affection differently reflects the actions taken by mothers to convey their love while having to temporarily suspend usual forms of affection toward their children. One of the mothers described how she kissed her child on the forehead as a new and special way to give kisses while she was going through chemotherapy. Following surgery, mothers could not lift, carry, or even hug their children in the usual way. Mothers encouraged their children to be gentle when running up to them and reminded their children to be gentle when hugging. Mothers said how they missed embracing their children tightly.

Staying in contact while separated: Mothers stayed in contact with their children while undergoing surgery, radiotherapy, or other forms of treatment. Twelve of the mothers lived more than 30 minutes from the main cancer center. Mothers maintained contact with their children by telephone on a frequent basis. One mother used Skype™ to stay in touch with her children every evening. She said, "We made the most of it, and then I would be on the phone and Skyping with the girls constantly. . . . [Using] the technology, they can see that you are OK."

Increasing Vigilance

Mothers explained that they focused all their attention on their children's verbal and nonverbal behaviors with increasing vigilance throughout the cancer journey. One mother said, "It was hard on me to be going through it and to watch the kids watch me go through it." Increasing vigilance consisted of two dimensions: keeping gaze on the children and promoting good health screening practices.

Keeping gaze on the children: Although most mothers keep their children's well-being uppermost in their minds as part of normal daily life, the mothers in the current study demonstrated a more intense watchfulness of their children. The term "keeping gaze on the children" reflected how the mothers constantly watched for behavioral changes in their children. Mothers were aware that their children, depending on their ages, may have had a very narrow understanding of cancer and, as a result, may have had fears that they were not able to express. Children who tended to "keep everything inside," as opposed to children who reacted immediately, were particularly the object of their mother's fixed gaze. For example, one mother described how her 5-year-old child had a psychosomatic complaint—an "upset tummy"—and did not want to go to school. She recognized that this may be the child's way of expressing concerns or fears about his mother's illness.

Mothers watched for signs that their children may be upset and possibly having some distress about their illness. The mothers were ready to intervene and offer reassurance to their children. Another mother described how she would use distraction when she noticed her daughter becoming upset by cancer commercials.

When those cancer commercials would come on, her little face would change, and she would be engrossed, and I would try and distract her, but I totally picked up that she knew a lot more than I thought she did.

This example highlighted how young mothers in the current study engaged in an activity of keeping gaze on the children that demonstrated a state of increased vigilance over their normal mothering behavior.

Promoting good health practices: Promoting good health practices of their children reflected the strategies that mothers adopted to ensure that their children were informed about ways to reduce their cancer risk and live healthy lives. A key health promotion activity is for children to learn about and eventually engage in cancer screening practices. Mothers were cognizant that their children may be genetically predisposed to cancer. Their oncologists advised them that their children should be screened in young adulthood; in the future, these children may even have to consider prophylactic surgery, such as bilateral mastectomy, to reduce their risk of breast cancer (Salhab, Bismohun, & Mokbel, 2010).

One of the key messages that mothers shared was about the need for women to listen to their bodies when something does not seem right and to follow up with a healthcare professional to have it investigated. Sometimes, this requires repeat visits to a healthcare professional to ensure that their concerns are addressed. For example, one of the mothers diagnosed with reproductive cancer described having to go to two healthcare

professionals before she was thoroughly investigated for her symptoms. She ultimately was diagnosed with endometrial cancer and underwent a hysterectomy, followed by radiotherapy. She explained to her daughter, who was learning about reproduction in school, the importance of listening to her body and following up with a healthcare professional if something did not seem normal.

Discussion

The current study adds important contributions to the research about young mothers who are diagnosed with cancer. The majority of the participants in the current study were within the first two years of their diagnosis and treatment for cancer. Billhult and Segesten (2003) and Elmberger, Bolund, and Lützén (2005) found in their respective studies that mothers had to find a way to strike a balance between engaging in treatment and caring for their children while maintaining everyday routines at home.

Mothers with cancer go through physical and psychosocial processes from diagnosis to treatment. During this time, they predominantly focus on protecting their children's psychological well-being. Two of the four strategies that emerged that highlight how mothers protected the psychological integrity of their children were customizing exposure and reducing disruption to family life. Although researchers have reported findings similar to the current study about mothers telling their children about cancer and maintaining family routines (Asbury, Lalayiannis, & Walshe, 2014; Billhult & Segesten, 2003; Campbell-Enns & Woodgate, 2013; Elmberger et al., 2005), the mothers in the current study added the dimension of what is selectively shown to the children in addition to what is told to the children. The mothers in the current study poignantly described the lengths they went to keep hidden the physical evidence of cancer so that their children would not be affected. The current study is significant in the finding that young mothers intentionally limited their children's exposure to their cancer situation through customizing verbal disclosure about their illness and selectively shielding the children from some of the physical aspects of their cancer.

Two additional strategies that were identified in the current study were finding new ways to be close and increasing vigilance. Campbell-Enns and Woodgate (2013) discussed mothers' desire to maintain the mother-child bond—they need to be physically and emotionally close to their children for the sake of their children and themselves. However, they also need to have distance between them and their children so they can have time to themselves to recover, not show their fears to their children, heal, and promote a "normal" childhood (Campbell-Enns & Woodgate, 2013). In contrast to the literature that supported the researchers' finding of moth-

Knowledge Translation

Young mothers engage in strategies to safeguard their children as they sacrifice their needs during cancer treatment to protect their children from psychological harm.

Nurses can use the explanatory model of Safeguarding the Children to understand how best to meet the maternal concerns of young mothers during the cancer experience.

Healthcare professionals can best respond to the concerns of young mothers by considering the needs of the whole family during the cancer diagnosis and treatment phases.

ers maintaining this closeness, the researchers could find no literature that discussed mothers' increasing vigilance over their children in the context of cancer. The young mothers wanted to put measures in place for their children so that they could exercise health promotion and screening practices that would prevent the development of cancer or catch it very early in the disease process.

The researchers were struck by the ability of the mothers to carry out their responsibilities for their children. Rempel and Harrison (2007) used the term "extraordinary parenting" to describe how parents with children with life-threatening heart disease safeguarded their children's survival. They found that parents' ability to manage their emotions and maintain normalcy as much as possible helped safeguard their children's precarious survival. The explanatory model that emerged from this study resonates with definitions of safeguarding, particularly those that refer to protecting children from harm to their health and development (National Society for the Prevention of Cruelty to Children, 2011).

In the current study, Safeguarding the Children emerged as the overarching explanatory model that explained how young mothers traversed the cancer journey, always with the intent of protecting their children from the psychological effects of cancer. Safeguarding children is important during the cancer event because they are at risk of being affected by the situation. Research findings suggest that children undergo tremendous worry associated with a mother's cancer (Zahlis, 2001), and that children are aware that something is wrong before they are told (Forrest, Plumb, Ziebland, & Stein, 2006). Children may blame themselves for a mother's cancer or believe that they will also be diagnosed with cancer. Elmberger et al. (2005) reported that children were so upset that they did not want to leave the mother's side and did not engage in usual play with their friends. Mothers were concerned that their children would resent them for being sick or for having to take on too much responsibility. In another study, the researchers discovered that mothers felt anxious when separated from their children during hospitalization,

wondering who would meet their children's emotional needs (Elmberger, Bolund, & Lützn, 2000). In the current study, when mothers were separated from their children because of hospitalization or travel for treatment, they found new ways to be close, including staying in contact by phone and through face-to-face computer platforms, such as Skype.

Implications for Nursing Practice and Conclusions

Although the mothers who participated in the current study managed to cope well, the toll that cancer exerts on the entire family, even temporarily, should not be underestimated. Cancer does not solely affect the individual diagnosed; it affects the whole family. The data suggest that when the young mothers went for diagnostic procedures and treatment, nurses and other healthcare professionals were sensitive to the fact that these patients were mothering dependent children and coparenting with their husbands. However, such sensitivity did not seem to translate into cancer care that anticipated supportive needs of these young families. By virtue of the therapeutic relationships established with young mothers during each phase of the cancer journey, oncology nurses are instrumental in addressing holistic needs and concerns. Like Asbury et al. (2014), the researchers discovered that mothers during the cancer journey sacrificed their

needs for comfort and assistance for the sake of their children.

The explanatory model of Safeguarding the Children can serve as a guide to nurses who are seeking to provide more holistic and individualized care to young mothers and their families while keeping up with the demands of a busy cancer care environment. For example, nurses may find it helpful to know that young mothers with cancer want to customize their children's exposure to the physical signs of cancer, and reducing disruption to family life is very important to them. They are patients focusing on what is best for them, but they are also concerned about their children and put great effort into taking care of them, even during cancer treatment. Using the model as a guide, oncology nurses can recommend relevant resources and referrals and provide appropriate counseling and support to this population of patients with cancer.

The authors gratefully acknowledge the participation of the 18 young mothers who shared rich information about their cancer journeys.

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