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## Being Fully Present

### Gains Patients Attribute to a Telephone-Delivered Parenting Program for Child-Rearing Mothers With Cancer

#### KEY WORDS

Cancer  
Mothers  
Parenting

**Background:** Oncology nurses can assist patients in gaining skills and confidence in multiple areas of illness self-management, including parenting skills. Child-rearing parents with cancer are a unique population because they must self-manage their illness and also help their child manage the intrusion of cancer on everyday life. The telephone offers an inexpensive channel for nurses to assist mothers in developing competencies to parent their child. The acceptability and attributed gains from such telephone services are unknown. **Objective:** The aims of this study were to (1) describe the gains child-rearing mothers attribute to participation in a nurse-delivered telephone cancer parenting program and (2) assess mothers' evaluation of the telephone as a channel for delivering the program. **Methods:** Study participants were child-rearing mothers diagnosed with cancer (N=31) who had completed a manualized telephone-delivered cancer parenting program by a nurse. Mothers were interviewed 1 month after exiting the program by a specially trained interviewer masked on the content of the program. **Results:** Most mothers were white (74%), highly educated, and had breast cancer (93.5%). Mothers attributed gains from the program in 3 areas: (1) being fully present for my child, (2) communicating in new ways, and (3) putting away my assumptions. **Conclusions:** Communication skills learned from nurses can assist mothers to self-manage the impact of the cancer on their own well-being and add to their parenting skills and

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competencies to help their children. **Implications for Practice:** The telephone is an effective and indeed preferred channel for delivering services to child-rearing parents impacted by cancer.

Self-management support has become a key concept for oncology nurses because the treatment trajectory for cancer has shifted from an acute life-limiting disease to a chronic condition that requires lifelong disease surveillance, managing symptoms, and managing the consequences of living with a chronic condition.<sup>1</sup> The 2003 Institute of Medicine Report, "Priority Areas for National Action: Transforming Health Care Quality," defines self-management support as "the systematic provision of education and supportive interventions to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support."<sup>2(p57)</sup> Self-management interventions are based on social learning and self-regulation theories.<sup>3</sup>

Mothers diagnosed with cancer are a unique and vulnerable population because they need skills to manage their illness and to build their confidence in supporting their dependent children. Managing the interpersonal relationships that are altered as a result of her cancer is part of self-management. To support their child's adaptation to the cancer diagnosis, mothers need communication skills that evolve as their child's cognitive abilities expand and as the disease trajectory changes. To date, self-management interventions in adults with cancer have focused on managing symptoms and monitoring disease and have shown positive effects on symptom distress, uncertainty, problem solving, communication, and general quality of life.<sup>1</sup> The primary categories of intervention are educational and/or counseling sessions, exercise, and complementary and alternative medicine.<sup>4</sup> Only 1 intervention, the Enhancing Connections Program (ECP), seeks to build self-management skills in mothers so that they can assist their children in managing the cancer and the impacts of their cancer on their children's lives. The ECP is the first cancer parenting intervention to be tested in a phase III randomized clinical trial.<sup>5,6</sup> The intervention, delivered in-person, improved maternal and child depressed mood, maternal parenting skills, and children's behavioral-emotional adjustment. These improvements were still evident at 1 year.<sup>5</sup> Outcomes of the same program, delivered by telephone (EC-T), met or exceeded those obtained from the in-person delivered ECP.<sup>7</sup> Notably, improvements in children's adjustment resulted from intervening with the mother, not the child. Furthermore, the intervention focused on communication and did not include cancer education.

The EC-T stands in contrast to the dominant tradition of assisting parents with cancer by instructing them on developmentally appropriate ways to discuss disease and treatment with their children. Printed materials by respected professional organizations including the American Cancer Society and the National Cancer Institute provide some information about age-appropriate language, behavioral issues, and the impact of a parent's cancer. Although a focus on explaining the cancer to children is helpful to gain knowledge, it does not provide mothers with self-

management strategies to carry out conversations with their child in ways that diminish the confusion or threat to the child or support their child's emotional development.<sup>6,8</sup> The EC-T positions the mother to have successful conversations about the cancer and its impact on the family by building developmentally appropriate communication skills that address the child's feelings and minimize the child's distress. The skills provided by the program transcend the cancer diagnosis and can be used by parents in health, as well as illness, and at any point along the treatment trajectory.

Exit interviews were conducted with mothers who completed the EC-T Program to obtain feedback about the program. Mothers who did not complete the program were not interviewed. The purpose of this analysis is to evaluate the elements of the intervention that contributed to its efficacy, from the perspectives of mothers who completed the program. The current study has 2 purposes: first, to describe the gains mothers attributed to their participation in the EC-T Program, based on an analysis of 2 questions: (1) "Thinking back on the program overall, what part, if any, was most helpful for you?" and (2) "What, if anything, have you learned about helping your child from this program?", and second, to describe mothers' reports on the acceptability of having the sessions offered by telephone.

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## ■ Methods

### Sample and Setting

Study participants in the EC-T Program were recruited from medical practices of surgeons, radiologists, and medical oncologists in the Pacific Northwest of the United States. Study participants were eligible if they were female, were given a diagnosis of early-stage (local or regional, stage 0–III) cancer within the recent 7 months, read and wrote English as one of their languages of choice, and had a child aged 5 to 12 years who was aware of their mother's cancer diagnosis. Mothers were eligible for the current analysis if they completed all five of the EC-T Program parent education counseling sessions. The outcomes from the EC-T were reported elsewhere.<sup>7</sup>

### Procedure

The EC-T Program consisted of 5 parent educational counseling sessions (see Table 1).<sup>5</sup> Sessions 1 and 3 are particularly germane to mothers' self-management skills in managing their relationship with the child that is altered by cancer: "Anchoring Yourself to Help Your Child" and "Building on Your Listening Skills." The first session, "Anchoring Yourself to Help Your Child," focuses on helping mothers manage their own emotions so she can help her child without emotionally flooding them. The third session, "Building on Your Listening Skills," builds on the mother's abilities to elicit their child's concerns and feelings, even when the child is withdrawn.

 **Table 1 • Description of EC-T Intervention Sessions**

Session 1. Anchoring yourself to help your child: This session focuses on mother's self-care and listening attentively to her child. It helps the mother recognize that their child's experience with the cancer is distinct from their own and suggests ways for them to manage their own emotions so they do not emotionally flood the child.
Session 2. Adding to your listening skills: This session assists mothers in developing skills to deeply listen and attend to the child's thoughts, feelings, and concerns complementing the parent's tendency to be a teacher and not a deep listener.
Session 3. Building on your listening skills: This session builds on session 2 and adds to the mother's abilities to elicit and assist the child to elaborate on their concerns or feelings, even if the child is withdrawn.
Session 4. Being a detective of your child's coping: This session helps the mother to see and nonjudgmentally interpret the child's ways of coping with the cancer. It includes exercises that assist the mother to relinquish negative assumptions about the child's behavior related to the mother's cancer.
Session 5. Celebrating your success: This session focuses on the gains the ill mother made in previous sessions and what she accomplished, in her own words, in parenting their child. Self-monitoring and self-reflection are key elements to enhancing the parent's self-efficacy in supporting and communicating with her their child.

Sessions were scheduled at 2-week intervals and lasted 30 to 60 minutes each. One month after completing the EC-T Program, mothers were recontacted by telephone for an exit interview by a specially trained interviewer who was masked on the content of the EC-T Program and was previously unknown to study participants. All questions and procedures were reviewed and approved by the human subjects committee at the study center. Mothers were asked 3 questions: (1) "Thinking back on the program overall, what part, if any, was most helpful for you?" (2) "What, if anything, have you learned from this program about helping your child?" (3) "How was it for you to have the sessions offered by telephone?" The interviews lasted between 15 and 30 minutes, were audio-recorded, transcribed verbatim by a trained transcriptionist, and verified 100% for accuracy.

## Data Analysis

Data analysis proceeded in 5 steps, based on coding methods adapted for single-occasion interviews from grounded theory.<sup>9–15</sup> Each of the interview questions was first analyzed separately, and then, results across study participants' interviews were aggregated to create the final categories and domains.

The inductive coding process involved the following steps: (1) the transcribed data were first unitized. A unit was defined as a complete idea and a verbal expression that included both a noun and a verb (explicit or implicit). All texts were unitized; none were discarded. (2) Each unit of data was then open coded; the initial categories were identified through constant comparative analyses. (3) The analyzed responses were then grouped

together to form an initial set of categories with definitions that clearly differentiated each category. (4) Constant comparative analysis was used to refine the initial categories and definitions. (5) These refined categories were then grouped into higher-order domains.<sup>14,16</sup>

Trustworthiness of study results was protected through formal peer debriefing by a senior member of the research team and by requiring 100% consensus between the peer debriefer and the primary coder. Peer debriefing involved 3 comparisons: (1) a comparison between all categories, including an examination of distinctions between categories for their uniqueness and nonoverlapping characteristics; (2) a comparison between each category and the adequacy of fit between the verbatim quote within each category; and (3) a comparison of each verbatim quote with all the other categories to verify the correctness of fit of each verbatim with its placement within the designated category. Peer debriefing also enabled us to increase the parsimony of the evolving categories while still maintaining distinctions between categories.<sup>9–15,17</sup>

## Results

Study participants were mothers with cancer (N=31) who had completed all 5 sessions of the EC-T Program and who had a school-age child between 5 and 12 years old. Most mothers were white (74%), highly educated, married and were diagnosed with breast cancer (93.5%) (see Table 2). The frequencies of each domain and category are presented in Table 3. Each domain and their related categories are now described.

 **Table 2 • Demographic and Clinical Characteristics of the Sample**

Demographic Information	Mean (SD) (N=31)
Patient age, y	42.5 (5.0)
Spouse age, y	46.0 (8.4)
Patient years of education	17.8 (2.6)
Spouse years of education	17.0 (4.9)
Years in relationship	16.4 (5.4)
	n (%)
Patient employed full or part time	16 (51.6)
Spouse employed full or part time	28 (93.3)
Patient, white	23 (74.2)
Spouse, white	25 (83.3)
Child age, y, mean (SD)	8.3 (2.4)
Child male	16 (51.6)
No. children in the house	
1–2	19 (61.3)
3–4	12 (38.7)
Diagnosis and treatment information	
Months since diagnosis, mean (SD)	3.5 (1.7)
Type of cancer, n (%)	
Breast (stages 0–III)	29 (93.5)
Colorectal	1 (3.2)
Thyroid cancer	1 (3.2)

**Table 3 • Frequencies of Emics by Domain and Category**

Domains and Categories	Total No. Emics
Being fully present for my child	58
Really listening to my child	18
Drawing out my child's thoughts and feelings	16
Being there for my child	1
Taking things from his/her level	5
Giving my child the space	9
Taking a breath and stepping away to think of my child's feelings	7
Taking care of myself	1
Learning from my child	1
Communicating in new ways	41
Asking and practicing open-ended questions	21
Keeping the conversation going	4
Empowering me with a particular language	10
Isolating my feelings from my child's	1
Carving out personal time for reflection	3
Staying calm	2
Encourage me to talk more to my child	
Putting away my assumptions	25
Putting away my teacher self	6
Not always needing to fix everything	8
Digging down and not assuming my child's feelings	6
Not trying to rescue my child from emotions	2
Not being afraid to approach serious subjects	3

## Domain 1: Being Fully Present for My Child

Eight categories comprised “Being Fully Present for My Child”: (1) really listening to my child, (2) drawing out my child's thoughts and feelings, (3) being there for my child, (4) taking things from her/his level, (5) giving my child the space, (6) taking a breath and stepping away to think of my child's feelings, (7) taking care of myself, and (8) learning from my child. This domain captured the skills mothers claimed they acquired in being fully present for their child, really listening to them, and helping them express their thoughts and feelings.

### REALLY LISTENING TO MY CHILD

This category was defined as listening attentively and being open to what their child said. A mother said, “I think I learned just to be a better listener.” Several mothers expressed learning how to listen to their children. An important part of “really listening” was “not rushing to fill the silence void after asking the question” and to “let the silence kind of hang there.” One mother referred to the active listening session as the “just shut up and quit talking session.”

### DRAWING OUT MY CHILD'S THOUGHTS AND FEELINGS

This category was defined as helping their child to open up and get at what was really underneath and bothering them. Mothers acquired skills in drawing out their child's thoughts

and feelings and letting them “voice what was on their mind.” One mother described the skill of not needing to “analyze what she was telling me, just letting her talk.” A mother expressed acquiring skills on “how to figure out what it is that he really needs, that he wants to know, that he is concerned about, and things like that.”

### BEING THERE FOR MY CHILD

This category was defined as being emotionally available for their child. One mother stated simply, “It can be more, or equally as important, just to be there for them.”

### TAKING THINGS FROM HER/HIS LEVEL

Mothers reported acquiring skills that helped them see things through their child's eyes and understand their perspectives better. A mother described “looking at it from purely his perspective versus what I might color it with my own mind.”

### GIVING MY CHILD THE SPACE

This category was defined as offering their child room to express their thoughts and feelings. They learned to provide space for their child to express herself/himself without blocking them. A mother claimed that she was able to “just allow them to be, to feel what they're feeling and express that you understand how they feel.” Another mother gained ways to avoid “shutting the kids down with statements about what they should be thinking or saying.” Mothers came to understand that they needed to give their child more time to respond to their questions without filling the space.

### TAKING A BREATH AND STEPPING AWAY TO THINK OF MY CHILD'S FEELINGS

This category was defined as stepping back to reflect on how their child was feeling. Mothers were able to reframe how and why their child was reacting in a certain way. They learned to take time to prepare before talking about difficult subjects with their child.

### TAKING CARE OF MYSELF

Mothers also learned that, to be fully present for their child, they needed to take care of themselves and manage their own fears about recurrence. The program was helpful in providing “different coping ideas” and “reminders of positive things to do to de-stress.” One mother stated, “I think those are like good basic life skills.”

### LEARNING FROM MY CHILD

Mothers acquired skills to find out how their child was really doing. For example, they learned “he was secure and trusting of us,” “he was coping better than I expected,” and “she's really open.” Another mother expressed, “I learned that she really enjoyed sitting down and spending a long time with me kind of going through with me and learning information.”

## Domain 2: Communicating in New Ways

The EC-T Program helped mothers acquire and practice new ways of communicating with their child and helping them open up. This domain was composed of 7 categories: (1) asking and practicing open-ended questions, (2) keeping the conversation going, (3) empowering me with a particular language, (4) isolating my feelings from my child's, (5) carving out personal time for reflection, (6) staying calm, and (7) encouraging me to talk more to my child.

### ASKING AND PRACTICING OPEN-ENDED QUESTIONS

Twenty-one mothers (72%) reported that acquiring skills for asking and practicing open-ended questions was the most helpful part of the program. As 1 mother said, "I don't think that in our everyday lives we always think about open-ended and closed-ended questions. And so that was definitely the most helpful because I definitely asked a lot of closed ended questions before." For many mothers, it was "a different way of asking."

Practicing the new communication skills was also an important part of the program. One mother explained, "It was useful to hear the parent educator speak in the role of the parent to give me ideas on how to respond to my child." Another mother offered, "You know having to say it out loud to the nurse...you feel better, more ready to say it out loud to your child."

### KEEPING THE CONVERSATION GOING

With the open-ended questions, mothers learned ways to initiate and sustain the dialog with their child. Mothers described this skill as "having a conversation or discussion" and "dialoging" with their child.

### EMPOWERING ME WITH A PARTICULAR LANGUAGE

Mothers acquired a new language and techniques for communicating with their child. These techniques helped by "encouraging me how to talk to her" and "giving some direction." A mother explained, the program "empowered me with the particular language, to clearly communicate things reassuringly to my daughter." Another mother stated, "It just kind of changed the whole dynamic with how my daughter and I were talking about things."

### CARVING OUT PERSONAL TIME FOR REFLECTION

This category was defined as mothers reflecting and expressing their own emotions so that others knew how they were feeling. One mother stated, "Helping me carve out personal time for reflection. That was the stand out thing for me."

Other important skills gained included encouraging them to talk more to their child, staying calm when talking to their child, and being able to isolate their personal feelings from their child's feelings. A mother stated, "It was helpful for me to continue to have the insight about how the cancer is affecting me."

## Domain 3: Putting Away My Assumptions

This domain described the mother's realization that communicating with her child did not require the mother to teach,

problem solve, or fix anything; it only required that she empathize with her child. Five categories comprised this final domain: (1) putting away my teacher self, (2) not always needing to fix everything, (3) digging down and not assuming my child's feelings, (4) not trying to rescue my child from emotions, and (5) not being afraid to approach serious subjects.

### PUTTING AWAY MY TEACHER SELF

Mothers learned to listen and investigate instead of teaching or providing advice. One mother stated, "I've learned that not every moment needs to be a teaching moment." Another mother said, "I learned not to be a teacher, but an investigator." This category included skills to avoid giving too much information and "shielding her from some heavy-duty information."

### NOT ALWAYS NEEDING TO FIX EVERYTHING

Mothers learned how to be empathic with their child without trying to solve their problems. A mother described learning to understand "why they feel that way without taking it one step further and trying to solve the problem or telling them, but-." Another mother said, "I realized that the goal wasn't really to solve the, or take away those emotions or fix it but just to make the child heard and that was empowering."

### DIGGING DOWN AND NOT ASSUMING MY CHILD'S FEELINGS

As 1 mother said, "I might have just assumed that she was acting a certain way because she was nervous about me when really she was nervous about something totally different."

### NOT TRYING TO RESCUE MY CHILD FROM EMOTIONS

A mother expressed learning how to listen and "not trying to rescue her from her emotions."

### NOT BEING AFRAID TO APPROACH SERIOUS SUBJECTS

One mother expressed, "I think not to be afraid to approach really serious subjects, even with a 6-year-old. And that if he can handle it, then I can as well."

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## ■ Telephone Delivery of the Program

During the exit interviews, mothers were asked, "How was it for you to have the sessions offered to you by telephone?" Ninety percent of the mothers stated that telephone delivery of the intervention was "good" or "great" and "very convenient." They reported that they would not have participated in the program were it delivered in person. A few mothers expressed some initial discomfort in not seeing the nurse educator in person but felt comfortable after a couple of sessions. This comfort was expressed as "I was amazed at how helpful they could be, and it enabled me to participate" and "I still felt like I had a warm relationship with the person over the phone...it's hard to say because I didn't do it face-to-face but I still felt supported and understood." Only 1 mother stated a preference for receiving the program in person but recognized the potential

difficulties: "I'm wondering if it might have been nice to talk to someone one-on-one but that, the logistics of that would probably be really hard."

## ■ Discussion

The exit interviews for this study elucidated the gains that mothers with cancer attributed to participation in the EC-T Program. The greatest gains were in acquiring skills to be fully present with their child and to listen deeply as their child expressed their thoughts, worries, concerns, and questions about the parent's cancer. Discovering the necessity of putting away their assumptions allowed them to empathize with their child and freed the parent from needing to teach, problem solve, or fix anything. Having the intervention delivered by telephone was essential for this group of mothers, who said that they would not have enrolled in the study if in-person sessions were required. The communication skills and self-care strategies that were offered to the mothers during the program are actually life skills that have the potential to enhance the parent-and-child relationship long term.

The advantages of telephone delivery include greater reach and geographical access; the main disadvantage is the nurse's inability to read the mother's body language and observe her social cues.<sup>18</sup> This study provides evidence that telephone delivery was not only acceptable but also preferred for this group of mothers who were receiving cancer treatment and parenting school-age children.

## Limitations

The results of this study are limited by a sample that was mostly white, highly educated, and married. Future studies are needed to see whether the intervention performs differently in non-white, less educated, and single mothers with cancer.

## ■ Implications for Nursing

Results show that mothers attribute many gains from a telephone-delivered cancer parenting program that involved only 30 to 60 minutes per session of a nurse's time. Perhaps, it is time for clinics and provider systems to reevaluate the channel and methods nurses can use to offer patient education programs. Using a scripted manual, nurses were able to systematically offer the program to 31 mothers with cancer during treatment, and mothers reported specific behavioral gains from such a program. Equipped with a manual and a simple telephone, nurses can extend their reach to patients who would otherwise not be served.

## ■ Conclusions

Brief nurse-delivered intervention sessions resulted in mother-reported gains in skills to elicit their child's thoughts and feelings and learning how to deeply listen rather than try to fix their child's concerns. This study found that mothers can develop competencies in child-focused communication even when they are in the throes of acute medical treatment for recently diagnosed cancer. Providing the program by telephone made it possible for them to participate.

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