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The Meaning of Comfort for Pediatric Patients With Cancer

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Positive treatment outcomes for childhood cancer survivors have become a priority in medical and nursing pediatric oncology. In addition to cure and disease-free living, treatment outcomes that include psychosocial functioning and the meaning of the cancer experience for this population also have gained importance. A research priority identified by Haase and Phillips (2004) is to understand the meaning that pediatric patients with cancer derive from their disease experience throughout its trajectory, from diagnosis through survivorship. Meaning of the cancer experience for adolescents is constructed from distressing as well as positive experiences. Distressing experiences are those that engender fears of alienation, changes in physical appearance, and dying, as well as general physical pain and discomfort (Hedstrom, Skolin, & von Essen, 2004). Hedstrom et al. reported that positive experiences often result from the adolescents' interactions and relationships with pediatric oncology nurses and the sense that their needs are being met. This study addresses the meaning of the cancer experience among older adolescent and young adult childhood cancer survivors in the context of being cared for by pediatric oncology nurses during treatment.

Pediatric Oncology Nursing Care

In providing effective nursing care to pediatric patients with cancer and their families, acts of caring or giving care result from a nurse's synthesis of scientific principles, artistry, and a deep sense of being present with patients (Cantrell, 2007). In one study (Doona, Chase, & Haggerty, 1999), nursing presence was found to

- Involve direct contact and being open with patients.
- Require and enable nurses to connect with patients' treatment experiences on a physical and psychosocial level.
- Include sensing and going beyond empirical data to

Purpose/Objectives: To describe the meaning of being cared for and comforted by pediatric oncology nurses among a sample of childhood cancer survivors.

Research Approach: A hermeneutic analysis was conducted to describe the meaning of the phenomenon.

Setting: An oncology treatment center in the northeastern United States.

Participants: 11 childhood cancer survivors.

Methodologic Approach: Four childhood cancer survivors participated in a focus group, and seven were interviewed one-on-one via telephone interviews. The focus groups and the one-on-one interviews were tape-recorded, and the audio recordings were then transcribed into an electronic text file.

Main Research Variables: Comfort and caring behavior.

Findings: All participants agreed that simple acts of caring by nurses were meaningful to them and provided comfort. The five themes generated from the data analysis were (a) You Just Can't Pretend to Care, (b) Try to Take the Hospital Experiences Out of the Hospital, (c) I'm Not Just Another Kid With Cancer—There Is a Lot More About Me That You Should Get to Know, (d) Caring for Me Also Includes Caring for My Family, and (e) Nurses Make Treatment Experiences More Bearable Through Their Small Acts of Caring.

Conclusions: Pediatric patients with cancer find physical and emotional comfort through nurses' acts of caring.

Interpretation: The findings highlight the significance of caring acts by pediatric oncology nurses that provide comfort for children and adolescents with cancer.

be perceptive to and accurately interpret cues from patients.

- Involve seeing the patient in the entire context of his or her life, not just from scientific medical data.
- Be exhibited when the patient's preferences are acknowledged and incorporated into the plan of care.
- Involve being with the patient and engaging in caring activities, such as listening, attentiveness, and technical competence.

The few investigations that have asked adolescents with cancer about their care needs suggest that these individuals are discriminating consumers who are perceptive and have expectations of receiving truthful, honest information from the healthcare team. In a study of 51 childhood patients with cancer aged 12–24 years, Dunsmore and Quine (1995) reported that adolescents with cancer wish to be more informed and involved in treatment decisions. Dunsmore and Quine also found that the ability to listen, having genuine concern, clinical expertise, and honesty facilitated healthcare professionals' communication with this population. However, adolescents and young adults with cancer reported that communication was hindered by an impersonal manner, use of technical jargon, haste, and the generation gap among healthcare providers. Hedstrom et al. (2004) interviewed 23 adolescents who described good care as being provided by healthcare professionals who gave age-appropriate information and were nice, friendly, supportive, and competent.

Hedstrom et al. (2004) posited that receiving information assists adolescents with cancer in being active participants in their care and promotes a sense of security and control. Past research also has demonstrated that providing information to children and adolescents about their cancer diagnosis and treatment plan positively influences their sense of well-being (Last & van Veldhuizen, 1996; Van Dongen-Melman, Pruyn, Van Zanen, & Sanders-Woudstra, 1986). Ongoing discussions throughout the treatment course can address the psychosocial needs of adolescents with cancer that are important to treatment outcomes (Decker et al., 2004).

A significant aspect of being cared for by nurses is being comforted by them, which is a universal goal of nursing care. Comfort is viewed as a positive outcome that has been empirically linked to successful engagement in health-seeking behaviors among hospitalized children and their families (Kolcaba & DiMarco, 2005). In an eloquent description of the meaning of being comforted by a nurse, Bottoroff (1991) emphasized that little things often count. Bottoroff noted that seemingly simple acts, such as repositioning a pillow, can foster a sense of comfort in patients. Bottoroff described the phenomenon of being comforted by a nurse as a community of comfort, which involves the presence of others, the talk of comfort, and the hands of comfort in patients. Bottoroff offered the following description of the community of comfort: "Through a sense of being together with another who comforts, we feel the security of [nurses'] presence and their unwavering belief in our ability to find a way to live through this despair, to find comfort" (p. 243). Bottoroff stated that through the presence of being with another, the nurse's feelings and regard for the other person and the desire for his or her well-being are revealed.

Being present in the treatment experience of adolescents with cancer requires pediatric oncology nurses to exhibit openness, commitment, and an understanding

of adolescents' world view (Ritchie, 2001). Ritchie recognizes that care for adolescent patients with cancer must be developmentally centered. Developmental theories have identified that adolescents seek privacy and time alone, but they also have needs related to the presence of others. Although seeking privacy and being alone are developmentally appropriate behaviors for healthy and ill adolescents, pediatric oncology nurses should not foster a sense of isolation for hospitalized adolescents. Adolescents with cancer require others (e.g., parents, nurses) to understand intuitively when and how much interaction these adolescents want and seek at any given moment in time. Cantrell (2007) suggested that knowing when to engage adolescents and when to provide them time and space is an effective component of pediatric oncology nursing. This act of caring can promote adolescents' sense of autonomy and independence and can foster positive outcomes, such as hopefulness and normalcy.

Bottoroff (1991) described the talk of comfort as the dialogue between nurses and patients that occurs around kitchen tables, in hospital rooms, during painful procedures, and anywhere else nurses and patients communicate. Bottoroff described the discussions as "social talk" about subjects that are unrelated to medical issues. In describing the self-sustaining process used by adolescents with cancer to comfort them and achieve competence in resolving health threats, Hinds and Martin (1988) stated that nonillness discussions were one nursing behavior identified by adolescents that positively affected their disease experience.

Procedures done with a skillful hand alone do not bring comfort (Bottoroff, 1991). Caring human touch provides support and a sense of security to adolescent patients with cancer (Hockenberry-Eaton & Minick, 1994). Weekes, Kagan, James, and Seboni (1993) reported that hand-holding aided in reducing tension associated with impending painful treatments, was a means of distraction, and provided a sense of security to adolescents with cancer. Adolescents preferred holding their mother's hand, but when the mother was not available, they sought to have the nurse hold their hand. Weekes et al. stated that hand holding was a simple act that mattered to adolescents, similar to Bottoroff's (1991) simple acts of caring.

The current study aimed to explore the meaning of being comforted during treatment from the perspective of childhood cancer survivors. The work of Bottoroff (1991) was used as the model to guide the study. Although several other studies have examined specific aspects of nursing care that were meaningful for pediatric patients with cancer, none have investigated the meaning and the significance of nurses' caring and comforting behaviors in the context of the overall treatment experience among survivors of childhood cancer. As a result, this study aimed to give voice to the survivors and recognize the significance of nurses' role in treatment outcomes for pediatric patients with cancer.

Methods

Sample

A purposive sample of 11 older adolescent and young adult survivors of childhood cancer from two data collection sites was used in this phenomenologic study. In December 2006, a focus group was conducted with four adolescents at an oncology center in the northeastern United States, where they had received treatment. Sixteen eligible survivors at the treatment center were identified through the patient registry, and letters were sent inviting them to participate in the study. Nine individuals were contacted and expressed interest in participating in the study. However, only four survivors were able to attend the focus group because of scheduling conflicts. One individual canceled the day of the focus group for illness-related reasons. In May 2008, another seven adolescents were interviewed individually via telephone. The individuals were recruited at a regional conference for childhood cancer survivors held in the northeastern United States. Inclusion criteria were (a) older adolescence (aged 18–22 years) or young adulthood (aged 23–30 years), (b) living disease-free in survivorship, (c) having experienced being cared for by a pediatric oncology nurse during treatment for cancer, and (d) being willing and able to describe the experiences. Written consent was obtained from survivors who participated in the focus group interview, and oral consent was obtained for those who were interviewed over the phone. Institutional review board approval for both methods of consent was obtained.

The 11 study participants ranged in age from 18–30 years; three were men and eight were women. Diagnoses reported included central nervous system tumor ($n = 3$), leukemia ($n = 2$), Ewing sarcoma ($n = 1$), lymphoma ($n = 2$), osteogenic sarcoma ($n = 2$), and testicular cancer ($n = 1$). Age at diagnosis had a wide range, with the youngest being aged 6.5 years and the oldest being aged 20 years. Nine of 11 participants were diagnosed during adolescence (defined as aged 12–22 years); one was 11 years old and another was 6.5 years old at diagnosis. Excluding the survivor who was 6.5 years old at diagnosis, the average age of diagnosis among study participants was 14.3 years. Average time spent in treatment for the sample was 15 months. Significant variability existed in length of time spent in survivorship because one survivor experienced survivorship for 20 years. For the other 10 participants, average time in survivorship was 4.4 years with a range of six months to 2.5 years. Of note, many participants noted that they began living as a childhood cancer survivor at the time of their diagnosis.

Research Design and Data Collection

The current study used the qualitative research method of interpretive phenomenology, hermeneutics, to investigate the phenomenon. Hermeneutics is a research tradi-

tion that focuses on meaning and interpretation to better understand how individuals perceive their world in a given context (Polit & Beck, 2008). The study's principal investigator conducted the focus group and each participant interview. The focus group and the one-on-one telephone interviews were tape recorded. The focus group was one hour in duration and the phone interviews ranged from 30–60 minutes. The research question posed during the focus group and each one-on-one interview was, "Please describe experiences you have had in being cared for by pediatric oncology nurses during your treatment for cancer." Participants were encouraged to share their thoughts, feelings, perceptions, and memories about the experiences until they had no more to say. Probes were used to add depth and clarification during the focus group and interviews. Upon conclusion of the focus group interview and when seven survivors were individually interviewed, data saturation was reached.

Data Analysis

The taped-recorded interviews were transcribed by the study's coinvestigator. The seven-stage process of data analysis in hermeneutics, as outlined by Diekelmann, Allen, and Tanner (1989), was used. Per Diekelmann et al., all transcribed interviews were read for an overall understanding and interpretive summaries were written. The principal investigator and research assistant analyzed the text independently; common meanings were identified, and themes with exemplars from the text were developed. Forty-three significant statements were extracted from the transcripts of the focus group interview and the seven one-on-one interviews. During the interviews, issues such as transitioning into survivorship, relationships with friends during and after treatment, and ongoing health problems also were discussed. These data did not specifically address the aim of the study, so they are not reported in this article. Table 1 provides examples of significant statements extracted from the transcribed text and their formulated meanings. The following five themes emerged when the 43 significant statements were clustered into groupings. The themes are intended to represent the collective voice of these childhood cancer survivors.

Results

You Just Can't Pretend to Care

The childhood cancer survivors did not hesitate to describe the authenticity they perceived in the caring behaviors of their pediatric oncology nurses. The feelings engendered in them by their nurses during treatment still were powerful emotions in survivorship. The survivors knew when nurses made a strong effort to be present emotionally for them. Feelings of being cared for included meeting the survivors' physical as well as psychosocial care needs during treatment. The survivors expected

Table 1. Significant Statements and Extracted Meanings

Significant Statement	Extracted Meaning
Getting my medication on time was obviously very important, but [nurses] having the kindness and compassion even when you're not feeling well and you might not be very nice, that's the number one thing that's important to me.	Nurses often experience pediatric patients with cancer at vulnerable times when they have pain and are fearful. Being responsive to physical care needs with kindness and compassion helps to lessen the patients' psychosocial distress and makes them feel cared for, even when they appear unappreciative of nurses' empathy.
Some [nonpediatric oncology nurses] . . . just go in and they do their job, they get paid, they go in, they go out. [Pediatric oncology nurses] really cared. You could tell that they really cared. Like I was a part of their family. I just think they need to really want to be there. . . . You can't pretend to care.	Pediatric patients with cancer are keenly aware of nurses' nonverbal behaviors and attitudes and can identify which nurses want to care for patients and are willing to do anything to make them more comfortable versus those who are just doing their job.
She [the patient's primary oncology nurse] would sit down and talk sports with me and talk baseball.	Pediatric patients with cancer want healthcare professionals to know about their "outside lives." Providing patients opportunities to reflect on and talk about other things in their lives makes them feel connected with their world separate from the cancer and treatment experience, which is very important to patients.
It's just the little things that [nurses did] were kind of inconsequential as I think back, but they meant a whole lot. Sometimes if [nurses] take time to do the little things, the medical things will almost work out better, because it eliminates stress because you don't have to worry about that, you can concentrate on getting better.	Pediatric patients with cancer perceived that their psychological distress negatively affected their physical health status and that nurses ameliorated some of the distress through small, seemingly insignificant acts of caregiving.

nurses to have a command of the science behind pediatric oncology nursing, but even expert care was incomplete if it was not accompanied by compassion and understanding of the patients' feelings and emotions.

Of note, many study participants began their responses to the interview question by stating that they did not remember much about their treatment experiences, particularly regarding when they were hospitalized. Many cited pain medications and other drugs that induced sleep or drowsiness as the cause of unclear memories. However, survivors were able to recall vivid memories of specific experiences and often the nurses' names when they talked about specific nurses and the care they provided during treatment. The positive and significant role that pediatric oncology nurses had in the survivors' treatment experiences became evident in the beginning phase of data analysis.

Two survivors had not received most of their care from pediatric oncology nurses. A four-year survivor received cared in a pediatric-based hospital on the west coast of the United States but often was hospitalized in other patient care units. Another 13-year survivor received his diagnosis and initial treatment in a general oncology floor in the northeastern United States that included adult as well as pediatric patients. The two individuals who had received a significant amount of treatment and care outside of the pediatric oncology nursing environment also were the only survivors who could recall negative experiences in being cared for by nurses while receiving cancer treatment. Of note, the two survivors recalled very positive caregiving experiences from instances in which they did receive care from pediatric oncology nurses. In

addition, the 13-year survivor said his treatment center was changed because of his parents' concern that the care he was receiving was not developmentally based and that the oncology nursing staff in the pediatric center lacked knowledge and expertise.

Survivors also recalled that nurses' acts of caring involved making the survivors do things that they did not want to do. Survivors described how angry and often uncooperative and ungrateful they were when they were made to do things unwillingly, but they now appreciated such acts of caring. When asked, "How did you manage or what was your response to constantly being interrupted and encouraged to do certain things, such as taking a shower, during your hospital admissions?" one survivor said,

I really tried to sleep through [chemotherapy treatments] because I couldn't do anything or go anywhere. One of my doctors would come in and literally open up the shades, make my bed go up, turn on the TV, and [say to me], "You need to wake up." I was so mad when he did this, but I appreciate [what he did] because he was getting me to do things that I needed to do to stay healthy and keep fighting.

Try to Take the Hospital Experiences Out of the Hospital

Survivors clearly expressed that they did not want to be in the hospital and perceived that they had little input or control about how long their length of stay would be or what physical care interventions they required. For example, survivors knew that admission for a central line

infection would require at least a 10-day hospitalization for IV antibiotics. Such knowledge left the patients feeling powerless, and they sought relief and comfort from the pediatric oncology nursing staff. During the focus group, a survivor said,

I hated going to the doctor's. I hated going to the hospital where it's hard. Like once you get [in the hospital] and you know you're going to be medicated with all this chemotherapy . . . it's like the nurse is the one that cares; she makes it fun for you while you're getting your treatment.

I remember my mom got me a free wig, which I hated and didn't want to wear. I thought it was itchy and it was weird looking. When we were out of my room and walking around, my nurses put my wig on and took funny pictures [of us wearing it]. That's how I knew they really cared because they wanted to hang out with me as a person. They weren't just there to put my IV in or something and just leave. Nurses that are just there to do their job, who really don't want to interact with you, don't really care.

I'm Not Just Another Kid With Cancer

Survivors knew that nurses cared “about them” in addition to “caring for them” when nurses engaged them in nonillness-related discussions. Survivors placed great value in having healthcare professionals see them not as patients with cancer but as individuals with interests and talents, such as being a dancer or soccer player. Engaging survivors in conversations about parts of their lives outside of their cancer diagnoses served as a significant indicator that nurses cared about them as individuals, which, in turn, provided comfort. One survivor explained,

[Nurses would] make you feel normal. . . . They made you feel that you're not just a patient. Nurses who care are just not going to come to give you your medicine and leave; they have conversations with you.

I think, too, it wasn't just them talking; it was actually they knew about you, like if they knew your birthday was coming up, they made sure to say, “Happy birthday.” Even though like they're not supposed to, they'd bring gifts in or things like that or they would find out about your family, so it'd be like, “How's your sister?” or, “How's she doing in college?” You would get so close that you end up, at least for me, asking about the nurses themselves, so then you could talk to them and ask, “How's your pet?” or, “How's your newborn baby?” I guess that wasn't just talking, they actually cared and they wanted to know you. [The nurses] would write in their note to the next nurse something that they had learned about me and [the next nurse

would] bring that up. It wasn't just talking. They actually wanted to know about you.

Another survivor said,

Sometimes, even if [the pediatric oncology nurses] didn't have a particular reason to come in, they would just come in and talk to me or you know, help me take my mind off the treatment.

[When I would] talk to them about like what was going on with me and like what I was thinking and feeling and just about regular stuff like plain old life, too, like forming an actual relationship, it made me feel better.

In addition, pediatric oncology nurses served as confidants.

I had one nurse that I now consider like a big sister. Like, she's been a mentor to me. I guess what I appreciate now is that she wasn't just being a nurse; she was also being a friend to me. If I needed to vent or if I needed to just talk about things that I didn't want to talk to my mom about it, like she was there. And she still is now. I think that was one of the things that I saw first. And I had a couple of nurses that you know are your favorites. I mean, most of the time they were the ones that you could talk to if you were feeling bad or feeling good about something, you could go to them and talk about it.

Caring for Me Also Includes Caring for My Family

Survivors stressed the importance of having their pediatric oncology nurses interact with and include their parents in care plans. Having their mothers present during hospital or clinical stays mattered to survivors because their mothers served as sentries for their care. The survivors relied on their mothers' ability to understand the medical information and use their discretion about agreeing to a plan of care. Nurses' acts of caring for the family involved including mothers in treatment decisions and serving as a support system for mothers. One young adult said that her primary nurse “was really there for mom. . . . That was like a huge deal for me.” Another described the importance of having her mother actively involved in treatment discussions.

[The treatment team] would explain it to my mom in a way that my mom could understand it, and then they'd explain it to me—even though I was only 12 and I was not going to remember all those medicines. So they explained it to my mom and then, they explained it to me in a way that I would understand and be comfortable with what was going on.

Nurses Make Treatment Experiences More Bearable Through Small Acts of Caring

The small acts of caring that the survivors remembered and described often were gestures that at first appeared inconsequential but were meaningful to the survivors while they were receiving treatment. A survivor recalled that a nurse would take povidone-iodine swabs and draw happy faces on his chest before accessing his catheter. Although the act had no therapeutic value with respect to further decreasing risk for infection when accessing his central catheter, the survivor perceived that the nurse's gesture made a painful procedure more bearable. The most often cited example of nurses' acts of caring that made the treatment experience less emotionally traumatic for pediatric patients with cancer was the nurse simply asking the patients how they were doing, even after treatment for cancer was completed. A survivor explained,

After I was done with my treatment, [the nurses and I] exchanged e-mails, Christmas cards, and stuff. That's how I knew that they actually cared. You know, cared enough to write me back and e-mail or, you know, want to talk to me after the fact, you know. That's how I knew. They supported me, too. Asking me if I was still okay and every time I see them, they're very friendly and caring.

In contrast to the positive experiences, one survivor recalled that a pediatric oncology nurse had committed to saying goodbye before leaving for the day and left without doing so. The survivor said, "I actually saw [the nurse] drive out and she forgot about me. That was devastating." The individual was in survivorship for 20 years at the time of the interview but still could painfully recall the experience, which had occurred two decades ago. The example further illustrates how caring behaviors or lack thereof among pediatric oncology nurses can have such a significant effect on patients.

Discussion

Examining the current study's findings in the context of Bottoroff's (1991) description of the community of comfort revealed that pediatric patients with cancer do experience security when nurses are present and express belief that the patients can live through suffering and despair. The survivors were comforted by nurses' presence and the talk of comfort as reflected in the five themes. According to Godkin, Godkin, and Austin (2002), being able to communicate is a key means of establishing nursing presence, which includes the six dimensions presented by Doona et al. (1999). The findings imply that communication that includes respect, empathy, and comfort is most important to pediatric patients. In addition, the results reflect the nursing behaviors identified by Hinds (2000), which positively

influence adolescents' ability to sustain themselves through the cancer experience. The nursing behaviors include truthful explanations, being caring, doing activities with patients and their families, nonillness discussion, clinical competence, focusing on the future, and sharing knowledge of survivors. In addition, Hinds identified that humor used by nurses positively affects adolescents' behavior. Although humor was not explicitly identified by the current study's participants as a nursing behavior that provided comfort during treatment, it was implied or described in most survivors' descriptions.

Although the presence and talk of comfort were evident in the survivors' descriptions of being cared for by pediatric oncology nurses, little was said about Bottoroff's (1991) hands of comfort. One young adult did say, "I remember Carol [a pediatric nurse] sitting down and like giving me hand rubs and back rubs when I wasn't feeling well." Her comment highlighted the importance of touching and reaching out to a patient who is uncomfortable.

The current study's findings offer healthcare providers a better understanding of the challenges faced by pediatric patients with cancer throughout their treatment experience. The results also provide insight to the significance of nurses and the care they give during treatment. For children and adolescents with cancer, repeated or prolonged hospitalizations cause fears of loneliness, losing the other aspects of their lives that they enjoyed before cancer, disconnection with the world outside of cancer treatment, and a deep concern for the welfare of their family. The fears are heightened by the seriousness of the disease and the intense treatment protocols that can cause patients pain and physical distress.

Nurses' presence, with focused attention on love and belonging, is an essential aspect of care that provides comfort and addresses the fears of children and adolescents with cancer. Caring behaviors that transcend IV lines, chemotherapy drugs, and painful medical procedures and highlight individual patients' unique qualities are part of a comprehensive plan of care that distinguishes the nursing role from other healthcare team members.

The current study's findings show that pediatric oncology nurses must have a well-defined and honed set of caring behaviors that are specific to this population. The caring behaviors include knowledge about the science of pediatric oncology, its treatment, and the specific physical and psychosocial care interventions designed for pediatric patients with cancer. Adolescent patients with cancer are discriminating consumers; through their care experiences with pediatric oncology nurses, adolescent patients gain the ability to assess nurses' competence in technical skills as well as the nurses' ability to truly understand and have empathy for the physical pain and emotional suffering that the patients must endure through treatment.

Conclusion

Pediatric patients with cancer find physical and emotional comfort through nurses' acts of caring. More intensive therapies and treatment protocols may increase suffering because of changes in normal function, sensation, or appearance. The changes, in turn, may cause physical discomfort, such as pain, nausea, vomiting, and fatigue, as well as emotional distress (Fochtman, 2006). The emotional distress children and adolescents experience can generate feelings of isolation, uncertainty, fear, and lack of normalcy in their lives (Hedstrom et al., 2004). The current study's

findings suggest that nurses can ameliorate some of the distress that pediatric patients with cancer experience. By demonstrating caring acts, pediatric oncology nurses can create a sense of comfort for these children and adolescents.

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