

The Importance of Being There: Perspectives of Social Support by Adolescents With Cancer

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Adolescents with cancer are confronted with many challenges. The extent to which they are able to deal with such challenges appears to be partly contingent on a positive strong social support system. In this article, the author describes findings specific to the sources of social support that 15 adolescents with cancer found to be most important in getting them through the cancer experience. Data were collected as part of a longitudinal qualitative interpretive study and involved individual interviews, focus group interviews, and participant observation as the main sources of data. The relationships that adolescents maintained with their nuclear families, health care team members, and special friends were the 3 main supportive relationships in the adolescents' lives. The act of others "being there" was seen by the adolescents as the key element of a supportive relationship and involved 6 main behaviors. Although the 3 key supportive relationships were essential in helping adolescents get through cancer, these relationships were at times a source of stress for adolescents.

Key words: adolescents, cancer, supportive relationships, family

The valuable effects of social support on individual physical and psychological well-being have been well recognized within the cancer literature for years. Wortman (1984), in her seminal paper on social support and the adult cancer patient, noted that despite

weaknesses in individual studies, the literature is nonetheless consistent in indicating that social support may constitute a significant resource in coping with cancer. The significance of strong social support systems in children with cancer and their families is also appreciated (Ell, 1996; Katz & Varni, 1993; Neville, 1998; Quittner, 1992) and is assumed to affect their quality of life (Hinds, 1990). For adolescents with cancer, a strong social support system is especially important in helping them cope, considering they have the potential to experience a "dual crisis" in having to deal with complex normative developmental tasks as well as cancer-related stressors (Kyngäs et al., 2001; Zevon, Tebbi, & Stern, 1987).

Part of a larger study that sought to describe how childhood cancer and its symptom course were interpreted and experienced by children (4-18 years of age) and their families (Woodgate, 2001), the aim of this article is to detail one of the study's main categories, the degree and type of social support from the perspectives of adolescent participants with cancer.

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Review of the Literature

The Construct of Social Support

Complicating our understanding of the social support experience in childhood cancer is that *social support* is a complex phenomenon whose actual meaning has not been clarified (Hupcey, 1998). For example, Caplan defined support as continuing social aggregates that provide individuals with opportunities for feedback about themselves and for validations of their expectations of others (in Wolchik, Beals, & Sandler, 1989). Cobb defined social support as information leading the individual to believe that he or she is cared for and loved and that he or she belongs to a network of communication and mutual obligation (in Sandler, Miller, Short, & Wolchik, 1989). Belle (1989) defined social support as resources that are provided by people within the context of interpersonal relationships. Although these definitions vary, they all underline the importance of supportive interpersonal relationships or networks.

In recognition of the complexity of the phenomenon of social support, Vaux (1990) suggests that social support be defined as a metaconstruct with the following dimensions: (1) support network resources or the set of relationships through which an individual receives help in dealing with demands and achieving goals, (2) supportive behaviors or the specific acts intending to help someone, and (3) subjective appraisals of these network resources and behaviors. Presently, what is known about each of these dimensions in the context of childhood cancer is in its infancy. This lack of understanding could be attributed to problems in securing adequate research tools that assess, in an appropriate and comprehensive manner, more than one dimension of social support (Woodgate, 1999).

Social Support in the Adolescent Cancer Experience

To date, asking adolescents with cancer to identify their support resources or sources has been the primary focus. Consistently, research reinforces that family members, especially mothers, are identified as the major source of support (Enskär, Carlsson, Golsäter, & Hamrin, 1997; Fowler-Kerry, 1990; Haluska, Jessee, & Nagy, 2002; Kazak, Christakis, Alderfer, & Coiro, 1994; Nichols, 1995; Rechner, 1990; Ritchie, 2001; Stern, Norman, & Zevon, 1993; Weekes, Kagan,

James, & Seboni, 1993). Subjective appraisal of the support resources is another research area. One study that compared the perceived sources of social support on adolescents with cancer to age-matched healthy adolescents found that both groups reported similar support sources and satisfaction levels, but adolescents with cancer perceived parental relationships as more supportive (Haluska et al., 2002). Supportive behaviors that adolescents have found to be helpful in getting them through cancer have also been studied. Behaviors that adolescents frequently report include having family and friends stay with them during their clinic appointments and hospital stays, not being treated differently because of their cancer, and having their hands held during painful procedures (Ritchie, 2001; Weekes et al., 1993; Weekes & Kagan, 1994). Adolescents clearly valued the support that they received from family and friends.

Although there is an increasing knowledge base about the type of supports that adolescents with cancer find to be helpful, there is still much to be learned from them, including understanding what it is about social support that adolescents with cancer view to be important. Because social support is seen to be an act of interpretation between support givers and support receivers, qualitative research is deemed valuable to the study of social support (Jacobson, 1990).

Methods

Design

A longitudinal qualitative research design guided by the philosophy of interpretive interactionism was conducted between July 1998 and December 2000 to address the phenomenon under investigation. This approach helped to (1) arrive at meaningful interpretations of the adolescents' perspectives, (2) support the view that adolescents are competent reporters of their own experiences, (3) put adolescents' views at the center of analysis, and (4) ensure that the research worked for the adolescents rather than on them (Denzin, 1984; Mayall, 1996).

Setting and Participants

The study took place in an inpatient and outpatient pediatric cancer unit located in a city in western Canada. Permission to carry out the study was first secured from

the Research Ethics Board of the University of Manitoba. Purposive sampling was used to optimize describing the full range of the phenomenon and variation in the data, including type of participants (Morse & Field, 1995). Families of children of varying ages (4-18 years of age) with different cancer diagnoses were invited to participate in the study. In total, 39 families agreed to participate. Both parental consent and child assent were obtained from the families.

Of the 39 families participating in the study, 15 had an adolescent between 12 and 18 years of age. The mean age of the adolescents was 14 years. Eight of the adolescents were male, and 7 were female. The majority of the adolescents were diagnosed with either leukemia or lymphoma ($n = 12$), and the other 3 were diagnosed with a solid tumor. All received chemotherapy. Four of the adolescents had undergone radiation, 6 had surgery, and 1 adolescent had a bone marrow transplant. Two had a history of relapse, and all were in remission at the end of the study. Twelve of the adolescents had 2 parents, and 14 had at least 1 sibling. Despite attempts to sample adolescents from diverse cultures, all but 1 was white.

Data Collection

Multiple data collection methods were used to arrive at a detailed description of the adolescents' experiences. This included all of the adolescents participating in open-ended interviews. The open-ended interview method helped to engage the adolescents in eliciting detailed responses deemed significant to the study's purpose and also afforded the opportunity for adolescents to focus their responses into areas previously not anticipated (Morse & Field, 1995). An interview guide grounded in the pediatric psychosocial oncology literature was developed to address the overall purpose of the study and included questions specific to eliciting adolescents' perspectives about their support experiences (eg, adolescents were asked to talk about those things they found to be helpful and not helpful to them in dealing with their cancer). The interviews varied in time between 35 and 120 minutes, depending on how the adolescents were feeling and/or how interested they were in being interviewed at that particular time. Follow-up questions to help adolescents develop their answers were then asked and varied depending on their initial responses. Field notes were made during the interviews. All interviews

were tape-recorded to preserve their authenticity. The majority of adolescents participated in 3 to 5 interviews. The first interview for each adolescent took place soon after the adolescent agreed to be in the study, with follow-up interviews occurring at various points in the adolescents' cancer trajectory. Follow-up interviews helped to clarify or build on issues identified by adolescents in the first interviews.

The data collection method of moderate participant observation was also used to appreciate the adolescents' meanings of actions and events. Adolescents were observed in the inpatient and outpatient units during various periods and at different points in time. Moderate participant observation supported a fairly nondisruptive presence by means of balancing participation with observation (Prus, 1996; van Manen, 1990). Observations were recorded in the form of unstructured field notes. Informal interviewing took place during periods of observation. Questions flowed from the immediate context and helped to verify what meanings the adolescents had assigned to their situations.

Two focus group interviews were scheduled near the end of the study to help validate emerging themes. One of the groups involved 4 male adolescents, and the other involved 5 female adolescents. Each focus group interview lasted approximately 2 hours and was audiotaped.

Data Analysis

Data analysis was ongoing and occurred concurrently with data collection. All interviews and filed notes were fully transcribed using the Microsoft Word word-processing program. Data were analyzed by the constant comparative method of data analysis (Morse & Field, 1995; Strauss & Corbin, 1990). Key steps involved coding or giving meaning to all units of information, revising codes and/or recoding previously coded data, and aggregating and clustering codes into theoretical categories. Asking questions and making memos related to code notes and data comparisons was part of the process of coding. Critical to the coding process was making comparisons within and between data sets. Operational definitions were written for all categories and subcategories. A second type of interpretive work, the development of illness narratives, provided a basis for understanding how cancer affected the adolescents by arranging cancer events in temporal order and relating them to other events in the participants' lives

(Hydén, 1997; Viney & Bousfield, 1991). Narrative analysis helped confirm the emerging categories.

Results

This study resulted in the development of a substantive theory entitled “Keeping the Spirit Alive.” This theory depicts how families of children with cancer used the core process of keeping their spirits alive in response to them having to experience the central problem or core phenomenon of getting through all the rough spots of the cancer experience. A detailed description of these 2 core variables and the overall theory is provided elsewhere (Woodgate & Degner, 2003). Affecting the adolescents’ response of getting through the cancer experience was the intervening condition or category identified as the type and degree of social support present in the adolescents’ lives. The degree and type of social support was represented by the following 3 subcategories: (1) supportive relationships, (2) being there, and (3) consequences of being there. The next sections describe in detail each subcategory and attributes of the subcategories (see Table 1).

Supportive Relationships

The first subcategory, supportive relationships, referred to the relationships formed between the adolescents and individuals whom the adolescents found to be supportive. The importance of supportive relationships to adolescents during the cancer experience was stressed by all adolescents in the study. One 16-year-old female adolescent expressed,

Because of family and friends and support. . . . If I did not have anybody, I would be in the garbage. The way I reason, the way I see it, is the only reason I have come this far is because of them.

Essential to defining a relationship as being supportive were those relationships that helped adolescents maintain a sense of being in the world and made them feel connected as well as loved and cared for. Adolescents identified 3 key supportive relationships: (1) support from my health care team, (2) support from my special friend, and (3) support from my family.

Support from my health care team. “Support from my health care team” refers to the supportive relationship

Table 1. List of Category, Subcategories, and Attributes of the Subcategories

<i>Category:</i> Degree and type of social support
<i>Subcategory 1:</i> Supportive relationships
Support from my health care team
Support from my “special friend”
Support from my family
<i>Subcategory 2:</i> Being there
Being there to comfort me
Being there to hold my hand
Being there to keep me from feeling lonely
Being there to help me feel like I have a life
Being there to keep me positive
Being there for me despite everything
<i>Subcategory 3:</i> Consequences of “being there”
Consequences associated with the health care team
Consequences associated with “special friends”
Consequences associated with the family

that adolescents maintained with professional members (eg, nurses, physicians, therapists) and nonprofessional members of the health care team (eg, nurses’ aides). The support from the health care team was so important to adolescents that some of them referred to the health care team as their “second family.” The adolescents had much love and high esteem for the health care team, as this 16-year-old adolescent reinforced:

Like those nurses are like really great. And Betty [nurse clinician], if it was not for her I could not do this. She helps quite a bit. Instead of being upset and sad, she looks at everything good, you know? And she shows it to me. . . . She is really great.

Although all adolescents valued the support that they received from the health care team as whole, most of the adolescents had identified one particular team member whom they found to be especially helpful in getting them through the cancer experience. Each adolescent gave different reasons for becoming closer to one member of the team than other team members (eg, having a good sense of humor).

Support from my special friend. “Support from my special friend” refers to that one really special friend who stood by the adolescent throughout his or her cancer experience. For about a quarter of the adolescents, the special friend was one of their peers whom

they had befriended in the cancer clinic. However, for most of the adolescents, it was their best friend whom they knew prior to the cancer experience. Adolescents really valued those friends who remained their friends and who treated them in the same way as they did prior to the cancer diagnosis. Having that one “special” friend was more important to the adolescents than having many friends who were not as close or supportive as that one “special” friend. One adolescent expressed,

I guess it also made me realize, like Kristie [friend] always came and sat with me when I needed her to be there. Some people always sometimes dropped in and said “hi” or phoned me to ask me how I was doing and there were some people who just never talked to me after I got cancer. That could be because they were really uncomfortable or that they really did not care enough! Quality over quantity!

Support from my family. “Support from my family” refers to the supportive relationship that adolescents maintained with their core family unit (parents and siblings). Although the supportive relationships with health care team members and their friends were key relationships in the lives of adolescents, it was the relationship that adolescents maintained with their families that was identified by adolescents as the most important supportive relationship experienced throughout the cancer course. Knowing that their families would always be there for them was what mattered most to the adolescents. The support that adolescents received from their families gave them the strength to continue, as made evident by the following comment:

I will keep on fighting. I am my mom and dad combined. Dad and Mom are my total role models because they have been through so much in their lives but they are still as strong and probably stronger than anyone else! If I was to die I could see it would hurt them.

Being There

The second subcategory of social support is the phenomenon of “being there.” Relationships that succeeded to help make adolescents feel connected and a part of the world were those relationships in which the individual in the relationship was seen by the

adolescent as “being there” for him or her. When talking about individuals in their supportive relationships, it was not uncommon for adolescents to refer to the phrase “they were there for me.” It was through the act of “being there” that adolescents experienced a sense of presence with the individual in the relationship and made the adolescents realize what really was important in life.

I think you realize how important family is to you. Like I guess before it was like the sisters I was stuck with having, but now I realize they are really important to me and you know when I need them they are there for me and when I am going for something, they will always be there.

Knowing that others were there for them was what really counted to the adolescents. Overall, the phenomenon of “being there” made adolescents feel that they were not alone in having to get through the cancer experience. One 15½-year-old female adolescent related,

When I was in the hospital one night with the total body radiation and I was sick before that and so it was hard for me to get through it because you have to be sitting in this room all by yourself for like 20 minutes. I was scared. And so what my mom did was to use the intercom and she read to me over the intercom. Boy, did that make a big difference!

Adolescents identified many ways that others could be there for them, but there were 6 ways of “being there” that were identified as being most important to the adolescents. The 6 ways were as follows: (1) being there to comfort me, (2) being there to hold my hand, (3) being there to keep me from feeling less lonely, (4) being there to help me feel like I have a life, (5) being there to keep me positive, and (6) being there for me despite everything.

Being there to comfort me. The first way of being there involved the act of being there to comfort the adolescents when they were not feeling well. It involved others having a physical presence around the adolescents and carrying out some type of act that helped adolescents feel better physically and/or mentally. Quite often, it involved either a family member or health care team member carrying out some type

of comforting measure for adolescents who were experiencing discomfort due to their symptoms. For example, one 12-year-old noted how her family was there for her when she experienced a stomachache by commenting,

Mom, Dad, even my like my sister helped . . . like, whenever my stomach was hurting my mom rubbed it and then like it made me fall asleep so, and like kind of forgot about it.

Special friends usually helped to comfort adolescents when they were not feeling well by trying to distract them and to get them to try thinking of something else. Special friends were also noted by adolescents to be there for them by acting in a more gentle and quiet physical manner around them when they were not feeling well. For example, one 13-year-old noted how his friend played less roughly around him when he felt sick, and this helped to comfort him.

Being there to hold my hand. This second way of being there involved the simple act of holding the adolescent's hand during a time when the adolescent was experiencing increased physical or mental stress. Although it was associated with the act of comforting, it was so important to adolescents that it deserved to be identified as another and distinct way for others to "be there." All adolescents, regardless of age, valued having a parent or nurse hold their hand during a painful procedure.

Special friends also were reported to "be there" for adolescents by holding their hand. However, adolescents equated hand-holding by friends metaphorically during those situations when they needed an extra boost of courage in doing something related to their world outside the illness world, such as going to a shopping mall for the first time after losing all their hair.

Being there to keep me from feeling less lonely. The third way of being there involved having a family member, health care team member, or special friend physically around the adolescents but not necessarily carrying out some specific physical act. Just being close by the adolescent was what was important to adolescents; that is, the other person did not necessarily have to say or do anything. What was valued about the physical presence of the individual was that it helped the adolescents to feel less lonely in their present situation.

I guess it is because you get so used to sitting by yourself that you do not want to sit by yourself. Even if you are not talking to them, you know if you wanted to turn and comment on something on the television show, you would have someone to turn to and say something to. . . . This probably sounds creepy but being able to hear someone next to you breathing . . . I mean if you are sitting by yourself, everything is just completely silent and everything feels so dead. I do not know you just feel so completely by yourself.

Adolescents especially felt protected when their family members were there to watch over them when they were hospitalized. When family members could not be there for adolescents, the presence of a health care team member was welcomed by the adolescents, as reinforced by this 16-year-old female:

Like I remember one night, I do not know where my mom was, I think she was driving my dad home and I could not sleep because she was not there and stuff like that. And I remember one of my nurses; she came in and sat with me until I fell asleep.

The special friend especially kept adolescents from feeling less lonely during those times when the adolescents were unable to spend a regular evening out with their other friends, like going to a movie or party. Having that special friend stay with them instead of the friend going out with other friends meant so much to the adolescents, as one 15½-year-old related:

Through all of my treatments or whatever, Karen [her friend] usually came over and . . . when I used to come back on Fridays and I had just gone to the operating room and I was still kind of dopey or whatever, and she always used to come over and just lay and watch television with me. And she said she knew we were not going to go out anywhere or do anything really interesting, she would just come over and watch television with me.

Being there to help me feel like I have a life. The fourth way involved others encouraging adolescents to maintain a life other than the life that evolved around the cancer and its treatment. For the adolescents, it was really important for others not to treat

them differently or as the sick patient. Adolescents wanted their family and friends to act “normal” around them. In helping adolescents feel like they have a life, it was important for their special friend to help them keep close ties with their peers and school, as one 15-year-old adolescent noted:

Like my best friend has been with me through everything and has always been with me. She knows that I have a life other than cancer. She knows! You know she still says “Oh, did you hear about what happened at school and so we did this and that, you know.” My friendship with her is just like before. But with other people I am not even sure why, they just seem all awkward around me and do not know what to talk to me about.

It was important for families to help adolescents to maintain a life with their friends. However, equally appreciated by adolescents was having their families help them to maintain a life with their own family. The adolescents really valued the time spent with their families such as going out for dinner or going to a movie. In helping adolescents maintain a life other than the life that evolved around the cancer and its treatment, it was important for health care team members to show adolescents that they were interested in adolescents as persons and not solely as patients. Health care team members needed to express an interest in the lives of adolescents and, when possible, scheduled treatments so that they did not interfere with events in their lives.

Being there to keep me positive. The fifth way of being there involved others in the lives of adolescents, not only maintaining a positive attitude about the cancer but also being there to help adolescents maintain a positive attitude. Especially important to adolescents was maintaining a positive attitude during the more difficult times, when adolescents talked about giving up on continuing the heavy cancer treatment regimens. As one 14½-year-old adolescent reinforced, it was her family that helped her to continue on and maintain a fighting attitude:

I think you get your attitude from your family! Like my dad said, “We are going to do it, we are going to get through it. You just have to go out and do it, and be done with it.” I think he is the one that I got that attitude from.

Adolescents also valued health care team members who were there to remind them of the importance of maintaining a positive attitude and getting on with life.

First you know Sandy [nurse clinician], one of the first things she says is “if you are going to sit in that bed and say my life is over, so I am dead, you will be because the chemotherapy may stop it at that point from coming back but it will not help you, rehabilitate you, and help you get better. It is you! It is a lot of times mind over matter, even if you do not want to you have to get out of bed and try your best.”

The adolescents really valued those special friends who helped them to believe and feel that they would be all right and get through the cancer experience.

Being there for me despite everything. The last way of being there involved others standing by the adolescents during those times when the adolescents felt or acted differently. Adolescents especially valued parents, siblings, and friends who were patient with their changing behaviors and moods and who did not judge them. The adolescents needed to know and feel that they were still cared for and loved by others, despite any unusual behaviors or moods on their part.

Consequences of Being There

Because of the supportive relationships, most adolescents realized for the first time what it truly meant to “be there” for others and to have others stand by despite everything. However, although the 3 key supportive relationships were essential in helping adolescents get through cancer, the dynamic nature of these relationships and the changing context of “being there” resulted in adolescents experiencing both positive and negative consequences.

Consequences associated with the health care team. Positive consequences of health care team members “being there” for the adolescents include adolescents developing a special respect for the health care team members. This respect was grounded in the adolescents viewing members of the health care team to be really hardworking individuals and “very special people, caring people.” Some of the

adolescents also developed an increased respect for the health profession in general to the point that they had plans to pursue some profession in the health care field. Another positive consequence included the adolescents gaining more self-confidence because of the recognition and praise that they received from the health care team members in relation to their determination and persistence in dealing with the cancer treatment regimens.

Adolescents, however, also acknowledged that there was a negative side to developing close relationships with members of the health care team. Specifically, some of the adolescents had a harder time dealing with the lesser amount of attention that they received from the health care team members as they became healthier and required less monitoring. These adolescents expressed a sense of sadness in feeling that they were no longer the most important patients. They felt that the health care team members no longer cared for them in the same way as they did when they were in the early stages of their cancer treatment. Although the adolescents were glad that they were getting better and did not have to spend as much time in the inpatient and outpatient cancer clinics, they missed being the center of attention or, as one 12-year-old female reinforced, "missed no longer being the star."

Consequences associated with special friends. Having friends stand by them during their cancer treatments made the adolescents not only appreciate the importance of having good friends in their lives but also resulted in them feeling more responsible and caring to their friends, as is made evident by the following comment of a 16-year-old female adolescent:

But with like my friends, I am very careful when it comes to my friends and stuff. Then again, they are really careful when it comes to me.

Just as important as it was to receive support, all adolescents stressed the importance of the need to reciprocate their support to their friends who were always there for them. However, one negative consequence of having a special friend was that the adolescents could not always be there for their special friend during those times when they needed their support. Even though this usually occurred during the times when the adolescents were not feeling well, it did not make it any easier for the adolescents. They

still experienced feelings of guilt for not being able to be there for their friend. Their feelings became only more intense when they sensed the frustration that their special friend was undergoing because of the adolescents' lack of support.

Consequences associated with the family. Understandably, because the family was identified by the adolescents as the most supportive relationship, it was the relationship that adolescents talked about most in terms of positive and negative consequences. On a positive note, always having their families stand by them confirmed to adolescents how much their families really cared for and loved them, as one 15-year-old female adolescent reinforced:

Well, you kind of knew that your family cared but, it is just that they never really had a chance to show you. It kind of gives them a chance to show you.

Although each adolescent stressed that every adolescent experiences cancer differently, the one thing that adolescents found they shared was acquiring a greater appreciation for their family. One 15-year-old adolescent related,

Well Ann [adolescent with cancer] and I were talking about how is cancer the same for us and we found that first of all it brings you a lot closer to your family because they are the ones that are with you, for all of it, for everything like that. . . . And me and her both agree on it that we would rather rent a movie and sit home and watch it with our families, then go out and sit in someone's basement with our friends.

Overall, the adolescents felt that having their family stand by them during difficult times resulted in the adolescents becoming closer to their family. This was even the case for those adolescents who experienced other family problems prior to and after cancer.

Despite the importance that "being there" had in family relationships to the adolescents with cancer, it also caused periods of increased stress and strain for the adolescents. Sometimes, the closeness to family members, especially parents, became too much for them, as one adolescent reinforced:

At times it kind of got overwhelming. When I just wanted everyone to leave me alone, it was like “Go away!” And now it still seems like my mom is always worried about me. I just feel like telling her, “Go away and leave me alone. I can take care of myself.”

Sometimes, the adolescents just wanted to be left alone but still have the support of their parents by “being there” in mind and spirit by providing psychosocial-emotional support but not necessarily having a physical presence around them. However, most parents felt that their being there was only valuable if they were actually “doing” something instead of “just being.”

Although adolescents wanted their families to be there for them, this was sometimes at the expense of spending less time with their friends. At times, the adolescents wanted to spend more time with their friends and/or were torn between wanting to be with their families and wanting to be with their friends. One 16-year-old female adolescent expressed,

Like I do not mind spending time with my family, in fact I love spending time with my family. Like that is what I have got to do is spend more time with my family. The part that makes me sad is not being able to spend as much time with my friends.

The increased support that adolescents received from their families also resulted in adolescents at times experiencing increased feelings of guilt for all the extra burdens they perceived their families had experienced because of the cancer diagnosis. Most often, they felt responsible for increased disruption their illness had on individual family members and on the family unit as a whole. They expressed guilt that their families were doing so much for them.

Adolescents especially expressed concern that their siblings missed out on a lot of things because of all the time the family had to direct in managing the illness. Also, although the adolescents recognized why their brothers or sisters sometimes felt left out at times, adolescents expressed frustration not knowing how they could “be there” for them. Adolescents also recognized the suffering that the family members experienced because of the need to “be there” for them, as this 15-year-old adolescent reinforces:

It is terrible going through it, but I can see it being more terrible, not more terrible, but really terrible to be part of the family who has to watch somebody go through it cause like you know you feel so bad, like there is just no way you can help them. It’s just that you feel really helpless not being able to do anything as a family member.

Discussion

Findings from this work reinforce previous studies that stress the importance of having a strong support system in helping adolescents cope with cancer (Haluska et al., 2002; Ishibashi, 2001; Kyngäs et al., 2001; Neville, 1998; Ritchie, 2001). As previously reported, adolescents value the support they receive from health care team members (Hedström, Skolin, & von Essen, 2004), friends (Manne & Miller, 1998; Ritchie, 2001), and especially the support that comes from their families (Haluska et al., 2002; Harris & Zakowski, 2003; Kyngäs et al., 2001; Neville, 1998; Ritchie, 2001; Trask et al., 2003). However, this study adds to our understanding of the importance that the phenomenon of “being there” has in the support experiences of adolescents with cancer. To date, the phenomenon of “being there” has received minimal attention in the pediatric oncology literature. Most of what is known about it is derived from the perspective of someone other than the child. For example, Romaniuk and Kristjanson (1995) revealed that parents identified being supportive to their children by “just being there.” However, “just being there” referred solely to the parents having a physical presence. In this present study, “being there,” as experienced by adolescents with cancer, involved more than just a physical present but also a psychosocial-emotional presence within a supportive relationship.

Other references to the phenomenon of “being there” originate mainly within the general nursing literature in relation to nursing presence and the different ways that nurses can be there for their patients (Doona, Haggerty, & Chase, 1997; Osterman & Schwartz-Barcott, 1996). Nursing presence is conceptualized as an intersubjective encounter involving one individual giving himself or herself to that other person and is viewed as essential to personalizing nursing care and maintaining the

sacredness of human suffering (Doona et al., 1997). This conceptualization of nursing presence is congruent with the adolescents' perspectives of those relationships that they found to be most supportive. The importance of conceptualizing social support within the framework of "being there" may serve to be more valuable with respect to helping adolescents with cancer sustain connections to those individuals most important in their lives.

Despite the importance that supportive relationships and the supportive behavior of "being there" had on adolescents getting through cancer, the adolescents nonetheless experienced periods when the support was a source of stress for them. With respect to supportive relationships involving health care team members, adolescents expressed feeling a sense of loss near the end of their treatment regimen. Although it was the support they received from the health care team members that helped to facilitate a therapeutic relationship, the downside of developing a close relationship was that adolescents experienced another loss or even feelings of abandonment when ending their close relationship with the team. Further research examining the transition experiences of adolescents with cancer is needed with attention to identifying key supportive behaviors that adolescents value at particular points in time of the cancer trajectory. Although none of the adolescents transitioned from pediatric to adult health care providers during the course of this study, this is a priority issue in the health care of youth with chronic conditions such as cancer that requires further understanding with respect to how nurses can best facilitate transitions (Reiss, Gibson, & Walker, 2005).

Adolescents had related a number of stressors with respect to their supportive relationships involving family and friends. This included adolescents experiencing feelings of guilt with respect to family members always having to "be there" for them at the expense of other family members and the family unit as a whole. In addition, adolescents experienced guilt and frustration in not always knowing how to "be there" for others, especially when it came to their siblings and their friends. Further investigation of adolescents' perceptions of what the roles of friends and especially siblings should be in their cancer care and how health care professionals and parents can best support these roles is warranted. More needs to be known about healthy and ill siblings' perspectives of

what it means to "be there" within the context of childhood cancer.

There was also a point of discrepancy between the central role of parents for support and the role of stress inherent in that parent-child constellation. Although adolescents viewed the support from their parents as extremely important, the adolescents did at times struggle wanting to be with their parents yet at the same time also be with their friends. With all the additional challenges that adolescents with cancer must face, it is not surprising that they may have difficulty in managing all their key relationships. The struggles that adolescents had in managing supportive relationships, coupled with their associated feelings of guilt and frustration, indicate the need for offering guidance in helping adolescents manage key supportive relationships.

Last, the finding that adolescents experienced an increased closeness and desire to be with their families may be perceived to be a maladaptive behavior, considering that adolescence is a stage where the adolescent should be in a period of transition and transformation in the parent-child relationship and should be experimenting with disengagement from family (Haluska et al., 2002). Indeed, there is the concern that adolescents may have difficulty establishing independence in young adulthood (Nichols, 1995; Ressler, Cash, McNeill, Joy, & Rosoff, 2003). However, for the adolescents in this study, developing an increased closeness to families was not seen as a loss of independence but more as an appreciation of what their families did for them. Although adolescents wanted their families to "be there" for them, the adolescents also wanted to "be there" for their families, which suggests awareness for increasing interdependence between family members and not increasing dependence on family members. However, further research is needed that will help determine the impact supportive relationships have on the lives of adolescents with cancer as they transition from adolescence to adulthood. The way in which adolescents and their families manage family closeness and disengagement during the childhood cancer trajectory may be central to future psychological and social adjustment, considering that the relationship between adolescents and their parents is important both as an outcome in its own right and as a precursor to adult functioning (Banner, Mackie, & Hill, 1996).

Limitations

There are limitations of this study. Foremost is that the findings are derived from a small number of adolescents and, therefore, future research is required to confirm the category of social support and its subcategories and attributes. Lack of cultural diversity in the sample is another limitation that warrants future work involving adolescents from different cultures.

Recommendations for Clinical Practice

Although the study's findings require further confirmation before they can be generalized to other adolescents with cancer, the knowledge gleaned from this study may help to guide nurses in their assessment and application of interventions directed at promoting positive social support experiences in adolescents with cancer. Specifically, it may be useful to focus more attention on how significant relationships in adolescents can be strengthened considering the phenomenon of "being there" was seen by the adolescents as a way to maintain connections with their families, friends, and other significant individuals. In determining what are the most appropriate support resources to offer adolescents, nurses need to take into account what resources will best strengthen key relationships in the adolescents' lives. Considering that peer relations are of central importance to adolescents, nurses may assist adolescents by suggesting strategies to them and their parents that will help adolescents nurture their relationships with friends. For example, having adolescents develop their own weekly activity schedule that would incorporate specific times set aside for their parents as well as their friends may help to ensure that adolescents can be with those individuals whom they most want to be with. Nurses also need to teach adolescents and their families that "being there" does not always have to involve the individual carrying out or "doing" some specific act of activity—"being there" in mind and spirit by providing psychosocial-emotional support at times may be more valuable than the act of physically doing something. Individual and group counseling that provides adolescents the opportunity to discuss their feelings about their encounters with positive and negative supportive relationships may also be helpful for those adolescents who experience increased

challenges related to relationships. Last, adolescents' feelings of abandonment from nurses and other health professionals reinforce the need for more careful planning for transitioning adolescents throughout the cancer trajectory. Nurses can assist adolescents by preparing adolescents for decreasing support by the health care team as well as plan provision of this support accordingly.

Conclusions

In conclusion, the act of others "being there" was seen by the adolescents as the key element of a supportive relationship. Although the 3 key supportive relationships in the lives of the adolescents were essential in helping adolescents get through cancer, these relationships were at time a source of stress for adolescents. Further research is required that adds to the key ways that others can "be there" for adolescents, with attention to capturing the similarities and differences of adolescents with diverse cancer diagnoses and illness trajectories.

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References

- Banner, L., Mackie, E., & Hill, J. (1996). Family relationships in survivors of childhood cancer: Resource or restraint? *Patient Education and Counseling*, 28, 191-199.
- Belle, D. (1989). Studying children's social networks and social supports. In D. Belle (Ed.), *Children's social networks and social supports* (pp. 1-12). New York: John Wiley.
- Denzin, N. (1984). *On understanding emotion*. San Francisco: Jossey-Bass.
- Doona, M., Haggerty, L., & Chase, S. (1997). Nursing presence: An existential exploration of the concept. *Scholarly Inquiry for Nursing Practice: An International Journal*, 11(1), 3-16.
- Ell, K. (1996). Social networks, social support and coping with serious illness: The family connection. *Social Science and Medicine*, 42(2), 173-183.

- Enskär, K., Carlsson, M., Golsäter, M., & Hamrin, E. (1997). Symptom distress and life situation in adolescents with cancer. *Cancer Nursing, 20*(1), 23-33.
- Fowler-Kerry, S. (1990). Adolescent oncology survivors' recollection of pain. In D. Tyler & E. Krane (Eds.), *Advances in pain research therapy* (Vol. 15, pp. 365-371). New York: Raven.
- Haluska, H., Jessee, P., & Nagy, C. (2002). Sources of social support: Adolescents with cancer. *Oncology Nursing Forum, 29*(9), 1317-1324.
- Harris, C., & Zakowski, S. (2003). Comparisons of distress in adolescents of cancer patients and controls. *Psycho-oncology, 12*, 173-182.
- Hedström, M., Skolin, I., & von Essen, L. (2004). Distressing and positive experiences and important aspects of care for adolescents treated for cancer: Adolescent and nurse perceptions. *European Journal of Oncology Nursing, 8*, 6-17.
- Hinds, P. (1990). Quality of life in children and adolescents with cancer. *Seminars in Oncology Nursing, 6*(4), 285-291.
- Hupcey, J. (1998). Social support: Assessing conceptual coherence. *Qualitative Health Research, 8*(3), 304-318.
- Hydén, L. (1997). Illness and narrative. *Sociology of Health and Illness, 19*(1), 48-69.
- Ishibashi, A. (2001). The needs of children and adolescents with cancer for information and social support. *Cancer Nursing, 24*(1), 61-67.
- Jacobson, D. (1990). Stress and support in stepfamily formation: The cultural context of social support. In B. Sarason, L. Sarason, & G. Pierce (Eds.), *Social support: An interactional view* (pp. 199-218). New York: John Wiley.
- Katz, E., & Varni, J. (1993). Social support and social cognitive problem-solving in children with newly diagnosed cancer. *Cancer Supplement, 71*(10), 3314-3319.
- Kazak, A., Christakis, D., Alderfer, M., & Coiro, M. (1994). Young adolescents cancer survivors and their parents: Adjustment, learning problems, and gender. *Journal of Family Psychology, 8*(1), 74-84.
- Kyngäs, H., Mikkonen, R., Nousiainen, E., Ryttilähti, M., Seppänen, P., Vaattovaara, R., et al. (2001). Coping with the onset of cancer: Coping strategies and resources of young people with cancer. *European Journal of Cancer Care, 10*, 6-11.
- Manne, S., & Miller, D. (1998). Social support, social conflict, and adjustment among adolescents with cancer. *Journal of Pediatric Psychology, 23*(2), 121-130.
- Mayall, B. (1996). *Children, health and social order*. Buckingham, UK: Open University Press.
- Morse, J., & Field, P. (1995). *Qualitative research methods for health professionals*. Thousand Oaks, CA: Sage.
- Neville, K. (1998). The relationships among uncertainty, social support, and psychological distress in adolescents recently diagnosed with cancer. *Journal of Pediatric Oncology Nursing, 15*(1), 37-46.
- Nichols, M. L. (1995). Social support and coping in young adolescents with cancer. *Pediatric Nursing, 21*(3), 235-240.
- Osterman, P., & Schwartz-Barcott, D. (1996). Presence: Four ways of being there. *Nursing Forum, 31*, 23-30.
- Prus, R. (1996). *Symbolic interaction and ethnographic research*. Albany: State University of New York Press.
- Quittner, A. L. (1992). Re-examining research on stress and social support: The importance of contextual factors. In A. La Greca, L. Siegel, J. Wallander, & C. Walker (Eds.), *Stress and coping in child health* (pp. 85-115). New York: Guilford.
- Rechner, M. (1990). Adolescents with cancer: Getting on with life. *Journal of Pediatric Oncology Nursing, 7*(4), 139-144.
- Reiss, J., Gibson, R., & Walker, L. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics, 115*(1), 112-120.
- Ressler, I., Cash, J., McNeill, D., Joy, S., & Rosoff, P. (2003). Continued parental attendance at a clinic for adult survivors of childhood cancer. *Journal of Pediatric Hematology/Oncology, 25*, 868-873.
- Ritchie, M. (2001). Sources of emotional support for adolescents with cancer. *Journal of Pediatric Oncology Nursing, 18*(3), 105-110.
- Romaniuk, D., & Kristjanson, L. (1995). The parent-nurse relationship from the perspective of parents of children with cancer. *Journal of Pediatric Oncology Nursing, 12*(2), 80-89.
- Sandler, I., Miller, P., Short, J., & Wolchik, S. (1989). Social support as a protective factor for children in stress. In D. Belle (Ed.), *Children's social networks and social supports* (pp. 277-307). New York: John Wiley.
- Stern, M., Norman, S., & Zevon, M. (1993). Adolescents with cancer: Self-image and perceived social support as indexes of adaptation. *Journal of Adolescent Research, 8*(1), 124-142.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Trask, P., Paterson, A., Trask, C., Bares, C., Birt, J., & Maan, C. (2003). Parent and adolescent adjustment to pediatric cancer: Associations with coping, social support, and family function. *Journal of Pediatric Oncology Nursing, 20*(1), 36-47.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Ontario: Althouse.
- Vaux, A. (1990). An ecological approach to understanding and facilitating social support. *Journal of Social and Personal Relationships, 7*, 507-518.
- Viney, L., & Bousfield, L. (1991). Narrative analysis: A method of psychosocial research for AIDS-affected people. *Social Science and Medicine, 32*(7), 757-765.
- Weekes, D., & Kagan, S. (1994). Adolescents completing cancer therapy: Meaning, perception, and coping. *Oncology Nursing Forum, 21*(4), 663-670.
- Weekes, D., Kagan, S., James, K., & Seboni, N. (1993). The phenomenon of hand holding as a coping strategy in adolescents experiencing treatment-related pain. *Journal of Pediatric Oncology Nursing, 10*(1), 19-25.
- Wolchik, S., Beals, J., & Sandler, I. (1989). Mapping children's support networks: Conceptual and methodological issues. In D. Belle (Ed.), *Children's social networks and social supports* (pp. 191-220). New York: John Wiley.
- Woodgate, R. (1999). Social support in children with cancer: A critical review of the literature. *Journal of Pediatric Oncology Nursing, 16*(4), 201-213.

- Woodgate, R. L. (2001). *Symptom experiences in the illness trajectory of children with cancer and their families*. Dissertation study, University of Manitoba, Winnipeg, Manitoba.
- Woodgate, R. L., & Degner, L. (2003). A substantive theory of keeping the spirit alive: The spirit within children with cancer and their families. *Journal of Pediatric Oncology Nursing*, 20(3), 103-119.
- Wortman, C. (1984). Social support and the cancer patient: Conceptual and methodologic issues. *Cancer Supplement*, 53(10), 2339-2360.
- Zevon, M., Tebbi, C., & Stern, M. (1987). Psychological and familial factors in adolescent oncology. In C. Tebbi (Ed.), *Major topics in adolescent oncology* (pp. 325-349). New York: Futura.



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