

FORUM FOCUS

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Shifting Perspectives

A symposium presented at the Seventh National Cancer Nursing Research Conference, February 2003



Adolescent-Focused Oncology Nursing Research

Pamela S. Hinds, PhD, RN

Purpose/Objectives: To describe contextual features of the experience of adolescents with cancer in the United States; to relate these features to a different theoretical perspective, the Shifting Perspectives Model of Chronic Illness; and to derive implications from that model for conducting research with adolescents who have cancer.

Data Sources: 64 qualitative and quantitative studies and clinical anecdotes.

Data Synthesis: Unique features of adolescents with cancer related to person, disease, and treatment indicate that existing theories on adolescence do not adequately guide research efforts with this patient population, nor do they adequately assist in explaining study findings.

Conclusions: The Shifting Perspectives Model of Chronic Illness is useful in generating potentially important hypotheses about adolescents and their experiences with cancer and has the promise of guiding research design and method selection for studies involving adolescents with cancer. The model also highlights a moral responsibility for researchers who conduct studies with this patient population.

Implications for Nursing: Nurse researchers who use this model to guide their research will create a purposeful balance in methods that allows adolescents with cancer to choose the amount of time and detail they will give to illness-related or to wellness-related responses in studies, particularly those that rely on self-report methods.

Adolescents with cancer are different yet similar to healthy adolescents, children with cancer, and adults with cancer. The differences and similarities can both elucidate and confuse healthcare professionals, family members, and others who interact with adolescents diagnosed with cancer and who want to understand an adolescent's experience accurately and sensitively enough to influence it in positive ways. One tool used to help illuminate is theory.

Varying types of theories have been posed in the 1900s to contribute to an understanding of adolescence. They have been developed from studying healthy adolescents (Asendorpf & Valsiner, 1992; Gilligan, 1982; Kindlon & Thompson, 1999; Muuss, 1996). The theories do not take

Key Points . . .

- ▶ Current theories derived from healthy adolescents do not adequately explain or predict the development of adolescents being treated for cancer.
- ▶ A new conceptual perspective that reflects the benefit to adolescents with cancer of shifting between a focus on their illness and a focus on their wellness is needed.
- ▶ Researchers can create designs and select methods that allow adolescents to shift between the focus on illness and the focus on wellness.

into consideration the life-threatening, aggressively treated disease of cancer and its unique presentation in adolescents or the chronic illness experience of adolescents with cancer that includes lengthy and intrusive treatment that could end with death, cure, or cure with potentially lifelong effects (Hinds, 2000; Neville, 2000). Because of these omissions, current theories on adolescence may not explain or predict the emotional, cognitive, physical, social, or spiritual development of adolescents with cancer and do not address whether the cancer experience speeds, slows, or redirects the developmental process (Hinds, 1994). As a result, the existing theories on adolescent development may not adequately inform research designs and methods for use with

Pamela S. Hinds, PhD, RN, is a director of nursing research in the Division of Nursing Research at St. Jude Children's Research Hospital in Memphis, TN. This manuscript was prepared for a plenary session of the Seventh National Cancer Nursing Research Conference, which took place in February 2003 in San Diego, CA. (Submitted January 2003. Accepted for publication July 30, 2003.)

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adolescents with cancer. The purpose of this article is to describe contextual features of the experience of adolescents with cancer treated in the United States and to relate those features to a different theoretical perspective developed from research with chronically ill adults, known as the Shifting Perspectives Model of Chronic Illness (Paterson, 2001; Thorne et al., 2002). Implications from that theoretical perspective for conducting research with adolescents with cancer will be identified.

Contextual Features of Adolescents With Cancer in the United States

One defining feature of adolescence is chronologic age. However, that seemingly straightforward characteristic is defined differently by theorists, professional associations, and federal agencies. Theorists have characterized adolescence as a time of transition that comprises three periods: early (10–13 years), middle (14–16 years), and late (17–21 years) (McGrath & Pisterman, 1991). The American Academy of Pediatrics defines pediatrics as through age 21 (although this is described as “negotiable,” with an extension beyond 21 years possible if special circumstances such as a chronic illness exist) (American Academy of Pediatrics Council on Child and Adolescent Health, 1988). The U.S. Food and Drug Administration defines children as 15 years and younger, and the National Institutes of Health policy on including children in clinical research defines children as younger than 21 years of age (Smith, Gurney, & Ries, 1999); the World Health Organization defines adolescence as 10–19 years of age (Lewis, Fallon, van Dongen-Melman, & Barr, 2002). Each respective association or agency reports its statistics related to adolescents with cancer in its own age-defining categories. As a result, making accurate comparisons of the statistics across reporting groups is difficult, if not impossible.

Another defining characteristic of adolescents that additionally distinguishes them from younger children and adults is the most common cause of death. Unintentional injury is the leading cause of death in people 10–19 years old; malignant neoplasm is the second-leading cause for people 10–14 years old and the fourth-leading cause in people 15–19 years old (following homicide and suicide as the second and third causes) (National Center for Health Statistics, 2001a, 2001b). The factor common to these age groups is that malignant neoplasm is the leading cause of death by disease.

Adolescents with cancer differ from children and adults with cancer in terms of the types of cancer they experience, although some overlap occurs with both of the other age groups (Ries, 1999; Smith et al., 1999). According to Bleyer (2002), about two-thirds to three-fourths of all adolescents with cancer have a pediatric cancer, but the rest have cancers of younger and older patients. Diagnoses differ in incidence even within the age range of adolescence. Hodgkin’s disease, germ cell tumors, and bone cancers are more common in adolescents than in children; leukemia, brain and central nervous system tumors, bone and joint tumors, and non-Hodgkin’s lymphoma are the most common cancer-related causes of death in the 10–14 age group; brain and central nervous system tumors, leukemia, bone and joint tumors, sarcomas, non-Hodgkin’s lymphoma, thyroid cancer, and malignant melanoma cause the

most common cancer-related deaths in the 15–19 age group (Bleyer; Institute of Medicine, 2003).

The incidence of cancer in adolescents 15–19 years of age in the 1990s was twice that of two other age groups of younger patients (5–9 and 10–14 years of age). From 1973–1992, the incidence of cancer rose the most and the death rate decreased the least in people 15–19 years old (Bleyer et al., 1997; Ries, 1999). Indeed, the annual incidence of cancer in adolescents increased from 183 per million from 1975–1979 to 203.8 per million from 1990–1995 (Smith et al., 1999). Clearly, adolescents with cancer have not fared as well as their younger counterparts. Such statistics have prompted a national focus on adolescents with cancer, including a committee established in the Pediatric Cancer Cooperative of North America and the Children’s Oncology Group, whose charge is to address the cancer care and treatment needs of adolescents and young adults.

Adolescents with cancer experience nausea, vomiting, mucositis, pain, alopecia, excessive weight gain or loss, bleeding, acne, infection, and intrusive procedures (Rhiner, Ferrell, Shapiro, & Dierkes, 1994; Rostad & Moore, 1997). In the midst of cancer treatment, some adolescents who normally would rely on their friends for support and social interaction must instead depend on their parents (Vannatta, Gartstein, Short, & Noll, 1998; Walker, Wells, Heiney, & Hymovich, 2002; Weekes & Kagan, 1994). Some adolescents rely additionally on their family members for assistance with basic care needs such as toileting, dressing, and eating. The presence and intensity of certain diseases and treatment-related symptoms may result in adolescents who previously had been involved in making decisions on issues affecting them now deferring decisions to their parents or healthcare providers (Ackerman, 1995; Leikin, 1993).

Even within the group of adolescents with cancer, important differences exist. For example, the incidence of cancer is 50% higher in Caucasians than in blacks; no difference exists in incidence by gender in people 15–19 years old, but boys younger than 15 years have a 20% higher incidence than girls in that age group (Bleyer, 2002). Treatment locale also differs within the group of adolescents. The majority of adolescents younger than 15 years are treated at National Cancer Institute-affiliated centers, and the majority of these are enrolled in clinical trials. In contrast, only 20% of adolescents 15–19 years of age are treated at such centers, and only about 10% are enrolled in clinical trials (Smith et al., 1999).

The national statistics, clinical and research findings, and theoretical perspectives noted previously indicate that adolescents with cancer share important and, in some instances, as yet unexplained similarities and differences with healthy adolescents, children with cancer, and adults with cancer. Healthcare professionals should consider the differences and similarities when planning care for adolescents with cancer and when designing research studies. A theoretical perspective that incorporates the differences and similarities may better direct both care efforts and the research needed to further advance the clinical care of this unique group of individuals. One promising theoretical approach is the Shifting Perspectives Model of Chronic Illness, a theory proposed by Paterson (2001) and Thorne et al. (2002) and derived from a metasynthesis of 292 qualitative studies of adults who had chronic physical illness.

The Shifting Perspectives Model of Chronic Illness

Paterson (2001) and Thorne et al. (2002) completed a three-step analytic process (metadata analysis, meta-method, and metatheory) with 292 qualitative studies to induce a new model for understanding the experience of adults who have chronic illness. The new model conveyed that living with chronic illness is not a linear, phased process that follows a predictable trajectory to an anticipated end goal. Instead, the experience of living with chronic illness is an ongoing, continually shifting process as an ill individual makes sense of the experience. The shifting process reflects the elements of wellness and illness that comprise chronic illness. The model is based on the assumption that an ill adult's perception of his or her illness becomes his or her reality and is the basis for his or her response to the illness.

According to Paterson (2001), illness-in-the-foreground involves an ill individual being focused on the illness, the suffering and loss that come with the illness, and the negative effect on self and others such as family members. This focus can be self-absorbing but also is protective with a utilitarian function. This focus prompts the ill person to learn about the illness and what can be done to live with it, including how to treat it and manage symptoms (see Figure 1).

With wellness-in-the-foreground, the focus of the chronically ill individual is on self as a person and not as a diseased body. A distancing from the illness occurs, and in its place is a focus on the emotional, spiritual, and social aspects of life. Outcomes of this focus can be a renewed appreciation of life and relationships and increased attention on the needs of others (see Figure 1).

Shifting from wellness-in-the-foreground to illness-in-the-foreground occurs when a threat to self is perceived related to the illness. Threats can be in the form of receiving bad news about the state of the illness or of key laboratory values, experiencing one or more symptoms that are controlled inadequately, being involved in a situation where assistance is required in ways that give notable emphasis to dependence on others, or becoming aware of lacking the knowledge or skills needed to manage the illness.

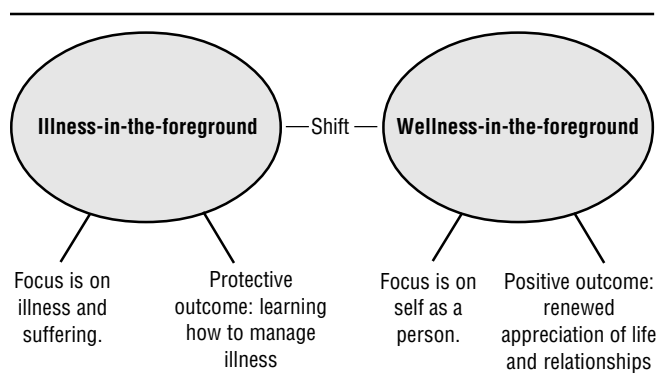


Figure 1. The Primary Focus and Outcome of Each Foreground

Shifting from illness-in-the-foreground to wellness-in-the-foreground can be facilitated with confidence in being able to handle the illness and related situations and by hope about the ability to find meaning in life and interactions with others. A shift between illness- and wellness-in-the-foreground can occur gradually or suddenly. A shift may be related to a host of factors, such as characteristics of illness (e.g., length, type of disease), person (e.g., gender, age), or context of care (e.g., personal and professional support). The shift itself is described as adaptive in important ways. Potentially, then, refusing to shift could contribute to a chronically ill person becoming more ill, leading to disease progression or emotional complications.

Perhaps because of the newness of the model, the characteristics of the shift have been understudied. Questions about the shift include the nature and purpose of the tension between the two foregrounds, including the implications of high, moderate, or low tension; speed of the shift within certain contexts; completeness of the shift from one foreground to the other; smoothness of the shift; an ill person's awareness of the shifting; and the understanding and appreciation of the shifting that a chronically ill person possesses. These questions about the shift have not been addressed in prospective studies with adults or adolescents.

Applying the Shifting Perspectives Model of Chronic Illness to Adolescents With Cancer

The model has not been applied yet to adolescents with cancer, but a systematic review of 64 qualitative and quantitative studies involving this target group indicated possible relevance of the model in explaining behaviors of adolescents with cancer and generating research questions or hypotheses. The reviewed studies suggest support for the existence of illness-in-the-foreground and wellness-in-the-foreground in adolescents being actively treated for cancer, as well as survivors of childhood cancer. Adolescents in both groups described the importance of focusing on the disease and its treatment for self-protective reasons (e.g., controlling nausea and vomiting to maintain adequate nutritional intake) but also out of concerns for others (Cotanch, Hockenberry, & Herman, 1985; Crom, Hinds, Gattuso, Tyc, & Hudson, in press; Haase, 1987; Haluska, Jessee, & Nagy, 2002; Hinds, Birenbaum, Pedrosa, & Pedrosa, 2002; Hockenberry-Eaton et al., 1998). Similarly, adolescents in both groups emphasized the need to focus on the positive aspects of treatment, such as new friends, strengthened family relationships, and improved view of self, that can emerge during or after illness (Crom et al.; Hinds & Martin, 1988; Hinds et al., 1999, 2000, 2002) (see Clinical Example 1).

The shift from wellness-in-the-foreground to illness-in-the-foreground in adolescents occurs during situations of threat, transition, or suffering, such as at diagnosis, at disease progression or recurrence, with pain or procedural distress, after successfully completing treatment, during reluctant reliance on parents, with physical or psychological limitations related to cancer, or when adolescents perceive distancing or commitment in an important relationship (Haase & Rostad, 1994; Hedstrom, Haglund, Skolin, & von

Clinical Example 1

When recurrent disease was diagnosed in a male 15-year-old with rhabdomyosarcoma, the adolescent reported privately considering suicide because of the certain burden the retreatment would be on his parents and younger brother. He later rebuked himself for this thinking and reminded himself that only God takes a life. While living in an extended-stay facility during his retreatment, he found much pleasure in using his mechanical skills with remote-control cars to repair a toy car and then use it to motivate a 4-year-old patient with cancer to walk again. He described special meaning in the opportunity to positively influence the life of another person, in particular, someone close to the age of his own brother.

Clinical Example 2

A female 16-year-old with newly diagnosed osteosarcoma participated in preliminary discussions with her attending physician and advanced practice nurse about treatment, including the likely side effects. The discussions then switched to favorite activities and hobbies and suggestions on ways to continue involvement in them during treatment. When the attending physician attempted to return to the previous discussion of side effects, including loss of hair, the adolescent initially refused to participate in the discussion. When the physician urged her “to be realistic about the side effects,” she stated, “I am not going to be like the other patients who lose all their hair.” She later confided that she recognized all along that she was going to lose her hair but did not want to continue to focus on the negative aspects of treatment during the clinic visit. Instead, she wanted to stay focused on the well aspects of her life.

Essen, 2003; Hinds et al., 2002; Hinds & Martin, 1988; Hinds, Martin, & Vogel, 1987; Manne & Miller, 1998; Tyc, Mulhern, Jayawardene, & Fairclough, 1995; Weekes & Savedra, 1988; Woodgate & Degner, 2003; Woodgate & McClement, 1998) (see Figure 2). For example, when an adolescent perceives a nurse with whom he or she had a close relationship as being distant and preoccupied or not personally invested in the adolescent, the adolescent assumes that the nurse is aware of “bad news” about the adolescent’s disease and is trying not to reveal this information before the attending physician can deliver the news. This assumption about forthcoming “bad news” may initiate the shift from wellness-in-the-foreground to illness-in-the-foreground. The shift in foregrounds can occur rapidly with adolescents, even during one conversation with a healthcare provider. Adolescents describe being aware of the shift and acknowledge at times resisting the shift from wellness- to illness-in-the-foreground (see Clinical Example 2).

Social support, competent care providers, hopefulness, and humor (Freeman, O’Dell, & Meola, 2003; Haase, 1987; Haluska et al., 2002; Hinds et al., 1987, 1999; Neville, 1998; Rhiner et al., 1994; Weekes, Kagan, James, & Seboni, 1993) influence the occurrence of a shift in either direction and also may affect the ease of the shift (see Figure 1). Aggres-

siveness of treatment and prior academic problems also may influence which foreground predominates (Freeman et al.; Hollen & Hobbie, 1993; Hollen, Hobbie, & Finley, 1997; Neville, 1998) (e.g., the more aggressive a treatment or the greater a toxicity, the more illness-in-the-foreground may predominate). No evidence suggests whether gender, diagnosis, or age influence the shift. No published data describe the features of an evolving foreground (i.e., how rapidly and in what way illness- or wellness-in-the-foreground changes over time and situations). Although this has not been addressed in a direct manner, feeling special rather than feeling different from others may help to keep the two foregrounds in equilibrium in adolescents with cancer (Hockenberry-Eaton & Minick, 1994; Woodgate, 1998). The usefulness of the Shifting Perspectives Model of Chronic Illness for research involving adolescents with cancer could include the identification of these and other variables that may comprise research hypotheses or research questions.

Using the Shifting Perspectives Model to Guide Research With Adolescents With Cancer

Inviting an adolescent to consider enrolling in a research study has the potential to initiate, delay, or increase the speed of a shift between the two foregrounds. The intent of research is to fully explicate a phenomenon (in this instance, the existence and nature of illness-in-the-foreground and wellness-in-the-foreground) and to do so accurately and sensitively without causing harm to the research participants. Adolescents with cancer have conveyed that an invitation to participate in a research study related to some aspect of the cancer experience can remind them of their illness (and thus create a shift from wellness-in-the-foreground to illness-in-the-foreground), and that reminder alone can provoke refusal to participate (Hinds, Quargenti, & Madison, 1995). Whether refusal rates differ when the focus is not on an aspect of the cancer experience (illness-in-the-foreground) but

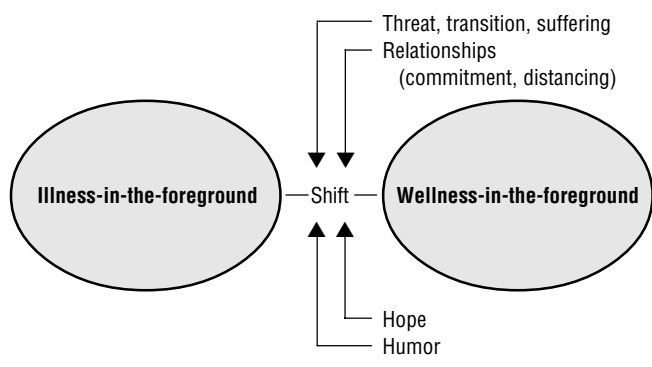


Figure 2. Factors Theorized to Influence the Shift Between Illness-in-the-Foreground and Wellness-in-the-Foreground in Adolescents With Cancer

instead on health promotion (wellness-in-the-foreground) is unknown.

A study that includes only an illness focus and requires an extensive time commitment from an adolescent participant could initiate a shift from wellness-in-the-foreground to illness-in-the-foreground or alter a shift between the foregrounds. The adolescent's experience of an undesired shift or the perception of a forced focus could alter the information reported by an adolescent with cancer. At its extreme, this influence could contribute to artificial or partial responses. To avoid or diminish this potential risk, researchers may need to use focused, nonrepetitive methods in study designs involving self-reports from these adolescents, methods that allow the adolescents to set the pace for data collection, as well as methods that allow adolescents to offer wellness- and illness-in-the-foreground responses. These strategies would allow adolescents to choose which foreground will dominate. Having this choice may increase adolescents' comfort with participating in research; their responses may be more truthful and accurate reflections of adolescents' perceptions of living with cancer. For example, in the author's research on quality of life of adolescents with cancer, she discovered that the most revealing self-report methods are two interview questions fashioned from two pilot studies involving 36 pediatric oncology patients. "During treatment, there are good days and there are bad days."

1. "What makes a good day for you?"
2. "How has being sick been for you?"

These questions allow adolescents to choose the context (illness- or wellness-in-the-foreground) when responding. For example, a female 17-year-old who had been diagnosed just seven weeks prior with acute lymphocytic leukemia responded to the second question: "It has made me a better person. I have always been tense, angry, and selfish. I feel I need my family more, I'm more emotional and cry more, but I have a better attitude toward life."

Methods that do not give a balanced emphasis to "feeling special" and "feeling different from others" may influence the shifting between foregrounds. For example, in a study of coping, quantitative measures had overlapping and repetitive items about worries, sad thoughts, and not being able to do what peers could do and few items about a positive future for self or others (Hinds et al., 2000). About 10% of the adolescents who participated in the study responded to follow-up queries about the impact of the study by expressing an uneasiness about the intent of the items: Were they somehow supposed to call attention to any mental instability that the adolescents already worried might be present in themselves? The uneven emphasis on illness and wellness may have contributed to this perception of being different.

The amount of time spent in one foreground or the other by adolescents who are in differing phases of care (i.e., active treatment, survivorship, or dying) is not known because this aspect has not been studied. Yet the amount of time spent in a foreground or the intensity of shifting between the two foregrounds may help to explain conflicting or unanticipated findings from previous studies that have eluded satisfactory explanation: (a) why adolescents do or do not engage in health-promoting activities (Hudson et al., 2002; Mulhern et al., 1995), (b) why they make reasoned or risky decisions

and how their decision-making is influenced by varying situations (Hollen & Hobbie, 1993; Hollen et al., 1997), (c) why they do not report the quality-of-life differences anticipated given the kind of cancer treatment (e.g., amputation versus limb sparing) that they have received (Hudson et al., 1998), and (d) how the cancer experience, including parental and patient behaviors, may affect their emotional, cognitive, social, and spiritual development (Kaplan, Busner, Weinhold, & Lenon, 1987; Kazak & Meadows, 1989; Neville, 1998; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Vannatta et al., 1998).

Because the focus or methods of a research study could influence the shift between foregrounds, researchers may have a moral obligation to ask adolescents about the impact of their participating in a study. After adolescents completed their participation in one of the author's studies on end-of-life decision making, the author and her colleagues asked them to identify what was good about being in the study, what was bad about being in the study, and whether they wanted to speak to a person about their feelings. Most of the adolescents indicated that explaining their rationale for choosing an end-of-life decision reminded them of the seriousness of their choice (illness-in-the-foreground) but also the respect others had for their ability to make the decision (wellness-in-the-foreground).

Conclusions

Current theoretical perspectives derived from well adolescents do not adequately address the impact of the diagnosis of cancer or the side effects of treatment on the physical, emotional, social, mental, or spiritual development of adolescents with cancer. These same theories do not explain or predict adolescents' behavioral responses to the cancer experience. Unique features of adolescents with cancer, including type of cancer, incidence, and mortality rates, also distinguish these adolescents from children and adults with cancer. These unique characteristics and the inadequacy of existing theories compel researchers to consider a new theoretical perspective. Although untested in adolescents with cancer, the Shifting Perspectives Model of Chronic Illness, with its movement between illness-in-the-foreground and wellness-in-the-foreground, has particular appeal in its application to this population. Potentially important hypotheses for clinical investigations that include the effect of variables such as hope, humor, treatment intensity, transition points, and relationships on the type of foreground that dominates or the shift between foregrounds can be deduced from the application of the model to this patient group. Research designs and methods that allow adolescents to move between foregrounds and researchers who are mindful of the potential that research studies have to affect the shift between foregrounds may fit well with this new theoretical perspective.

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Author Contact: Pamela S. Hinds, PhD, RN, can be reached at pam.hinds@stjude.org, with copy to editor at rose_mary@earthlink.net.

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- ▶ Kids Cancer Network
www.kidscancernetwork.org
- ▶ CancerSourceKids
www.cancersourcekids.com
- ▶ Candlelighters Childhood Cancer Foundation
www.candlelighters.org

Links can be found at www.ons.org.

