Shifting Perspectives

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

Adolescent-Focused Oncology Nursing Research

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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; Kiplon & Thompson, 1999; Muuss, 1996). The theories do not take 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

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.

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Digital Object Identifier: 10.1188/04.ONF.281-287
adolescents with cancer. The purpose of this article is to
describe contextual features of the experience of adoles-
cents with cancer treated in the United States and to relate
those features to a different theoretical perspective devel-
oped from research with chronically ill adults, known as the
Shifting Perspectives Model of Chronic Illness (Paterson,
2001; Thorne et al., 2002). Implications from that theoreti-
cal 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 de-

dined differently by theorists, professional associations,
and federal agencies. Theorists have characterized adoles-
cence as a time of transition that comprises three periods: young-
ner (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 de-
scribed as “negotiable,” with an extension beyond 21 years possible if
special circumstances such as a chronic illness exist) (Ameri-
can Academy of Pediatrics Council on Child and Adolescent
Health, 1988). The U.S. Food and Drug Administration de-

defines children as 15 years and younger, and the National Insti-
tutes of Health policy on including children in clinical research
defines children as younger than 21 years of age (Smith, Gur-
ney, & 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 can-

cer 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 addi-
tionally 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, al-
though 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 can-
cer 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 adoles-
cents than in children; leukemia, brain and central nervous sys-
tem tumors, bone and joint tumors, and non-Hodgkin's lym-
phoma 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 lym-
phoma, 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, ado-
lescents with cancer have not fared as well as their younger coun-
terparts. Such statistics have prompted a national focus on ado-
lescents 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,
bloating, acne, infection, and intrusive procedures (Rhiner,
Ferrell, Shapiro, & Dierkes, 1994; Rostad & Moore, 1997).
In the midst of cancer treatment, some adolescents who nor-
mally would rely on their friends for support and social in-
teraction must instead depend on their parents (Vannatta,
Gartstein, Short, & Noll, 1998; Walker, Wells, Heiny, &
Hymovich, 2002; Weekes & Kagan, 1994). Some adoles-
cents 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, impor-
tant 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 ado-
lescents 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 ado-
lescents 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 perspec-
tive that incorporates the differences and similarities may
better direct both care efforts and the research needed to fur-
ther advance the clinical care of this unique group of indi-
viduals. 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, 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.

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.

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, Quargnenti, & Madison, 1995). Whether refusal rates differ when the focus is not on an aspect of the cancer experience (illness-in-the-foreground) but...
Instead of a focus on illness, as has been the case in previous research, the study examined the impact of the illness on the adolescents' quality of life. The researchers aimed to understand how the illness influenced the adolescents' perceptions of living with cancer. For example, in one study, adolescents were asked to describe their experiences during treatment, and the responses indicated a shift from wellness-focused responses to illness-focused responses. This shift was influenced by the adolescents' need to express their fear, anxiety, and concern about their health. The researchers concluded that the ill-health-promotion approach could be beneficial in promoting the adolescents' well-being and resilience.
References


Acknowledgments. This work was supported by the National Cancer Institute, SEER Program. NIH Pub. No. 99-4649.


**For more information . . .**

- 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.*