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.

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.

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 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...