Cancer-Related Patient Education: An Overview of the Last Decade of Evaluation and Research

Jane Harper Chelf, MDiv, RN, Patricia Agre, EdD, RN, CHES, Alan Axelrod, MSW, LICSW, Lydia Cheney, MEd, Diane D. Cole, MPH, Kathryn Conrad, MSN, RN, AOCN®, Sally Hooper, MSW, LICSW, Irene Liu, MPH, CHES, Annette Mercurio, MPH, CHES, Karen Stepan, MPH, CHES, Louise Villejo, MPH, CHES, and Carolyn Weaver, MSN, RN, CNS, AOCN®

Purpose/Objectives: To provide an overview of cancerrelated patient-education research to determine future research needs.

Data Sources: A literature search of peer-reviewed articles from 1989–1999. Databases that were searched included MedlineTM, CINAHLTM, HealthStarTM, ERICTM, CancerLitTM, and PubMedTM.

Data Synthesis: 176 articles were analyzed and synthesized into narrative form.

Conclusions: Patients with cancer want and benefit from information, especially when making treatment decisions. Education helps patients manage side effects and improves adherence. Literacy is an important factor in materials development. The efficacy of computer-assisted learning, audio and video programs, and telephone interventions is supported in a variety of patient groups. Pain education can improve pain control, but the impact on fatigue has not been well researched.

Implications for Nursing Practice: Patient education is an important component of nursing care. Research has confirmed its impact in many areas but questions still remain

he National Cancer Institute (NCI) Cancer Patient Education Network (CPEN) is comprised of leaders in cancer patient education at NCI-designated cancer centers. A strategic goal of NCI CPEN is to promote the use of evidence-based education practices at NCI-designated cancer centers. As the first strategy toward meeting this goal, the NCI CPEN Research Committee examined published reports from 1989–1999 on research in the field of patient education.

Education evaluation research examines a specific program, curriculum, or medium using the scientific method to evaluate educational practice and focuses on processes, outcomes, and goals. Educational research, however, typically is not related to a specific program. The purpose of educational research is to contribute to the body of knowledge about the field (Rankin & Stallings, 1990).

Leaders in patient education contend that patient education is an art rather than a science and is not well developed in regard to methodology (Lorig, 1996; Redman, 1993). This literature review examines research published in peer-reviewed journals over a 10-year period. An overview of the studies is provided as well as summaries about what has been learned

Key Points...

- ➤ Cancer-related patient education research conducted more than 10 years confirmed that patients with cancer want information.
- ➤ Patients want their doctors to be their primary source of information and see written materials as supplemental to the learning process.
- Many print materials are written at a reading level that is too high for the target population.
- Computers, videotapes, audiotapes, and telephones can help to educate patients.

Jane Harper Chelf, MDiv, RN, formerly an educator at the Mayo Clinic Cancer Center and chair of the National Cancer Institute Cancer Patient Education Network Research Committee, is a PhD student at the University of Minnesota in Rochester; Patricia Agre, EdD, RN, CHES, is director of patient/family education at Memorial Sloan-Kettering Cancer Center in New York, NY; Alan Axelrod, MSW, LICSW, is director of social work and community outreach at the Cancer Institute of New Jersey in New Brunswick; Lydia Cheney, MEd, is a cancer education specialist at the University of Alabama Comprehensive Cancer Center in Birmingham; Diane D. Cole, MPH, is an education coordinator in the Cancer Center at the University of Virginia in Charlottesville; Kathryn Conrad, MSN, RN, AOCN®, is a program leader for Cancer Education and Standards Integration at the University of Pittsburgh Cancer Center; Sally Hooper, MSW, LICSW, is coordinator for the Cancer Resource Room: The Network for Patient and Families at Massachusetts General Hospital Cancer Center-Dana Farber/Partners Cancer Care in Boston; Irene Liu, MPH, CHES, formerly a health education specialist for the National Cancer Institute-Patient Education Branch, is a program analyst in the National Center for Complementary and Alternative Medicine at the National Institutes of Health in Bethesda, MD; Annette Mercurio, MPH, CHES, is the manager of health education services at City of Hope National Medical Center in Duarte, CA; Karen Stepan, MPH, CHES, is a health education coordinator at M.D. Anderson Cancer Center in Houston, TX; Louise Villejo, MPH, CHES, is the director of the patient education office at M.D. Anderson Cancer Center; and Carolyn Weaver, MSN, RN, CNS, AOCN®, is the patient education coordinator and a clinical nurse specialist at Fox Chase Cancer Center in Philadelphia. (Submitted June 2000. Accepted for publication January 10, 2001.)