

# Creating the Basis for a Breast Health Program for Female Survivors of Hodgkin Disease Using a Participatory Research Approach

Deborah B. Crom, PhD, RN, PNP, Pamela S. Hinds, PhD, RNC,  
Jami S. Gattuso, MSN, RN, CPON<sup>®</sup>, Vida Tyc, PhD, and Melissa M. Hudson, MD

**Purpose/Objectives:** To learn from female survivors of Hodgkin disease about their perceptions of their current health status and future health risks, self-care practices to prevent or diminish health risks, and what kind of breast health program could benefit them, including the most effective methods and optimal times for learning about breast health.

**Design:** Participatory research using focus groups.

**Setting:** Urban pediatric cancer center.

**Sample:** 1 African American and 19 Caucasian female survivors of Hodgkin disease aged 16–26 years, diagnosed at least two years before the start of the study, and treated with mantle radiation therapy. Participants were recruited during visits to an outpatient clinic.

**Methods:** Six open-ended questions were asked during three separate focus group sessions. Transcribed data were evaluated by content analysis techniques and analyzed to identify common themes.

**Main Research Variables:** Current health status and perceived health risks, current health practices, and effective methods and timing for breast health teaching.

**Findings:** Survivors reported feeling damaged by their cancer and its treatment and perceived that they were at risk for breast cancer. Self-care and risky behaviors also were reported. Internal influences (e.g., fear) and external influences (e.g., family) motivated survivors to participate in health promotion activities. Effective methods identified for learning about breast health included having access to other survivors, being respected as an adult, and having one-on-one staff teaching and peer support. The preferred timing of teaching varied, but survivors generally supported a gradual provision of information.

**Conclusions:** A positive listening environment is important for developing a breast health program for survivors. An essential first step is to create an opportunity for survivors to tell about their experiences with cancer, including its impact on their lives. Information regarding breast health must be provided in multiple formats during and after treatment if good practices are to be undertaken.

**Implications for Nursing:** The provision of adequate information during and after therapy as well as peer counseling in a positive listening environment are important in helping survivors participate in health promotion activities.

Five-year survival rates of pediatric patients with Hodgkin disease now are approaching 90% (Hudson & Donaldson, 1997; Ries et al., 2001). Therefore, increasing attention is being focused on long-term sequelae, including second cancers. Women who have survived Hodgkin disease and received thoracic irradiation during puberty have a risk of developing breast cancer that is estimated to be 35–75 times greater than age- and race-matched controls (Bhatia et al.,

## Key Points . . .

- ▶ Female survivors of Hodgkin disease who received thoracic irradiation as a part of their therapy have a risk of developing breast cancer that is estimated to be 35–75 times greater than age- and race-matched controls.
- ▶ Despite education regarding the risk, 86% of survivors do not participate in any behaviors to promote breast health.
- ▶ Oncology nurses can facilitate survivors' self-care behaviors by listening to patients and giving risk-related information, teaching breast self-examination in multiple formats at various times during and after the completion of therapy, and creating or promoting opportunities for peer-based counseling.

2003; Sankila et al., 1996; Wolden, Lamborn, Cleary, Tate, & Donaldson, 1998). Numerous studies have documented that breast cancer is the most frequent solid tumor in women previously treated for pediatric Hodgkin disease (Bhatia et al., 1996; Hudson et al., 1998; Sankila et al.; Wolden et al., 1998, 2000). Research findings indicate a need for risk education and heightened breast cancer surveillance in this group of cancer survivors.

Oncology nurses are in a unique position to educate female survivors of Hodgkin disease about the risk of secondary

*Deborah B. Crom, PhD, RN, PNP, is a nurse practitioner in the Department of Hematology/Oncology at St. Jude Children's Research Hospital in Memphis, TN, and an assistant professor in the College of Nursing at the University of Tennessee in Memphis. Pamela S. Hinds, PhD, RNC, is director of the Division of Nursing Research, Jami S. Gattuso, MSN, RN, CPON<sup>®</sup>, is a nursing research specialist in the Division of Nursing Research, Vida Tyc, PhD, is an associate member in the Division of Behavioral Medicine, and Melissa M. Hudson, MD, is a member in the Department of Hematology/Oncology, all at St. Jude Children's Research Hospital. The research for this article was funded by an ONS Foundation Research Grant supported by Ortho Biotech Products, L.P., a National Cancer Institute Cancer Center Support Grant (No. CA21765), and the American Lebanese Syrian Associated Charities. (Submitted October 2003. Accepted for publication February 17, 2005.)*

Digital Object Identifier: 10.1188/05.ONF.1131-1141