Evaluation of Nurses and Genetic Counselors as Providers of Education About Breast Cancer Susceptibility Testing

Barbara A. Bernhardt, MS, CGC, Gail Geller, ScD, Teresa Doksum, PhD, MPH, and Sharon A. Metz, RN, MPH

Purpose/Objectives: To compare outcomes of pretest education about breast cancer susceptibility testing provided by nurses and genetic counselors.

Design: Two-group, post-test only evaluation of an educational intervention.

Setting: A tertiary care hospital.

Sample: 87 women who had a first-degree relative with premenopausal breast cancer; six specially-trained providers (four genetic counselors and two nurses).

Methods: Self-administered questionnaire completed immediately following education sessions.

Main Research Variables: Subjects' understanding of the limitations of testing, perceived autonomy in decision making, and satisfaction; partnership as perceived by subjects and providers.

Findings: After the sessions, 62% of subjects understood the limitations of testing, 98% reported a high degree of perceived autonomy in decision making, 81% were highly satisfied with the session, and 91% reported forming a partnership with their providers. Lower perceived partnership reported by genetic counselors was the only significant difference by provider type.

Conclusions: With training and supervision, nurses and genetic counselors can be equally effective in providing education about genetic testing for breast cancer susceptibility in research settings. Additional research is needed to determine the outcomes of education provided in clinical settings.

Implications for Nursing Practice: As the demand for education about genetic testing for cancer susceptibility increases, nurses need to be educated and trained to provide this service.

Key Points . . .

- As genetic testing becomes more widespread, nurses will become more involved in counseling and risk-assessment activities.
- Informed consent regarding genetic testing must be provided in the context of a patient-provider partnership.
- With appropriate training, nurses can adequately provide education about breast cancer susceptibility testing.
- Relationships between patient autonomy and partnerships with and confidence in the provider deserve further study.

Significant progress has been made in understanding the genetic components of familial cancers. Genes associated with familial breast and ovarian cancers have been cloned, and molecular testing is available. A growing number of women are seeking information about genetic susceptibility testing for breast cancer risk (Baron & Borgen, 1997). The American Society of Clinical Oncology Subcommittee (1996) recommended that women be educated and counseled by providers who are knowledgeable about the risks, benefits, and limitations of testing before they undergo testing. The National Society of Genetic Counselors (McKinnon et al., 1997) and the Task Force on Informed Consent of the National Institutes of Health Genetics Studies Consortium (Geller, Botkin, et al., 1997) have outlined the components of the needed education. Although no good estimates exist of what the actual

Barbara A. Bernhardt, MS, CGC, is an associate professor of pediatrics and oncology, and Gail Geller, ScD, is an associate professor of pediatrics, both at Johns Hopkins School of Medicine in Baltimore, MD. Teresa Doksum, PhD, MPH, is a senior analyst at Abt Associates, Inc. in Cambridge, MA, Sharon A. Metz, RN, MPH, is coordinator of the Parkinson Center at St. Mary's Medical Center in West Palm Beach, FL. At the time this article was written, Doksum was a senior research assistant and Metz was a project coordinator in the Department of Pediatrics, both at Johns Hopkins School of Medicine. This work was supported by grant R01-RR04062 from the National Institute of Nursing Research, National Institutes of Health. (Submitted February 1999. Accepted for publication August 2, 1999.)