

Parental Decision Making Regarding the Disclosure or Nondisclosure of a Mutation-Positive *BRCA1/2* Test Result to Minors

Kendra-Ann I. Seenandan-Sookdeo, RN, BN, MN, Thomas F. Hack, PhD, Michelle Lobchuk, RN, PhD, Leigh Murphy, PhD, and Sandra Marles, MD, FRCPC, FCCMG

Seenandan-Sookdeo is an adjunct nursing faculty member in the Faculty of Nursing at Minneapolis Community and Technical College in Minnesota; Hack is a professor in the College of Nursing, Lobchuk is an associate professor and Manitoba Research Chair in Caregiver Communication in the College of Nursing and Faculty of Health Sciences, and Murphy is a professor in the Department of Biochemistry and Medical Genetics, all at the University of Manitoba in Winnipeg, Canada; and Marles is a clinical geneticist at the Health Sciences Centre in Winnipeg, Manitoba, Canada.

This research was funded by Hack's Canadian Breast Cancer Foundation (Prairies/NWT) Chair in Psychosocial and Supportive Care Oncology Research, the Foundation for Registered Nurses of Manitoba, Inc., Graduate Award, the Marion Saydak Memorial Scholarship, and Lesley F. Degner's Chair in Evidence-Based Nursing Practice Graduate Studies Tuition Award from the Canadian Institute of Health Research, all awarded to Seenandan-Sookdeo.

Seenandan-Sookdeo contributed to the conceptualization and design, data collection, and analysis. Seenandan-Sookdeo, Hack, Lobchuk, Murphy, and Marles contributed to the manuscript preparation.

Seenandan-Sookdeo can be reached at kendraanniss@gmail.com, with copy to editor at ONFEditor@ons.org.

Submitted January 2015. Accepted for publication July 11, 2015.

Key words: *BRCA1/2*; hereditary; breast; ovarian; minors; cancer; oncology

ONF, 43(3), 330–341.

doi: 10.1188/16.ONF.330-341

Purpose/Objectives: To gain insight into parental decision making regarding the disclosure or nondisclosure of a mutation-positive *BRCA1/2* test result to minors.

Research Approach: A qualitative study based on Heidegger hermeneutic phenomenology was undertaken to explore the lived experience of parental decision making regarding high-risk *BRCA1/2* disclosure.

Setting: The study's recruitment site was a western Canadian hereditary breast and ovarian cancer clinic.

Participants: Fifteen female mutation-positive *BRCA1/2* carriers who had at least one child aged 6–18 years.

Methodologic Approach: The use of a demographic questionnaire, semistructured interviews, and conversation summaries were employed to gain an understanding of participants' lived experience. van Manen's selective approach was used to conduct a thematic analysis.

Findings: Collectively, parents wanted clinicians to discuss implications of disclosing and not disclosing a mutation-positive *BRCA1/2* test result to minors in greater detail. The findings were categorized under the following emergent themes: influential factors, parental decision making, supportive resources, the inner circle, knowledge deficit, and parental recommendations.

Conclusions: Participants' stories identified the need for auxiliary support pertaining to the decision-making process and suggested ways in which parental support may be coordinated.

Interpretation: Oncology nurses with advanced genetics training should assist mutation-positive *BRCA1/2* carriers in meeting their genetic risk information needs; this requires nurses to stay informed about a multitude of issues that affect this population of patients.

About 23,800 cases of breast cancer and 2,600 cases of ovarian cancer are diagnosed each year in Canada (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013). Roughly 5%–10% of these two groups combined are at high risk for hereditary breast, ovarian, and other cancers; consequently, genetic services are offered to high-risk individuals (Patenaude et al., 2013; Seenandan-Sookdeo & Sawatzky, 2010). The proband (family member who initiates genetic testing) is then responsible for sharing the test result with family members. This action has the potential to affect individuals physically, psychologically, and socially (Bradbury et al., 2007, 2012).

A review of the *BRCA1/2* peer review literature was conducted using the CINAHL® and PubMed databases from 2005–2015. The key word searches included *hereditary breast and ovarian, BRCA1/2 parental decision making, and disclosure*