

Self-Surveillance for Genetic Predisposition to Cancer: Behaviors and Emotions

Ellen Giarelli, EdD, RN, CRNP

Purpose/Objectives: To describe the kinds of self-monitoring activities and the emotional responses associated with those activities in patients with a genetic predisposition to multiple endocrine neoplasia type 2a (MEN2a) or familial adenomatous polyposis (FAP).

Research Approach: Thematic analysis of the transcripts of patient interviews conducted for two previous grounded theory investigations of participation in lifelong surveillance for patients with cancer predisposition syndromes and their family members.

Setting: In the original studies, participants were recruited through a high-risk gastrointestinal cancer clinic (for FAP) and pediatric and adult endocrinology clinics (for MEN2a) at two eastern U.S. medical centers and by patient referral.

Participants: 58 transcripts of interviews with 29 patients; 17 diagnosed with FAP or the variants of Gardner syndrome and attenuated FAP and 12 patients diagnosed with MEN2a.

Methodologic Approach: Informants participated in two hour-long, in-depth interviews and completed a self-administered sociodemographic questionnaire.

Main Research Variables: Types of self-surveillance activities.

Findings: Patients engage in an elaborate set of self-surveillance activities that are grouped into five categories of behavior: Medication Appraisal, Phenotype Tracking, Intake and Output Monitoring, Laboratory and Treatment Recording, and Tracking of Visits. Self-surveillance behaviors are grouped independent of type of syndrome, penetrance, age, or gender of the patient. Each category comprises a variety of behaviors that correspond with treatment recommendations and understanding of the disorder.

Conclusions: Self-surveillance may be driven by a combination of anticipation and the need for control and understanding.

Interpretation: Findings from the study could be used to create an assessment tool to evaluate the extent to which patients are involved in day-to-day self-monitoring. Clinicians may use the categories to better understand patients' knowledge deficits and the emotional impact of enhanced vigilance. Self-surveillance activities performed by patients with MEN2a and FAP also may be performed by patients with other cancer predisposition syndromes.

Key Points . . .

- ▶ How patients think about the implications of their genetic predisposition and the meaning of lifelong surveillance for cancer affects their ability to accept and practice behaviors that promote health.
- ▶ The majority of patients interviewed reported adhering to formal surveillance guidelines for annual medical follow-up visits.
- ▶ All patients develop an elaborate set of self-surveillance behaviors.
- ▶ Clinicians must evaluate the extent and appropriateness of patients' behaviors and emotions relative to lifelong self-management.

disease prevention. Patients who engage in self-surveillance interpret what they observe and decide to either self-treat, seek help, or avoid professional intervention. The observations and interpretations patients make of their physical signs and feelings are the sources of essential data that often are sought and used by clinicians to make medical judgments.

How patients think about the implications of their genetic predisposition and the meaning of lifelong surveillance for genetic risk of cancer affects their ability to accept and practice behaviors that promote health. Surveillance guidelines, however, do not elaborate on how, or the extent to which, patients should engage in self-surveillance activities. Although nurses, justifiably, presume that self-surveillance may contribute to good health care, significant gaps remain in the knowledge of patients' experiences. The purpose of this article is to describe the kinds of self-monitoring activities performed by patients with one of two types of cancer predisposition syndromes and the emotions associated with engaging in the self-surveillance activities. The

Ellen Giarelli, EdD, RN, CRNP, is a research assistant professor in the School of Nursing at the University of Pennsylvania in Philadelphia. This research was funded by a 2003 ONS Foundation small research grant supported by Ortho Biotech Products, LP. (Submitted February 2005. Accepted for publication May 30, 2005.)

Digital Object Identifier: 10.1188/06.ONF.221-231

The importance of surveillance to controlling cancer is explicit. Guidelines for lifelong cancer risk management and prevention invariably comprise periodic medical evaluation and patient instruction about the value of adherence to follow-up guidelines. Another element of lifelong management is patient self-monitoring or self-surveillance. Although self-surveillance occurs out of the purview of clinicians, it plays a significant role in lifelong health promotion and