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Bringing Threat to the Fore: Participating in Lifelong Surveillance for Genetic Risk of Cancer

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Purpose/Objectives: To explain how patients with multiple endocrine neoplasia type 2a (MEN2a) and family members conceptualize participation in lifelong surveillance in genetic cancer care.

Design: Qualitative naturalistic inquiry.

Setting: Northeastern United States. Data were collected during interviews in informants' homes.

Sample: 12 adult patients and 9 family members were recruited purposively through endocrinology clinics at two East Coast medical centers.

Methods: A grounded theory design was used. Subjects completed a demographic questionnaire and were interviewed on two occasions. In-depth interviews were audiotaped. The core concept and process variables emerged through three levels of narrative content analysis, theoretical sampling, and constant comparison. The generated theory was presented to the participants for validation.

Main Research Variables: The basic psychological issue associated with participation in lifelong surveillance and the psychosocial processes used by individuals to deal with the issues.

Findings: MEN2a patients and family members experience surveillance as a (Re)Minding of a threat to health. Once threat is brought to the fore, participants interpret the meaning and negotiate control of the impact of the diagnosis, related events, and consequences. Meaningful information from surveillance activities is incorporated into participants' self-image and daily lives through a process of (Re)Integration. The genetic nature of MEN2a did not emerge as a significant subcategory in relation to the core variable.

Conclusions: Finding meaning in the outcomes of surveillance events is a psychosocial process that is central to participation in lifelong surveillance. Genetic predisposition to cancer was a peripheral concern to subjects as they dealt with surveillance issues.

Implications for Nursing: This investigation provides a model for the development of a grounded theory for understanding how people with other genetic cancer syndromes participate in lifelong surveillance.

Key Points . . .

- Two types of lifelong surveillance activities exist: planned surveillance events and incidental surveillance events.
- Patients and family members conceptualize surveillance as a personal and family phenomena rather than the responsibility of healthcare professionals.
- Self-monitoring and observation of affected loved ones by family members dominate the surveillance phenomena.
- Incidental surveillance events may replace planned events as indicators of health and wellness.

Surveillance is a risk management strategy used in health care for the early detection of disease and for complications associated with medical treatment. Once a diagnosis or risk of disease is known, healthcare professionals advise patients to participate in lifelong surveillance activities to monitor for the expression of disease and the physical and psychological consequences of treatment. In the context of genetic cancer care, monitoring an individual who is predisposed to cancer is referred to as "enhanced surveillance." These activities occur more frequently than in the general population and continue over a lifetime. In social context, surveillance occurs within the relationship constructed between the observer and the one who is observed. The social relationship may be impersonal or intimate, yet within this relationship, the observer and the one observed watch and wait for a threatening event (Giarelli, 2002).

How patients think about participating in lifelong surveillance will affect their ability to accept, adhere to, and adopt behaviors that promote health. This article describes how people in families with the genetic cancer syndrome multiple endocrine neoplasia type 2a (MEN2a) conceptualized their participation in lifelong surveillance.

Background

MEN2a is a rare genetic cancer syndrome that leads to abnormal cell growth in endocrine glands. Medical geneticists consider MEN2a a prototype for their clinical practice because patients have access to a reliable and accurate genetic

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