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

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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 “enlarged 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...