

Notification of a family history of breast cancer: issues of privacy and confidentiality.

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摘要

Abstract

Little information is available about notifying individuals with a family history of cancer about their risk of cancer. With the recent identification of BRCA1, an important predisposition gene for breast and ovarian cancer, genetic testing is becoming available to high-risk women and their families. Some of these individuals, may not be aware of their family history and may be notified of their family history by medical personnel or biomedical investigators. This disclosure could be detrimental to the individual by changing their perception of risk, sense of privacy, or psychosocial well-being. Members of 544 breast cancer families are currently being contacted as part of an epidemiologic follow-up study at the University of Minnesota. Some family members were unaware of their relative's diagnosis and therefore, notification occurred when they were contacted by study personnel. To determine the impact of risk notification in this context, 376 male and female relatives of 160 breast cancer probands were surveyed to assess their prior knowledge of their family history of cancer, issues relating to study participation, and their concerns regarding the possibility of developing cancer. Following a telephone interview about family history, family members were administered a short, open-ended questionnaire. The majority of individuals (82%) were blood relatives of the proband and 71% were either first- or second-degree relatives. A proportion of blood relatives (24%) were not aware of their family history of breast cancer. More blood relatives (76%) than nonblood relatives (62%, $P < 0.01$) were aware of their family history. 43 respondents (12%) expressed specific concerns about participating in the large genetic follow-up study and 16 comments concerned privacy issues. Neither the reasons for participation nor an individual's concern about developing cancer was associated with gender of the respondent, relationship to the proband, or awareness of breast cancer in the family. Interestingly, individuals who were notified about their family history through the large follow-up study were no more likely than other family members to be more concerned about developing cancer. Understanding the privacy and psychosocial issues of family members who are informed about a family history of breast cancer

may aid in developing appropriate guidelines for notification. Risk notification in this setting does not appear to have a significant impact on these family members