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Original article

Does perceived risk predict breast cancer screening use? Findings from a prospective cohort study of female relatives from the Ontario site of the Breast Cancer Family Registry

Meghan J. Walker [a,b,*], Lucia Mirea [c,d], Gord Glendon [e], Paul Ritvo [a,f], Irene L. Andrulis [e,g], Julia A. Knight [b,e], Anna M. Chiarelli [a,b]

[a] Prevention and Cancer Control, Cancer Care Ontario, Toronto, Ontario, Canada
[b] Division of Epidemiology, Dalla Lana School of Public Health, Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada
[c] Division of Biostatistics, Dalla Lana School of Public Health, Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada
[d] Maternal-Infant Care Research Centre, Mount Sinai Hospital, Toronto, Ontario, Canada
[e] Samuel Lunenfeld Research Institute, Mount Sinai Hospital, Toronto, Ontario, Canada
[f] Faculty of Health, School of Kinesiology and Health Science, York University, Canada
[g] Department of Molecular Genetics, University of Toronto, Toronto, Ontario, Canada

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ABSTRACT

While the relationship between perceived risk and breast cancer screening use has been studied extensively, most studies are cross-sectional. We prospectively examined this relationship among 913 women, aged 25–72 with varying levels of familial breast cancer risk from the Ontario site of the Breast Cancer Family Registry. Associations between perceived lifetime breast cancer risk and subsequent use of mammography, clinical breast examination (CBE) and genetic testing were assessed using logistic regression. Overall, perceived risk did not predict subsequent use of mammography, CBE or genetic testing. Among women at moderate/high familial risk, those reporting a perceived risk greater than 50% were significantly less likely to have a CBE (odds ratio (OR) = 0.52, 95% confidence interval (CI): 0.30–0.91, $p = 0.04$), and non-significantly less likely to have a mammogram (OR = 0.70, 95% CI: 0.40–1.20, $p = 0.70$) or genetic test (OR = 0.61, 95% CI: 0.34–1.10, $p = 0.09$) compared to women reporting a perceived risk of 50%. In contrast, among women at low familial risk, those reporting a perceived risk greater than 50% were non-significantly more likely to have a mammogram (OR = 1.13, 95% CI: 0.59–2.16, $p = 0.78$), CBE (OR = 1.11, 95% CI: 0.63–1.95, $p = 0.74$) or genetic test (OR = 1.29, 95% CI: 0.50–3.33, $p = 0.35$) compared to women reporting a perceived risk of 50%. Perceived risk did not significantly predict screening use overall, however this relationship may be moderated by level of familial risk. Results may inform risk education and management strategies for women with varying levels of familial breast cancer risk.

Introduction

Family history is one of the most important risk factors for the development of breast cancer. Women with one affected first-degree relative are about twice as likely to develop breast cancer compared with women who have no affected relatives, and risks are higher when more than one first-degree relative is affected or the relative is younger at diagnosis [1–3].

A reduction in breast cancer mortality attributable to mammography screening among women aged 50–74 has been demonstrated [4]. In Ontario, mammography is freely available to average-risk women aged 50–74 every 2–3 years through the Ontario Breast Screening Program (OBSP), or with physician referral through imaging facilities outside of the OBSP [5]. The impact of mammography on reducing mortality in women with a family history of breast cancer is unknown; however, some studies have shown that screen-detected tumors in women with a family history are smaller [6,7], less likely to demonstrate nodal or distant

* Corresponding author. Prevention and Cancer Control, Cancer Care Ontario, 620 University Avenue, Toronto, Ontario M5G 2L7, Canada. Tel.: +1 416 971 9800; fax: +1 416 971 6888.
E-mail address: meghan.walker@cancercare.on.ca (M.J. Walker).

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metastases [6,8,9], and diagnosed at an earlier stage [7,9] compared to symptomatic cancers. Breast screening guidelines for women with a family history of breast cancer are based on expert opinion, and typically include screening mammography, clinical breast examination (CBE) and/or MRI on an annual basis starting at age 40 or 10 years prior to the earliest age of diagnosis in the family, or as young as age 25 for BRCA mutation carriers [10–16]. Certain women with a strong family history of breast or ovarian cancer are also eligible for referral to a specialist genetic clinic where genetic testing may be performed [17]. In 2011, the OBSP was expanded to include annual combined MRI and mammography for women aged 30–69 considered to be at very high risk of breast cancer (i.e. BRCA1/2 mutation carriers or family history suggestive of hereditary breast cancer) [18].

While there is a positive association between family history of breast cancer and mammogram use [19], rates of adherence to screening guidelines in women with familial risk remain suboptimal. One Australian population-based study of women with familial risk demonstrated high adherence (74%) to mammography guidelines, but lower adherence (55%) to CBE guidelines [20]. Several North American population-based studies have demonstrated lower rates of adherence; in one study, 40% of women with familial risk screened with mammography in the previous 11 months [21], while another study reported 36% of women at low familial risk and 55% at moderate/high risk screened with mammography in the previous year [22]. An inverted U-shaped relationship has also been suggested [23], wherein women at the extreme ends of risk may screen less, in a relationship mediated by worry [24,25].

The relationship between perceived risk of breast cancer and breast cancer screening behaviors has been widely studied. The construct of perceived risk is central to health behavior theories, including the Health Belief Model (HBM) [26], and Protection Motivation Theory [27]. Briefly, it is suggested that a realistic perception of risk motivates individuals to engage in health behaviors appropriate to the level of risk [28,29]. Two meta-analyses found a small, significant association between perceived risk and mammogram use in women with population-level breast cancer risk [19,30]. This was confirmed for women with familial risk in our recent review [31].

We previously conducted a cross-sectional study examining the relationship between perceived risk and breast cancer screening behaviors in this study population, finding a significant positive relationship between higher levels of perceived risk and annual use of screening mammography [32]. Few prospective studies among women with familial risk have been conducted [20,33–35], and are necessary to confirm previous cross-sectional findings. The few prospective studies may not generalize to the broader population of women with familial risk. As in many previous studies, Diefenbach et al. [35] recruited women with strong family histories from a clinical setting, and Lemon et al. [34] examined screening in the year following relative's breast cancer diagnosis when screening behaviors may be modified. The objective of the present study was to prospectively assess the influence of perceived risk of breast cancer on subsequent breast cancer screening practices and genetic test use in women with varying levels of familial breast cancer risk.

Materials and methods

Study population

This study utilized data from a cohort of female relatives of incident cases of invasive breast cancer identified from the Ontario site of the Breast Cancer Family Registry (BCFR), funded by the United States National Cancer Institute. Details of the BCFR and the Ontario site of the BCFR have been previously described [36,37]. Briefly, cases of pathologically-confirmed invasive breast cancer (probands), diagnosed between 1996 and 1998 were identified from the Ontario Cancer Registry. Physicians were contacted to obtain permission to mail their patients a cancer *Family History Questionnaire (FHQ)*. Respondents meeting a defined set of high-risk criteria [37] and a random sample (25%) of those not meeting these criteria were asked to participate in the Ontario site of the BCFR. Of the 2587 eligible probands, 1851 (71.5%) participated. Probands were then asked for permission to contact specific living relatives (all first-degree relatives, any other relatives affected with breast, ovarian or certain other cancers and their first-degree relatives). An invitation letter to participate in the Ontario site of the BCFR was sent to all relatives ($n = 8416$), and the 5122 who agreed to be contacted were mailed an *Epidemiology Questionnaire (EQ)* between 1998 and 2004.

This prospective cohort study was conducted several years after the initial recruitment of relatives to the Ontario site of the BCFR. All female relatives enrolled in the Ontario site who completed an *EQ*, were 20–69 years of age and unaffected by breast cancer at the time of the proband's diagnosis were eligible to participate. From the 3374 participating female relatives, 1514 met these study criteria. A baseline *Personal History and Screening Questionnaire (PHSQ)* was sent between November 2005 and March 2007 to the 1514 eligible women, of which 1308 (86.4%) could be contacted and 1114 (85.2%) were interviewed. A follow-up questionnaire was sent to 1077 eligible women approximately one year following the baseline *PHSQ*, of which 1062 could be contacted and 975 (91.8%) were interviewed. We further excluded 6 women diagnosed with breast cancer, 26 women without a first-degree family history of breast/ovarian cancer, 5 women who had undergone bilateral mastectomy, 10 women who were pregnant or breastfeeding, and 15 women missing data on their perceived breast cancer risk. The final cohort consisted of 913 women. This study was approved by the Mount Sinai Hospital, the University Health Network and the University of Toronto Research Ethics Boards, and written informed consent was obtained from all women.

Data collection

Information was obtained from three questionnaires. The first (*EQ*) was self-administered during recruitment of female relatives to the Ontario site of the BCFR and collected detailed information on demographics and key behavioral risk factors for breast/ovarian cancer. As several years had elapsed since recruitment to the registry, subsequent questionnaires (baseline and year 1 *PHSQ*) with similar content were telephone-administered to update changes in demographic and health behavior characteristics, and collect detailed information on cancer screening. Eligible participants were sent a copy of the *PHSQ* approximately two weeks prior to contact by telephone. This allowed time for participants to recall specific dates and events, and allowed reference to the questionnaire during the interview. Further details of the questionnaire instruments have been previously described [22,32,36].

Data measures

Perceived risk was assessed in the baseline *PHSQ* with two questions adapted from Lipkus et al. [38]. The first asked, "On a scale from 0 to 100%, where 0 = certain not to happen and 100 = certain to happen, how likely are you to get breast cancer in your lifetime?" The second asked, "Compared with other women your age, how likely are you to get breast cancer in your lifetime?" Responses ranged from "much below average" to "much above average." The outcomes of interest were use of screening

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