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Adherence

An exploratory study of patients' views about being at high-risk for breast cancer and risk management beliefs and intentions, before and after risk counselling: Preliminary evidence of the influence of beliefs on post-counselling prevention intentions

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ABSTRACT

Objectives: 1) To describe how women at high-risk for breast cancer (BC) perceive their at-risk status and the options available to manage this risk, before and after risk counselling; 2) to explore the contributions of pre-counselling demographic, clinical, cognitive and emotional factors to post-counselling risk management intentions.

Methods: 58 of 173 eligible patients (34%) enrolled and were asked to fill surveys including measures of 1) subjective risk, 2) illness (being at high-risk for BC) and 3) treatment (surveillance, lifestyle modifications, and chemoprevention) cognitions, 4) BC fear and 5) future risk management intentions, prior to and 3 months after risk consultation.

Results: 48 of 58 participants (83%) completed both surveys. Beliefs and emotions about their condition and its management were stable over time. Surveillance and lifestyle were associated with stronger intentions, higher perceived need, and lower concerns than chemoprevention (all $ps < 0.001$). The strongest predictors of intentions strengths were the women's beliefs about the risk reduction methods, especially for lifestyle and chemoprevention (all $ps < 0.01$).

Conclusions: The findings emphasize the importance of patients' beliefs in risk management decisions. **Practical implications:** Patients' treatment beliefs appear to influence their choice of BC risk reduction strategies and should be discussed during risk reduction consultations.

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1. Introduction

Breast cancer (BC), the most feared cancer among women [1], continues to be a major health problem worldwide [2]. However, it is widely recognized that women can undertake measures to lower their risk of BC [3–6] and that early detection improves outcomes [7,8]. Risk reduction and early detection are particularly important for women at high-risk for the disease. Many studies have highlighted the complex decisions facing very high-risk BRCA1/2 gene mutations carriers [9–13]. However, mutation carriers are rare in the population and only 1–10% of BC cases are hereditary [14,15]. Nonetheless, 15% of North American women between 35 and 79 years old are at *high risk* [9,16–20] for other reasons, such as age, reproductive history, alcohol consumption, prior radiation

therapy for Hodgkin's disease before age 30, prior lobular carcinoma in situ or atypical hyperplasia without family history of BC, or history of BC in only one or two first degree relatives occurring over the age of 40. This group of women was the focus of the present investigation.

Clinical guidelines [21–25] recommend that *high-risk* women receive counselling about risk reduction methods including lifestyle modifications (regular physical activity, healthy weight, and moderate alcohol consumption), chemoprevention, and surveillance. Despite evidence supporting these recommendations, adherence levels are low [26–40] and it is important to understand why this is the case. Theories of health behavior [41–45] contend that intentions to adopt a preventative behavior are a prerequisite for performing the behavior in the future. Consequently, to improve prevention outcomes in the BC *high-risk* setting, it may be appropriate to determine whether patients intended to adopt the risk reduction methods that they were asked to consider during risk counselling and to understand the factors

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that are associated with these intentions. Health psychology theories provide a framework for investigating these issues. Two complementary self-regulatory models, the Leventhal's Common-Sense Model [46] and Horne's Necessity/Concerns framework [47] emphasize the contribution of beliefs about health status (illness perception) and treatment (treatment cognition) to health behavior. Illness perceptions are conceived as being multidimensional and include: 1) Identity: symptoms associated with the condition, 2) Time line: beliefs about the duration of the condition, 3) Consequences: beliefs about the effects of the condition, 4) Control/cure: beliefs about the controllability of the condition and recovery from it, 5) Cause: perceived cause of the condition and 6) Emotional impact of the condition. Stronger beliefs that a condition is uncontrollable or that it has no serious consequences have been found to hinder self-management behaviors [48–52]. In addition, patient's beliefs about the interventions recommended to them (treatment cognitions) also impact upon health behaviors. Horne [47] suggested that treatment cognitions comprise two dimensions: Treatment necessity (beliefs that a condition warrants treatment) and treatment concerns (beliefs about the risk of the treatment offered). Across several illnesses [53], it is clear that when patients have doubts about the necessity of a treatment and when they are concerned about its adverse effects, then the likelihood that they will adopt and maintain the treatment is low. In addition, several authors have proposed that the emotional representation of the condition also influence how patients will choose to act in order to manage the condition [44]. Consequently, in the *high risk* setting, it may be important to understand whether patients' precounselling views about illness (being at *high-risk*) and treatment (how to lower this risk) exert an influence on the intentions that *high-risk* women will form *after* receiving risk counselling. There is a dearth of prospective studies which have examined *high-risk* women's pre-counselling cognitions and their influence on future BC risk reduction intentions.

To address this gap, the present pilot study was undertaken to describe how *high-risk* women perceive their at-risk status and the options available to manage this risk and to examine whether these beliefs change after risk counselling. Furthermore, the unique contributions of pre-counselling demographic, clinical, cognitive and emotional factors to post-counselling risk reducing intentions were investigated separately for each of the three risk reduction methods typically recommended to high-risk women (surveillance, lifestyle modifications, and chemoprevention).

2. Method

2.1. Participants

Unaffected *high-risk* women referred to the High-Risk Breast Assessment clinic of The Ottawa Hospital by their primary care provider were eligible for the study. Known mutation carriers were excluded. Objective risk was assessed using the Gail model¹ [20] and Gail score over 1.66% were considered high-risk [21]. Between November 2009–March 2013, 209 women were referred and 173 high-risk women were sent a recruitment letter. Response rate was low (34%) and 58 patients enrolled.

2.2. Procedure

Participants were exposed to the routine clinical care at the clinic which was as follows. An advance practice nurse reviewed

the information provided by referring physicians and telephoned women asking them to fill a preliminary questionnaire² concerning their medical, reproductive, and family history of cancer. A multidisciplinary team used this information for calculating Gail score and for recommending risk reducing options to be conveyed to patients during a subsequent individual nurse-led risk counselling session which also included general discussions of risk factors, meaning of high-risk, risk assessment methods and risk management. For the present study, this routine care was minimally altered to recruit women by mail before their counselling session. Interested participants were asked to phone the clinic and were sent a consent form and the baseline (T1) questionnaires to be returned by mail within 2 weeks. A second mailing took place 3 months after the counselling session (T2). The authors were not involved in the counselling sessions and the nurse was blinded to patient's enrolment status. The study was approved by the Institutional Ethics Board at our institutions.

2.3. Measures

2.3.1. Demographic and clinical variables

Age, education, marital status, ethnicity, 5 years Gail score and BMI were either self-reported or obtained from medical records.

2.3.2. Subjective risk

Women rated their likelihood of developing BC from 0 (definitely will not get it) to 100 (definitely will get it). An "I cannot tell" option indicated uncertainty (i.e., "I really don't know") [54].

2.3.3. Illness cognitions

The revised Illness perception questionnaire (IPQ-R) anchored in being at risk of developing BC [55] was administered. IPQ-R has demonstrated validity and reliability across a range of illness groups [56] and, in this study, Cronbach's alphas were adequate, ranging from 0.64 to 0.93. Illness identity was evaluated by presenting 14 symptoms to participants who indicated whether they had experienced this symptom and whether it related to being at high-risk for BC. The remaining items were rated on a 1 (strongly disagree) to 5 (strongly agree) scale and total scores for each dimension were calculated. The dimensions consisted of (1) consequences ("My risk of developing BC has major consequences on my life"); six items; Cronbach's $\alpha=0.84$ (T1) and 0.74 (T2); (2) treatment control ("There is very little that can be done to improve my risk"; five items; $\alpha=0.75$ (T1) and 0.80 (T2); (3) timeline-cyclical with unpredictable course ("My symptoms come and go in cycles"; four items; $\alpha=0.64$ (T1) and 0.70 (T2); (4) timeline-acute ("My risk will last for a long time"; six items; $\alpha=0.84$ (T1) and 0.76 (T2); (5) personal control ("There is a lot which I can do to control my risk"; six items; $\alpha=0.86$ (T1) and 0.92 (T2), (6) illness coherence ("My risk doesn't make any sense to me"; five items; $\alpha=0.78$ (T1) and 0.74 (T2); and (7) emotional representation ("I get depressed when I think about my risk"; six items; $\alpha=0.93$ (T1) and 0.89 (T2). Higher scores indicate stronger beliefs.

2.3.4. Treatment cognitions

The Beliefs about Medication Questionnaire (BMQ) [57] was adapted. The necessity subscale was composed of five items such

¹ Gail score takes into account a women's age, age at menarche, age at first live birth, number of previous breast biopsies, prior lobular carcinoma in situ or atypical hyperplasia and history of breast cancer among her first-degree relatives.

² It should be noted that data from the preliminary questionnaire that was routinely administered to women after their referral to the clinic was used exclusively for routine clinical purposes and, after study enrollment, were not accessible for this research purposes. Consequently, it is not possible to determine whether and how women who enrolled differ from those who did not reply to the recruitment letter.

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