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Original article

Women's preferences for contralateral prophylactic mastectomy following unilateral breast cancer: What risk-reduction makes it worthwhile?

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ABSTRACT

Objectives: Contralateral prophylactic mastectomy (CPM) reduces the risk of contralateral breast cancer (BC) following unilateral BC, but may not increase survival in BRCA1/2 mutation negative women. Despite this, and the risk for adverse physical and psychological impact, uptake is increasing in BRCA1/2 mutation negative women. We aimed to quantify the degree of reduction in lifetime contralateral BC risk women required to justify CPM, and to explore demographic, disease and psychosocial predictors of preferences using Protection Motivation Theory (PMT) as a theoretical framework. Reasoning behind preferences was also examined.

Materials and methods: 388 women previously diagnosed with unilateral BC, of negative or unknown BRCA1/2 status, were recruited from an advocacy group research database. Two hypothetical risk trade-off scenarios were used to quantify the reduction in lifetime contralateral BC risk that women judged necessary to justify CPM, using a 5% and 20% baseline. Demographic, disease and PMT measures were assessed using a questionnaire.

Results: Most women required their risk to be more than halved from a 5% or 20% baseline to justify CPM. Polarised preferences were also common, with some women consistently accepting or refusing CPM independent of risk/benefit trade-offs. Preferences were associated with coping self-efficacy and having a prior CPM. Explanations for judging CPM worthwhile included reducing or eliminating contralateral BC risk, attaining breast symmetry and reducing worry.

Conclusion: Risk-reduction preferences were highly variable. Decisive factors in women's preferences for CPM related to clinical, psychological and cosmetic outcomes, but not to demographic or disease characteristics.

1. Introduction

Women diagnosed with unilateral breast cancer (BC) are increasingly undergoing contralateral prophylactic mastectomy (CPM) worldwide [1,2]. Amongst 1.1 million American BC patients,

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CPM rates rose from 2.0% to 12.3% from 1998 to 2011 [3]. CPM reduces risk of contralateral breast cancer (CBC) [4] and may increase life expectancy for BRCA1/2 carriers, who have a 3–4% annual risk of CBC [5,6].

For women without BRCA1/2 mutations, however, CBC risk is often much lower, estimated in contemporary reports at 0.19–0.5% per annum on average [7,8], and CPM is unlikely to improve life expectancy, thus uptake is controversial. Close surveillance often facilitates early detection and curative treatment of any occurring CBC's [9]. Furthermore, CPM cannot prevent metastatic disease from the first BC, which often poses a substantially higher risk than CBC and principally determines overall survival [10]. CPM carries a risk of postoperative complications [11], and can negatively impact on body image, perceived femininity and sexual intimacy [12], leading to post-surgical regret [13].

Despite this, women without BRCA1/2 mutations are increasingly undergoing CPM. A study of 2695 BC patients reported 24.2% CPM uptake, yet only 13% had documented BRCA1/2 mutations [14], leading to concerns about potential overtreatment without objective medical necessity [15].

Research has explored clinical, demographic and psychological predictors of CPM uptake, including overestimated perceptions of CBC risk and CPM's survival benefit [16], avoidance of future breast surveillance [2,16], and desire for breast symmetry after unilateral mastectomy [17]. Social-cognitive and emotional factors identified as influential in CPM decision-making include women's expectations of positive or negative CPM outcomes, avoiding uncertainty and regret, reducing recurrence-related anxiety, and social norms [17–19]. Demographically, women who are younger, with higher education, Caucasian ethnicity, a family history of BC, and intentions for breast reconstruction, are more likely to undergo CPM [20,21]. However, research has typically focused on high-risk mutation carriers, or failed to identify mutation status [22]. Thus, findings may not generalise to lower-risk women. Reviews highlight the need for more evidence about factors prompting CPM uptake in BRCA1/2 negative women [22,23].

Risk-trade off scenarios provide insight into how patients weigh treatment benefits against treatment harms or inconveniences [24]. Understanding the minimum benefit needed to justify CPM is important to guide ethical, preference-sensitive discussion of CPM. Studies of early BC patients find that many women accept adjuvant endocrine and chemotherapy for 0.1–2% absolute gains in survival [25,26]. Yet no published study has quantified the amount of risk-reduction women require to justify CPM.

Protection Motivation Theory [27] is a theoretical framework that aims to explain patient preferences, emphasising: perceived: *severity* and *vulnerability* to a disease threat, *efficacy* of a health-protective behaviour in reducing threat, *self-efficacy* to undertake the behaviour, and *response costs* or negative behavioural consequences [27]. PMT has shown utility in explaining intentions for numerous cancer preventative behaviours including adjuvant therapy uptake [28], breast self-examination [29], gene mutation screening [30], and CPM [18].

Accordingly, we aimed to determine the minimum degree of CBC risk-reduction that women of negative or unknown BRCA1/2 status required to justify CPM. We also aimed to identify demographic, clinical and psychosocial predictors of women's risk-reduction preferences using PMT as a theoretical framework. Participants reporting greater severity, vulnerability, self-efficacy, response efficacy, and lower response cost scores, were expected to require less risk-reduction.

2. Method

2.1. Participants

Participants were members of Breast Cancer Network Australia's (BCNA) Review and Survey Group database. BCNA is Australia's largest BC advocacy organisation, comprising over 110,000 members. Participants were aged 18–70, and had completed primary treatment (i.e., surgery, chemotherapy, radiotherapy) for a unilateral BC diagnosis 0–10 years prior. Participants could be continuing endocrine therapy. Exclusion criteria included: (i) a diagnosis of metastatic or second primary BC, (ii) known BRCA1/2 positive status, and/or (iii) inadequate English language skills to complete the questionnaire.

2.2. Procedure

BCNA database members were sent an introductory email including eligibility criteria, a participant information sheet and survey web-link. Individuals could anonymously complete the questionnaire after providing online consent or seek clarification from the research team. Reminder emails were sent twice, two weeks apart. Participants completed demographic and disease items, then read a fact sheet and hypothetical scenario. The fact sheet was based on National Cancer Institute online materials [31], designed in liaison with two medical oncologists, and outlined risks and benefits of different CBC risk-management options (CPM, chemoprevention, hormone therapy, surveillance), to ensure all participants responded with similar knowledge. The hypothetical scenario described a pre-menopausal 48-year-old woman (Mary) diagnosed with early-stage unilateral BC, deliberating her CBC-risk management options after a unilateral mastectomy and chemotherapy. This hypothetical scenario aimed to minimise distress by distancing women from personal treatment decisions. Participants were asked to complete PMT and risk trade-off measures considering Mary's scenario, alongside their own values.

2.3. Measures

2.3.1. Demographic and disease variables

Demographic variables assessed included: age, ethnicity, language/s spoken, Aboriginal or Torres Strait Islander background, current children, plans for future children, dependents, marital status, education and residential location. Disease variables included age at unilateral BC diagnosis, primary unilateral BC treatment, lymph node surgery, hormone treatment, private health insurance, CPM status (having had a prior CPM vs. not), and intentions for breast reconstruction if CPM were undertaken.

2.3.2. Risk-reduction preferences

Risk-reduction preferences were assessed using two risk trade-off scenarios adapted from Simes and Coates [32], aiming to determine the minimum degree of risk-reduction required to justify CPM. Participants were asked to sequentially indicate whether they would, or would not, have CPM for increasing degrees of reduction in lifetime CBC risk from a 5% or 20% baseline (the two separate scenarios). These baselines were chosen to cover the range of risks likely in the modern treatment context. For example, in the 5% scenario, participants sequentially indicated whether they would, or would not, have CPM if it reduced their risk from a baseline of 5%–0% (i.e., completely eliminated risk) then to 0.5%, 1%, 1.5% (and so on by 0.5% increments to 5%, at which point CPM offers no risk-reduction). Free-text questions then asked