



Original article

Psychological factors associated with the intention to choose for risk-reducing mastectomy in family cancer clinic attendees



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ARTICLE INFO

Article history:

Received 22 March 2016

Received in revised form

30 August 2016

Accepted 30 August 2016

Keywords:

Mastectomy

Prophylactic surgical procedures

Counseling

BRCA1

BRCA2

Shared decision making

ABSTRACT

Objectives: Women seeking counseling because of familial breast cancer occurrence face difficult decisions, such as whether and when to opt for risk-reducing mastectomy (RRM) in case of *BRCA1/2* mutation. Only limited research has been done to identify the psychological factors associated with the decision for RRM. This study investigated which psychological factors are related to the intention to choose for RRM.

Materials & methods: A cohort of 486 cancer-unaffected women with a family history of breast cancer completed the following questionnaires prior to genetic counseling: the Cancer Worry Scale, Positive And Negative Affect Scale, Perceived Personal Control Scale, Hospital Anxiety and Depression Scale and State Anxiety Scale and questions regarding socio-demographic characteristics, family history, risk perception and RRM intention. Multivariate logistic regression was used to analyze the relation between psychological factors and women's intention to choose for RRM.

Results: Factors associated with RRM intention were high positive affect (OR = 1.86, 95%CI = 1.12–3.08), high negative affect (OR = 2.52, 95%CI = 1.44–4.43), high cancer worry (OR = 1.65, 95%CI = 1.00–2.72), high perceived personal control (OR = 3.58, 95%CI = 2.18–5.89), high risk-perception (OR = 1.85, 95%CI = 1.15–2.95) and having children (OR = 2.06, 95%CI = 1.21–3.50).

Conclusion: Negative and positive affects play an important role in the intention for RRM.

Furthermore, perceived personal control over the situation is associated with an intention for RRM. In addition to focusing on accurate risk communication, counseling should pay attention to the influence of perceived control and emotions to facilitate decision-making.

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Introduction

Women who carry a *BRCA1* or *BRCA2* mutation have a significantly higher risk of developing breast cancer and ovarian cancer

and a higher risk to develop cancer earlier in life, compared to the general population [1–5]. *BRCA1/2* mutation carriers have to decide between the two main risk management options to cope with the increased breast cancer risk: breast cancer surveillance aimed at the early detection of breast cancer, and risk-reducing mastectomy (RRM) aimed at preventing breast cancer [6,7].

RRM results in an actual breast cancer risk reduction of about 90% [8,9] and a decrease of general and breast cancer specific distress [10], but is also associated with a negative impact on the

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sexual relationship, sexual satisfaction and body image [10–12]. Previously, sociodemographic (e.g. age, having children) and medical factors (e.g. mutation status, previous breast or ovarian cancer) have been found to influence the RRM decision-making process [13]. However, only limited research has been done to identify the psychological factors associated with the decision for RRM. So far, this research has primarily focused on perceived risk, anxiety & worry [13].

Specifically, a higher perceived cancer risk has been associated with uptake of, or intention to choose for RRM [14–22]. Furthermore, increased cancer-related distress, (cancer specific) anxiety and cancer worry are associated with a preference for RRM [17,19,21–23].

As several studies have emphasized the role of emotions and underlying affect on medical decision-making [24–27], it is very plausible that more psychological factors, such as affect, influence the decision to undergo RRM. Identifying these factors is important for health care professionals providing decisional support and permits improved shared decision-making. This study specifically investigated which psychological factors are related to the intention to choose for RRM.

Method

Population

The population of the current study was recruited in the context of the Breast Cancer Risk Communication (BRISC) study, which is a prospective study carried out in three academic familial cancer clinics in the Netherlands, i.e. University Medical Center Groningen, VU University Medical Center Amsterdam and Leiden University Medical Center [28]. Included in the BRISC study were women with a family history of breast cancer who sought first time genetic counseling concerning their breast cancer risk. A family history of breast cancer was defined as having at least one first-degree- and/or paternal second-degree family member with breast cancer. Women were not eligible to participate in this study if they were younger than 18 years of age, suffered from evident psychiatric illness, were terminally ill or had a personal history of breast and/or ovarian cancer.

Protection of the patients' identity was guaranteed by assigning study-specific, unique patient numbers. The Medical Ethics Committees of all three centers approved the BRISC study protocol in 2005.

Data collection

All the data used in this paper was collected as part of the BRISC study of which recruitment took place between December 2005 and November 2007.

Various questionnaires were completed at multiple time points. The questionnaires and administration procedure are described in more detail in the BRISC study protocol [28]. The questionnaires analyzed in the current study were filled out prior to intake consultation and concerned questions regarding sociodemographic factors (age, level of education, having children, relationship status, religiousness), family breast cancer history (first degree relatives with breast cancer), psychological scales (Cancer Worry Scale (CWS) [29], Positive And Negative Affect Scales (PANAS-PA and PANAS-NA) [30], State-Trait Anxiety Inventory-state (STAI-state) [31], Hospital Anxiety and Depression Scales (HADS-A and HADS-D) [32] and Perceived Personal Control (PPC) [33], risk perception and RRM intention.

To determine risk perception, women's appraisal of perceived breast cancer risk was assessed independently of actual risk that

was going to be determined and communicated after intake. Women were asked to appraise their perceived breast cancer risk independent of their actual risk. Women could select an answer on a 7-point scale, the options ranging from "very small" (1) to "very large" (7). Women were considered to have a high risk-perception if they selected "large" or "very large" as the answer.

To determine RRM intention, women answered the following question: "If you would be a proven *BRCA1/2* mutation carrier, would you choose for RRM?". Women could select an answer on a 7-point Likert-type scale, with options ranging from "No, definitely not" to "yes, definitely". Women were considered to have the intention to choose for RRM if they selected "probably yes", "yes" or "yes, definitely" as the answer.

Table 1

Patient characteristics prior to genetic counseling in women with and without intention to choose for RRM (N = 486).

| Patient characteristics | (N = 486) ^b n (%) | Intention for RRM | |
|---|---------------------------------|-------------------------------|------------------------------|
| | | Yes (N = 125, 25.7%) n (%) | No (N = 361, 74.3%) n (%) |
| Age (years) | | | |
| <40 | 240 (49.4) | 54 (22.5) | 186 (77.5) |
| ≥40 | 246 (50.6) | 71 (28.9) | 175 (71.1) |
| Having children | | | |
| No | 153 (31.5) | 25 (16.3) | 128 (83.7) |
| Yes | 332 (68.5) | 100 (30.1) | 232 (69.9) |
| Has first degree relative with BC | | | |
| No | 107 (28.9) | 28 (26.2) | 79 (73.8) |
| Yes | 263 (71.1) | 59 (22.4) | 204 (77.6) |
| Highly educated ^d | | | |
| No | 282 (59.1) | 82 (29.1) | 200 (70.9) |
| Yes | 195 (40.9) | 40 (20.5) | 155 (79.5) |
| Married or cohabiting | | | |
| No | 98 (20.2) | 21 (21.4) | 77 (78.6) |
| Yes | 387 (79.8) | 104 (26.9) | 283 (73.1) |
| Actively religious | | | |
| No | 348 (72.2) | 90 (25.9) | 258 (74.1) |
| Yes | 134 (27.8) | 34 (25.4) | 100 (74.6) |
| Perceived risk | | | |
| Low | 217 (45.5) | 43 (19.8) | 174 (80.2) |
| High | 260 (54.5) | 81 (31.2) | 179 (68.8) |
| Cancer worry ^d | | | |
| Low | 286 (59.1) | 56 (19.6) | 230 (80.4) |
| High | 198 (40.9) | 69 (34.8) | 129 (65.2) |
| Positive affect ^d | | | |
| Low | 254 (54.2) | 55 (21.7) | 199 (78.3) |
| High | 215 (45.8) | 63 (29.3) | 152 (70.7) |
| Negative affect ^d | | | |
| Low | 344 (73.3) | 75 (21.8) | 269 (78.2) |
| High | 125 (26.7) | 43 (34.4) | 82 (65.6) |
| State anxiety ^c | | | |
| Low | 244 (50.7) | 56 (23.0) | 188 (77.0) |
| High | 237 (49.3) | 66 (27.8) | 171 (72.2) |
| Hospital anxiety ^d | | | |
| Low | 403 (82.1) | 97 (24.1) | 306 (75.9) |
| High | 83 (17.9) | 28 (33.7) | 55 (66.3) |
| Hospital depression ^d | | | |
| Low | 436 (89.9) | 109 (25.0) | 327 (75.0) |
| High | 49 (10.1) | 16 (32.7) | 33 (67.3) |
| Perceived personal control ^c | | | |
| Low | 226 (47.2) | 32 (14.2) | 194 (85.8) |
| High | 253 (52.8) | 91 (36.0) | 162 (64.0) |

RRM = risk-reducing mastectomy.

BC = breast cancer.

^a Yes: Vocational or research university.

^b Some variables have missing cases, therefore the cases of some variables do not add up to 486.

^c Cut-off point based on median/equal group sizes.

^d Cut-off point based on a previously defined score from literature.

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