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Original article

An exploration of Australian psychologists' role in assessing women considering risk-reducing or contralateral prophylactic mastectomy

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ABSTRACT

Objectives: Given increasing rates of risk-reducing mastectomies (RRM) and contralateral prophylactic mastectomies (CPM), and the potentially significant psychological sequelae of this irreversible procedure, health professionals (HPs) regularly refer patients to psychologists for pre-operative assessment and support. This is the first study to provide qualitative insights from HPs into the role of psychologists who are working with women considering RRM or CPM.

Materials and methods: 24 HPs (psychologists, surgeons, breast care nurses and genetic counsellors) experienced in treating patients before or after RRM/CPM completed semi-structured interviews (n = 15) or participated in a focus group (n = 10). Interviews were qualitatively analysed using Framework methods.

Results: Qualitative analysis revealed four interconnected themes: (1) perceived patient motivation to undergo RRM/CPM; (2) HP reasons for psychologist referral; (3) role of the psychologist; and (4) value of psychologist involvement. The reported psychologist role included: mental health assessment, checking understanding of information, ensuring informed decision-making, preparation for the procedure, and management of post-surgical challenges.

Conclusion: Psychologists are perceived by HPs to have a key role in the multi-disciplinary care of patients considering RRM or CPM.

1. Introduction

The number of women undergoing risk-reducing mastectomies (RRM) and contralateral prophylactic mastectomies (CPM) has increased significantly over the last twenty years [1–3]. These procedures involve the surgical removal of breast tissue, often with immediate or delayed breast reconstruction. Women who seek RRM may be carriers of the BRCA 1 or BRCA 2 genetic mutation [4] or have a strong family history of breast cancer without carrying a known genetic mutation [5]. Women who have a cancer diagnosis in one breast are also increasingly opting to undergo a bilateral mastectomy, although this is typically defined as CPM [6].

RRM has been shown to reduce risk of developing breast cancer by up to 90% [7], while CPM has similarly been shown to reduce risk of recurrence by up to 90% [8], although the initial risk of recurrence may be relatively low. Undergoing RRM or CPM has been linked with significantly decreased cancer worries [9,10], cancer-related intrusive thoughts [11], and general distress [12]. However, mastectomies remain irreversible procedures with potential physical risks, with one population study revealing that up to 52% of women experienced one or more complications, including, skin necrosis, infection, and in some cases, implant loss [13]. General numbness and pain in the chest area have also been reported across several studies [14–16]. RRM and CPM have also been associated with psychological costs, including feelings of regret post-RRM [17–19], long-term changes to an individual's body image [20,21], and declines in sexual satisfaction [9,17,22]. Thus mastectomies have a large psychological component to consider pre-operatively, in addition to the physical risks.

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Limited research has explored psychologist involvement in the context of pre-surgical assessment, despite suggestion that this should be standard practice [23]. In the only study that has administered a standardised psychological assessment to 70 women considering RRM [23], a substantial proportion required further support following the initial assessment (31%) or reported a past history of psychological treatment (36%) [23]. This reflects the high psychological needs of this population. A study of 108 women who had either undergone or were considering RRM/CPM were asked about the hypothetical inclusion of a pre-surgical psychological consultation [24]. All women considering RRM/CPM endorsed the usefulness of this, with many reporting decision-making difficulties, grief associated with the loss of family members to breast cancer and anxiety about developing breast cancer themselves [24].

Psychological consultation could potentially reduce time demands on surgeons [24] and facilitate more informed decision-making [23] by providing a forum for discussion of emotional issues, decision-making and assisting the patient to identify questions for their surgeon. Subsequently, it may reduce the need for long-term psychological intervention following mastectomy, and therefore result in a reduction to overall healthcare costs. As such, pre-surgical psychological consultations are potentially cost-effective in the risk-reduction setting. Further, a timely psychological assessment could assist with identifying people with psychiatric conditions that may be influencing the decision-making process. Therefore, pre-surgical psychological intervention appears not only acceptable to patients, but also valuable to the multidisciplinary team. However, to our knowledge, there is no literature exploring the potential type or content of psychologist involvement or role.

This qualitative study aimed to elicit the opinions of Australian health professionals (HPs), to explore the psychologists' role when working with the RRM/CPM population.

2. Methods

2.1. Participants and procedures

Twenty-four HPs consisting of 5 surgeons, 12 psychologists, 4 breast care nurses, 2 radiation oncologists and 1 genetic counsellor were recruited from tertiary cancer services, specialist breast cancer centers and an established special interest group of psychologists. Purposive sampling aimed to capture the views of HPs varying in age, gender and amount of experience in the RRM area, in order to yield a range of HP views and allow a broad understanding of the psychologist's role. Eligibility criteria required that HPs had current experience in treating women seeking RRM and/or CPM procedures.

Participants completed a demographic questionnaire, and participated in individual semi-structured interviews (n = 14) or took part in a focus group (n = 10). HPs who participated in interviews were approached by researchers via an invitation email. Interested participants were sent further information and contacted for a face-to-face or telephone interview. The focus group was conducted within a meeting of an established group of psychologists working in oncology. Potential focus group participants were notified of the study prior to the meeting, and were given further information prior to consenting to participate. Recruitment continued until interviews no longer revealed new themes or subthemes pertaining to the research question, known as data saturation [25]. Ethics approval was obtained from the Human Research Ethics Committee at the University of Sydney.

Table 1
Demographic and clinical practice characteristics of health professionals.

Characteristic	Health professionals (n = 24)
Age	
Mean [range]	45 [30–65]
Gender	
Male	5
Female	19
HP type	
Psychologist	12
Surgeon	5
Nurse	4
Radiation oncologist	2
Genetic counsellor	1
Years experience as an HP	
Mean [range]	17 [2–45]
Years experience in oncology	
Mean [range]	12 [0.5–35]
Years working with RRM patients	
Mean [range]	9 [0.5–21]
Primary patient group	
Oncology	24
Work setting	
Private	11
Public	6
Combination	7

2.2. Measures

A questionnaire elicited demographic and clinical practice information (see Table 1 for items).

A semi-structured interview protocol was developed by the research team, informed by empirical literature [20,26–28] and expert clinicians (JG; LK). Questions related to three main areas: (1) Referral of a patient to a psychologist, (2) Psychological assessment of the patient, and (3) Outcomes and adjustment. The same interview protocol was used for the focus group and individual interviews. See Box 1 for interview items.

2.3. Data analysis

Descriptive statistics of questionnaire data were analysed using SPSS version 18. Homogeneity of interview and focus group data justified combining these for analysis and reporting of results. Data was transcribed verbatim and thematically analysed with five stages of framework analysis [29]. Following familiarization with the data, 20% of transcripts were independently analysed by LB and RL-P and a provisional thematic framework was discussed. All transcripts were coded accordingly and emerging themes were iteratively discussed with the research team. Data was organized into a framework matrix using MS Excel to identify relationships between themes. Rigour was addressed with independent coding of transcripts and iterative discussion of themes and the framework.

3. Results

Of the 37 HPs invited to participate, 24 consented to participate (response rate: 65%). The main reasons for not participating were lack of time or not responding to researcher contact. All participants worked primarily in oncology, and were highly experienced (mean = 17 years). Table 1 summarises participants' demographic and clinical practice information. The average length of the individual interviews was 27 min and the focus group lasted 44 min.