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Patients' perspectives and experiences concerning barriers to accessing information about bilateral prophylactic mastectomy

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ABSTRACT

Purpose: To explore the barriers and experiences of accessing information for women who have received genetic risk assessment/testing results for breast cancer (BC) and are considering a bilateral prophylactic mastectomy (BPM) and, exploring participants' preferences concerning information and support needs.
Methods: A qualitative retrospective study guided by interpretative phenomenological analysis was utilised. Semi-structured interviews were conducted with forty-six women who were either considering BPM or had already undergone the surgery.
Results: Three themes identified barriers to accessing information; difficulties accessing information, inconsistent information and clinical focus/medicalized information. A fourth theme - preferences of information and support needs, identified three subthemes; these were, psychological support, clearly defined processes and photos of mastectomies/reconstruction surgeries.
Conclusions: Barriers to accessing information appeared to be widespread. A lack of integrated services contributed to inconsistent information, and medicalized terminology/clinical focus of consultations further complicated understanding. Preferences for information include clearly defined processes, so women know the pathways after confirmation of familial BC risk. Clinical implications include a multidisciplinary team approach, and a protocol that reflects current practice.

1. Introduction

Women who choose bilateral prophylactic mastectomy (BPM) desire more information concerning psychological well-being, body image and sexuality after surgery, and post-operative pain management [1–4]. They often report inconsistent and conflicting recommendations, and at times misinterpret information [5]. As a consequence, many fail to accurately understand their familial BC risk and strategies to modify their risk [3,6,7]. At present, there are gaps in our understanding of how this information should be provided. Insufficient information has been associated with dissatisfaction following BPM [8].

A protocol for women at familial BC risk choosing BPM was developed in 2000 [9]. A multidisciplinary (MD) team approach was encouraged, including patient consultations with a geneticist/oncologist, a psychiatrist (for a psychological consultation) and a breast and/or plastic surgeon. An oncologist/geneticist would conduct genetic counselling. With advances in genetic testing and availability of genetic counsellor's, aspects of this protocol may be outdated. Currently those at familial BC risk may not consult with oncologists or psychiatrists and such extensive consultations would not be cost-effective in current clinical practice. Nevertheless, other aspects of these recommendations, such as a psychological consultation, is still not standard practice across clinics in Australia and New Zealand (NZ) [10].

Similar recommendations have been developed, which discuss the management of those choosing BPM [11]. Furthermore, a

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decision-aid [12], telephone peer-support program [13] and MD clinic [14] have been adopted with some success, to further address the reported lack of information provided to those at familial BC risk. More recently a model for understanding information needs of BRCA$^+$ carriers before and after genetic testing is being explored [15]. The main focus of such interventions is assisting genetic counselling and testing, decision-making and reducing distress [15–17]. These studies do not focus specifically on BPM or the associated issues with choosing BPM, such as compromised psychological well-being, body image, sexuality and intimacy and they fail to address the lack of information women report [1–4].

Predominately, BPM research has focused on BRCA$^+$ carriers [15,18], rather than those at familial BC risk without an identified mutation. Women choosing BPM continue to desire more information [2,19,20]. We know little concerning the barriers to accessing information or the influences on decision-making. This is vital to ensure that misinterpretation or lack of risk understanding does not cause women to undergo BPM unnecessarily.

The main aim of this research was to explore the barriers to and experiences of accessing information for women who have received genetic risk information and when considering BPM, and explore participants' preferences concerning information and support needs.

2. Method

2.1. Design

Interpretative Phenomenological Analysis (IPA) [21] guided this retrospective qualitative study and allowed in-depth explorations of the barriers to accessing information and understanding of patient preferences for information and support needs.

2.2. Recruitment and procedure

Ethical approval was obtained from four locations (Fig. 1). Participants were recruited from Australia and NZ through, two hospitals in Perth, Genetic Services Western Australia, Register4 and kConFab (HREC # 97_27) (whereby participants were invited to participate), and online via a Facebook post (whereby interested participants contacted the researcher directly). Eligibility was based on family history evidenced by the National Breast and Ovarian Cancer Centre classification [22]. The sample consisted of 46 women who had undergone BPM ($n = 26$) and were considering BPM ($n = 20$). Due to the multiple methods of recruitment, including online and through third parties (Register4 and kConFab) the number of women invited to participate or how many saw the Facebook advertisement is unknown, therefore, a response bias analysis could not be conducted. Women with insufficient fluency in written/spoken English or a previous BC diagnosis were excluded. Further details are published elsewhere [23].

Written informed consent was provided and semi-structured interviews conducted by an experienced interviewer (RG) (supplementary appendix A). The study team, Cancer Council helpline and a clinical psychologist's contact details were given to participants in case the interview raised concerns. Data collection continued until data saturation was reached [24]. Data were audio recorded and transcribed verbatim.

2.3. Analysis

Data were analyzed consistent with IPA. Two researchers (RG, SH) independently read each transcript as a whole to acquaint with the account. Exploratory coding [21] was conducted and comments made in the left hand margin. A second reading of each transcript was undertaken and initial comments formed phrases (codes) capturing meaning. Themes were developed from codes that clustered together and coding between transcripts were connected. Transcripts were compared and contrasted and repeating patterns were identified to finalize themes [25]. Both researchers discussed their independent findings and after cross-checking for overlapping themes they reached consensus [26].

Data is a credible interpretation evidenced by continuation of data collection until data saturation was reached [27]. There were no predetermined themes and therefore inductive inference was used in the data interpretation. Independent analysis and coding of findings by two researchers contributes to credibility and rigor, interpretation by reflection and exploration of the data. We

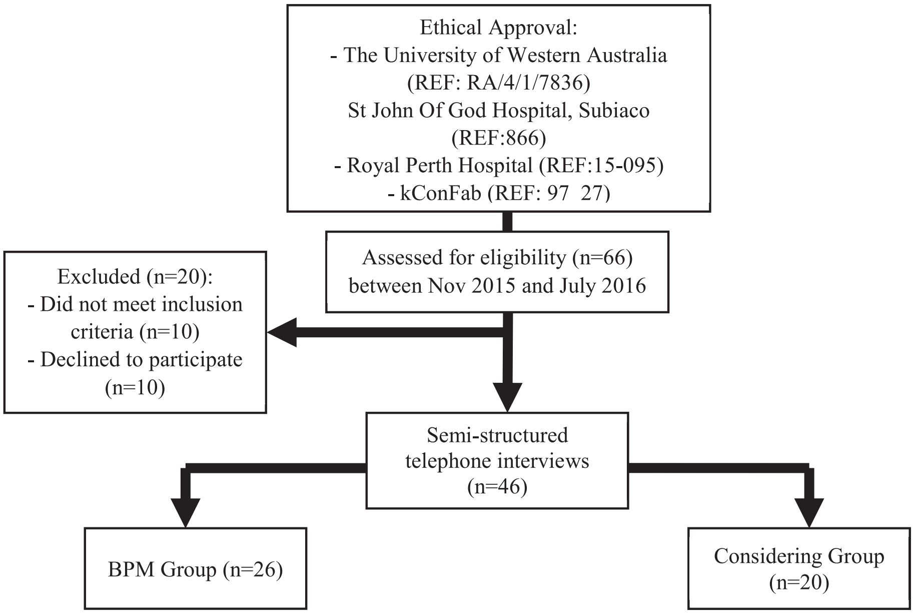

Fig. 1. Flow diagram of recruitment and procedure.