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Influences on decision-making for young women undergoing bilateral prophylactic mastectomy

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ABSTRACT

Objective: The objective of this study was to explore the influences on decision-making of younger women (<35) undergoing or considering bilateral prophylactic mastectomy (BPM).
Methods: Qualitative interviews guided by interpretative phenomenological analysis (IPA) were conducted with forty-six women who had a strong family history of breast cancer (BC) who had either undergone (n = 26) or were considering (n = 20) BPM. Participants were recruited from Australia and New Zealand (NZ) via hospitals, a genetics clinic, a research cohort, a registry and online.
Results: Four themes underpinning the influences on decision-making were identified: fear and anxiety, children, personal experiences with BC, health professional's influence.
Conclusions: The decision to undergo BPM for younger women (< 35) was multifaceted, however, it appeared that fear and anxiety were the main influence. Younger women appear more anxious than previous research with older women. There appears to be few differences between those with confirmed BRCA1/2 mutations and those with no known mutation and this is clinically significant.
Practice implications: These findings have important practice implications, particularly improving communication of risk statistics, especially to those with no known mutation. Health professionals need to take into account the way younger women perceive information given to them when discussing risk.

1. Introduction

Bilateral prophylactic mastectomy (BPM) is an option for women at high risk of developing breast cancer (BC) [1] reducing the risk by up to 95% [2]. The greatest risk reduction occurs if BPM is undertaken before age 40 [3]. Uptake of BPM differs worldwide; in Australia and the United States (US), it has been low (21% and 23% respectively) [4,5]. In England and Denmark, uptake is between 40 and 50% [6,7]. BPM uptake and intention has been associated with younger age (<35 years and <40 years respectively) [6–8], however, the literature focusing on younger women (<40) and BPM is scarce [9].

Research with older women (>40 years) has found a number of indicators for choosing BPM; including a close family member's cancer death [10], strong family history of BC [11], desire to live longer for family [12] and heightened BC risk perception [13,14]. Women's confidence in screening methods may influence their decision to undergo BPM. Lloyd et al. [12] found women expressed concern that if BC developed it would not be detected by screening methods. The initiation of discussion about BPM could influence decision-making [15]. Women with regrets about their surgery reported that a health professional(s) initiated discussion of BPM, rather than the woman herself.

Few studies have reported on BPM decision-making in younger women (<40). Findings from these studies are similar to research with older women (>40), such as, not wanting children to experience their mother's treatment for BC [16] and the possibility

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of children losing their mother [17]. Screening fatigue, encouragement from family, age a relative developed BC, inevitability of a BC diagnosis and fear of developing BC also contribute to BPM decision-making in younger women (<40) [17,18].

Women in their 20′s and 30′s are underrepresented in the BPM literature [9]. Younger adults face new challenges, such as, career choices, exploring relationships, and family planning [19,20]. In comparison, older women (>40) are frequently more settled, in a long-term relationship, have school age or older children, an established career [21], and may be more comfortable with their body image [22]. Younger women with a family history of BC are balancing multiple emerging roles and significant life events while making decisions about their increased BC risk [17]. Subsequently their decision-making processes may differ to older women's.

Existing research provides a basis to understanding influences on decision-making for this age group. Further research exploring BPM decision-making to assist specialists and counsellors when dealing with younger women is needed. Existing research has not compared the decision-making of those who have undergone BPM with those still considering the surgery, which has been reported as a limitation of previous research [12]. It is important to explore what influences timing of undergoing BPM for younger women and how this affects them [18] i.e. why some women rush the decision [23] and others wait. These studies have only included women with BRCA1/2 mutations, however, younger women are undergoing BPM in the absence of a known mutation [4,24]. It is important to understand what influences women with a strong family history of BC to choose BPM, and whether their decision-making processes differ to those with a confirmed mutation. Existing research is limited to the US. Women receive different information, genetic services vary by country and research is needed specific to the national setting.

The aim of this study was to explore the influences on decision-making for younger women (< 35) living in Australia and NZ at high risk of developing BC who are undergoing or considering BPM.

2. Methods

2.1. Design

The qualitative design for this study was based on Interpretative Phenomenological Analysis (IPA) [25]. IPA allowed in-depth explorations of what contributes to decision-making for younger women undergoing or considering BPM [26].

2.2. Participant recruitment

Ethical approval was gained from Royal Perth Hospital (REF:15-095), St John Of God Hospital, Subiaco (REF:866) and The University of Western Australia (REF: RA/4/1/7836). To increase the likelihood of reaching data saturation we recruited widely, including participants from throughout Australia and NZ via five different routes: 1) two Perth hospitals (one public, one private) where women were invited to participate by their specialist; 2) Register4 (a registry for BC research) via written invitation to participate; 3) through kConFab (a national familial cancer research consortium) via written invitation to participate (HREC # 97_27); 4) online via Facebook post to two private groups for those with family histories of BC, where participants contacted the researcher directly, 5) Genetic Services WA where women at follow-up were invited to participate. The guideline recommendations for BPM are the same in Australia and NZ.

Participants were eligible if they had a family history of BC per the National Breast and Ovarian Cancer Centre classification for women who are at high risk of developing BC [27], had undergone BPM <35 years old or were considering BPM and were <35 years. Women who self-reported seeking information from health professionals (e.g. geneticist, breast physician, surgeon, high risk clinic) about their high risk of BC and exploring BPM as a management option were recruited to the considering group. Women considering BPM were included as a reference group to interpret decision-making prior to undergoing BPM.

Exclusion criteria included a previous diagnosis of BC, insufficient fluency in written/spoken English and older than 40 years old at recruitment. Participants provided written informed consent before the interview.

2.3. Data collection

Semi-structured interviews were used to explore influencers to decision-making. Participants were asked questions concerning risk perceptions, decision-making, cancer related worry and psychological well-being. An experienced interviewer (RG) conducted interviews between November 2015 and July 2016. Interviews took place at the researcher's office, and continued for up to 60 min. Interviews were guided by an interview schedule, were digitally audio-recorded and transcribed verbatim. Data collection continued until data saturation was reached [28]. Demographic information (including genetic status) was collected from participants by self-report, via an online survey.

2.4. Data analysis

Data were analyzed independently by two researchers (RG, SH), consistent with IPA. Transcripts were read and initial coding conducted. Transcripts were read a second time by both researchers and themes identified. Once all transcripts had been read, analyzed and themes identified the researcher looked for patterns between participants to connect themes [29]. The researchers discussed themes, cross checked for overlap and reached consensus.

As with all qualitative research, our interpretation of the data is subjective and we acknowledge other interpretations are possible. One of the researchers (SH) had no prior knowledge of the literature, which enabled a more open analysis of findings. We offer a credible interpretation of the data by continuing data collection until data saturation, having two researchers independently analyzing the data, and by using direct quotes providing thick description allowing reader interpretation of the findings [30].

3. Results

Forty-six women participated in the study. Twenty-six had undergone BPM and twenty were considering BPM (Table 1). The mean age of the sample at participation was 30.4 years. Thirty-six women were BRCA carriers and ten had no known mutation (three had a family member inconclusive and seven were not tested for BRCA). Participants were knowledgeable concerning their genetic status and were quickly able to identify whether they were BRCA1/2 positive, or had not undertaken genetic testing. There were no women from BRCA positive families who were negative for the family mutation. Three women underwent BPM with no known mutation. The women in the BPM group were between one and six years post-surgery. Influences on decision-making were identified by four themes: fear and anxiety, children, personal experiences with BC, and health professionals' influence. Each quote is followed by pseudonym (used to report participants views), age and BPM

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