Exploring resilience in decision making for breast reconstruction in women with breast cancer

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Overview

This thesis portfolio comprises three parts:

Part One: Systematic Literature Review

The systematic literature review explored women's experiences of shared decision-making for breast reconstruction following a mastectomy. Following a systematic search of six databases, eleven qualitative studies were identified and analysed using thematic synthesis. Three main aspects of shared decision-making important to women when making breast reconstruction decisions were generated: patient-clinician relationship, information preferences are individual, and the need for shared decision-making post-surgery. Clinical implications and further areas of research are discussed.

Part Two: Empirical Paper

The empirical paper explored experiences of resilience is decision-making for breast reconstruction following a mastectomy in women with breast cancer. Eight participants participated in semi-structured interviews. Using Interpretive Phenomonological Analysis (IPA), resilience was present in three areas of decision-making: actively participating in decision-making, asserting values and goals, and accepting the unexpected: effects, delays and complications. Clinical implications and suggestions for future research are discussed.

Part Three comprises the Appendices

The appendices include the researcher's epistemological and reflective statements. Information related to the quality and characteristics of the studies included in the systematic literature review is also present. Materials related to the design and procedure of the empirical paper are also included.

Total word count (excluding appendices): 22,358

Contents

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Part One – Women's experiences of shared decision-making in breast reconstruction

This paper is written in the format ready for submission to the European Journal of Cancer Care.

Please see Appendix C for the Guideline for Authors.

Word count: 11,302

Abstract

Women with breast cancer have to consider a number of factors when making decisions concerning breast reconstruction (BR). This process can be overwhelming, and women might feel conflicted in their decisions which impact their capacity to make a decision based on their values. Shared decision-making (SDM) encourages women who are considering BR following mastectomy treatment to be involved in the decision-making through a collaborative approach with their clinicians. Whilst SDM has been shown to have positive effects on patients' decision-making, qualitative literature considering women's experiences of aspects relating to SDM suggest the implementation of this model is not always consistent. This systematic literature review aimed to synthesise this literature to improve our knowledge and understanding of what women find important for SDM to be effective. Eleven studies were included in this review and following thematic synthesis, three main themes relating to women's experiences of SDM in BR were derived: (1) Patient-clinician relationship foster or hinders SDM; (2) Information preferences are individual; and (3) the need for SDM post-surgery. This review highlights the importance for women to feel empowered by their clinician to engage in SDM, and to be provided with information that is relevant to them as an individual. Lastly, it identifies women's need for SDM to feel better prepared during the postoperative period.

Introduction

In women with breast cancer (BC), breast reconstruction (BR) following a mastectomy can largely improve their mental health, self-esteem, and self-perceived body image (Chen et al., 2018). However, for women considering BR, the decision-making process can be complex, and women have to consider a number of varying factors in the process. Factors relating to the timing of their BR (Yoon et al., 2018) and feasibility factors such as finances, time off work or caring for others (Giunta et al., 2021). Service-related factors such as the surgeon's input and experience, support provided from their care team, and whether the service can offer immediate BR (Flitcroft et al., 2017). Social influences come from family, friends, colleagues, and public opinion (Giunta et al., 2021). BR also comes with its own risks associated with the type of BR procedure and individual characteristics (e.g. age, medical history etc.) (Wilkins et al., 2018; Bennett et al., 2018). Physical and psychological factors such as stage of cancer, time pressure, recovery time, mental well-being, and fear of surgery or recurrence (Brown et al., 2017) also need to be considered.

Due to the overwhelming nature of the decision-making process for BR, it is unsurprising that women can experience high levels of decisional conflict, particularly those who do not have a strong preference or are susceptible to anxiety (ter Stege et al., 2020). Although some level of decisional conflict is expected with this type of decision, high levels of decisional conflict might lead to feelings of depression and decisional regret (Van Randenborgh et al., 2010; Becerra-Perez et al., 2016). This can hinder their cognitive functioning and capacity to cope with decision-making (Gorini & Pravettoni, 2011). Therefore, it is important for healthcare providers to support women with BC when they are considering this decision.

To support women with BC who have received a mastectomy and are considering BR, shared decision-making (SDM) has been found to be a preferrable model of care. SDM is a collaborative approach between clinician and patient in making decisions around the patient's healthcare. Rather than clinicians making decisions on behalf of the patient, SDM aims to support patient autonomy and seeks to promote patient involvement (Elwyn et al., 2010). Elwyn et al. (2012) proposed a three-step model of SDM for clinical practice: choice talk; option talk and decision talk, whilst deliberation is supported throughout the process. According to this model, SDM involves providing the patient with time and space to understand new information, to consider the patient's personal preferences, to think about potential outcomes, and to discuss their options with others (Elwyn et al., 2012). The model also places an importance on the use of patient decision aids (PDAs) which summarise information in formats that are accessible to patients such as brochures, videos, or through websites (Stacey et al., 2024).

SDM has been increasingly referred to within UK healthcare policies and agendas in the last five years (Coulter et al., 2022). In 2020, the General Medical Council (GMC), the regulatory body for all UK doctors, revised its guidance on decision making and consent which included clear links to SDM and its relationship with good medical practice (GMC, 2020). The National Institute for Health and Care Excellence (NICE; 2021) published guidance, alongside an online learning package, demonstrating how to implement SDM at an organisational and patient-care level. NICE guidelines for BR published in 2018 frequently refer to and recommend SDM in its guidance (NICE, 2018). Whilst SDM has gained favour and activity, there are barriers to implementing SDM for BR. For example, clinicians have reported difficulties in embedding the use of PDAs into BC treatment pathways, including time constraints, length of consultations, and SDM competency (Savelberg et al., 2019; Burton et al., 2021; Savelberg et al., 2021). Additionally, patient-related factors such as age, race, socioeconomic status and literacy levels have also been reported as barriers to SDM (Oprea et al., 2023).

When these barriers restrict the implementation of SDM, patients report poorer scores in physical and mental health, and increased utilisation of healthcare services (Hughes et al., 2018). If participants perceive SDM as occurring, they are more likely to experience improved outcomes in knowledge and understanding of their treatment options; satisfaction in their decisions; and trust in their healthcare team (Shay & Lafata, 2015). Whilst these studies provide evidence for the effectiveness of SDM in BR for women with BC, these findings are not sufficient to understand what aspects of SDM are most helpful to women when decision-making. Therefore, it is important to understand how women experience SDM and what aspects are important to them for it to be effective.

A recent scoping review identified eight qualitative studies which focused on patients' experience and perception of SDM for BR (Li et al., 2021). They found these studies focused primarily on patients' attitudes toward SDM, including their feelings about the information and acceptability of PDAs, and they briefly suggest the qualitative data gathered may not have captured a detailed picture of how patients experienced or were impacted by SDM. Whilst this review offers some insight into how studies of SDM are conducting qualitative research into women's experiences of SDM, it does not look at those studies systematically and only briefly refers to the findings of these studies. A systematic review (Berlin et al., 2019) found evidence that PDAs can improve the quality of BR decision-making and reduce decisional conflict for BC patients. However, SDM is not limited to the implementation of PDAs as reviewed by this study, nor does this study consider qualitative data focusing on patients' perspectives of PDAs (Berlin et al., 2019). It would be helpful to understand in more detail the qualitative data examining women's experiences of SDM to continue to inform the development of effective SDM for BR in the future. Therefore, this review aimed to understand the following question: How do women with breast cancer experience shared decision-making for breast reconstruction?

Method

Search Strategy

A search strategy was developed with the support of an academic and library specialist with particular specialised knowledge in systematic literature reviews (SLRs). Academic Search Premier, APA PsychArticles and APA PsychInfo, CINAHL Complete, and MEDLINE were included in the database search. Reference lists from articles found in the final search were also reviewed to attain any potential suitable articles related to the aim of the review that may have been missed from the initial search. Five additional articles were found. Articles from a scoping review (Li et al., 2021) and an SLR (Berlin et al., 2019) focused on SDM and BR were reviewed alongside the use of the SPIDER tool (Cooke et al., 2012) to develop search terms. The following search terms were used to search across all databases:

(breast* (reconstruct* OR surg* OR procedu*)) AND TI (cancer* or neoplasm* or oncolog* or tumour* or tumor* or malignan*) AND ("shared decision making" OR "SDM" OR involv* or decision* OR “decision aid”) AND (experienc* or perception* or attitude* or view* or feeling* or qualitative or perspective)

The search terms specifying cancer were limited to title due to too many irrelevant articles returned in the initial search. Limiters were applied to retrieve articles written in English so as to ensure the researcher could read and understand them. The search was completed in January 2024.

Study inclusion and exclusion criteria

Duplicate studies were removed during the screening stage. Remaining studies were then screened by title and abstract according to the inclusion and exclusion criteria (see Table 1).

Table 1

Study Inclusion and Exclusion Criteria

Inclusion criteria	**Exclusion criteria**	**Rationale**

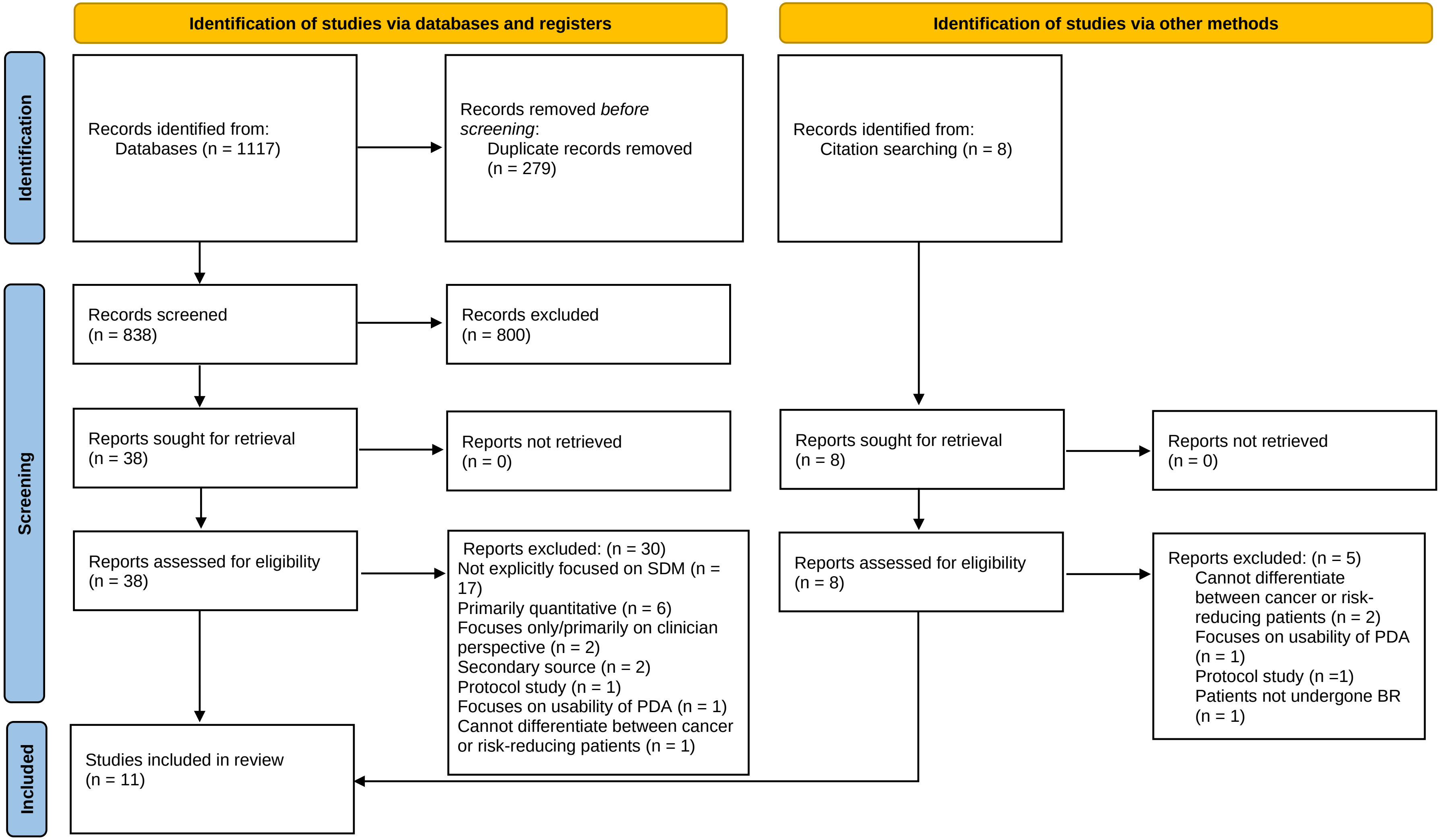
Studies involving women with BC who had experienced or about to undergo a mastectomy and considering BR	Studies involving women who had experienced or about to undergo a prophylactic, or risk-reducing, mastectomy and considering BR	Women undergoing risk-reducing surgery do not experience the same pressures during decision-making as perceived by women diagnosed with BC
Studies explicitly focusing on SDM or aspects related to SDM in BR (e.g. patient involvement, information provision, PDAs).	Studies that focused on patient influential factors and preferences for BR	The aim of this review was to understand women's experiences of SDM. Therefore studies that did not explicitly focus on SDM were excluded
Studies using qualitative (or predominantly qualitative methods) (e.g focus groups, semi-structured interviews, written questionnaires).	Quantitative and mixed-methods studies which predominantly used quantitative methods	This review aimed to gather and synthesise qualitative data related to women's experiences of SDM for BR.
Studies that include the patient perspective and experience of SDM in BR	Studies focusing predominantly on surgeon/clinician experience of SDM in BR or in which the patient perspective cannot be differentiated from surgeon/clinician	This review was interested in only the patient's perspective thereore studies which combined both of these perspectives without making clear distinctions or focused heavily on the clinician/surgeon perspective were excluded.
Studies from the UK and outside the UK		SDM is not limited to the healthcare in the UK (Härter et al., 2017) and therefore

		studies outside of UK were also included

The criteria for eligible studies were discussed and developed with the research supervisor. Figure 1 shows the full process for article selection. Studies that were clearly irrelevant were excluded and potential studies were moved to the next stage. Next, the author screened studies in full text for eligibility and relevance to the research question.

Figure 1

Article Selection Summary (PRISMA) Flow Diagram (Moher et al., 2009)



Data Extraction and Quality Assessment

It was noted during the full article screening that data was reported in various ways across different studies, and thus, it was sometimes more difficult to identify key themes and concepts when, for example, author's briefly described findings than when author's provided evidence of patient's own perspective (e.g. verbatim quotes). For this reason, data was extracted according to Thomas & Harden's (2008) methodological framework for thematic synthesis. Their framework suggests extracting and analysing all data under 'results' or 'findings' rather than attempting to 'pick out' key concepts from the data. Study characteristics (e.g. participant demographics, study-design, geographical origin) and key themes highlighted by the studies were then extracted and collated into a table using Microsoft Excel. To assess quality, each article was checked against the National Institute for Health and Care Excellence (NICE) quality appraisal checklist for qualitative studies (NICE, 2012). This quality checklist provides comprehensive guidance of its application and allows thorough consideration of each area important to qualitative studies (See Appendix D). Each article was assessed first by the author and then again by a second researcher independent of the study. Any disagreements in quality were discussed until consensus was reached.

Data synthesis

Continuing with Thomas & Harden's (2008) framework for thematic synthesis, any data labelled as 'findings' or 'results' was analysed. This included copying and pasting the data in verbatim and coding each line according to its meaning and content. This was repeated for each article. When all articles were coded, the researcher reviewed the codes for similarities and differences to begin developing descriptive themes. Descriptive themes of patients' perspectives of SDM for BR were then used to develop analytical themes by inferring what experience patients had of SDM for BR and what barriers and facilitators they came across in these experiences. This process was repeated until the analytical themes adequately described and explained the initial descriptive themes. A difficulty within this method is that analytical themes generated are dependent on the researcher's inference of the descriptive themes and therefore are at risk of the researcher's own views or biases. The researcher was aware that she will be shaped by her own experiences as a woman, and as a woman who has been personally connected to women with BC who have shared their experiences. The researcher will have been shaped by their own and others' experiences of decision-making in their own healthcare in the past and present, particularly in the current climate of the NHS. The researcher was also aware of their professional position within the NHS. To help minimise potential researcher bias in this process, the researcher engaged in regular supervision and reflection to discuss and think about the themes in light of their positions (Kacen & Chaitin, 2006).

Results

Study characteristics

Of the initial 46 retrieved papers, 11 studies met the eligibility criteria to be included in this review. Of these 11 studies, 4 examined participants' experiences of SDM in the context of decision aids (Sherman et al., 2014; Tollow et al., 2021; Boateng et al., 2021; Foraker et al., 2023); 3 focused on participants' experiences of information sharing (Potter et al., 2015; Webb et al., 2018; Jacox et al., 2020); and 4 focused on barriers and facilitators to SDM as perceived by participants (Potter et al., 2013; Hasak et al., 2017; Flitcroft et al., 2019; Flitcroft et al., 2020). All twelve studies were conducted in culturally Western countries: the USA (N=3), Australia (N=3), the UK (N=3), and Canada (N=2). The combined total of participants across the review was 155, with sample sizes ranging from 10 to 31 per study. Three pairs of studies included data from the same sample of participants. Potter et al. (2013) and Potter et al. (2015) included data from the same 31 participants as part of the Breast Reconstruction and Valid Evidence study (BRAVE). Flitcroft et al. (2019) and Flitcroft et al. (2020) included data from 22 participants from Improving Breast Reconstruction Equity of Access through Stakeholder consultation and Translation (I-BREAST) study. Webb et al.

(2018) and Jacox et al. (2020) reported data from the same 19 participants as a two-part study. All participants were women diagnosed with BC who had undergone or were due to undergo a mastectomy and had undergone BR or were considering BR. Several studies also gathered data from health professionals' perspectives, however, only patient perspectives were extracted for analysis in this review. All studies involved semi-structured interviews (see Appendix E for a full list of study characteristics and key findings).

Quality assessment

Following the quality assessment process, 9 of the studies met more than half of the checklist criteria and were rated '++', whilst two studies met less than half of the checklist criteria and were rated '+' (Sherman et al., 2014; Flicroft et al., 2019). A full list of the quality assessment outcomes including ratings of each checklist item for all studies is included in Appendix F. Most papers were clear in their methodology and analysis procedures; however, two studies did not use a theoretical model to analyse their data (Flitcroft et al., 2019; Flitcroft et al., 2020). All studies but one (Sherman et al., 2014) were rated 'rich' for their results and included an appropriate amount of raw data. Despite the lack of richness in Sherman et al.'s (2014) study, the findings were still considered relevant to this review. One study was rated 'inadequate' in its conclusion because it did not discuss any limitations (Foraker et al., 2023). A common deficit in the quality of trustworthiness across all studies but one (Tollow et al., 2021) was the lack of reflexivity around the researchers' roles. Some studies attempted to enhance trustworthiness by using multiple coders during analysis (Sherman et al., 2014; Hasak et al., 2017; Webb et al., 2018; Jacox et al., 2020; Boateng et al., 2021; Foraker et al., 2023), some by confirming themes with other members of the research team (Potter et al., 2015; Flitcroft et al., 2019; Flitcroft et al., 2020) whilst one study referenced reflective notes (Potter et al., 2013). Most studies referenced gaining ethical approval from an ethics committee and addressed consent and anonymity. Two studies did not address ethics (Boateng et al., 2021; Tollow et al., 2021).

Findings

Three superordinate themes were derived from the thematic synthesis (Thomas & Harden, 2008), along with 7 subordinate themes:

1. **Patient-clinician relationship fosters or hinders SDM**
    1.1 Being human
    1.2 Giving time
    1.3 Empowering the patient
    1.4 PDAs support the relationship
2. **Information preferences are individual**
    2.1 Information content
    2.2 Sources of information
    2.3 Information delivery style
3. **The need for SDM post-surgery**

1. *Patient-clinician relationship fosters or hinders SDM*

This theme explores participants' experiences of the patient-clinician relationship during SDM. This is derived into four subordinate themes which encompassed both positive and negative factors related to this experience. These themes were identified across all studies but one (Jacox et al. 2020).

1.1 Being human

Participants were relieved and thankful when they entered consultation rooms to find their clinicians were approachable and friendly in their manner (Hasak et al., 2017; Tollow et al., 2021). Participants also described engaging in SDM with clinicians who demonstrated they were attentive and available within the consultation (Hasak et al., 2017).

> *"Like I said, she [surgeon] was open. I could sit there and talk to her just, not only as a doctor but as a friend. She always listened. She always looked at you when you talk. That was so very important to me.". (Hasak et al., 2017, p5)*

The demonstration of being a human, and not only an 'expert', minimised the power-imbalance between patient and clinician in that the clinician appeared less intimidating to the participant (Hasak et al., 2017). In contrast, clinicians who appeared abrupt and dismissive left participants feeling as though the clinician did not care or was not willing to engage in SDM (Flitcroft et al.., 2020).

1.2 Giving time

The perception of time given by clinicians helped participants to feel as though they were a priority and not a burden (Hasak et al., 2017; Tollow et al., 2021). When first faced with information, being provided the time and space from their clinicians to ask questions and voice concerns was important for participants to gather a level of confidence in the decision-making (Potter et al., 2015; Hasak et al., 2017; Tollow et al., 2021).

> *"[The plastic surgeon] would take his time … [I was] in there for three-quarters of an hour … and you needed that time for whatever discussion you were having." (Potter et al., 2015, p735)*

In contrast, participants who perceived little time from their clinicians felt overwhelmed and rushed into making their decision (Potter et al., 2013; Potter et al., 2015; Flitcroft., 2020). As a result, participants found it difficult to weigh up their options to gather a balanced understanding of their BR (Potter et al., 2013; Potter et al., 2015).

1.3 Empowering the patient

Participants were empowered to engage in SDM by clinicians who invited and urged them to ask questions, showed interest in and asked questions about their goals, and assured participants they were supportive of their decisions (Hasak et al., 2017; Tollow et al., 2021). This promoted participants' level of autonomy in the decision-making which was particularly important when participants initially relied solely on the clinician's professional opinion (Hasak et al., 2017; Tollow et al., 2021). As a result, participants felt confident enough to actively participate in decision-making and sought out further resources and support to help inform SDM (Potter et al., 2015; Hasak et al., 2017; Webb et al., 2018; Flitcroft et al., 2020). This initiated a sense of trust between the participant and their clinician, and participants then felt able to bring their own BR information and ideas to inform decision-making (Hasak et al., 2017; Webb et al., 2018). This collaborative approach allowed participants to feel supported in their decision whilst maintaining the feeling they had made the decision themselves (Tollow et al., 2021).

> *"I was so relieved to have somebody who I could actually really ask things about. [...] she definitely didn't make the decision for me, but things she said prompted me to make a decision" (Tollow et al., 2021, p7)*

On the other hand, some participants felt more confident when their clinician had a more didactic style of care delivery (Potter et al., 2015), however, this was not commonly shared amongst participants. Didactic and inflexible styles of care generally discouraged participants from engaging in SDM and, in some cases, led to disengagement from the clinician completely (Potter et al., 2013; Flitcroft et al., 2019; Flitcroft et al., 2020). Some participants experienced clinicians who '*told*' them what BR they were having, or that attempted to persuade them towards certain BR procedures even when participants had expressed that they did not want that particular BR (Potter et al., 2013; Hasak et al., 2017; Flitcroft et al., 2019). As a result, some participants felt like they were "*not powerful enough"* to challenge these decisions and felt their choice was limited in the decision-making (Potter et al., 2013; Flitcroft et al., 2019; Flitcroft et al., 2020) which, at times, led to negative emotional-wellbeing (Flitcroft et al., 2019) and decisional regret (Hasak et al., 2017).

1.4 PDAs support the relationship

The use of PDAs during SDM appeared to be valued by participants as tools to initiate discussions with their clinicians. At the point of diagnosis, participants were '*bombarded with information and decision-making'* which leaves them feeling '*overwhelmed*' and '*confused*' (Tollow et al., 2021). Therefore, actively participating in the SDM for BR as a patient was initially difficult. PDAs were perceived by participants as a helpful and encouraging tool to help make sense of BR options and procedures and begin decision-making (Sherman et al., 2014; Boateng et al., 2021; Tollow et al., 2021; Foraker et al., 2023).

> *"Sometimes… you don't know where to start, so those focus questions did assist" (Sherman et al., 2014, BRECONDA, p837)*

> *"It was good at gathering and pulling my thoughts together in one place. That is definitely something that is going to help . . . most women . . . especially right at the time when they get their diagnosis and they're trying to decide what they're going to do . . . their brain is all over the place." (Boateng et al., 2021, BREASTChoice, p5)*

When presented with PDAs, participants had greater clarity on how to approach their decision-making and what further information they needed to make their decisions (Sherman et al., 2014; Boateng et al., 2021; Tollow et al., 2021; Foraker et al., 2023). In response, participants felt more capable to participate in the decision-making with their clinicians. PDAs were frequently referred to by participants as a tool to consult to prepare themselves for discussions with their clinicians (Sherman et al., 2014; Boateng et al., 2021; Tollow et al., 2021; Foraker et al., 2023). As a result, participants felt more confident and prepared to actively participate in SDM by sharing their goals and expectations (Tollow et al., 2021; Foraker. et al., 2023).

> *"If you have any questions, you'd be more prepared for the doctor visit or at least have an idea of what you want so when you're in there with the doctor, the patient can be more confident and say what they want or what they think they want and then start the conversation there with the doctor." (Foraker et al., 2023, BREASTChoice, p7)*

Overall, the patient-clinician relationship for participants in this review appeared to facilitate a strong and trustworthy foundation for effective SDM. The relationship was aided by clinicians that were human in their approach and that appeared to have time for the participants. Participants were empowered by clinicians who initiated SDM and focused on their goals. PDAs appeared to enhance this relationship, particularly when used early on in the process.

2. Information preferences are individual

This theme explores participants experiences of information provision during SDM. Preferences for the content, source, and style of delivery of information was commonly referred to by participants across studies. Three sub-ordinate themes detailing these experiences are discussed.

2.1 Information content

Most participants appreciated or would have appreciated information detailing the range of BR options available to them (Sherman et al., 2014; Potter et al., 2015; Flitcroft et al., 2019; Boateng et al., 2021; Foraker et al., 2023). One participant was surprised by the number of options they had to choose from (Jacox et al., 2020).

> *"I thought I'd just be told you're getting this or that. I had no idea I'd have all these options to consider." (Jacox et al., 2020, p198)*

Not being provided with information on BR options left participants feeling as though they had no choice in decision-making (Potter et al., 2013; Hasak et al., 2017; Flitcroft et al., 2019). In private healthcare, some participants wondered if this was because surgeons were restricting options to support their business (Flitcroft et al., 2019). Differences in the availability of BR options was also discussed in relation to living in urban versus rural areas (Flitcroft et al., 2019). Some participants felt information regarding BR options was biased because of their age and race (Hasak et al., 2017).

Information on the pros and cons, associated risk, potential complications, and realistic outcomes of BR was frequently cited as important to participants (Potter et al., 2013; Webb et al., 2018; Flitcroft et al., 2020; Jacox et al., 2020; Boateng et al., 2021; Foraker et al., 2023). This type of information was not always provided (Potter et al., 2013; Potter et al., 2015; Webb et al., 2018; Jacox et al., 2020). Whilst most participants appreciated this information, some found it confusing and daunting (Potter et al., 2015; Boateng et al., 2021). Other information participants appreciated was the impact of other BC treatments on BR, secondary procedures, and the impact of BR on their sexuality and relationships (Jacox et al., 2020).

2.2 Sources of Information

Most participants valued information shared directly from the clinician/surgeon and found this the most trustworthy (e.g. verbal, PDAs, leaflets, brochures etc.) (Hasak et al., 2017; Webb et al., 2018). However, participants also sought information from other sources outside of their healthcare teams as a means to further inform and confirm their decisions. Information from peers who had undergone BR was highly valued as this provided a sense of connectedness and reassurance (Potter et al., 2015; Hasak et al., 2017; Webb et al., 2018), although some found this unhelpful and felt more isolated (Potter et al., 2015). Having connections to those who have experienced a similar BR procedure was considered helpful and seemed to normalise the experience of BR for participants (Sherman et al., 2013; Potter et al., 2015; Flitcroft et al., 2020). Participants typically sought their own connections with peers; however, some appreciated or would have appreciated their healthcare teams organising access to peers (Flitcroft et al., 2020). The Breast Reconstruction Awareness Day, an international event aimed at educating the medical and general community on BR, was described by some participants as informative and affirming (Webb et al., 2018).

> *"I was very indecisive of whether to go the route of the tissue expanders or the Alloderm and having the opportunity to speak to a couple of patient s ...that was really helpful. That certainly helped me in my decision in terms of which route I wanted to go so that was great." (Webb et al., 2018, p30)*

Participants also sought information online to inform their decision by cross-checking information from their clinicians, seeking information their clinicians missed, and looking at photos and videos of BR's. (Hasak et al., 2017; Webb et al., 2018). Some participants felt affirmed in their decision after accessing online information (Webb et al., 2018). Participants were also conscious of the quality of online information and its origins (Webb et al., 2018). Others discussed feelings of fear as a result of online material (Hasak et al., 2017; Webb et al., 2018), however, they also felt this prepared them for potential negative outcomes (Webb et al., 2018).

Photographs were frequently referred to as helpful aspects of SDM across most studies (Sherman et al., 2014; Webb et al., 2018; Potter et al., 2015; Boateng et al., 2021). Photographs helped participants to understand what to expect, what was feasible from the surgery, what was a reasonable expectation of the outcomes of surgery, and what could go wrong in the surgery (Webb et al., 2018; Potter et al., 2015; Boateng et al., 2021). Photographs were most helpful when participants could see examples of their type of BR and see bodies that looked like their own (Potter et al., 2015; Hasak et al., 2017; Webb et al., 2018). One study referred to how participants had suggested photos could be helpful to provide to partners and other family members to inform them of what to expect (Webb et al., 2018). Seeing photographs of BRs with negative outcomes was also considered important to prepare for potential complications (Flitcroft et al., 2020).

> *"I said 'Well, what are they going to look like … and he shows me a picture of somebody else, and it's like… well that looks fantastic, but he should have showed me 20 of them, that this can go wrong and this can go wrong'." (Flitcroft et al., 2020, p1966)*

2.3 Information delivery style

Some participants welcomed information that was detailed and thorough (Potter et al., 2015; Hasak et al., 2017; Webb et al., 2018). Other participants preferred a step-by-step approach to information delivery so that only the necessary information to the stage of the decision-making was provided (Webb et al., 2018). Having the opportunity to process and deliberate the information at home in their own time was important for participants (Sherman et al., 2014; Hasak et al., 2017; Boateng et al., 2021; Foraker et al., 2023). Information could initially be overwhelming, but participants reflected that it was necessary due to the importance of the decision (Hasak et al., 2017; Boateng et al., 2021). Participants needed time to comprehend the information they were given

(Potter et al., 2013). Sometimes information was too difficult to comprehend, and participants doubted they had processed it (Potter et al., 2015; Hasak et al., 2017).

> *"Everything's bombarded at you, and you've just been told you're having a mastectomy ... it could be that the information was there an' I wasn't digesting it." (Potter et al., 2015, p736)*

From these themes, it was clear from the varying experiences participants described that the appraisal of information during SDM was dependent on the individual, and at times, their clinician/surgeon. Having sufficient information on BR options was particularly important for participants to feel they had a choice during SDM. It was important that sources of information discussed or illustrated BR options that were representative of the participant to provide them with reasonable expectations of the BR. When information is delivered during SDM, some participants could reason that the amount and detail is necessary for a BR decision, whilst others might feel overwhelmed and prefer this in parts. Overall, information aimed towards the individual and their needs appeared to be most valued.

3. The need for SDM post-surgery

This theme explores the participants experiences of postoperative information and support during SDM (Potter et al., 2013; Potter et al., 2015; Hasak et al., 2017; Webb et al., 2018; Flitcroft et al., 2020; Boateng et al., 2021; Tollow et al., 2021; Foraker., 2023).

When considering postoperative information, some participants acknowledged they may have received this but could not recall it following the surgery (Potter et al., 2013; Webb et al., 2018). Some participants felt that the surgery itself might have impacted their cognitive ability to recall this information (Webb et al., 2018). The lack of postoperative information led to feelings of shock and regret. One participant was shocked to find out she required a secondary surgery following their BR (Webb et el., 2018). When unexpected negative aesthetic results of the BR occurred, participants were disappointed with and regretful of their BR decision (Potter et al., 2013; Hasak et al., 2017). Some participants were surprised by the extent to which the physical recovery impacted their lives (Potter et al., 2013; Hasak et al., 2017; Jacox et al., 2020).

> *"…more emphasis and information on what to expect post-surgery. Like the fact that you can't take care of your children on your own for a good two to three weeks. Also, things like you can't lift, you can't carry, you can't raise your arms, and you have to sleep on your back." (Jacox et al., 2020, p198)*

Participants found it important during SDM to be provided with information and support that fully prepared them for living with a reconstructed breast (Foraker et al., 2023). This involved an understanding of the reasonable expectations of what their body will look and feel like following BR so they could prepare themselves psychologically (Webb et al., 2018; Jacox et al., 2020; Boateng et al., 2021). Photographs that illustrated what the completed BR might look like and what the typical/untypical healing process should look like were also considered helpful to alleviate anxiety during the post-operative period (Webb et al., 2018; Jacox et al., 2020; Boateng et al., 2021). Participants valued information that prepared them for possible risks of infections (Foraker et al., 2023) and side effects following BR (Hasak et al., 2017). Whilst most participants accepted pain and other bodily sensations (e.g. numbness) as a typical side effect of the BR, others were worried and unsure of how normal these sensations were and wanted quick access to a reliable source of support to check these out (Hasak et al., 2017; Jacox et al., 2020). When participants did not receive this information during SDM, they sought this information for themselves (Webb et al., 2018) which might put them at risk of accessing unsolicited low-quality information. Having loved ones in the consultations and directing postoperative information to them was considered important to remove some of the pressure off themselves (Webb et al., 2018).

Two studies reported participants who discussed the loss of SDM. One participant described feeling alone following the planning of their delayed BR whilst they were waiting for the procedure (Flitcroft et al., 2019). Following surgery, for some participants, the sudden loss of the support element of SDM was difficult to understand and left them feeling abandoned (Flitcroft et al. 2020).

> *"I don't see anyone till the middle of the year; it should be nice to see someone. It's, sort of, reassuring to go and see people along the way. All of a sudden, it's like, 'No, come back in like seven months.'" (Flitcroft et al., 2020, p1971)*

Post-operative information and support before, during and following the surgery was considered an important aspect of SDM by participants to help them prepare for the appearance, recovery, and possible complications. Some participants reflected that this information might have been provided, but that following the surgery, it was difficult to recall. Others indicated a lack of postoperative information during SDM, and that having such information could have helped alleviate concerns. When SDM is longer available, some participants feel a sense of abandonment.

Discussion

This study is, to the author's knowledge, the first systematic review using thematic synthesis to explore women's experiences of SDM in BR following a mastectomy. All the studies contributed to the development of themes related to women's experiences of SDM following BR. Three main aspects of SDM were found: Patient-clinician Relationship; Information Preferences are Individual; and the Need for SDM Post-Surgery. Subthemes included facilitators and barriers to these three aspects: being human; giving time; empowering the patient; PDAs support the relationship; information content; sources of information; and information delivery style. Findings contributed to potential future directions of research, to be discussed below.

The relationship between patient and clinician was crucial for participants’ engagement in SDM for BR. First, it was important for the participant to perceive the clinician as a human, and not only as an expert. Demonstrating humanism in patient care requires the clinician to listen, to focus intentionally on the patient, and to show sensitivity and empathy to the patient and their needs (Krist et al., 2017; Roze des Ordons et al., 2018). Additionally, patients are more likely to engage with clinicians who are friendly and approachable (Cvetanovska et al., 2023). In a review of SDM in musculoskeletal physiotherapy, being listened to and perceiving empathy fostered trust in the relationship (Grenfell & Soundy, 2022).

Spending adequate time with the plastic surgeon can also develop trust in the patient-clinician relationship during SDM for BR and enhance patients’ knowledge and understanding of the procedure (Myckatyn et al., 2020). Similar findings were found in the current review. Studies reported on participants that perceived time from their clinicians felt comfortable and confident to initiate discussions. A review on the patient-clinician relationship highlighted the importance participants place on not feeling hurried and feeling able to discuss their health to maintain a positive patient-clinician relationship (Ridd et al., 2009). In SDM, time is often referenced to as a barrier by patients and clinicians, particularly the amount and quality of face-to-face time during patient-clinician interactions (Yahanda & Mozersky, 2020). Indeed, studies in this review reported that participants that felt rushed by their clinicians found it difficult to engage in SDM. It should be acknowledged that clinicians and health services are currently working under high-pressure conditions and that giving more time is likely not a feasible nor effective solution. It might be more appropriate for clinicians and services to focus on enhancing the quality of time rather than the quantity, through the use of PDAs or simply asking questions directed at goals (Yahanda & Mozersky, 2020).

When clinicians appeared human and gave their time in consultations, participants were more likely to feel empowered to engage in SDM. In contrast, when clinicians appeared to take a paternalistic approach with participants in these studies, they did not feel powerful enough to voice their concerns or goals. Feeling excluded from participating in SDM by the clinician has been reported elsewhere in healthcare settings (Grenfell & Soundy, 2022). Furthermore, Hasak et al., (2017) highlighted several participants' experiences of SDM in which they felt information was exclusionary to them due to their age and race. Such biases have been reported elsewhere as a barrier to SDM (Opera et al., 2023), indicating this is not an isolated issue. Participants who reported positive experiences of SDM described moments in which the clinician appeared to initiate SDM by inviting them to ask questions and attempting to establish their goals for BR. Myckatyn et al. (2020) suggested clinicians should lead SDM in BR due to the likelihood of patients perceiving the decisional power as residing with the clinician who is in the 'expert' role. Patients themselves have also highlighted the importance of clinicians and services creating an environment in which they feel confident to ask questions and communicate with the clinician (Cvetanovska et al., 2023).

On the other hand, it is also possible that some women do not want this level of involvement in decision-making. Indeed, one of the studies in this review found that women preferred their clinician to take the lead in the decision making (Potter et al., 2015). Taking a passive role in SDM is not uncommon (Li et al., 2021), however, most patients prefer a collaborative approach (Gurmu, 2022). Differences in preferences for patient involvement in SDM might be determined by sociodemographic characteristics (e.g. age, education) (Opera et al., 2023). However, a scoping review of patient-related characteristics in treatment SDM cautioned against the assumption that SDM will most likely occur with patients with certain characteristics, such as age or education, after they found little evidence to support the notion (Keij et al., 2022). The authors reflected on whether there might be psychological or social characteristics not typically studied that might be associated with the likelihood of engagement in SDM. For example, perceived social support and levels of self-efficacy (Keij et al., 2022). To promote and encourage SDM for patients who might initially avoid participating in decision-making, clinicians have employed the use of PDAs.

Whereas PDAs have typically been used to help patient and clinician clarify patient goals and expectations of BR (Li et al., 2021), in this review, PDAs were most valued by participants in the initial stages of decision-making as a framework in which they and the clinician could begin discussing BR. Other studies have highlighted how PDAs might enhance the interaction and communication in the patient-clinician relationship (Ankolekar et al., 2018). Therefore, it might be that PDAs act as more than an informational resource and are also a supplementary facilitator to the patient-clinician relationship. Similar to findings from Rake et al. (2022), PDAs helped initiate and improve communication in the relationship by encouraging participants to ask questions and prompting clinicians to establish patients' goals. As a result, participants were more informed and empowered to engage in SDM.

Information provision preferences in terms of the content, the source and the style of delivery varied amongst participant during SDM. These findings indicated information is effective when it is tailored to the individual. Previous reviews of SDM in BC and other areas of oncology have identified tailored information as a key factor of effective SDM (Covvey et al., 2019; Li et al., 2021). A lack of information, particularly BR options, was reported as a frequent occurrence in participants' experiences of BR decision-making, echoing previous findings (Flitcroft et al., 2017). Participants sometimes perceived this as their clinician unwilling to consider other BR options or demonstrating bias towards a certain BR option. Clinician bias in surgery has been linked to clinicians not considering alternative options and holding inaccurate risk-benefit estimations (Armstrong et al., 2023). This is particularly problematic when we consider that some participants in these studies valued the clinician as their most trusted source of information. Other studies referred to potential system level factors (e.g. geographical location). This might be as simple as differences in patient-demand, particularly in rural areas, however, variations in surgical availability across geographical regions could also be due to clinician attitudes and beliefs (Birkmeyer et al., 2013). Irrespective of the reason for why some participants may have not received sufficient information, not having this information is more likely to result in decisional regret (Flitcroft et al., 2018) which is associated with feelings of anxiety and depression (Sheehan et al., 2007). In contrast, when participants were well-informed, they were more likely to report feeling confident and positive in SDM.

Some studies reported the clinician as the most trusted source of information. However, similar to findings from Berlin et al. (2019), studies in this review showed that PDAs helped participants feel knowledgeable and involved in decision-making. As time is a common barrier to information provision in SDM, clinicians might not always be available to deliver information to the extent patients need or desire. Cvetanovska et al. (2023) found that women were willing to engage with PDAs when it is acknowledged that the desired involvement from clinicians may not be possible for SDM. Although Dobler et al. (2019) warns against the use of PDAs as a replacement to clinicians and encourages the use of PDAs as a supplementary resource.

Similar to findings in other areas of health decision-making, peer support was highly valued during SDM (Sheppard et al., 2013; Ziegler et al., 2022). Sheppard et al. (2013) found that participants who engaged in peer support reported increased self-efficacy in communicating with healthcare providers and in decision-making. Peer support can be perceived as a calming and supportive presence amongst the complex and anxiety-provoking decision-making (Joo et al., 2022). However, in Ziegler et al.'s (2022) systematic review, findings highlighted that peer support might also lead to increases in anxiety and dysfunctional coping and therefore be unhelpful, as reported in one of the studies in this review. Some studies in this review reported participants who indicated they would have liked more access to peer support. This echoes findings from Jansen et al. (2023) who found that 23.1% of the 225 patients with BC reported an unmet need to talk to someone who had experienced BC. Therefore, services might consider how to promote peer support during SDM.

Many studies in this review reported participants who sought further information on BR online. Bruce et al. (2015) found that of 45 websites purporting BR information and advice, 73% included information relevant to BC and its treatments, however, information was poor quality in relation to BR. Most importantly, 84% did not report information related to SDM standards (e.g. possibility of more than one BR option, risks of BR, benefits of BR). When accessing information online, many participants were seeking information and photographs of BR options that were relevant to them and their body type. However, Lee et al. (2024) found that online resources for BR based on the top 10 Google websites and the first 400 Google images were not reflective of the patient population seeking reconstruction. Whilst it might be more reliable to seek this information from clinicians, studies in this review also highlighted clinicians did not always have adequate photographs. It is important, therefore, for healthcare providers to consider, and at the very least acknowledge to the patient, that the photographs they are using to illustrate BR might not be relevant to the patient.

It was frequently highlighted in the reviewed studies that postoperative information and preparation during SDM was lacking for participants. In line with Carr et al.’s (2019) review of women’s information needs and experiences of BR, some participants were surprised by the recovery process and the sensations they experienced whilst others were regretful of their decisions following unexpected negative outcomes. It has been highlighted that health-related outcomes in BR SDM likely differ to other general surgical SDM due to the importance of aesthetics and body image which women pay more attention to during decision making, in addition to the effects this can have on anxiety and depression (Li et al., 2021). Therefore, particular care and attention towards preparing and managing expectations of postoperative outcomes is vital in SDM for BR.

Clinical implications and Future Research

Engaging in SDM with a clinician who is human and takes time to empower their patients was crucial for women to perceive a positive experience of SDM. Feeling overpowered by their clinician reduced engagement in SDM and left them feeling unable to voice their preferences. Therefore, it is important for oncology teams and plastic surgeons to reflect upon and consider the meaning of power in their ‘expert’ and ‘doctor’ roles during SDM. It is acknowledged by the author that difficulties in the current organisational and system levels of healthcare might prevent clinicians from initiating SDM, and therefore, future SDM research should build on studies that also consider perspectives beyond the clinician-patient relationship and consider the role of organisational and system level factors (Waddell et al., 2021).Additionally, whilst most studies reported participants who appeared to want to be engaged in SDM, it was noted that some patients might not want or do not believe they have the capacity to engage in SDM. Future research might focus on what potential psychological factors could play a role in women’s preferences for engagement in SDM for BR.

Findings add to the already extensive literature on the importance of individually tailored information during SDM, particularly relating to BR options and postoperative expectations. This appears to be particularly important in the context of SDM for BR due to the nature of the surgery and the impact of outcomes on body image and wellbeing. Because the clinician is typically the most trusted source of information, it is important they deliver BR options that are unbiased and relevant to the patient during SDM. It has been highlighted that unexpected postoperative outcomes and complications could lead to feelings of regret. Future research might consider qualitative methods to explore women’s experiences of postoperative complications to understand this issue further. Additionally, healthcare providers might consider how to implement psychological and physical prehabilitation into SDM to improve patient outcomes.

Limitations

This review has several limitations. First, whilst this review brings together qualitative understandings of women's experiences of SDM in BR, it must be noted that three pairs of studies included data from the same sample of participants; Potter et al. (2013) and Potter et al. (2015); Flitcroft et al. (2019) and Flitcroft et al. (2020); Webb et al. (2018) and Jacox et al. (2020). Although the author deemed these studies worthy of inclusion due to the quality of qualitative insight they provided to the topic, including multiple 'salami publication' papers in a review could lead to an exaggeration of the results (Norman & Griffiths, 2008). It therefore must be considered that including these studies in this review may have threatened how representative these findings are in relation to women's experiences of SDM for BR.

Further, this review only included studies that were characterised using terms such as 'SDM', 'decision-aids', and 'decision', therefore it is possible that relevant articles were missed. Using terms such as 'patient centred care' or 'person centred care' might have acquired additional articles (Grenfell & Soundy, 2022). However, a comprehensive search strategy was implemented which increases support for the likelihood that key studies were identified. Moreover, studies were excluded that focused on women's general BR decision-making as they were deemed to not predominantly focus on aspects of SDM as per the eligibility criteria to the aim of this review. These studies typically focused on topics outside of SDM but may have briefly referred to it in their findings. Aspects of SDM (e.g. information provision) have been noted to be influential to women's decision-making (Flitcroft et al., 2017). Therefore, it must be acknowledged that experiences potentially relating to SDM were missed in this process. Future reviews might consider reviewing aspects of SDM that have been influential in women's BR decision-making.

A strength of this review is that it provides an in-depth view of qualitative data relating to how women experience PDAs during SDM for BR, whereas previous reviews have focused on quantitative data (Berlin et al., 2019). However, the richness of the data in one of these studies

(Sherman et al., 2014) did not meet quality criteria. Furthermore, studies included participants experiences of three different PDAs and so we cannot assume these experiences are generalisable to all BR PDAs. Still, experiences of PDAs relating to the patient-clinician relationship were relatively homogeneous.

Conclusion

This review provides qualitative insights into women's experiences of SDM in BR following a mastectomy. It highlights several key areas of SDM which were most important to women when they are making decisions for BR. The patient-clinician relationship was a key factor in empowering women to engage in SDM which was enhanced by PDAs. It is important for women to be provided with or guided to individually tailored information that is relevant and helpful to them. Participants reported on a greater need for postoperative information and support, and therefore healthcare providers should ensure these needs are addressed in SDM. Future research should explore organisational and system level barriers to SDM and possible psychological factors that impede or enhance women's involvement SDM.

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Part Two – Exploring resilience in decision making for breast reconstruction in women with breast cancer

This paper is written in the format ready for submission to the European Journal of Cancer Care.

Please see Appendix G for the Guideline for Authors.

Wordcount: 11, 056

Abstract

Breast reconstruction (BR) following a mastectomy as breast cancer (BC) treatment can largely improve women's physical and psychosocial wellbeing. Decision-making for BR is a complicated and distressing process, and, if one regrets their decision, can lead to poorer mental well-being and quality of life. It is unclear what psychological processes support or hinder women's decision-making. In health decision-making, possible resilient factors have been linked to positive experiences of decision-making and higher decisional satisfaction, however, this had not been explored in the context of women's decision-making for BR. Understanding what aspects of resilience contribute to decision-making could inform services on how to implement psychological interventions which improve and maintain resilience to support women in their decision-making and reduce the likelihood of post-decisional regret. Therefore, this study aimed to explore women's experiences of resilience in decision-making for BR. Interpretative Phenomenological Analysis (IPA) was conducted to gather and analyse qualitative data from eight women who had undergone BR. Three themes within women's experiences of resilience in decision-making were described: (1) actively participating in decision-making, (2) asserting values and goals, and (3) accepting the unexpected: effects, delays, and complications of BR. During decision-making, several factors that supported and hindered their resilience were identified.

Introduction

In women with breast cancer (BC), breast reconstruction (BR) has been shown to largely improve their mental health, self-esteem, and self-perceived body image following a mastectomy (Chen et al., 2018). Those who undergo BR tend to report higher psychological well-being scores than those who undergo a mastectomy alone (Jeevan et al., 2014). For women with BC, however, the decision-making for BR can be complicated and overwhelming (Zhong et al., 2013; Boateng et al., 2021). There are a number of social, psychological, and physical factors women will consider when making the decision (Brown et al., 2017; Wilkins et al., 2018; Bennett et al., 2018; Giunta et al., 2021). Some women experience emotional distress and anxiety due to the pressures of the BC diagnosis and the decisions they are forced to make (Mertz et al., 2012; Iddrisu et al., 2020). In turn, this can hinder their cognitive functioning and psychological capacity to cope during decision-making (Gorini & Pravettoni, 2011). Due to the psychological benefits of undergoing BR, alongside the complex nature of making this decision, it is important to consider how women experience this process and what aids them in making such decision.

In the UK, health policies and guidelines have attempted to employ strategies to involve patients in their own health care and decision-making. In 2019, the NHS England and Improvement body launched the Universal Personalised Care strategy which aims to give patients greater control over their care based on what matters to them (NHS England, 2019). Additionally, the National Institution for Health and Care Excellence (NICE; 2018) guidelines for BR encourage clinicians to implement a shared decision-making (SDM) model to support women during decision-making. SDM promotes a collaborative approach between clinician and patient when making decisions around the patient’s care and treatment (Elwyn et al., 2010). According to Elwyn et al. (2015), patient involvement can lead to less decisional regret; increased realistic expectations; and improved resilience and self-efficacy. In BR, patients who engaged in SDM felt more informed, confident and satisfied in their decisions (Hasak et al., 2017; Foraker et al., 2023). Further, women who feel involved in their decision-making are more likely to report positive experiences of decision-making, higher scores in decision-satisfaction, and higher scores on Quality of Life (QOL) measures (Ashraf et al., 2013). On an organisational level, patient involvement in decision-making could enhance patient-clinician relationships; improve scores on organisational outcome measures; improve staff morale and reduce occurrences of staff burnout; and ultimately improve cost-effectiveness (Elwyn et al., 2015).

On the other hand, women who have little involvement during BR decision-making have reported feelings of decisional regret. Decisional regret can lead to poorer mental wellbeing and lower scores on QOL measures (Calderon et al., 2019), higher scores in negative body image (Sheehan et al., 2008), and higher scores in depression, anxiety and stress (Sheehan et al., 2007). This can also negatively impact the wider health system in that decisional regret could lead to further demand of healthcare services and clinicians (Elwyn et al., 2015). A systematic review by Flitcroft et al. (2018) found that, whilst levels of decisional regret were relatively low for women following BR, higher levels were associated with a lack of involvement in decision-making. Although these findings were not always significant, similar findings have also been reported in a systematic review of decisional regret in surgical decisional making, including BR in women with BC (Wilson et al., 2017). Women might feel less involved during decision-making due to the lack of SDM implementation (Myckatyn et al., 2020). However, whilst most women themselves take an active approach to decision-making, some also take on a more passive role (Li et al., 2021). Differences in patient involvement in health decision-making might be related to sociodemographic characteristics such as age, race and education (Opera et al., 2023). However, there is also a growing body of evidence to suggest psychological factors may also play a role (Keij et al., 2022). Whilst it is likely that differences are due to a combination of these factors, psychological factors are less understood in the literature.

Resilience as a positive psychological concept has been regularly referred to in research concerning individuals with cancer and women with BC (Eicher et al., 2015; Aizpurua-Perez &

Perez-Tejada, 2020). In the BC literature, resilience has been described as a *trajectory* of healthy functioning after an adverse event (Bonanno et al., 2011); an *ability* to have biological, mental and spiritual balance in adverse conditions (Alizadeh et al., 2018); a *process* that promotes a successful adaptation to cancer-related adversity (Aizpurua-Perez & Perez-Tejada, 2020); and a *coping style* in the face of adversity (Yoo & Pasick, 2014). In psychology literature, resilience is generally defined as "the process and outcome of successfully adapting to difficult or challenging life experiences" (APA, n.d.). Southwick et al. (2014) suggested resilience exists on a continuum rather than as a binary concept (a woman either has the capacity to be resilient or does not have the capacity to be resilient). On a continuum, resilience is enhanced or diminished over time, depending on the context of the adversity and the individual's interaction with this adversity. A commonality across these definitions appears to be that resilience is a dynamic process, so changeable over time, and that resilience is demonstrated by the capacity to successfully adapt to adversity. However, what is considered successful adaption and what this equates to is subjective to the individual (Vella & Pai, 2019). The varying definitions of resilience in the literature and its subjective meaning make it difficult to understand what it could mean for women's decision-making in BR. However, in health decision-making, emerging research has demonstrated that factors related to resilience might underlie women's involvement in decision-making.

Self-efficacy, the belief that oneself has the capacity to successfully perform actions to achieve a desired outcome, particularly in the face of challenges (Bandura, 1997), is generally associated with resilience as the extent to which the patient believes they can cope with and adapt to the disease (Eicher et al., 2015; Karademas et al., 2023). This might extend to how women cope and adapt to decision-making for treatment of BC, including BR. In BR, Zhong et al. (2013) found that women with higher levels of self-efficacy were more likely to report satisfaction with preoperative information and experience less regret in their decisions. However, without qualitative measures, it is unclear to what extent these women felt involved in their decision-making. Self-efficacy has been referred to in other areas of health decision-making. In a mixed-methods study, Salinger et al.

(2024) found that women with higher scores of self-efficacy were more likely to report they had engaged in decision-making around their health than women with lower scores of self-efficacy. Through qualitative analysis, they also found that those with higher levels of self-efficacy reported a greater conviction for making decisions based on their preferences, even when others appeared to value alternatives. In BR decision-making, Sun et al. (2014) found that women who had stronger preferences for certain outcomes could make decisions easier than those that demonstrated indifference or avoidance towards outcomes. However, this study involved healthy women without BC who were making hypothetical BR decisions. It is important to note that none of these studies found clear evidence for causal relationships between self-efficacy and active decision-making, and it is perhaps more likely that associations are bidirectional. Nevertheless, these studies together point towards self-efficacy as a possible resilient factor in women's decision-making.

Another study highlighted that in individuals with advanced stage lung and colorectal cancer, when making decisions around their treatment, higher levels of self-efficacy was associated with a problem-focused coping style and higher satisfaction with the chosen intervention (Yildiz et al., 2023). Problem-focused coping (Carroll, 2020) is considered a positive coping strategy that aims to resolve or alter the stressful situation by taking control of the situation. In BC, problem-focused coping and other positive coping strategies have been linked to higher levels of resilience (Lai et al., 2020; Tu et al., 2020; Ulibarri-Ochoa et al., 2024). Whilst these studies point to the possible involvement of positive coping strategies during decision-making, the use of quantitative measures does not allow us to understand how these strategies might be understood and used by women during decision-making. Carroll (2020) suggests that individuals with a problem-focused coping style will seek information and support in order to manage and gather control of the adverse situation, however, further research is needed to understand if this is how women might demonstrate such coping styles in decision-making.

Perceiving control, or an internal locus of control, has been linked to resilience in adults with BC (Eicher et al., 2015). An internal locus of control is the extent to which we believe that outcomes are guided by our own decisions and efforts as opposed to an external locus of control in which we believe that outcomes are influenced by others (Rotter, 1966). In decision-making, Dopelt et al. (2022) used qualitative measures to identify several areas of decision-making in which individuals with cancer appeared to demonstrate an internal locus of control. The authors found the following themes of active participation, seeking a second opinion, actively discussing issues and asking questions with the clinician, seeking further information, choosing the treatment and negotiating with the doctor, and fighting for their rights. In contrast, themes in decision-making related to an external locus of control were accepting solely oncologist recommendations, leaning on powerful others, and believing in fate (Dopelt et al., 2022). It must be noted this study was carried out in Israel in which culture might have played a role in participants experiences and responses. However, Dopelt et al. (2022) does manage to highlight some differences in decision-making involvement in which individuals might demonstrate resilience. In contrast to the above findings, Keinki et al. (2016) found that patients with cancer and higher external locus of control significantly used sources of information more often and significantly needed more information. It might be that those who have a higher external control during this time attempt to reclaim control by seeking further information. These studies highlight possible areas of decision-making in which locus of control as a resilient factor might be involved in decision-making, however, none have considered this in relation to decision-making for BR.

So far, research in cancer and other areas of health decision-making research has demonstrated that possible resilient factors could underly patients’ decision-making. Qualitative studies were able to highlight how these factors might be present during decision-making, however, little research has considered this in the context on decision-making for BR. Given the distressing nature of BC, and the decision-making process of BR, it is important to understand what aspects and levels of resilience during different stages and areas of decision-making are present for women.

Aims

The overall aim of this research was to explore women’s experiences of resilience in the decision-making process for BR in women diagnosed with BC following a mastectomy. As resilience in decision making has not been investigated in a clinical setting before, the research also aimed to identify specific aspects of resilience that might have contributed to women’s active engagement in decision-making for BR. Due to the limited amount of research into this topic, a qualitative approach allowed for a foundational understanding of how resilience is experienced by women when decision-making.

The findings of this research have potential clinical relevance due to the psychologically distressing nature of making these decisions and the risk of poorer mental well-being should an individual regret their decisions. Existing research suggests that individuals who actively engage in decision-making are more likely to report positive experiences and outcomes of their decisions. Understanding what role resilience might play in decision-making can inform future practices in implementing psychosocial interventions which enhance and maintain aspects of resilience during and after the decision-making process to protect against decisional-regret and enhance quality of life. Additionally, patients engaging in decision-making can lead to a number of beneficial implications in the wider health system. Some studies have highlighted potential resilient factors that underlie active decision-making, but no study has explored these processes in the context of women’s decision-making for BR. Therefore, this research has the potential to contribute to the growing body of research on this topic.

Research question

1. How do women experience resilience in the decision-making process for BR following a mastectomy?

Method

Design

This study used an exploratory qualitative design with semi-structured interviews to explore participants' individual experiences. Interpretive Phenomenological Analysis (IPA), as described by Smith et al. (2022), was selected for this study because it focuses on detailed exploration of people's experiences and their meaning-making of those experiences which was deemed appropriate for the research question. IPA has also been a useful method in other studies related to exploring lived experiences of BC (Williams & Jeanetta, 2016; Le Boutillier et al., 2022; Sumari et al., 2022). Narrative analysis was considered, however, due to the nuanced nature of BR decision-making within the broad experience of BC, the author felt this method might pose difficulties in focusing in on this phenomenon.

Participants

Participants were recruited from adverts posted to social media (see Appendix H) and the charity Breast Cancer Voices research bulletin (see Appendix I). Following the IPA methodology, purposive sampling based on a researcher developed inclusion and exclusion criteria was used to promote homogeneity. From 2018, the National Institute for Health & Care Excellence (NICE) updated guidelines for BR and women will have more likely received similar treatment and care protocols under these guidelines. Therefore, participants were eligible for this study if they were women who had received a diagnosis of BC and undergone a mastectomy and BR between 2018-2023. Women were included if they had finished treatment (excluding hormone therapy) as those still undergoing treatment may not have completed their BR treatment. Women who had undergone BR as risk-reducing surgery (prophylactic mastectomy) were excluded due to the differing experiences of BR decision-making to those with a BC diagnosis Eight women participated in the study. This sample size aligns with the proposed sample size (6-10) for IPA research at the doctorate thesis level to allow sufficient time, reflection, and discussion for a successful analysis (Smith et al., 2022).

Ethical considerations

Ethical approval was granted from the Faculty of Health Sciences Research Ethics Committee at the University of Hull (see Appendix J). Participants received a copy of the information sheet (see Appendix K) via email and were invited to ask questions before and throughout the study. All participants gave informed consent (see Appendix L) and were given the opportunity to ask questions relating to the points on the form. The information sheet and the researcher signposted sources of support to participants following interviews. Participant information was stored securely in line with ethical guidelines. Confidentiality was ensured by using pseudonyms, storing participant demographic information numerically (e.g. Participant 1), only the researcher having access to recordings, and anonymising any interview data that may have identified participants.

Procedure

All participants showed interest in participating via the researcher's email address. Following initial contact, participants were asked to provide demographic information to confirm eligibility. When eligibility was confirmed, participants were sent the information sheet and a mutually convenient time and platform for the interview was agreed. All participants were interviewed via an online video-conference platform. Participants were sent and asked to read and electronically sign the consent form via email following confirmation of interview date/time. If participants were unable to sign electronically, verbal consent was audio-recorded before the start of the interview.

Interview questions were developed by the researcher. To support the development of the interview questions, the researcher attended a local BC support group to explore the attendees' thoughts and ideas of decision-making for BR and the concept of resilience. Since attending this group, the author became aware of the patient and public involvement (PPI) guidance when interacting with public members to help design the study. Guidance recommends, to avoid 'tokenistic' involvement, that researchers can consider ways to disseminate their research to these members (Biggane et al., 2019). A semi-structured interview style was adopted to allow the participant to lead the interview and so interview questions were used as a guide and were flexible according to the participant's responses (Smith et al., 2022).

Interviews were audio-recorded, ranging from 37-81 minutes (*mean = 55.93 minutes),* using an online video-conference platform. Interviews were downloaded to an encrypted NHS laptop, only accessible to the researcher, before being deleted from the platform. At the start of the interview, participants were asked for verbal consent to record and asked if they had any questions. At the end of the interview, participants were thanked for participating and asked if they had anything further to add that the researcher had not asked. Participants were also asked for permission to contact again should the researcher need to follow-up on any of the information provided and encouraged to get in touch with the researcher should they have any queries. The research focus was essentially asking women to 'relive' their experience of breast cancer and therefore the risk of psychological distress was high. Time was allocated at the end of the interview for a debrief and check-in of sources of support for the individual. Participants were reminded of the information sheet regarding further support.

Data analysis

Interview data was analysed according to Smith et al.'s (2022, Chapter 5, p. 75) recommendations for IPA analysis. First, transcripts were read and re-read to allow the researcher to immerse themselves in the original data whilst making exploratory notes of anything of interest in the transcripts' margins. Experiential statements (Smith et al., 2022), revised from 'emergent themes' (Smith et al., 2009), were constructed using sections of the transcript and the exploratory notes. The intention behind this process is to summarise the descriptive (transcript, participant) and the interpretive (exploratory notes, researcher). Similarities and differences across experiential statements were noted to begin developing clusters which were then grouped together as Personal Experiential Themes (PETs). The researcher then moved onto the next transcript and repeated the process. PETs from all transcripts were then compared for similarities and differences to develop Group Experiential Themes (GETs).

Researcher position

In line with IPA methodology, the double hermeneutic (Smith et al., 2022) was considered, and so it was acknowledged that the researcher's interpretation was not based solely on what the participants reported as their interpretation of the experience, but also the researcher's own experientially informed lens. The researcher, a woman, who has personal connections with other women who have experienced BC, brought with them into this study their own experience and understanding of the topic and with that came expectations and assumptions about the participants and their experiences. The researcher kept a reflective diary throughout the research process and engaged in regular supervision to help maintain the researcher's awareness of their role and position.

Results

Participants' ages ranged from 39 to 66 years. All participants had undergone a mastectomy and BR between the years 2018-2023. Four participants had BR with implants and four had BR with deep inferior epigastric perforator flap (DIEP). Six of the women had immediate BR, and two women had delayed BR.

During interviews, participants were asked what resilience meant to them during their decision-making experience. All participants described resilience as a means to '*carry on*', '*get on with it*', and ‘*to keep going’*. Many of the women described resilience as having ‘*the ability to cope’* during the decision-making process. For others, it was having the ‘*capacity’* to make these decisions in a *‘negative’* and ‘*horrible’* situation. One woman described resilience as ‘*being adaptable’* to the *‘uncertainty’* of the BR decision-making process.

All participants described experiences of resilience in the context of decision-making for BR with three superordinate themes emerging from the data. These themes formed three aspects of decision-making in which resilience was experienced for these participants. Interwoven within these themes were factors that facilitated and threatened resilience.

- Actively participating in decision-making
- Asserting values and goals
- Accepting the unexpected: effects, delays, and complications in BR

Actively participating in decision-making

All participants discussed resilience as a source of motivation and control to process and proceed through their emotional responses of the BC diagnosis to actively participate in the decision-making for BR. This was discussed in various ways across different aspects of the decision-making process.

Discussions around BR were typically posed to participants at the point of diagnosis or following their first round of treatment (e.g. chemotherapy, radiotherapy). Here, participants were faced with copious amounts of information and various decisions to make regarding BR. Participants reflected on feelings of fear, confusion, pressure, and a sense of *‘losing control’* (Hayley). Angela explained “*You have to make an awful lot of decisions very, very quickly”*. Participants discussed resilience as a readiness to *“get on with it”* (Zoe) and were *“optimistic”* (Claire) when considering decision-making. Emma conveyed this as:

> *"I did have a bit of a meltdown, bit of a wobble right at the first diagnosis…But after that I was like, right, this is like, something we've got to do, to get fixed like, bang, bang, bang! Let's do it, let's do what needs to be done, and let's get on with it."*

Emma's repetitive use of the term '*let's*', or *let us*, provided the sense she felt she was not alone in this experience and that she was sharing this with her healthcare team. Sharing the decision, or SDM, with the healthcare team or members of the healthcare teams (e.g. surgeons, nurses, oncologists) was discussed by most participants. To engage in SDM, participants talked about resilience as a source of self-motivation. For example, Claire said "*it's having that confidence and that push, you know, to go and ask questions"*. Asking her breast care team "*tons of questions*" helped Claire to have a sense of "*control and understanding*" in her decision-making. Similarly, Angela said "*I made myself go and sit with the plastic surgeon"* to go through photographs of BR options which helped her to feel "*confident and reassured*" in her decision. Resilience might act as a motivator for participants to proceed through the emotional impact of the BC diagnosis and actively participate in SDM for BR. This could have been supported by the sense of control participants garnered from their healthcare teams involving them in SDM.

Participants also looked to themselves to garner a sense of control and asked themselves *"What can I do?"* (Sophie). In this manner, participants spoke about taking action in the decision-making by conducting their own research and information gathering on BR, attending online and in-person peer-support groups, and taking steps to prepare their body for surgery. For example, Hayley said:

> "*But then I was like, well, what can I do, you know, to firstly, to strengthen myself up for the surgery, especially being like underweight, I wanted to like, put on a bit of weight really. So, a lot of it was like diet based. That's really one of the only things I could control*."

Similarly, Emma considered herself "*a firm believer that you can control how you respond to things*" and talked about being *"proactive in my own care*". As a result, participants felt like they were "*doing something positive"* (Caire) towards the decision-making. It might be that participants were drawing from an internal locus of control to actively participate in the decision-making, that sense that the actions they were taking had an impact on how the decision was made.

This sense of control was acknowledged to fluctuate at times during the decision-making, particularly when participants felt SDM was lacking. For example, when attempting to schedule BR with her oncologist, Angela had the impression "*it was his way or no way"* whilst Hayley said decision-making felt *"more like they were telling me what to do"*. For Sandra, this didactic style of care *"threatened my whole being, not just my resilience, not just my determination* ". As a result, participants found it difficult to seek information from their healthcare team to inform their decision. Hayley said she *"never really questioned the doctors"* about her BR. Amy described a similar experience and wondered if this was because she *"probably didn't know I needed to question so much"*. When reflecting on this experience, both Amy and Hayley discussed how it had changed their attitudes towards decision-making. Amy discussed how she *"asked a lot more questions this time, you know, about the surgery."* during a consultation for a revised BR. Hayley echoed this sentiment:

> "*You know, before the cancer, I'd never really had any health problems so I just, sort of, left it to the experts, you know? I see now that you can kind of question medical professionals and decide more about your own care, and you know, reconstruction"*.

The motivation and control participants needed to take action in the decision-making was threatened when they perceived a lack of SDM from their healthcare team. It could be that potential power-imbalances between clinicians and participants limited that level of resilience participants required to actively participate.

Asserting values and goals

Participants spoke about resilience as having the power to deliberate and assert their values and goals of their BR decision during a time when this felt difficult and shameful to do so.

For some participants, losing their breast/s was difficult to comprehend. Sandra expressed how it would have felt for her *"to have lost forever, really a breast, and not had anything there, to me, would have been devastating"*. This sense of loss and its impact was felt by other participants. Amy described how she *"cried for quite a long time in therapy about how, like, it's gone. It's put in the bin. You can never get it back."*. Amy's use of the phrase '*put in the bin'* gave the impression she felt this important part of her as a woman had been discarded, as though what her breast represented did not matter. Other participants described similar experiences during decision-making which left them feeling as though others underestimated or dismissed what it meant to them to lose their breast. Angela reflected on this in relation to how she felt her clinician considered her concerns of BR:

> *"I think there's almost a paternalistic way of looking at somebody who is in their sixties and thinking, 'God, surely, you're not having sex anymore, anyway. So, it doesn't matter', you know, that was almost like what came across."*

Similarly, Sophie felt as though *"I was being told 'that your surgery isn't a risk to life or limb, and therefore it's not important'. That's how I felt"*. The author wondered whether Sophie meant "*and therefore* I am *not important"*. These interactions with others seemed to contribute to a feeling of shame in wanting a reconstructed breast that '*looks as normal as possible'* (Zoe) whilst also '*getting the cancer out'* (Hayley). For example, Sandra worried how she was perceived by the author when discussing how important the appearance of her breasts was to her: "*you're probably thinking what a vain person this is.*". The feeling of shame might come from societal norms concerning humility and vanity, in that society tends to favour women who are modest in regard to their body over women who care about their appearance. The idea that women with BC should "*look on the bright side, cause I'm alive!"* (Amy) rather than focus on what their new reconstructed breast will look like.

In response, participants described asserting their values and goals for BR. This involved first deliberating with themselves on what was important to them. For example, Claire described battling with the decision of having implants or staying flat because she initially felt she no longer needed them to breastfeed. Following conversations with her family and establishing what was important to her, she later reflected:

> *"I can think about my breasts now, and they are important and, and they are a huge part of me as a woman, and I want them … And I just kind of thought, well, I'm young enough and healthy enough that you know, yeah, I'll give myself the option of having new boobs, because I was very, very top heavy, really, really heavy. I just thought new boobs! So that was a plus really*".

Similarly, Sandra, whose first surgeon refused to provide an immediate BR, recalled having "*a little chat to myself and I said, right, come on, you're not doing his* [surgeon] *decision"* and going on to get a second opinion in line with her goals. It seemed that once participants had established their goals, and their values, they could then assert them to others. For example, Sophie recalled approaching her initial surgeon who offered her a BR that did not fit with her goals:

> *"I'd listen to this other guy* [2nd surgeon] *talk, and I went back, and I said, 'Look, I've listened to him. He says that there are options. I know you can use my love handles and things like that' and he* [1st surgeon] *said, 'I think I need to refer you to him, don't I?' And I said, 'Yeah.'"*

A recurring aspect of this part of the decision-making experience for participants was the level of social support they perceived for their decisions. Zoe shared how her husband encouraged her to *"'do what's best for you, not for us'"*. Feeling supported to focus on what was important to them by members of their healthcare team or by their friends and family seemed to provide a sense of reassurance and safety in their willingness to share these in decision-making.

Accepting the unexpected: effects, delays, and complications in BR

Resilience was also discussed by some participants as having the capacity to accept and cope with unexpected effects and consequences of their BR decisions. This supported participants to avoid feelings of remorse or regret for their decision when unexpected effects, delays and complications of the BR arose.

Some participants discussed feeling surprised at how long and painful the recovery time was following their BR. Zoe said she *"didn't fully appreciate the number of weeks that I'd need to recover"*. Emma conveyed a similar sentiment: *"I was surprised that, that first week and a half, in terms of pain, was really difficult*". Both Zoe and Emma discussed accepting this as part of the process of BR and remained certain this decision was right for them. Zoe talked about *"knowing this* [recovery] *was hard, but it was the right decision for me."*. There was a sense that Zoe was rationalising the surprising length of recovery time. Emma explained this further:

> *"I asked myself, 'if I knew before, what I know now, when I was making the decision, would I have gone along with it? If I knew what the recovery was like?'...But then I answered myself by saying, actually yes, I would have, because I know that I'm, I'm actually fine. It's not the nicest thing, but I know that, again, this is a process, and that I am actually fine. Yeah, I'm in a lot of pain, discomfort, but this is the best thing for me."*.

This method of rationalisation allowed participants to think logically about the unexpected effects of their BR as a typical part of the recovery which helped them justify to themselves why their decision was still the right decision for them. Participants were able to cope with unanticipated consequences of their BR decisions when they could be accepted as part of the general process of having BR. This was more difficult when participants felt what they were experiencing was not part of the typical process of BR, such as delays and surgical complications.

During the COVID-19 pandemic, the NHS had to restrict immediate BRs and postpone delayed BRs even further. Sophie discussed how postponing her delayed BR made her fear the surgeon would refuse to ever carry out the BR, and that "*they would say, 'Well actually, no, we're not gonna do it anymore'*". There is a sense of uncertainty and worry in Sophie's words which was mirrored in the general feeling of the world at the time of the COVID-19 pandemic. It might be that during this time resources of support from healthcare teams and peer support groups were limited so that Sophie felt isolated and abandoned in her experience which could have exacerbated that sense of uncertainty and worry. For Sophie, this uncertainty led her to wonder about her decision to have delayed-BR before the pandemic rather than immediate BR: *"I thought, you know, what if I've got to wait years? Maybe I should've done it then and risked it."*. But, for Sophie, this thought was fleeting, mirrored by the swiftness in which she shifted the discussion:

> *"But I told myself, I remembered I didn't want to do that, because I wanted to do it all by the book you, know, the best outcomes for me, and I'm glad I did. I've got my boob, with my own tissue, yeah, I had to wait, but I'm happy with my decision."*

By reminding herself of her rationale for BR, Sophie was able to accept the delay and justify it as means to accomplish her goals. This was likely strengthened when the BR was completed, and Sophie could observe the positive outcome.

For Amy and Angela, it was more difficult for them to cope with the surgical complications they experienced because they were dissatisfied with the outcome. Both participants discussed a sense of regret for their decisions. Amy shared how she *“regretted it, I regretted it because I was unhappy with the outcome”*. Angela reflected: *“if I had any inclination that that would have been the outcome, I would have got implants”*. How they coped with this feeling depended on how much responsibility they attributed to themselves in the decision-making. Amy, for example, considered herself responsible for her decision and *“struggled with me making the decision to have that surgery and regretting it*”. Angela, on the other hand, considered the responsibility of her healthcare team:

> *“And okay, shit happens. And that happened to me. But what's the learning point from that? Well, and the learning point from that would be that they have to be more honest and say, you know what, it could be more than one surgery, and you could be quite ill.”*

Angela’s use of the phrase ‘*shit happens’* provided a sense of acceptance. It might be that resilience acted as a buffer to the negative feelings associated with the regret Angela was experiencing by transferring the responsibility onto her healthcare team. This then allowed Angela to accept this unexpected outcome of her BR and the decision that was made. For Amy, accepting this decision came later following engagement in therapy: *“I'm not like that now, like, I've reconciled a few things since my therapy.”.*

Although two participants felt unhappy with the outcome of the BR, other participants described feeling positive with the outcome of their BR and were happy and confident this was the right decision for them:

> “*But what I did was the right decision for me, it's still not perfect, it never will be, but I've got shape. I've got a thing there, got something there. I can feel it. It doesn't work, it doesn't,*

> *you know, it's not got a nipple. It's just a big, it's just a big lump. But does it matter? It's my lump.*" *(Sandra)*

Discussion

This study sought to explore and understand the meaning and experience of resilience for women with BC in relation to decision-making for BR following a mastectomy. Earlier studies have highlighted that decision-making for BR, whilst faced with a life-threatening diagnosis of BC, is overwhelming and complex (Mertz et al., 2012; Iddrisu et al., 2020), and that psychological processes associated with resilience might play a role in how women make these decisions. Whilst previous studies have explored the meaning of resilience for women during the BC experience generally, no study had explored the meaning of resilience for women during the stages of decision-making for BR. In interviews with eight participants who have undergone BR following a diagnosis of BC, resilience was described in three aspects of their decision-making: actively participating in decision-making, asserting values and goals, and accepting unexpected effects, delays and complications of BR. Several factors were discussed that facilitated and limited participants resilience: SDM; feelings of shame; social support; unexpected complications; and decisional regret.

Actively decision-making

When confronted with decision-making, resilience was described by all participants as a motivator to overcome the initial emotional impact of the BC diagnosis and take a level of control in decision-making. When motivated, participants had an optimistic readiness to actively participate in SDM. Similar to findings from Dopelt et al. (2022), participants appeared to demonstrate an internal locus of control (Rotter, 1966) when consulting their healthcare team to seek further information, establish goals and evaluate options. SDM supported participants to feel informed and confident in their decision-making, mirroring findings from Hasak et al. (2017) and Foraker.et al (2023). The social support element of SDM appeared to enhance participants' perception of control and satisfaction in their decision-making experience. A recent qualitative study focusing on key factors involved in women's BR decision-making reported a similar finding (Blackmore et al. (2024). Resilience, therefore, was a motivator to engage in decision-making which was maintained by participants' involvement in SDM.

This motivation and internal locus of control extended to decision-making outside of interactions with their clinicians. With a higher internal locus of control, participants were motivated to seek supplemental/alternative information and support to inform their decisions and prepare themselves for BR. This made participants feel as though they were contributing positively and proactively to the decision-making. Echoing previous findings (Siebert et al., 2020), participants who discussed this proactive approach to decision-making generally discussed positive experiences of decision-making and satisfaction with the outcomes. However, some participants' motivational approach to decision-making was hindered at times by a perceived lack of control.

Participants perceived a lack of control in the decision-making when their involvement in SDM was limited, typically due to the clinician's didactic style of care delivery. Some participants fought against this and sought second opinions with other clinicians whilst others trusted their clinicians to make the decision for them. These findings could support Dopelt et al.'s (2022) notion that those with an internal locus of control are more likely to approach other clinicians in their decision-making whilst those with a less internal locus of control accept decisions solely based on their clinician. Demonstrating an external locus of control with clinicians, typically surgeons, in health decision-making is not that surprising given the power-imbalances in these interactions when the patient views the clinician as the 'expert'. However, if one has experienced previous health difficulties, and therefore has greater expertise in interacting with clinicians in health decision-making, they might be more likely to exert a higher internal locus of control (Hasak et al., 2017). This was demonstrated by two participants in this cohort who later reflected they would feel able to question their surgeons following their BR experience. Whilst this could indeed be resilience linked with an internal locus of control enhanced by previous experience, this might also be explained as post-traumatic growth, the process of going through positive changes in coping with adverse experiences (Tedeschi & Calhoun, 1996).

Although some participants in this cohort indeed appeared to exhibit an external locus of control when decision-making with their clinicians, these same participants also demonstrated an internal locus of control in other aspects of the decision-making. This builds on the notion of resilience as a dynamic process that fluctuates across time and different contexts (Southwick et al, 2014; Eicher et al., 2015). It might be then, for participants in this cohort, that resilience was experienced as the motivation to engage and perceive a level of control in the decision-making, but the extent and maintenance of this was perhaps dependent on SDM.

Asserting values and goals

In congruence with other literature, some participants in this cohort discussed feelings of loss and grief for their breast/s following mastectomy (Gershfeld-Litvin, 2021; Singh et al., 2021) and valued maintaining femininity and sexuality in their decision-making for BR (Park et al., 2021; Blackmore et al., 2024). As a result, these participants typically valued and had the goal of immediate BR. When interacting with others, including the author, being perceived as prioritising the aesthetics of their reconstructed breast brought about feelings of shame for participants. The author reflected on their own potential bias as a woman when they considered this as a possible result of societal pressures on women to present humility rather than vanity. However, other research has also highlighted this issue in other women who felt the need to justify their decisions to have BR (Retrouvey et al., 2019). On the other hand, previous literature has also reported findings in which women have felt the need to defend their decisions to not have BR (Singh et al., 2021). Clearly values differ for women when decision-making, however, irrespective of which decision they choose, women still feel pressured to justify and defend either decision to others.

In response to this feeling of shame, participants in this cohort appeared to demonstrate high levels of self-efficacy to defend and assert their values echoing findings from Salinger et al. (2024). Therefore, it might be that participants with higher levels of self-efficacy had the power to assert what *they* value most during decision-making to achieve their preferred outcomes, rather than making decisions based on what they perceived others to value. This appeared to be further strengthened when participants perceived social support for their desired outcome either through SDM or friends and family. Similar findings were revealed in Park et al.’s (2021) study which showed women were more likely to choose the option that would meet the needs they reported were important to them (e.g. body recovery and physical appearance) during BR decision-making when they had social support from friends and family. Other literature has suggested perceived social support allows for higher decisional competence and lower decisional conflict (Lawson & Pierson, 2007). Patients perceiving the availability of social support are more likely to demonstrate higher levels of resilience (Aizpurua-Perez & Perez-Tejada, 2020). Thus, social support might have upheld participants’ level of resilience so that they felt capable of choosing what was important to them.

Accepting the unexpected

When participants experienced unexpected complications and outcomes of their BR, this led to feelings of uncertainty and worry for their decision, and for two participants, decisional regret. Indeed, complications and decisional regret following BR have been linked to poorer emotional well-being (Sheehan et al. 2007; Zhong et al., 2013; Cai & Momeni, 2022). Resilience was discussed as coping with these negative feelings and in doing so, participants also justified these unexpected effects and complications to themselves so that they could accept their decision. Studies have shown links between resilience and coping styles that employ strategies to minimise adverse events (Lai et al., 2019) and enhance positive acceptance (Tu et al., 2019) in women with BC. It might be that participants were minimising the impact of these unexpected effects and complications and positively accepting them as part of the BR process.

For two participants who did not perceive positive outcomes and felt decisional regret following their BR, it was more difficult to minimise these unexpected complications. One of these participants appeared to minimise the impact of not feeling adequately prepared by their surgeon for her experience of postoperative complications and seemed to positively reframe this experience as a lesson to be learned to accept the outcome. Conversely, the other participant considered decisional regret a result of their own decision-making and could only begin to accept the outcome following engagement in therapy. In a study by Hernandez et al. (2022), those with a higher internal locus of control are more likely than those with lower internal locus of control to attribute responsibility externally, and experience less regret, when the decision is incongruent to perceived norms. Therefore, differences in these two participants' responses to unexpected complications might be explained by differences in their locus of control. However, these findings were not significant (Hernandez et al., 2022), and thus, this is a tentative interpretation of this phenomena.

Clinical implications

Previous literature has reported on the positive impact resilience has on women's emotional wellbeing following a BC diagnosis (Aizpurua-Perez et al., 2020). Specific clinical, psychological, and social factors associated with resilience were highlighted in participants' experiences of decision-making. This provides some insight into what aspects of decision-making resilience is involved and when it might need to be enhanced to ensure a positive experience of decision-making and minimise the risk of decisional regret. Therefore, implementing individual and group interventions that seek to promote resilience before, during, and after decision-making will likely be effective in supporting a positive experience of decision-making. Several reviews have attempted to identify effective psychosocial and clinical interventions that can enhance and maintain resilience in adults with cancer and women with BC (Eicher et al., 2015; Aizpurua-Perez et al., 2020; Ding et al., 2024).

Additionally, participants who perceived control and demonstrated self-efficacy were proactive and assertive in decision-making. These participants were more likely to discuss positive experiences of decision-making and satisfaction in their decisions. Implementing interventions which promote a higher internal locus of control and self-efficacy will likely support women in BR decision-making. This might also lead to greater use of patient-led interventions such as self-care and seeking/accepting social support which can help to enhance and maintain resilience and engagement in decision-making (Aizpurua-Perez & Perez-Tejada et al., 2020; Guan et al., 2021; Abdollahi et al., 2022). However, it is important for decision-making to remain collaborative to be most effective (Livaudais et al., 2013).

SDM was a significant factor that facilitated resilience and maintained active engagement in participants' decision-making. Feeling valued and involved by their healthcare teams resulted in generally positive experiences of decision-making. Whilst UK healthcare models and policies have taken steps to promote SDM in BR (Coulter et al., 2022), some participants' experience of poor SDM indicated possible inconsistencies in this model of care delivery. Engaging in SDM was particularly challenging when participants perceived a didactic and inflexible approach of care delivery that possibly perpetuated power-imbalances in their relationship with their clinicians. A review on SDM in BR (Myckatyn et al., 2020) found that clinicians' lack of awareness for the potential power imbalances their patients might perceive could impede on their willingness to share their values and preferences for BR. This seems particularly pertinent if we consider feelings of shame described by participants in this cohort and other studies. Based on the reviewed literature, they go on to recommend several strategies clinicians could implement in their communications with their patients to minimise these perceived power-imbalances (Myckatyn et al., 2020). For example, utilising decision-aids and open-ended questions, and also avoiding medical jargon. Additionally, clinicians who appear approachable and attentive in their manner might help patients to feel comfortable to engage with them in SDM (Hasak et val., 2017; Tollow et al., 2021).

Two of the eight participants in this cohort experienced decisional regret which, as previously stated, can negatively affect emotional wellbeing. Decisional regret following BR could be due to a number of factors including postoperative complications, unmet expectations, patient characteristics, and inadequate information, however, there is a lack of sufficient research to have a clear understanding of this topic (Jones et al., 2023). One participant attributed receiving inadequate information from their surgeon about realistic outcomes to their decisional regret. Indeed, other women with BC have described similar experiences (Carr et al., 2019). Resilient coping strategies and higher internal locus of control might help women avoid the feeling of regret as a result of unexpected complications in BR, however further research is needed on this relationship.

Limitations and future research

This study highlighted several aspects in women's experience of decision-making for BR in which resilience appeared to be involved. However, as this study used a small, relatively homogeneous sample of women, these findings are not generalisable to other women's experiences of resilience in decision-making. Further research is needed to understand the potential impact of resilience on BR decision-making.

Factors relating to the homogeneity of the sample might limit the findings of this study. This study did not account for variation in oncology care delivery across the UK and so participants were recruited nationally from England, Scotland, and Wales. Differences in delivery of oncology services across NHS Trusts, for example, the availability of BR options, might have impacted participants' experiences of decision-making, and thus, the homogeneity of the sample. However, participants' meaning making of their experiences of resilience in decision-making for BR were fairly homogenous.

This study included participants who had undergone BR in the last five years during which the COVID-19 pandemic occurred. As a result, BC treatments including BR procedures in the UK were affected and the lasting impact of these effects are still unknown (Lohfeld et al., 2024), however, it is likely this affected some participants' experiences in this cohort. Three participants underwent BR pre-pandemic whereas five did so post-pandemic. Surprisingly, only one participant discussed the pandemic in their experience of decision-making, however, the author did not seek this information during the interviews and so participants may have assumed this was not relevant. Future studies using IPA might consider the impact of the COVID-19 pandemic when planning their inclusion criteria to ensure homogeneity. Still, due to the exploratory nature of this study and its small sample, it did not aim for generalisability. Future qualitative research might consider the impact of COVID-19 on patients' experience of decision-making for BR and their experience of resilience.

Further exploration is needed on resilience and decisional regret following BR complications. This study highlighted potential resilient coping strategies that women might employ when they are at risk of or are facing decisional regret, however, it is unclear to what extent these and perhaps other factors of resilience might be involved in the defence against decisional regret. Additionally, because this study was asking participants to look back on these experiences retrospectively, the meaning-making of resilience, decision-making, and decisional regret might have been experienced differently if the study was conducted prospectively. Finally, this study identified two participants who experienced decisional regret and whilst literature suggests most women are satisfied with their decisions and outcomes of their BR, little contemporary research has studied this phenomenon.

Conclusion

This study highlighted the meaning of resilience for women making decisions in BR following a mastectomy. Resilience was identified in three aspects of decision-making: (1) actively participating in decision-making, (2) asserting values and goals, and (3) accepting the unexpected effects, delays, and complications of BR. Participants demonstrated motivation and control when participating in decision-making. They defended themselves against feelings of shame in order to assert their values and goals to others and they employed coping strategies to cope with surgical complications and adverse outcomes. Further research is needed to understand the possible relationship between resilience and BR decision-making, including the impact resilience might have on decisional regret.

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Part Three: Appendices

Appendix A: Reflective statement

"*Well, they'll just lob it off and put a new one on, won't they? They know what they're doing, they do it every day*". This is a statement from a female relative who was discussing her upcoming mastectomy and immediate breast reconstruction (BR) after a diagnosis of breast cancer (BC) two months prior. This statement has always stuck with me. I remember thinking how nonchalant she was about losing her breast and how she made the surgery sound like a benign everyday occurrence. I wondered if this was how she really felt, or whether this was perhaps her way of coping with how quickly her life was changing following the diagnosis. This led me to read upon how other women with BC experience mastectomies and BR.

In doing so, I came across concepts like 'decisional-regret' and 'decisional-conflict' and the impact these could have on women psychologically. I wanted to know why they experienced this. There were a number of reasons, all connected to the various factor's women had to consider when making the decision. I recall feeling shocked by how much women did consider when making this decision. I wondered how some women managed to navigate through this process, to make this important decision in the face of such adversity, and not feel so conflicted or regretful. What psychological factors might be involved? Around this time, I had shared my ideas for exploring BR decision making with my research supervisor who brought up the topic of positive psychology. From here, I reviewed the literature and found many studies that referenced resilience as a concept often understood in women's capacity to cope with BC, but none had considered this in terms of decision-making for BR. This led me to question how resilience is experienced by women during this process.

Designing the study

When initially designing this research, I was sure I needed to approach the research question qualitatively after reviewing the literature on this topic. A quantitative study might have allowed a direct measure of resilient factors during decision-making, but due to the lack of research, I felt strongly a qualitative approach could provide a deeper and richer understanding of an area that was still relatively unknown (Creely et al., 2020). I was aware I needed to consider an approach that explores meaning and experience, rather than generating themes and patters as observed in Thematic Analysis. Initially, I was drawn to narrative analysis as a methodological approach due to its story-telling element and what personal, social and cultural influences might shape women's stories of resilience and BR (Weatherhead, 2011). However, I was also interested in the IPA approach because of its attention to meaning making which I thought was vital to understand how women made meaning of their experiences of resilience in decision-making rather than the various meanings these topics have acquired in the literature. When I brought this dilemma to the research proposal presentations and asked my peers and academic team their thoughts, one of the tutors asked how I planned to focus in on the BR decision-making stage of women's experiences of BC with a narrative approach. I reflected that I had not sufficiently considered how women, with a narrative approach that uses a non-directive interview procedure, would tell their story of BR without also describing the many other important stories involved in BC. Therefore, due to its involvement of semi-structured interviews in which I could somewhat navigate the discussion to the focus of the research question, IPA was ultimately chosen.

In discussions with my supervisor, we both agreed it would be beneficial to involve women with experience of BC in the design of the study. I was acutely aware of my lack of knowledge on the subject of BC and BR apart from the personal connections I had with women with BC in my life. Additionally, I was curious as to what women with BC think of the concept of resilience. I was conscious that during some of our teaching the term resilience appeared to be perceived negatively when it was defined as a binary concept, that one either has it or they don't. Therefore, I wondered how accessible this term would be to participants. I visited a BC support group who kindly allowed me to attend. Their thoughtful and open responses to the topic were helpful in considering BR and how they interpreted resilience as women with BC. Their contribution helped shape how I thought about resilience and decision-making in the design of the study.

At one point, contacting clinicians in an oncology setting was discussed in the design of the research. At the time, I was concerned this might contribute to a loss of the woman's, or the patient's, voice in the research. As an inexperienced researcher, I was worried that the focus of the research from the women's perspective might be easily saturated by the professional perspective. Looking back, I think it would have been helpful to have this contact to help fill some gaps of knowledge surrounding BR decision-making procedures.

Ethics Process and Recruitment

I was very aware during the design of this research how potentially distressing it might be for women to participate when recounting their BC experiences. The ethics application process helped to gather my reflections and plan for this possibility when interviewing participants. I considered how we, the participants and I, could plan for such possibility together at the beginning of interviews (e.g. frequent check-ins, pausing/ending the interview). I was mindful of how I would present myself during interviews, taking care to be considerate and empathic of participants experiences, but not falling into 'psychologist' mode to do so. I was initially at a loss when considering what possible benefits participating in this research could be. However, I considered how empowering it could be to have this opportunity to reflect upon and share one's experiences (Steir., 1991). The ethical application process overall was helpful to think more deeply about the research and what I was asking of participants.

I started the recruitment process with the assumption that I might struggle to reach participants. Other cohorts had discussed such difficulties with recruitment, so I considered how to plan for this effectively. I made contact early on with local support groups and the Yorkshire Cancer Community (YCC) charity organisation. I also registered my research with Breast Cancer Now Voices (BCNV) research bulletin. In supervision, I reflected on feeling vulnerable at this stage of the research. This was driven by the fear of not gathering interest or support for my research. In my reflective diary, I wrote of this feeling:

> *"Feeling vulnerable – I feel like it's* [research] *not important enough, people won't be interested. It's going to take me forever to do this."*

It took revisiting my reflective diary and encouragement from my supervisor to remind myself that I had planned the recruitment process thoughtfully and that by doing so, the recruitment process would likely not be too difficult. Following advertisement of the research on my personal social media and the (YCC) who had agreed to advertise my research on their social media sites, in addition to the advert on the BCNV bulletin, participants showed interest relatively quickly.

During the recruitment process, I noticed that the majority of the participants were recruited from the BCNV bulletin. I was curious as to why this could be. In the context of the research topic, I thought about possible resilient characteristics that women might be demonstrating by subscribing to research-focused information and choosing to participate in such research. In my reflective-diary, I reflected on this in the context of my research:

> "*What about the women who don't look at research? What about women who do not participate in research? Are they less resilient? What if I'm missing these women's voices in the research?"*

I addressed this in supervision. We reflected on how by requesting women to participate in the research, I might be essentially only recruiting women who hold 'enough' resilience to respond and participate. However, we were able to think about my attempts to mitigate this during the recruitment process by advertising through platforms that were not research focused.

Interviews

Reflective note from diary following first interview:

> *"I'm nervous. I'm worried I've strayed from the IPA procedure. Have I just said the wrong thing? I'm speaking too much. But I don't want to seem cold. I need to make them feel comfortable."*

As a novice researcher, these thoughts and feelings were present during the first few interviews. As the reflective note illustrates, my first concern was that I was not following IPA or 'correct' procedure during those initial interviews. Listening back to those first few interviews was helpful in highlighting where I was perhaps leading the participant or not asking follow-up questions to potentially relevant experiences related to the research. As a trainee clinical psychologist, I was mindful during interviews to avoid taking the 'psychologist' or indeed, the 'expert' role. In my attempt to avoid this, I was worried that I would appear 'too friendly' by engaging in irrelevant discussions which would keep myself and the participant from the intention of the interview. This battle between both positions became less intense as I progressed through the interview process. In the end, I began to find the interviews enjoyable and looked forward to them.

It was most important to me, during interviews, that participants felt comfortable. I was aware that whilst I might feel nervous, I was not the person being interviewed by a stranger about a difficult and distressing period of my life. Indeed, their willingness to discuss such topics with me was humbling and I felt privileged to be there to listen. Looking back, I often felt energised and productive around the time of the interviews. I have wondered if this was because I was reminded of the importance and purpose of this research.

Data analysis

Initially, after reading around the theory of IPA in Smith et al.'s (2022) guide, I found the prospect of using this analysis daunting. I spent time reading other IPA research and the author's reflections on their positions within their research to begin to improve my understanding and consider my own position in my research. The double hermeneutics principle interested me early on and throughout the research. I considered how my own experiences and assumptions could influence the meaning I gathered from participants' own meaning-making of their experiences (Giddens, 1982). For example, how did my experience of my female relative's BC diagnosis inform my assumptions? Through the use of a reflective journal, I could attempt to monitor and manage these effects to enhance methodological rigour through the analysis process (Smith et al., 2022).

During the initial stages of transcribing, similar to interviewing, I was worried that I was straying from procedure, and at times, pondered as to whether I was interpreting too early or describing when I should have been interpreting. At the time, I reflected that my need to capture something 'relevant' and 'important' was perhaps preventing me from writing 'whatever came into my head' (Smith et al., 2022). I recalled a member of the research team discussing seemingly irrelevant concepts like 'Snow White' appearing during her research, and this helped to remind me that I had space in this part of the process to explore wherever the data takes me. Moreover, engaging in verbal discussions around potential emerging themes during supervision helped to extend and deepen the meaning I was attempting to derive from the data. A huge lesson during this process was giving myself time to fully immerse myself in the data. I noticed quickly that intermittently engaging in the data due to other academic and clinical placement commitments made it difficult to reconnect to the participant's voice.

There were topics discussed by participants that I noticed I was particularly drawn to due to my own personal connection with the content. For example, when participants discussed experiences of femininity and womanhood. My supervisor and I both reflected upon our positions as women when discussing themes relating to this topic to ensure I (and she) was not diverging from the research aim and question. I made a reflective note of this in my diary:

> *"Participants' value of femininity and womanhood – am I considering this topic too deeply as a woman myself? I notice I become quite passionate when discussing this topic in supervision, to a point where I feel like I'm coming away from the research. But this feels important to tell."*

Upon reflection, I feel this topic was highly relevant to the research as the meaning-making of some participants' experiences of resilience in decision-making.

Systematic literature review (SLR)

As it was important to me to consider a positive psychological concept in the empirical, it was also important when considering the SLR to find a topic that encompasses what can be helpful to women during BR decision-making. Initially, I planned to review the effectiveness of psychological prehabilitation interventions in BR, however, a couple of studies had already considered this. When reviewing the literature for the empirical, I was aware that shared decision-making (SDM) was a supportive and effective model of care in health decision-making, including BR. I found qualitative studies that referred to the possible barriers and facilitators in SDM for BR according to women and wondered if anyone had brought these together to understand women's experiences of SDM. A scoping review brought several of these articles together and suggested a systematic review might be able to deepen our understanding of this experience for women. Thinking about promoting patient active engagement in decision-making for BR, I hoped a synthesis of these studies would highlight what aspects of SDM are helpful and unhelpful according to women.

At first, I was confused and frustrated by the review search process. After a few attempts at tackling this on my own, I admitted defeat, reminded myself I have never conducted an SLR, and made my way to the University library skills centre for help. This was hugely helpful in refining my search terms to produce a reliable and relevant literature search. Despite this, I still found that many of the articles were medically focused. I have reflected upon the multiple terms of 'cancer' I included in the search terms and thought about whether these might have drawn more of these types of studies. However, due to the nature of topic, it was to be expected that these types of studies would be generated.

The process of coding and generating themes from these studies was, at first, challenging. Similar to my empirical, I often wondered if I was ‘doing it right’. I have wondered if this is because, at first, qualitative research feels ‘too big’, and has many possible roads and turns for one to venture down. As a novice in qualitative research, I think I found this process initially overwhelming. However, as I continued down the many paths, and began to observe relationships, I found it quite enjoyable and gained a level of clarity, which I hope was translated into the write up of this work.

Final reflections

As I write these final reflections and look back upon the process of conducting and writing this research, I am somewhat in awe of how I got here. If I recall the feeling of being an ‘imposter’ as I began designing this research, and the many times I backed away from it due to feelings of uncertainty and incompetence, I often wondered if ‘here’ was even possible. But I can recall also feeling excited and passionate during this experience, and that I was contributing to something meaningful. Conducting this research has allowed me to develop my research competencies, learn about myself as a researcher and the value of psychological research. Further, it has allowed me the opportunity, and privilege, to sit with women who have made difficult decisions in the face of a devasting illness and share their meanings of this experience to inform others and hopefully elicit deeper understanding and necessary movement in this field. As I look to the next step, research does not appear so daunting, and I look forward to contributing to research in the future.

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Appendix B: Epistemological statement

This statement outlines the ontological and epistemological stance the author held throughout the research.

Ontology refers to the study of being, of what exists and of what is in reality (Crotty, 1998). Due to the subjective nature of decision-making and the concept of resilience, the author approached the research from an idealist ontological position (Hiller, 2016). From this stance, how we build knowledge of the world is considered through subjectivism, and that we construct experiences of reality in our own minds. In this way, the knowledge of what reality is, is open to interpretation. This stance aligns with the research question in that it is searching for how women have subjectively interpreted their experience of resilience and decision-making.

Epistemology is concerned with the study of knowledge, and how we have come to know what we know about the phenomena of interest. From a social constructionist position in research, it is acknowledged that what we have come to know is co-constructed between the researcher and the participant within each of our own experiences and interactions with the world (Given, 2008). The acknowledgement of the researcher position is important to consider during this research due to the interpretivist element of the Interpretative Phenomenological Analysis approach. From a social constructionist position, my own experiences as a woman, and a woman who has close connections to women with cancer has contributed to the knowledge I have constructed about breast cancer and reconstruction. Therefore, engaging in reflexivity to promote self-awareness and careful consideration of possible assumptions was important throughout the research process.

References

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Appendix C: Guidelines for Publication of the Systematic Literature Review (European Journal of Cancer Care)

Submission

At submission you will need to register for a Wiley Researcher ID if you do not already have one (no need to create a new account if you have previously submitted to a Wiley journal or used Wiley Online Library). You will be asked to upload your manuscript file which will automatically be scanned and displayed for you to verify and confirm before submitting. Please note that author details and emails for all co-authors are required at the point of submission. Your manuscript will then be sent on for editorial evaluation and peer review. For technical help, please contact submissionhelp@wiley.com.

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Manuscripts must be submitted on the understanding that they are not published, in press, or submitted elsewhere (with the exception that articles are permitted to be submitted to preprint servers) The submitting author is responsible for ensuring that the article's publication has been approved by all the other co-authors. It is also the submitting author's responsibility to ensure that the article has all necessary institutional approvals. Only an acknowledgment from the editorial office officially establishes the date of receipt. Further correspondence and proofs will be sent to the author(s) before publication, unless otherwise indicated. It is a condition of submission that the authors permit editing of the manuscript for readability. All submissions are bound by the publisher's terms of service.

Peer review

The journal follows a single-anonymized peer review model, for applicable article types.

Information on the Peer Review model can be found here.

Wiley's policy on the confidentiality of the review process is available here.

All submitted articles are subject to assessment and peer review to ensure editorial appropriateness and technical correctness.

Research published in the journal must be:

- Scientifically valid - adhering to accepted community standards of research.
- Technically accurate in its methods and results.
- Representative of a specific advance, or replication, or null/negative result, which is worthy of publication.
- As reproducible as possible - sharing underlying data, code, and supporting materials wherever able.
- Ethically sound and transparent - adhering to best practice with respect to animal and human studies, consent to publish, and clear declaration of potential conflicts of interests, both real and perceived.

In the spirit of sharing findings through our open science mission, emphasis is not placed on novelty, interest, or perceived impact. Replication studies, particularly of research published in this journal, are encouraged.

In order for an article to be accepted for publication, the assigned editor will first consider if the manuscript meets the minimum editorial standards and fits within the scope of the journal. If an article is considered suitable for the journal, the editor will ideally solicit at least two external peer reviewers (who will remain anonymous to the authors unless they choose to disclose their identity by signing the review report) to assess the article before confirming a decision to accept. Decisions to reject are at the discretion of the editor.

Our research integrity team will occasionally seek advice outside standard peer review, for example, on submissions with serious ethical, security, biosecurity, or societal implications. We may consult experts and the editor before deciding on appropriate actions, including but not limited to: recruiting reviewers with specific expertise, assessment by additional editors, and declining to further consider a submission.

Concurrent submissions

In order to ensure sufficient diversity within the authorship of the journal, authors will be limited to having three manuscripts under review at any point in time. If an author already has three manuscripts under review in the journal, they will need to wait until the review process of at least one of these manuscripts is complete before submitting another manuscript for consideration. This policy does not apply to editorials or other non-peer-reviewed manuscript types.

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The journal accepts articles previously published on preprint servers, and does not consider this to compromise the novelty of the results. Articles based on content previously made public only on a preprint server, institutional repository, or in a thesis will be considered. The preprint should be cited.

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When publishing clinical trials, the journal aims to comply with the recommendations of the International Committee of Medical Journal Editors (ICMJE) on trial registration. Therefore, authors are requested to register the clinical trial presented in the manuscript in a public trial registry and include the trial registration number at the end of the abstract. Trials should be registered prospectively before patient recruitment has begun. Where this has not happened, the study must be registered retrospectively, and the date of registration should be clearly stated in the manuscript.

Preregistration of studies

Authors are encouraged to indicate whether the conducted research was preregistered in an independent, institutional registry (e.g., http://clinicaltrials.gov/, https://www.socialscienceregistry.org/, http://osf.io/, https://egap.org/

registry/, http://ridie.3ieimpact.org/). Preregistration of studies involves registering the study design, variables, and treatment conditions prior to conducting the research.

Preregistration of analysis plans

Authors are encouraged to indicate whether or not the conducted research was preregistered with an analysis plan in an independent, institutional registry (e.g., http://clinicaltrials.gov/, https://www.socialscienceregistry.org/, http://osf.io/, https://egap.org/registry/, http://ridie.3ieimpact.org/). Preregistration of studies involves registering the study design, variables, and treatment conditions. Including an analysis plan involves specification of sequence of analyses or the statistical model that will be reported.

ORCID

At submission, an ORCID iD must be provided for the submitting author(s). If you already have an ORCID iD, you will be asked to provide it.

Article types

The journal will consider the following article types:

Research articles

Research articles should present the results of an original research study. These manuscripts should describe how the research project was conducted and provide a thorough analysis of the results of the project. Systematic reviews may be submitted as research articles.

Reviews

A review article provides an overview of the published literature in a particular subject area.

Formatting

We recommend that all manuscripts include line numbers and follow the structure below:

Title and authorship information

The following information should be included:

- Manuscript title
- Full author names

- Full institutional mailing addresses
- Email addresses

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Abstract

The manuscript should contain an abstract. The abstract should be self-contained, citation-free, and should not exceed 300 words.

Introduction

This section should be succinct, with no subheadings.

Materials and methods

The methods section should provide enough detail for others to be able to replicate the study. If you have more than one method, use subsections with relevant headings, e.g. different models, in vitro and in vivo studies, statistics, materials and reagents, etc.

The journal has no space restriction on methods. Detailed descriptions of the methods (including protocols or project descriptions) and algorithms may also be uploaded as supplementary information or a previous publication that gives more details may be cited. If the method from a previous article is used then this article must be cited and discussed. If wording is reused from a published article then this must be noted, e.g. This study uses the method of Smith et al. and the methods description partly reproduces their wording [1].

If a method or tool is introduced in the study, including software, questionnaires, and scales, the license this is available under and any requirement for permission for use should be stated. If an existing method or tool is used in the research, the authors are responsible for checking the license and obtaining any necessary permission. If permission was required, a statement confirming permission was granted should be included in the materials and methods section.

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You can make your protocol public before publication of your article if you choose, which will not harm the peer review process of your article and may allow you to get comments about your methods to adapt or improve them before you submit your article (see also the protocols.io FAQ page).

Results and discussion

This section may be divided into subsections or may be combined.

Main text (review only)

This section may be divided into subsections or may be combined.

Conclusions

This should clearly explain the main conclusions of the article, highlighting its importance and relevance.

Data availability

Authors must include a data availability statement with their submission.

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Conflicts of interest

Authors must declare all relevant interests that could be perceived as conflicting. Authors should explain why each interest may represent a conflict. If no conflicts exist, the authors should state this. Submitting authors are responsible for co-authors declaring their interests.

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If you are in any doubt about declaring a potential conflict, remember that if it is revealed later - especially after publication - it could cause more problems than simply declaring it at the time of submission. Undeclared conflicts of interest could lead to a corrigendum or, in the most serious cases, a retraction.

Funding statement

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Acknowledgments

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Date formatting

Dates should be written out fully to avoid confusion with different all-numeral date styles. For example, 11/10/2018 could be 10 November 2018 or 11 October 2018 depending on the reader, therefore, the date should be written out in full. For example, the date September 1, 2018 should be used rather than 01/09/2018 or 09/01/2018.

Units of measurement

Units of measurement should be presented simply and concisely using the International System of Units (SI).

Preperation of figures

Upon submission of an article, authors should include all figures and tables in the file of the manuscript. If the article is accepted, authors will be asked to provide the source files of the figures. Each figure should be supplied in a separate electronic file. All figures should be cited in the manuscript in a consecutive order. Figures should be supplied in either vector art formats (Illustrator, EPS, WMF, FreeHand, CorelDraw, PowerPoint, Excel, etc.) or bitmap formats (Photoshop, TIFF, GIF, JPEG, etc.). Bitmap images should be of 300 dpi resolution at least unless the resolution is intentionally set to a lower level for scientific reasons. If a bitmap image has labels, the image and labels should be embedded in separate layers.

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Preparation of tables

Tables should be cited consecutively in the text. Every table must have a descriptive title and if numerical measurements are given, the units should be included in the column heading. Vertical rules should not be used.

Supplementary materials are the additional parts to a manuscript, such as audio files, video clips, or datasets that might be of interest to readers. A section titled supplementary material should be included before the references list with a concise description for each supplementary material file.

Supplementary materials are not modified by our production team. Authors are responsible for providing the final supplementary material files that will be published along with the article.

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Authors are strongly encouraged to use appropriate reporting guidelines when preparing and submitting manuscripts, to maximize transparency and reproducibility. Our editors and reviewers are also encouraged to use them in the review process. Completed checklists should be provided in the supplementary files on submission. We particularly encourage the use of:

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- TREND for non-randomized trials
- PRISMA for systematic review and meta-analyses
- CARE for case reports

- STROBE for observational studies
- STREGA for genetic association studies
- SRQR for qualitative studies
- STARD for diagnostic accuracy studies
- ARRIVE for animal experiments

Ethical guidelines

For any experiments on humans, all work must be conducted in accordance with the Declaration of Helsinki (1964) Manuscripts describing experimental work that carries a risk of harm to human subjects must include a statement that the experiment was conducted with the human subjects' understanding and written informed consent, as well as a statement that the responsible ethics committee has approved the experiments.

In the case of any animal experiments, the authors must provide a full description of any anaesthetic or surgical procedure used, as well as evidence that all possible steps were taken to avoid animal suffering at each stage of the experiment. Approval must be obtained from the relevant ethics committee/Institutional Animal Care and Use Committee where required.

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Authors may appeal if they feel that the decision to reject was based on: i) a major misunderstanding over a technical aspect of the manuscript; or ii) a failure to understand the scientific advance shown by the manuscript. Appeals requesting a second opinion without sufficient justification will not be considered. To lodge an appeal, please contact the journal by email, quoting your manuscript number. Appeals will only be considered from the original submitting author.

Appendix D: **Quality Appraisal Checklist for Qualitative Studies (NICE, 2012)**

Study identification: Include author, title, reference, year of publication		
Guidance topic:	**Key research question/aim:**	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:
Study design		
3. How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach?	Defensible Indefensible Not sure	Comments:

• Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?		
Data collection		
4. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:
Trustworthiness		
5. Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: • Was data collected by more than 1 method?	Reliable Unreliable Not sure	Comments:

- Is there justification for triangulation, or for not triangulating? - Do the methods investigate what they claim to?		
Analysis		
8. Is the data analysis sufficiently rigorous? For example: - Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? - How systematic is the analysis, is the procedure reliable/dependable? - Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:
9. Is the data 'rich'? For example: - How well are the contexts of the data described? - Has the diversity of perspective and content been explored? - How well has the detail and depth been demonstrated? - Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
10. Is the analysis reliable? For example: - Did more than 1 researcher theme and code transcripts/data? - If so, how were differences resolved? - Did participants feed back on the transcripts/data if possible and relevant? - Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing?	Convincing	Comments:

For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Not convincing Not sure	
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		
14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
Overall assessment		

As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

Appendix E: Study characteristics and key findings

Author (year)	**Aims/Research Questions**	**Location**	**Methodology**	**Participant Demographics**	**Key Findings**	**Quality Rating**
Boateng et al. (2021)	To explore barriers and facilitators to implementing an evidence-based PDA (BREAST Choice) about breast reconstruction into routine care.	USA	Qualitative Semi-structured interviews with patients, clinicians, and informatics professionals (only patient data was extracted) Themes were generated according to constructs of the Consolidated Framework for Implementation Research (CFIR) (CFIR Research Team, 2020) Purposive and snowball sampling	Women who had completed surgery in the last 5 years (n=13) **Age range:** 41-71 (*M*=51.8) Immediate BR (n=9) Delayed BR (n=3) No BR (n=1)	Four themes were identified which included patient perspective: **1. Stakeholders found the tool useful and thorough overall [CFIR constructs: Relative Advantage, Knowledge and Beliefs]** - The tool was helpful in pulling information together and providing a clear picture of choices available. - It helped them to make decisions jointly with the clinician. - Personalised risk information was helpful in supporting patient decision. - Realistic and diverse photographs of BR outcomes were particularly helpful **2. Some stakeholders suggested content or formatting edits [CFIR constructs: Design Quality Packaging and Compatibility]** - Patients reported the tool felt long but that this seemed appropriate for the amount of information to consider. - Preparation for the amount of information in the tool could be helpful. **3. Some worried about the cost, timing, and security of integration, and suggested ways to simplify the programming [CFIR constructs: Adaptability, Cost, Complexity, and Intervention Source]** - Some patients expressed concern for the security of their health information. - Patients were happy for their information to be shared as long as it was only shared with the necessary systems/services and was protected. **4. Stakeholders differed in their perspectives, but felt that patients needed some time before or after a clinical encounter to process a cancer diagnosis to think about**	++

Author (year)	Aims/Research Questions	Location	Methodology	Participant Demographics	Key Findings	Quality Rating
					reconstruction [CFIR constructs: Implementation Climate and Other Personal Attributes] - Patients reported they would feel productive if they had access to the tool in between appointments. - Patients emphasised the tool should be accessible from various devices. - Patients reported they would likely complete the tool at home where there is less distractions.	
Flitcroft et al. (2019)	To document the negative impact lack of choice has had on some Australian women	Australia	Qualitative Data from semi-structured interviews were extracted and assigned to categories for the purpose of the current study – no model of analysis was undertaken. Study was part of the project 'Improving Breast Reconstruction Equity of Access through Stake holder consultation and Translation into policy and practice (I BREAST)' (2014-2019) Purposive sampling	Women with cancer who had undergone mastectomy and were dissatisfied with their BR experiences (n=22) **Age range –** 33-62 Immediate BR (n=12) Delayed BR (n=6) No BR (n=4) Length of time between BR and interview: ranging from 0-168 months	**1. Preference for BR over no BR** - Women who are not offered a choice of BR following mastectomy might be negatively impacted. - Opportunity to explore all options was important to some women - Pressure from clinicians to have treatment locally **2. Preferences regarding the timing of BR** - Lack of surgeons in local area to perform BR surgery - Women struggle to get delayed BR and are on long waiting lists if receiving public health care - Some women want more time to make decisions. **3. Preferences regarding type of BR** - Some women's preferences for BR did not align with the type of surgery offered.	+
Flitcroft et al. (2020)	Three aims; to develop an original set of generalisable	Australia	Qualitative Semi-structured interviews with	Women with cancer who had undergone mastectomy and were dissatisfied with their	Ten principles of patient-centred care were identified from interviews. Extracted findings focused on women's reported barriers they experienced to the implementation of these principles:	++

Author (year)	**Aims/Research Questions**	**Location**	**Methodology**	**Participant Demographics**	**Key Findings**	**Quality Rating**
	patient-centred care principles (PCCPs); to identify barriers to the implementation of these principles in a real-world setting, using breast reconstruction (BR) services in Australia as a case study; and to document examples of successful patient-centred care in relation to BRs		women who had undergone mastectomy, clinicians, and surgeons (only data from women who had undergone mastectomy was extracted) – no model of analysis reported. Study was part of the project 'Improving Breast Reconstruction Equity of Access through Stake holder consultation and Translation into policy and practice (I BREAST)' (2014-2019) Purposive sampling	BR experiences (n=22) **Age range –** 33 to 62 Immediate BR (n=12) Delayed BR (n=6) No BR (n=4) Length of time between BR and interview: ranging from 0-168 months	- Surgeon does not encourage shared decision-making. - Inadequate information provided. - Not encouraged to seek or lack of access to BR peer support. - Services not available or surgeon does not offer BR - Local services offer poorer quality care - Public health care difficulties; long waiting lists, prioritised waiting lists, and not enough surgeons and resources. - Breast cancer nurse not available - Lack of referrals to other services/support for travel to services - Costs of care - Inadequate follow-ups of long-terms BR issues Evidence of high-quality patient-centred care was gathered from the interview data; however, it was unclear which participants (women or clinicians) reported these experiences, so this data was excluded.	
Foraker et al. (2023)	To elicit patients' and clinicians' perspectives on barriers and facilitators for implementing the BREASTChoice decision aid	USA	Qualitative Semi-structured interviews (online) – Thematic analysis according to an adapted sociotechnical framework	Women who had undergone BR following cancer diagnosis (n=10) **Age range –** 35-59	High level of usability and potential for sustainability of BREASTChoice use among patients and clinicians. Key findings from patients: - Help shared decision making between patients and providers. - Prepare better for their first appointment - Receive the patient's BREASTChoice summary right before the patient is seen - Patients prefer to use the tool at home - Beneficial for patients to use the tool prior to their plastic surgery appointment - Some found the tool to be a little "text heavy" and preferred content be easier to read and digest	++

Author (year)	**Aims/Research Questions**	**Location**	**Methodology**	**Participant Demographics**	**Key Findings**	**Quality Rating**
Hasak et al. (2017)	Study sought to explore stakeholders' perspectives on ways to support BR decision-making	USA	Qualitative Semi-structured interviews with patients and clinicians (only patient data was extracted) – Grounded Theory analysis Purposive sampling from a single institution	Women who were <5 years post-mastectomy (n=20) **Age range** 30-40 (n=5) 41-50 (n=4) 51-60 (n=3) 61-70 (n=6) 71-80 (n=2) Immediate BR (n=12) Delayed BR (n=3) No BR (n=5)	Four key themes were identified from the analysis: 1. **Engagement in SDM is variable.** - Some patients reported a good level of participation in SDM - Many patients felt they did not have a choice 2. **Stakeholders described many barriers to SDM, including limited information-sharing, clinician pressure, and clinician biases.** - When SDM was not occurring, patients wanted more information for BR - Patients felt pressure from clinicians to choose between options - Some patients felt that clinicians were biased in their presentation of options because of age, race and socioeconomic status. - Lack of SDM often led to decisional regret. 3. **SDM was particularly challenging when patients and clinicians disagreed about the best BR option for a patient. However, those who engaged in SDM during disagreements often ended up with more satisfied patients.** - During times of disagreement, SDM was an effective technique to provide patient-centred care and increase patient satisfaction. 4. **Stakeholders described factors that facilitated SDM, including patient–clinician trust, time during and outside consultations, an engaged care team, and supple mental resources used outside of the clinic visit.** - Patients who trusted their clinicians perceived SDM - Availability of time to consider options was an important factor of SDM	++

Author (year)	Aims/Research Questions	Location	Methodology	Participant Demographics	Key Findings	Quality Rating
					- Resources outside of patient-clinician relationship were useful to increase engagement in SDM - External resources were not always perceived as positive (e.g. fear inducing, questionable credibility)	
Jacox et al. (2020)	To determine the type of information women want to be provided in order to make an informed decision as to whether, when, and using what technique to proceed with breast reconstruction.	Canada	Qualitative Semi-structured interviews (data extracted and analysed from author's previous publication (Webb et al., 2018) Thematic analysis (Braun & Clarke, 2006) Questioning based on three primary subjects of interest: (1) Breast reconstruction information, (2) content delivery, and (3) information sources Purposeful sampling from a single surgeon's practice	Women who had recently undergone BR (n=19) Age range: 38 years – 69 years Immediate BR (n=17) Delayed BR (n=2) Length of time between BR and interview: 15-286 days (*M*=108 days)	Twelve themes were identified in previous publication (Webb et al., 2018) of which eight were reported in current study as relating to primary subjects of interest: **1. Pros and cons of reconstructive options** - Patients interested in pro's and con's due to the number of BR options available - Patients sought more information for BR procedures that might impact lifestyle, responsibilities, and goals - A need for all aspects of each BR procedure to be explicitly laid out - Final appearance of breasts following particular BR procedure **2. Post-operative recovery and expectations** - Amount of post-op period preparation and organisation required depended on individual lifestyle and responsibilities - Clear information on how much women will need to modify life for post-op period - Unanticipated aftereffects of BR (e.g. sleep difficulties, anaesthesia) - Patients' knowledge of healthy versus concerning wound - Women would feel reassured by candid photos of 'normal' and not normal incisions - Unanticipated sensations of BR (e.g. extensive pain, itching, burning) **3. Immediate breast reconstruction** - Some women were not aware of immediate BR as on option as, in some cases, it had not been discussed. - Women who were aware expressed gratitude and a conviction it should be routinely discussed. - Immediate BR alleviated some women's concerns over their sense of femininity and the chance of further surgeries	++

Author (year)	Aims/Research Questions	Location	Methodology	Participant Demographics	Key Findings	Quality Rating
					4. Nipple-sparing mastectomy - Celebrity publicising own nipple-sparing BR generated interest for some women - Simultaneous consults with breast and plastic surgeons to explore newer procedures and their implications. **5. Oncologic safety/monitoring and prophylactic mastectomy reconstruction** - Women wanted accurate information of oncological risks (e.g. checking for cancer with implants) - Discussion of the increased risk of operating on both breasts and the inability to guarantee symmetry needs to be undertaken - Information regarding the availability of bilateral breast reconstruction in the face of hereditary risk or unilateral disease diagnosis was important **6. Secondary procedures** - Patients wanted to know more about secondary procedures (e.g. contralateral balancing operations and nipple reconstruction) - Patients were surprised to learn that these insured services do not require patients to pay out of pocket in the Canadian health care system. - Nipple reconstruction - women wanted information ranging from where and how to get the procedure done, to the realities of living with a reconstructed nipple. **7. Impact of chemotherapy and radiation** - Patients were uncertain how chemotherapy and radiation therapy affect breast reconstruction options and results. - Radiation was the biggest concern, as it most directly affects reconstruction options and results. - Having the opportunity to speak with someone who had been through the chemotherapy was very much appreciated. 8. **Managing relationships and intimacy issues** - Women wanted more information for themselves and those they were close to about managing close personal and intimate relationships post-reconstruction (e.g. partners, children)	

Author (year)	**Aims/Research Questions**	**Location**	**Methodology**	**Participant Demographics**	**Key Findings**	**Quality Rating**
					- Women were concerned how their altered appearance might affect intimacy in relationships. - Information on navigating issues around body image and intimacy would be welcomed by many of the women consulted.	
Potter et al. (2013)	To explore access to care and the provision of procedure choice to women seeking reconstructive surgery.	UK	Qualitative Semi-structured interviews with both health professionals and patients– Grounded Theory (only data from patient perspective was extracted) Patients recruited from breast and plastic surgical units in south-west England. Purposive sampling	Women who had undergone BR (n=31) **Age** < 45 (n=7) 45-60 (n=17) >60 (n=7) Immediate BR (n=20) Delayed BR (n=8) Immediate/Delayed (n=4) *One participant had bilateral BR which was classified as two surgeries Months since surgery (10-23)	Most women felt they had shared decisions with surgical team. A minority reported being dissatisfied with the level of involvement in their care. Three main themes were identified: **1. Lack of information and time for decision-making** - Lack of high-quality information about different procedure types and probable outcomes - Some women felt they did receive adequate information but perceived a lack of time to consider the information fully and some women felt rushed into their decision. - Many women felt they were not prepared for the outcomes of the surgery. - Some women felt anger and frustration and sought additional information independently. **2. Mismatches between patients' desired and actual involvement in decision making.** - A minority of women reported being dissatisfied with the level of involvement in their care. - Women who perceived a lack of choice in their BR regretted their decision. **3. Service provision and organisation of care.** - Some women felt they had been dissuaded from seeking immediate BR because the service they received treatment did not provide BR surgery. - Some women felt frustrated to be referred to a surgeon who could only perform a limited number of procedures. When free and open choice of care is provided, women's choice is limited due to their desire for continuity of care with their initial care team.	++

Author (year)	Aims/Research Questions	Location	Methodology	Participant Demographics	Key Findings	Quality Rating
Potter et al. (2015)	To explore patients' and health professionals' (HPs) perceptions of the adequacy of information provided for decision-making in BR.	UK	Qualitative Semi-structured interviews with both HPs and patients– Grounded Theory (only data from patient perspective was extracted) Patients recruited from breast and plastic surgical units in south-west England. Purposive sampling	Female patients who had undergone BR (n=31) **Age** < 45 (n=7) 45-60 (n=17) >60 (n=7) Immediate BR (n=20) Delayed BR (n=8) Immediate/Delayed (n=4) *One participant had bilateral BR which was classified as two surgeries Months since surgery (10-23)	Patients described different experiences of information provision to HPs. Data was assigned to three headings: **1. Information from health professionals** - Almost all patients reported they were given the opportunity to discuss BR with healthcare team. - Some women felt that some information was difficult to understand, misleading or unbalanced. - Most women appreciated a certain level of detail as it allowed them to adequately prepare for surgery. - Other women found some of the information quite harrowing but acknowledged the importance of such information to consider risks and benefits. - Plastic surgeons appeared to be favoured by some women for providing information as they took time to explain procedures. - Some women who were treated only by breast surgeons often felt they had been rushed in consultations. - Written information and photographs were generally perceived to be useful, however, some found these confusing or not relevant to them. **2. Information from additional sources** - Women sought information from online resources and peer-to-peer support. - Peer-to-peer support was perceived as the most useful by women. - This information was perceived to be less valuable than surgeons' information. - Some women resented the additional burden that the need to seek further information represented. - Others commented that they may have been too distressed by the cancer diagnosis to process information. **3. Patients' perception of the adequacy of information for decision-making** - Time for information gathering and assimilation appeared to have been an important consideration for most women.	++

Author (year)	Aims/Research Questions	Location	Methodology	Participant Demographics	Key Findings	Quality Rating
					- Women who did feel well-informed described some decision regret and dissatisfaction with the outcome of the BR. - Women who actively sought information for themselves generally felt their decisions were more informed than those who only relied on information from HPs. - Generally, women who perceived they were well-informed about BR felt this was mainly due to 'luck' or 'good fortune' rather than a standard of care. - Some sources of information were encountered by chance (e.g. peer-support, DVDs, access to other HPs) and appeared to dramatically affect women's decision-making experiences. - More educated women were more motivated to seek out additional information and this appeared to positively influence their experience.	
Sherman et al. (2014)	To develop and evaluate acceptability of a Breast RECONstruction Decision Aid (BRECONDA)	Australia	Mixed methods Telephone interviews – Content Analysis Purposive sampling	Women who had been diagnosed with breast cancer scheduled to undergo a mastectomy and eligible for a BR (n=13) Age range: 31 years - 64 years	**Key findings of the women's perception of the BRECONDA Tool:** - Women described how they benefitted from reading about reconstruction options and viewing the testimonials and photo galleries. - They commended the 'clear' and 'professional' layout and described the ability to tailor the resource to their own preferences as 'invaluable'. - The second theme referred to BRECONDA providing 'support for a difficult decision'. - Women who had not finalised their decision explained how BRECONDA helped them to consider what was personally important, and those who already preferred reconstruction described how it made them feel more secure in their decision.	+
Tollow et al. (2020)	To explore patients' and health professionals' experiences of using the intervention and	UK	Qualitative Semi-structured interviews with women considering BR and healthcare professionals (only	Women considering BR and receiving the PEGASUS intervention (n=11) or receiving the 'usual care' intervention (n=16)	Two key themes were identified in the PEGASUS intervention group: **1. Focus amongst the frenetic** - Participant described the PEGASUS tool as useful to focus their mind and frame discussions regarding BR.	++

Author (year)	Aims/Research Questions	Location	Methodology	Participant Demographics	Key Findings	Quality Rating
	its implementation.		data from women was extracted) – Thematic Analysis (Braun & Clarke, 2006)		- Helped process information at a time when emotions were heightened. - The tool helped to focus decision-making on their own goals and expectations. - Helped to focus conversations with healthcare professionals to ensure they discussed elements which were important to them. 2. **More than a number** - Many women suggested they felt the discussions they had during consultations were focused on their wishes and that clinicians had a good understanding of them as individuals. - Women suggested this experience gave them further confidence in their clinicians and trust in their recommendations. - With PEGASUS, they described their conversations as more open and focussed on their needs. - Participants did not directly attribute these feelings to the PEGASUS intervention but participants describe interactions where PEAGSUS took place. Two themes were identified in the 'usual care' intervention group: **1. Bombarded** - Participants described the initial consultation as overwhelming and difficult to process. - Almost all participants suggested they were unable to take in all the information given to them. - Several women suggested they were tempted to give the decision-making responsibility to their clinician. **2. Process of elimination** - Some women engaged in a self-driven process of elimination. - Several women described undertaking their own research to understand available options and identify own priorities.	

Author (year)	Aims/Research Questions	Location	Methodology	Participant Demographics	Key Findings	Quality Rating
					- This was not presented as a failure of clinician but as a way for women to ensure their choice was right for them. - The self-driven nature if information seeking left some women feeling that information was inaccessible.	
Webb et al. (2018)		Canada	<u>Mixed methods</u> (only qualitative data was extracted) **Qualitative**: Semi-structured interviews - Thematic analysis (Braun & Clarke, 2006) Purposeful sampling from a single surgeon's practice	Women who had recently undergone BR (n=19) Age range: 38 years – 69 years Immediate BR (n=17) Delayed BR (n=2) Length of time between BR and interview: 15-286 days (*M*=108 days)	Five themes related to information delivery and information transference between patient and health professionals were identified: **1. Multiple informant resources** - Most women valued and consulted multiple information resources. - Plastic surgeon was most valued source – women noted plastic surgeon had first-hand experience in pre-, intra-, and post- operative aspects of BR journey and could be a trusted guide to trustworthy online or print resources. - Trustworthy online and printed resources allowed patient to collect information confidently and at their own pace. - Women found bringing a companion to health-care appointments valuable to help remember information. - Women appreciated 2 preoperative consultations which allowed them the opportunity to consider options before making final decision. - Written information was appreciated, but tolerance for the amount of information varied - Patients often noted health nurses did not provide sufficient information relating to BR and often focused on BC. - Individual approach to information provision appeared important. **2. Finding reliable information online** - Many women seek information online - Finding reliable information online was a common concern. - Both positive and negative ramifications for finding frightening material online - Women often compared and contrasted online information to plastic surgeon information.	++

Author (year)	Aims/Research Questions	Location	Methodology	Participant Demographics	Key Findings	Quality Rating
					- Women brought online information to consultations. - Women found comprehensive information online was lacking and questioned objectivity. **3. Seeing numerous photographs** - Was important to women to see numerous photographs of BR. - Women did not feel they had enough access to before and after photographs. - Women would feel reassured by candid photos of ‘normal’ and not normal incisions/wounds - Women thought it was important for them and partner to see final outcome photos. - Women would have appreciated photographs depicting various body types and outcomes. **4. The importance of peer connections** - Patients regularly sought out BR peers - Peer encounters were organised by women themselves with acquaintances whilst some appreciated encounters arranged by the surgeon’s office. - Varied methods of communication were used (e.g. online, telephone and in-person) - Several women found Breast Reconstruction Awareness Day events helpful. - Peer connectedness offers information and information style that may not be covered by professionals. **5. Identifying frequently asked questions** - Even patients who were active information seekers felt that gathering and organising information to inform their decision was daunting. - Resources that addressed common questions can help patients prepare and ease feelings of uncertainty.	

Appendix F: Quality Assessment Summary Table

	Quality Checklist Item														
Author/Year	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**Overall Quality**
Boateng et al. (2021)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Not sure	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	++
Flitcroft et al. (2019)	Appropriate	Clear	Not sure	Not sure	Not described	Unclear	Not sure	Not rigorous	Rich	Unreliable	Convincing	Relevant	Adequate	Appropriate	+
Flitcroft et al. (2020)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Foraker et al. (2023)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Inadequate	Appropriate	++
Hasak et al. (2017)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Jacox et al. (2020)	Appropriate	Mixed	Defensible	Appropriately	Not described	Clear	Reliable	Not rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	++
Potter et al. (2013)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Potter et al. (2015)	Appropriate	Clear	Defensible	Appropriately	Clear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Sherman et al. (2014)	Appropriate	Clear	Not sure	Inadequately reported	Unclear	Clear	Reliable	Not rigorous	Poor	Reliable	Convincing	Relevant	Not sure	Appropriate	+
Tollow et al. (2021)	Appropriate	Clear	Defensible	Appropriate	Clearly described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	++

Webb et al. (2018)	Appropriate	Mixed	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Appropriate	++

Appendix G: Guidelines for Publication of the Empirical Paper (European Journal of Cancer Care)

Submission

At submission you will need to register for a Wiley Researcher ID if you do not already have one (no need to create a new account if you have previously submitted to a Wiley journal or used Wiley Online Library). You will be asked to upload your manuscript file which will automatically be scanned and displayed for you to verify and confirm before submitting. Please note that author details and emails for all co-authors are required at the point of submission. Your manuscript will then be sent on for editorial evaluation and peer review. For technical help, please contact submissionhelp@wiley.com.

Terms of submission

Manuscripts must be submitted on the understanding that they are not published, in press, or submitted elsewhere (with the exception that articles are permitted to be submitted to preprint servers) The submitting author is responsible for ensuring that the article's publication has been approved by all the other co-authors. It is also the submitting author's responsibility to ensure that the article has all necessary institutional approvals. Only an acknowledgment from the editorial office officially establishes the date of receipt. Further correspondence and proofs will be sent to the author(s) before publication, unless otherwise indicated. It is a condition of submission that the authors permit editing of the manuscript for readability. All submissions are bound by the publisher's terms of service.

Peer review

The journal follows a single-anonymized peer review model, for applicable article types.

Information on the Peer Review model can be found here.

Wiley's policy on the confidentiality of the review process is available here.

All submitted articles are subject to assessment and peer review to ensure editorial appropriateness and technical correctness.

Research published in the journal must be:

- Scientifically valid - adhering to accepted community standards of research.
- Technically accurate in its methods and results.
- Representative of a specific advance, or replication, or null/negative result, which is worthy of publication.
- As reproducible as possible - sharing underlying data, code, and supporting materials wherever able.
- Ethically sound and transparent - adhering to best practice with respect to animal and human studies, consent to publish, and clear declaration of potential conflicts of interests, both real and perceived.

In the spirit of sharing findings through our open science mission, emphasis is not placed on novelty, interest, or perceived impact. Replication studies, particularly of research published in this journal, are encouraged.

In order for an article to be accepted for publication, the assigned editor will first consider if the manuscript meets the minimum editorial standards and fits within the scope of the journal. If an article is considered suitable for the journal, the editor will ideally solicit at least two external peer reviewers (who will remain anonymous to the authors unless they choose to disclose their identity by signing the review report) to assess the article before confirming a decision to accept. Decisions to reject are at the discretion of the editor.

Our research integrity team will occasionally seek advice outside standard peer review, for example, on submissions with serious ethical, security, biosecurity, or societal implications. We may consult experts and the editor before deciding on appropriate actions, including but not limited to: recruiting reviewers with specific expertise, assessment by additional editors, and declining to further consider a submission.

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In order to ensure sufficient diversity within the authorship of the journal, authors will be limited to having three manuscripts under review at any point in time. If an author already has three manuscripts under review in the journal, they will need to wait until the review process of at least one of these manuscripts is complete before submitting another manuscript for consideration. This policy does not apply to editorials or other non-peer-reviewed manuscript types.

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When publishing clinical trials, the journal aims to comply with the recommendations of the International Committee of Medical Journal Editors (ICMJE) on trial registration. Therefore, authors are requested to register the clinical trial presented in the manuscript in a public trial registry and include the trial registration number at the end of the abstract. Trials should be registered prospectively before patient recruitment has begun. Where this has not happened, the study must be registered retrospectively, and the date of registration should be clearly stated in the manuscript.

Preregistration of studies

Authors are encouraged to indicate whether the conducted research was preregistered in an independent, institutional registry

(e.g., http://clinicaltrials.gov/, https://www.socialscienceregistry.org/, http://osf.io/, https://egap.org/

registry/, http://ridie.3ieimpact.org/). Preregistration of studies involves registering the study design, variables, and treatment conditions prior to conducting the research.

Preregistration of analysis plans

Authors are encouraged to indicate whether or not the conducted research was preregistered with an analysis plan in an independent, institutional registry (e.g., http://clinicaltrials.gov/, https://www.socialscienceregistry.org/, http://osf.io/, https://egap.org/registry/, http://ridie.3ieimpact.org/). Preregistration of studies involves registering the study design, variables, and treatment conditions. Including an analysis plan involves specification of sequence of analyses or the statistical model that will be reported.

ORCID

At submission, an ORCID iD must be provided for the submitting author(s). If you already have an ORCID iD, you will be asked to provide it.

Article types

The journal will consider the following article types:

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Research articles should present the results of an original research study. These manuscripts should describe how the research project was conducted and provide a thorough analysis of the results of the project. Systematic reviews may be submitted as research articles.

Reviews

A review article provides an overview of the published literature in a particular subject area.

Formatting

We recommend that all manuscripts include line numbers and follow the structure below:

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The following information should be included:

- Manuscript title
- Full author names

- Full institutional mailing addresses
- Email addresses

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Abstract

The manuscript should contain an abstract. The abstract should be self-contained, citation-free, and should not exceed 300 words.

Introduction

This section should be succinct, with no subheadings.

Materials and methods

The methods section should provide enough detail for others to be able to replicate the study. If you have more than one method, use subsections with relevant headings, e.g. different models, in vitro and in vivo studies, statistics, materials and reagents, etc.

The journal has no space restriction on methods. Detailed descriptions of the methods (including protocols or project descriptions) and algorithms may also be uploaded as supplementary information or a previous publication that gives more details may be cited. If the method from a previous article is used then this article must be cited and discussed. If wording is reused from a published article then this must be noted, e.g. This study uses the method of Smith et al. and the methods description partly reproduces their wording [1].

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Results and discussion

This section may be divided into subsections or may be combined.

Main text (review only)

This section may be divided into subsections or may be combined.

Conclusions

This should clearly explain the main conclusions of the article, highlighting its importance and relevance.

Data availability

Authors must include a data availability statement with their submission.

When submitting a manuscript, submitting authors will be asked to select from several pre-written statements or use the text editor to tell us about data availability with regard to their submission. Review our Data Sharing Policy to understand which data availability statement is right for your submission.

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- TREND for non-randomized trials
- PRISMA for systematic review and meta-analyses
- CARE for case reports

- STROBE for observational studies
- STREGA for genetic association studies
- SRQR for qualitative studies
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- ARRIVE for animal experiments

Ethical guidelines

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In the case of any animal experiments, the authors must provide a full description of any anaesthetic or surgical procedure used, as well as evidence that all possible steps were taken to avoid animal suffering at each stage of the experiment. Approval must be obtained from the relevant ethics committee/Institutional Animal Care and Use Committee where required.

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Authors may appeal if they feel that the decision to reject was based on: i) a major misunderstanding over a technical aspect of the manuscript; or ii) a failure to understand the scientific advance shown by the manuscript. Appeals requesting a second opinion without sufficient justification will not be considered. To lodge an appeal, please contact the journal by email, quoting your manuscript number. Appeals will only be considered from the original submitting author.

Appendix H: Social Media Research Advertisement

Participants Needed

What is the study?

Research study exploring women's experiences of making decisions around breast reconstruction following a mastectomy for breast cancer treatment

What to expect

If eligible, you will be invited to participate in a 1-1 interview either in-person or online, depending on your preference. The interview will last approximately 50-60 minutes. You will be invited to tell your story of your experiences of making decisions around breast reconstruction as a woman undergoing treatment for breast cancer.

Eligibility Criteria

1. Female
2. 18+ years of age
3. Received a diagnosis of breast cancer
4. Finished active treatment (excluding hormone therapy)
5. Undergone breast reconstruction following a mastectomy within the last 5 years

Research is being conducted as part of a Doctorate in Clinical Psychology. If interested in participating, please contact Karla on:

✉ **Email:** K.REVELL-2018@hull.ac.uk

☎ **Call/Text:** 07977052451

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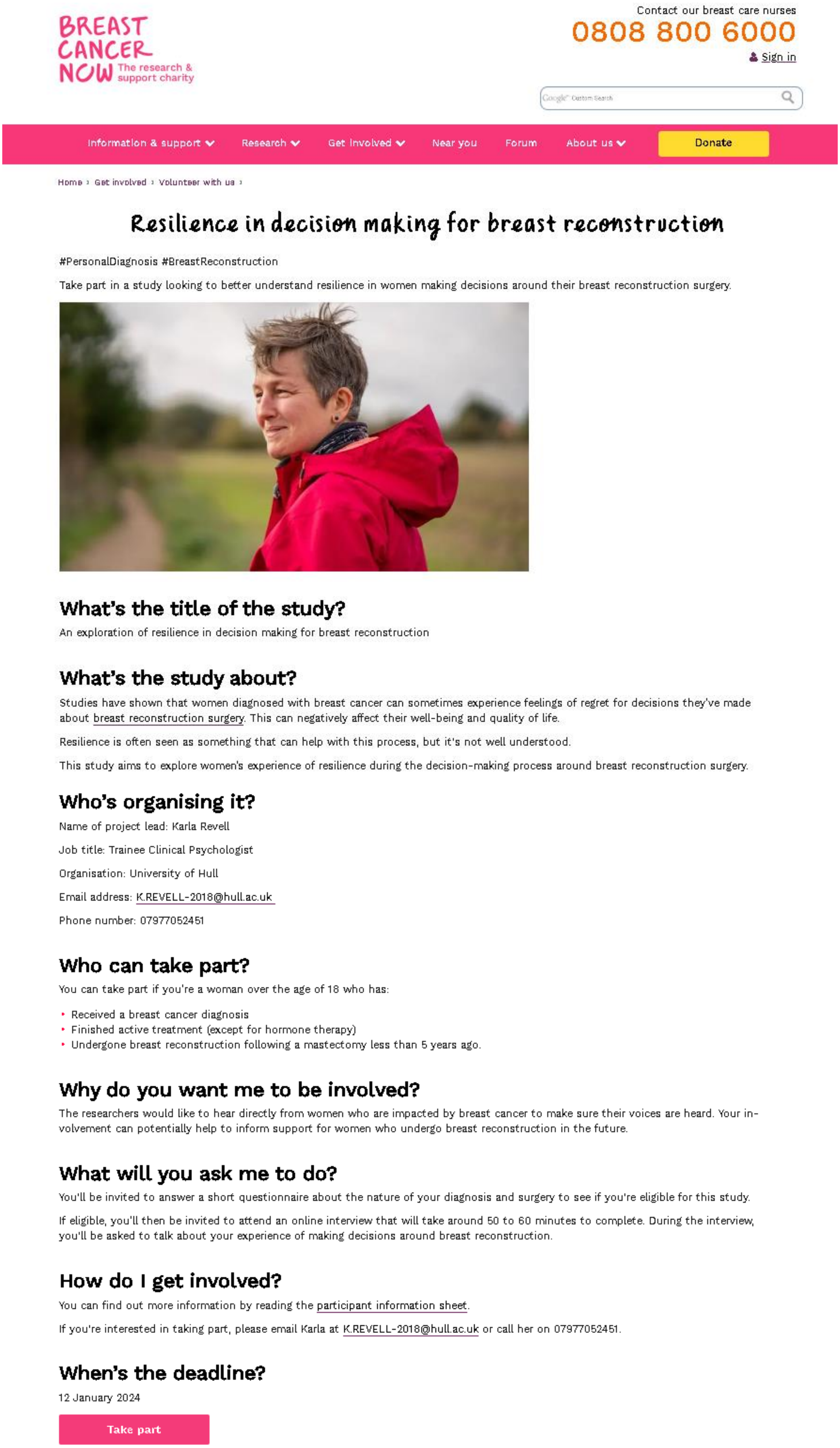
Appendix I: Breast Cancer Now Voices Research Bulletin Advert



Resilience in decision making for breast reconstruction

#PersonalDiagnosis #BreastReconstruction

Take part in a study looking to better understand resilience in women making decisions around their breast reconstruction surgery.

What's the title of the study?

An exploration of resilience in decision making for breast reconstruction

What's the study about?

Studies have shown that women diagnosed with breast cancer can sometimes experience feelings of regret for decisions they've made about breast reconstruction surgery. This can negatively affect their well-being and quality of life.

Resilience is often seen as something that can help with this process, but it's not well understood.

This study aims to explore women's experience of resilience during the decision-making process around breast reconstruction surgery.

Who's organising it?

Name of project lead: Karla Revell

Job title: Trainee Clinical Psychologist

Organisation: University of Hull

Email address: K.REVELL-2018@hull.ac.uk

Phone number: 07977052451

Who can take part?

You can take part if you're a woman over the age of 18 who has:

- Received a breast cancer diagnosis
- Finished active treatment (except for hormone therapy)
- Undergone breast reconstruction following a mastectomy less than 5 years ago.

Why do you want me to be involved?

The researchers would like to hear directly from women who are impacted by breast cancer to make sure their voices are heard. Your involvement can potentially help to inform support for women who undergo breast reconstruction in the future.

What will you ask me to do?

You'll be invited to answer a short questionnaire about the nature of your diagnosis and surgery to see if you're eligible for this study.

If eligible, you'll then be invited to attend an online interview that will take around 50 to 60 minutes to complete. During the interview, you'll be asked to talk about your experience of making decisions around breast reconstruction.

How do I get involved?

You can find out more information by reading the participant information sheet.

If you're interested in taking part, please email Karla at K.REVELL-2018@hull.ac.uk or call her on 07977052451.

When's the deadline?

12 January 2024

Appendix J: Ethical Confirmation Form

UNIVERSITY
OF HULL

University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 463336 | **E:** Maureen.Twiddy@hyms.ac.uk
w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL
Karla Revell
Faculty of Health Sciences
University of Hull
Via email

Wednesday 26th July 2023

Dear Karla,

FHS 22-23.77 – The role of resilience in decision-making for breast reconstruction following a mastectomy in women diagnosed with breast cancer.

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

The approval is valid until 1st June 2024. If you require an extension to this end date or you need to report any further amendments to your study please complete Form C which can be found at Research Ethics (sharepoint.com) for staff and Student Research Ethics (sharepoint.com) for students.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Maureen Twiddy

Dr Maureen Twiddy
Chair, FHS Research Ethics Committee

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OF HULL

Maureen Twiddy | Senior Lecturer in Applied Health Research Methods | Faculty of Health Sciences
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Appendix K: **Information Sheet**

V2.0 18/07/23

INFORMATION SHEET FOR PARTICIPANTS

Title of study: The role of resilience in decision-making for breast reconstruction following a mastectomy in women diagnosed with breast cancer

I would like to invite you to participate in a research project which forms part of my Doctorate in Clinical Psychology research. This study is interested in the experiences of women with breast cancer who have made the decision to undergo breast reconstruction following a mastectomy. The sponsor for this research is the University of Hull**.** Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of the study is to explore the role of resilience during decision-making for breast reconstruction following a mastectomy as treatment for breast cancer. Studies have found that some women experience regret following their treatment decision which can lead to poorer mental health and lower quality of life. Many studies have investigated the overwhelming factors that women must consider and navigate when making these decisions, however, it is unclear what psychological processes might hinder or support women to make these decisions. Resilience has been identified as a positive psychological process in which women successfully adapt to a diagnosis of breast cancer, however, it is unclear what and if aspects of resilience play a role in decision-making for breast reconstruction specifically.

Why have I been invited to take part?

You are being invited to participate in this study because you are female; at least 18 years of age; have received a diagnosis of breast cancer; for which you have finished active treatment (excluding hormone therapy); and have undergone breast reconstruction following a mastectomy in the last five years. Individuals who are still receiving ongoing treatment for breast cancer or have undergone breast reconstruction following a lumpectomy will not be included in this study.

What will happen if I take part?

If you choose to take part in the study you will be asked to participate in a 1-1 interview at a location/online platform that is most appropriate for you (home, local health centre, online). The interview will last 60-75 minutes. If you consent to participate in this study, the interview will be audio recorded on a laptop. The following are some examples of what you will be asked during the interview:

- Could you tell me briefly about your experience of what it was like for you when considering breast reconstruction?
- What would you do the same or different regarding this decision?
- What does resilience mean to you?
- What aspects of resilience felt helpful or unhelpful when making your decision?

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact me if you have any questions that will help you make a decision about taking part. If you decide to take part, I will ask you to sign a consent form and you will be given a copy of this consent form to keep.

What are the possible risks of taking part?

Some people might experience distress when discussing their experiences of living with a diagnosis of breast cancer. I will discuss this with you at the beginning of the interview to form a plan in how you would like to proceed should you feel distressed during the interview. At the end of the interview, there will be time for a debrief and I can direct you to support organisations should you wish to access these.

How will I use information about you?

I will need to use information from you for this research project. I will keep all information about you safe and secure. Only the research team will have access to your data.

Once I have finished the study, I will keep some of the data so I can check the results. I will write my report in a way that no-one can work out that you took part in the study.

Your data will be processed in accordance with the UK-GDPR and the Data Protection Act 2018. Personal information (name, email address and phone number) will be stored on a NHS encrypted laptop in a Microsoft Excel document in case of any follow up questions in relation to interview during transcribing stage. Personal information will be deleted once interview is transcribed.

Research data including transcriptions and demographic information (i.e. age; year of breast cancer diagnosis; year of breast reconstruction procedure; type of breast reconstruction procedure; and whether you had an immediate or delayed breast reconstruction) will be assigned a pseudonym for anonymisation and stored on an NHS encrypted laptop.

What are your choices about how your information is used?

You are free to withdraw from the study at any time without giving any reason. If you withdraw before the point of transcribing data, all your data will be destroyed. If you withdraw from the study after the point of transcribing data, your personal data will be destroyed but your interview and demographic data will be retained and used in the study as this will have been anonymised and will not be identifiable.

Your rights to access, change or move your information are limited, as I need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, I will use the minimum personally identifiable information possible.

Where can you find out more about how your information is used?

You can find out more about how I use your information:

- By asking one of the research team
- By contacting the University of Hull Data Protection Officer by emailing dataprotection@hull.ac.uk or by calling 01482 466594 or by writing to the Data Protection Officer at University of Hull, Cottingham Road, Hull, HU6 7RX
- By reviewing the University of Hull Research Participant privacy notice: https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/docs/quality/research-participant-privacy-notice.pdf

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'

If you are not happy with the sponsor's response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

What will happen to the results of the study?

The results of the study will be summarised in the researcher's thesis for their Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk. The research may also be published in academic journals or presented at conferences. If you want to hear about the results of the study then do contact the researcher, Karla Revell, who will be happy to provide you with a written summary of the research.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by the Faculty of Health Sciences Ethics Committee, University of Hull.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Email: K.REVELL-2018@hull.ac.uk
Phone: 07977052451

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

Dr Emma Lewis
Email: e.lewis@hull.ac.uk

Alternatively, please contact university-secretary@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Support

If you feel that you need support for any reason following your participation in this study, the following contacts might be helpful.

- Your local GP
- Family and friends (your support network)
- Local breast cancer support groups. The Yorkshire Cancer Community have a directory of active local cancer support groups.

  Website: https://yorkshirecancercommunity.co.uk/charity-directory/
- Breast Cancer Now

  Phone: 0808 800 6000
  Website: https://breastcancernow.org/information-support/support-you
- Macmillan Cancer Support

  Phone: 0808 808 0000
  Website: https://www.macmillan.org.uk/cancer-information-and-support

Appendix L: Consent form

V1.0 05/05/23

CONSENT FORM

Title of study: The role of resilience in decision-making for breast reconstruction following a mastectomy in women diagnosed with breast cancer

Name of Researcher: Karla Revell **Please initial box**

1. I confirm that I have read the information sheet dated 05/05/23 version 1.0 for the above study. I have had the opportunity to consider the information, ask questions and have had any questions answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I understand that any data that has been anonymised up to the point of withdrawal will be retained. ☐

3. I understand that the research interview will be audio recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations. ☐

4. I understand that the research data, which will be anonymised (not linked to me), will be retained by the researchers and may be shared with others and publicly disseminated to support other research in the future. ☐

5. I understand that my personal data will be kept securely in accordance with data protection guidelines and will only be available to the immediate research team. ☐

6. I give permission for the collection and use of my data to answer the research question in this study. ☐

7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.
Name of Person taking consent	Date	Signature

Appendix M: Interview Schedule

Introduction to the interview: Thank you for agreeing to take part in this study and joining me today. As you are aware, this study is interested in your experiences of resilience during the time you were making decisions for your breast reconstruction. I have a few questions written down and I might refer to these during the interview, but I'm mostly interested in your experience so please talk about whatever you feel is relevant. Do you have any questions before we begin?

Breast Reconstruction Decision Making

1. Could you tell me about your experience of what it was like for you when considering breast reconstruction?
2. What parts of the decision-making do you feel you were involved/not involved in?
3. What helped or did not help you during this time?
   Prompts: How did you cope with that at the time? What or who supported you during this time?

Participant Meaning of Resilience

1. I'm aware resilience can be a broad subject, so I'm really interested in what it means to you?
2. Where does resilience in yourself come from and how would you describe that?
   Prompts: Past experiences of resilience, what does resilience look like in your life?

Resilience in decision-making

1. Can you recall any of those elements of resilience when you were making your decision?
2. What aspects of that resilience felt helpful or unhelpful when making your decision?
3. How were these aspects maintained or disrupted during this time?
   Prompts: What helped you to hold onto that resilience? Were there times when that resilience felt difficult to hold onto during decision-making? Was there ever times when resilience got in the way of decision-making?

Decisional Satisfaction

1. How have you felt about this decision over time?
2. Why did you/do you feel this way about the decision?

3. What would you do the same or different regarding this decision?

   Prompts: Was there anything you would change about this experience? How do you feel about this decision-now?

Appendix N: Example of data analysis

Data	Descriptive	Emerging themes
P: so you're like assigned a breast cancer nurse, and I	Breast cancer nurse was helpful	
remember going in especially just so they could show me the implants. And they sat down	Actively seeking support to prepare self for implants	**Active participation**
with me, and they went through the bras and stuff like that I'd need. And that was	Sat down with me – sounds supportive	**SDM – support, preparation**
really good, actually to be able to feel it and to get an idea of what it was. And I did. I very	Supported to prepare for what the reconstructed breast would feel like.	
much kept away from Google. But I was looking at breast cancer now website, which I	Avoiding misinformation/information that might evoke fear?	
found amazing. Their forums and things like that, and also the information on there, and	Seeking information external to clinician	**Control/internal locus of control.**
the booklets that the nurses give you, which is from either breast cancer now, or Macmillan, or wherever,	Attending to information from the nurse	**Active participation**
they're written, really well, and they explain everything. And there's so many of them,	Information that is presented well and is detailed helps to inform	**Information is Key**

Data	**Descriptive**	**Emerging themes**
for every like little bit of treatment you go through. There was. There was a lot		
about the kind of the exercises I'd need to do afterwards, and there was advice to try the exercises beforehand. So you	Focusing on information that can support readiness and recovery of surgery	**Proactive/Motivated**
kind of know what your body can do and what feels right before you do the post surgery. So there was a lot of	What body 'can do' – being aware of own limits (Internal locus of control?)	**Internal locus of control**
kind of preparation and almost like, because when you	Preparing self for surgery	
get given the cancer diagnosis, you like, you kind of lose control over a lot of things in your life.	A sense of losing control over elements of their life due to the cancer	**Threat to control**
But then there were things that, you know, I could do. I could be proactive about still, you know, get as much	*Swiftly moving on to* 'what I can do' – not dwelling on loss of control – **change in tone**	**Control/internal locus of control**
information as you can, and from the right people.	'Proactive' – seeking information the 'right' people – who?	**Proactive/Motivated**

Data	**Descriptive**	**Emerging themes**
I: Yeah, thank you for that? Could you tell me a bit more about being proactive?		
P: Yeah. So I think because my breast cancer is the hormone based one. So once I was diagnosed, I had the contraceptive implant. I was told to take that out straight away, and I was also still		
breastfeeding. My he was 2 and a half then, and I was told to stop doing that straight	Taking out birth control from body	
away. But other than that, there wasn't really anything	Stop breastfeeding child – taking away motherhood?	**Threat to control**
that I felt like I had done to get	*'Told to'* – interesting phrasing	**Motherhood/womanhood**
the breast cancer, you know, like relatively healthy. Probably at the time I was the	Searching for 'what had I done to get cancer?'	
fittest I've ever been then, because I did a lot of walking and stuff at that time.	Feeling physically fit before diagnosis	
Don't drink much, don't smoke that kind of thing. But then I was like, well, what can I do,	A past self? – fit, healthy	

Data	**Descriptive**	**Emerging themes**
you know, to firstly, to strengthen myself up for the		
surgery, especially being like underweight I wanted to like put on a bit of weight really. So, a lot of it was like diet based. That's really one of the	'What can I do?' - repeated phrasing. Despite loss of control, searching for ways to be involved in preparation for decision-making.	**Active participation**
only things I could control. And I've got a lot of friends who are	Wanting to prepare self and body for surgery 'strengthen'.	**Locus of control – looking inward**
really health conscious, they're brilliant. And they got me.		
Someone bought me a book called How Not To Die. It sounds horrible, but it just goes through lots of illnesses,	Influenced by friends to focus on healthy behaviours? Accepting social support	
and what specifically the superfoods and stuff you can eat for them. So, it was a chapter on breast cancer. So, I just wrote down a list of	Book 'How Not to Die' – 'sounds horrible' *why does this sound horrible?*	**Social support**
the things I could get and bought them. Green tea things, like that. So, I changed a bit about how I live my life in terms of things like that which is just made me feel like, oh,	Engaging in health behaviours – finding information	

Data	Descriptive	Emerging themes
this. you know, all this is out of my control. I'm going to have to have a year of treatment. Well, more than a year treatment. But this is something that I can do that makes me feel like, yeah, I'm doing something positive I suppose.	A sense of being able to do something 'positive'.	**Positive thinking**