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Psychosexual Impacts of Bilateral Prophylactic
Mastectomy: A Qualitative Analysis of Reddit
Discussions Among Women with a BRCA Mutation

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Preface

Writing this thesis has been one of the most meaningful experiences of my academic journey. I found myself becoming increasingly invested in the stories behind the data. Although my research focused on online narratives, it never felt as though I was analysing anonymous text. Instead, I was reading the experiences of women navigating uncertainty, identity, family, and life-changing decisions. Their stories strengthened my interest in women's health research and reinforced my belief that patients' perspectives should have a more prominent place in healthcare management and research.

I would like to thank my family, friends, and colleagues for patiently listening to me talk about my research for way longer than you probably would have liked to, for encouraging me whenever I needed some motivation, and for believing and supporting me throughout my entire academic journey. Your continuous support has played an invaluable role in helping me reach this milestone, and I could not have done it without you.

Secondly, I would like to thank my fellow thesis student. Going through this process together made the journey much more enjoyable. We supported one another, exchanged ideas, and celebrated each other's progress. The many conversations we had about women's health, our research, and our personal development made this experience more meaningful. I am grateful to have shared this journey with you.

Finally, I would like to express my gratitude to my supervisor. From the beginning, you showed genuine enthusiasm for my research topic and continuously encouraged me throughout the entire process. Your confidence in my abilities gave me confidence in myself, and your thoughtful guidance, constructive detailed feedback, and unwavering support allowed me to grow both as a researcher and as a person. I always felt welcome to discuss ideas, ask questions, and reflect on my work, and I am grateful for the time, dedication, and trust you invested in me. The three of us together created an environment in which I felt empowered by the meaningful conversations we had, which made this thesis project even more valuable.

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Abstract

Background: Women carrying a pathogenic BRCA1 or BRCA2 mutation face a substantially elevated lifetime risk of breast cancer, and many opt for bilateral prophylactic mastectomy (BPM) as a preventive strategy. While BPM significantly reduces cancer risk, its psychosexual consequences, encompassing body image, sexual functioning, intimacy, femininity, and identity, remain insufficiently explored from women's own perspectives.

Objective: This study explores how women with a BRCA1 or BRCA2 mutation describe the psychosexual impacts of BPM in online discussions on Reddit, with particular attention to lived and embodied experiences and identity-related changes.

Methods: An exploratory qualitative design was adopted using reflexive thematic analysis. The sample comprised 129 posts from publicly accessible communities focused on BRCA mutations, BPM, and breast reconstruction. Posts were systematically selected based on predefined inclusion criteria requiring first-person, experience-based accounts of psychosexual, embodied, or identity-related impacts of BPM. The relative anonymity of Reddit was identified as particularly suited to eliciting open discussion of sensitive psychosexual concerns.

Results: Five themes were identified: (1) trading cancer-related fear for peace of mind, (2) mourning the loss of the familiar body, (3) learning to live in a reconstructed body, (4) reclaiming control through preventive surgery, and (5) negotiating femininity, motherhood, and attractiveness. Findings demonstrated that psychosexual experiences following BPM were highly variable and emotionally complex. Women simultaneously described relief and grief, empowerment and bodily alienation, and ongoing processes of adaptation and identity renegotiation.

Conclusion: BPM is not solely a preventive medical procedure but a deeply embodied and emotionally significant life event that reshapes how women experience their bodies, identities, relationships, and futures. The findings highlight the need for more comprehensive preoperative counselling and long-term psychosexual support within hereditary cancer care and demonstrate the value of patient-generated online narratives as a data source for healthcare management research.

Keywords: BRCA mutation, bilateral prophylactic mastectomy, psychosexual wellbeing, embodied identity, qualitative research, Reddit, hereditary breast cancer, body image

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1. Introduction

1.1 Problem analysis

Breast cancer is the most common cancer among women, affecting approximately 13% of the population (National Cancer Institute, 2025). Women carrying a pathogenic BRCA1 or BRCA2 mutation face a substantially increased lifetime risk of developing breast cancer, estimated at 85-90% (Hayes et al., 2023). Following genetic testing, women are confronted with a series of risk management options, including intensified surveillance, chemoprevention, and bilateral risk-reducing mastectomy. While not medically necessary, bilateral prophylactic mastectomy (BPM) is an elective preventive intervention (Heemskerk-Gerritsen et al., 2013). Study indicates that approximately 40% of women with a BRCA mutation opt for BPM, with factors such as prior pregnancy, having a first-degree relative with breast cancer, and cancer-related worry influencing this decision (Henry et al., 2018). The surgery reduces breast cancer risk by approximately 90-95%, making it the most effective available preventive strategy (Rebbeck et al., 2004).

Despite BPM's efficacy of reducing breast cancer risk, it is an invasive and irreversible procedure, with profound consequences for women's bodies and lived experiences. Women with a BRCA mutation often describe a liminal state between health and illness, characterised by vigilance and anticipatory fear of cancer (Dean, 2016). Surgery is frequently framed as a means of regaining control and alleviating anxiety (Hallowell et al., 2004), yet it simultaneously introduces new concerns related to bodily integrity, sexuality, and identity. Importantly, this decision is not only invasive but also irreversible, meaning that women must come to terms with long-term bodily changes. While cancer-related anxiety is often significantly reduced shortly after surgery, research suggests that changes in body image and psychosexual wellbeing may persist over time and may not fully return to pre-surgical levels (Brandberg et al., 2008; Howard et al., 2009; Razdan et al., 2015). This highlights a lasting trade-off between reducing cancer risk and adapting to enduring changes in embodied experience.

In recent years, increasing attention has been paid to the psychosocial consequences of BPM, yet its psychosexual dimension remains less extensively examined. Psychosexual wellbeing encompasses body image, sexual functioning, intimacy, femininity, and sexual self-esteem (Flynn et al., 2016). Empirical studies demonstrate heterogeneous outcomes following BPM. Some women report relief, empowerment, and satisfaction with their decision, while others

experience grief, altered body image, diminished sexual confidence, or ambivalence (Brandberg et al., 2008; Howard et al., 2009). Furthermore, BPM is not a uniform procedure, but a highly preference-sensitive intervention in which women may choose between different reconstructive options when medically feasible. Choices such as implant-based reconstruction, autologous reconstruction (e.g., DIEP flap), nipple preservation, or flat closure each involve distinct implications for bodily appearance, sensation, recovery, and perceptions of bodily authenticity (Cordeiro, 2008; Damen et al., 2011). These decisions therefore extend beyond biomedical risk reduction alone and may substantially shape women's embodied and psychosexual experiences following BPM.

Despite this growing body of evidence, psychosexual concerns remain insufficiently addressed within clinical encounters. Consultations in hereditary cancer care predominantly focus on biomedical risk reduction, surveillance protocols, and surgical outcomes, often leaving limited space for in-depth discussion of sexuality, intimacy, and embodied identity (Dean, 2016; Hallowell et al., 2004). Studies in both oncological and risk-reduction contexts demonstrate that healthcare professionals frequently report discomfort or lack of time when addressing sexual wellbeing, resulting in unmet informational and emotional needs among women (Flynn et al., 2016; Reese et al., 2017).

Taken together, these findings point to a persistent gap in understanding how women with a BRCA mutation themselves experience the psychosexual consequences of BPM. While existing research provides valuable insights into clinical outcomes and biomedical aspects, it offers limited understanding of the lived and embodied dimensions of these experiences, as well as how women experience and renegotiate their identities in relation to them. As a result, important aspects of women's wellbeing may remain insufficiently addressed in clinical care, particularly in relation to sexuality, intimacy, and identity. When these experiences remain underexplored during clinical consultations, women may feel inadequately prepared for the long-term emotional and embodied consequences of BPM, potentially contributing to distress, uncertainty, or difficulties adjusting to postoperative changes. This may limit the extent to which preventive care is experienced as person-centred and responsive to women's lived realities.

1.2 Relevance of the study

From a scientific perspective, existing research is largely dominated by quantitative outcome measures and short-term follow-up, which may inadequately capture the complexity and meaning-making processes underlying women's own perspectives on how BPM reshapes their psychosexual wellbeing (Howard et al., 2009). Consequently, the intersection between embodied surgical intervention, sexuality, and identity remains insufficiently theorised. Addressing this gap is necessary to deepen understanding of how preventive risk management reshapes lived wellbeing beyond functional outcomes.

From a societal and healthcare perspective, the prevailing biomedical focus on statistical risk reduction may marginalise quality-of-life considerations, potentially leading to unmet psychosexual support needs (Reese et al., 2017). Exploring women's own accounts can therefore inform more person-centred preventive care practices by helping healthcare professionals better recognise, discuss, and address concerns related to body image, intimacy, sexuality, and identity before and after surgery. Improving attention to these experiences may contribute to more realistic patient expectations, improved emotional preparation for surgery, and greater support during postoperative adjustment. Online platforms such as Reddit, where semi-anonymous discussion enables open disclosure of sensitive experiences (Barak et al., 2008; Ziebland & Wyke, 2012), provide access to naturally occurring narratives that illuminate how psychosexual wellbeing is articulated outside clinical contexts.

1.3 Research objective and research question

This study explores how women with a BRCA1 or BRCA2 gene mutation describe the psychosexual impacts of BPM in online discussions on Reddit. In clinical settings BPM is primarily positioned as a biomedical risk-reducing intervention aimed at lowering breast cancer incidence and mortality (Heemskerk-Gerritsen et al., 2013). However, research increasingly demonstrates that its impact extends beyond physical outcomes and risk reduction alone. Psychosexual wellbeing plays a central role in how women evaluate and live with the consequences of preventive surgery (Brandberg et al., 2008; Hayes et al., 2023). Despite this, psychosexual outcomes remain insufficiently explored from women's own perspectives, particularly regarding how women experience bodily change, intimacy, and identity following surgery. As a result, healthcare professionals may have limited insight into the everyday

emotional and relational consequences of BPM, even with these experiences playing an important role in women's long-term wellbeing and adjustment after surgery (Hayes et al., 2023).

By adopting a qualitative, exploratory design based on publicly available Reddit discussions, this study analyses naturally occurring narratives in which women articulate their experiences of BPM. Online peer-to-peer platforms provide access to discussions that may differ from responses elicited in clinical or research settings (Ziebland & Wyke, 2012). The semi-anonymous nature of Reddit may further encourage open discussion of psychosexual concerns, which are often underreported in clinical encounters (Barak et al., 2008).

By examining how women describe the psychosexual impacts of BPM in these discussions, this study seeks to contribute to a more holistic understanding of preventive care trajectories in the context of genetic risk, with particular attention to lived and embodied experiences and identity-related changes. To address this gap, the following research question is formulated:

How do women with a BRCA gene mutation describe their lived experiences of the psychosexual impacts of bilateral prophylactic mastectomy on Reddit?

1.4 Reading guide

This thesis is structured as follows. Chapter 2 presents the theoretical framework, in which key concepts such as psychosexual wellbeing and identity are further elaborated and positioned within the existing literature. Particular attention is given to how identity is understood as dynamic and subject to renegotiation in the context of embodied experiences of medical interventions. Chapter 3 outlines the research methods, including the study design, data collection, sampling strategy, and analytical approach. Chapter 4 presents the results of the analysis, focusing on how women describe their psychosexual experiences and identity-related changes. Chapter 5 discusses these findings in relation to the theoretical framework and existing literature, and concludes the thesis by summarising the main findings and outlining implications for further research and practice.

2. Theoretical framework

This chapter develops the theoretical framework that underpins this study. Building on the research problem outlined in Chapter 1, it further explores how the psychosexual impacts of BPM can be understood from an experiential perspective. The framework draws on concepts of psychosexual wellbeing, embodied identity, and identity negotiation to provide a lens through which women's accounts can be interpreted. Together, these concepts enable an analysis of how bodily changes are experienced, how they shape perceptions of self, and how women make sense of these changes in relation to their identities. The framework integrates perspectives from health sciences, psychology, and sociology, thereby enabling a multidimensional understanding of how preventive surgery is experienced not only as a medical intervention, but also as an embodied and socially situated process. In this study, the concepts of psychosexual wellbeing, embodied identity, and identity negotiation function as sensitising concepts (Blumer, 1954) that guide the analysis by directing attention to relevant dimensions of women's experiences while remaining open to emergent meanings within the data.

2.1 The context of BPM

Women who carry a pathogenic BRCA1 or BRCA2 mutation have a substantially elevated lifetime risk of developing breast cancer, with estimates ranging up to 85-90% (Hayes et al., 2023). As a result, preventive strategies play a central role in clinical management. Among these, BPM is considered the most effective intervention, reducing breast cancer risk by up to 90-95% (Rebbeck et al., 2004).

Although the effectiveness of this intervention is well established, its experiential implications are more complex. A key distinction in the literature is that between curative and preventive surgery. While curative mastectomy follows a cancer diagnosis and is embedded in a trajectory of illness and recovery, BPM is primarily performed in the absence of disease. Importantly, BPM is also a highly personal and preference-sensitive decision rather than a medically mandatory intervention. Women may choose whether to undergo surgery at all, as well as which reconstructive pathway to pursue when medically feasible (Damen et al., 2011). This preventive logic fundamentally shapes how the surgery is experienced, as women undergo an irreversible bodily intervention not in response to illness, but in anticipation of potential future disease. This positions women in a unique context characterised by anticipation, uncertainty, and risk

management, in which decisions are made under conditions of risk rather than certainty (Dean, 2016; Witte et al., 2025).

Several studies have described this situation as a liminal state, in which individuals are neither fully healthy nor ill, but instead live with an ongoing awareness of potential disease (Dean, 2016; Timmermans & Buchbinder, 2010). Women with a BRCA mutation are therefore often referred to as “previvors”, a term that reflects living with an increased cancer risk without having developed the disease and highlights the distinctive experiential position between health and illness (Dean & Davidson, 2018). This liminality shapes not only decision-making processes, but also how the consequences of surgery are experienced. Women may frame surgery as a proactive and empowering decision, yet at the same time experience it as a loss of bodily integrity or normalcy (Dean, 2016).

Importantly, these experiences are not uniform and may also change over time. While 61-100% of women who underwent BPM were satisfied with the surgery and 86% reported lower cancer distress afterwards (Razdan et al., 2015), studies also demonstrate that psychosexual and body image outcomes may fluctuate during recovery and adjustment. Brandberg et al. (2008) found that although cancer-related anxiety decreased following surgery, negative effects on body image and sexuality persisted for some women one year postoperatively. Similarly, D’Alonzo et al. (2018) reported that 30% of women described depressed mood following surgery and 35% experienced worsening body image, with some women reporting gradual adaptation over time while others continued to experience distress in the longer term. These findings suggest that BPM cannot be fully understood as a standardised intervention with predictable outcomes, but rather as an experience shaped by temporal, relational, and contextual factors. In addition, variations in surgical approach may further contribute to differences in women’s experiences. Options such as implant-based reconstruction and autologous procedures can result in different physical, sensory, and aesthetic outcomes, which may influence body image, sensation, and perceptions of bodily authenticity (Damen et al., 2011).

2.2 Psychosexual wellbeing definitions

Psychosexual wellbeing is widely recognised as a multidimensional construct encompassing body image, sexual functioning, intimacy, sexual satisfaction, and perceptions of femininity and attractiveness (Flynn et al., 2016; Ussher et al., 2015). It reflects the interplay between physical, emotional, relational, and socio-cultural dimensions of sexuality.

Breasts hold strong symbolic significance within many cultural contexts, often associated with femininity, sexuality, attractiveness, and motherhood. Alterations to this body part may therefore extend beyond physical change to affect how women experience themselves as embodied subjects. Body image theory suggests that perceptions of bodily appearance and integrity are closely tied to self-esteem and sexual confidence (Cash & Pruzinsky, 2002). In oncological research, changes in breast appearance and sensation have been linked to altered sexual self-perception and relational intimacy (Fobair et al., 2006). Although BPM differs from cancer treatment in that it is preventive rather than curative, it similarly involves a transformation of a body part that carries intimate and symbolic meaning.

A substantial body of research has examined psychosexual outcomes following BPM using quantitative measures, such as validated questionnaires assessing sexual functioning or quality of life. These studies have provided important insights, particularly regarding the prevalence of issues such as decreased sexual desire, altered body image, and dissatisfaction with reconstruction outcomes. For example, studies report that approximately 30-40% of women experience a deterioration in body image following surgery, while a substantial proportion also report changes in sexual functioning, including decreased sexual desire and reduced sexual satisfaction (D'Alonzo et al., 2018; Karaçin & Küçükşahin, 2025). At the same time, studies often conceptualise psychosexual wellbeing as a set of measurable outcomes, which may obscure the subjective and contextual nature of these experiences.

Recent qualitative research has sought to address this limitation by exploring how women themselves describe their psychosexual experiences. These studies highlight that psychosexual wellbeing is not solely determined by physical changes but is shaped by how these changes are interpreted and integrated into women's lives. For example, the loss of breast sensation may be experienced as highly distressing by some women, while others may place greater emphasis on the reduced cancer risk and report a sense of relief, highlighting the heterogeneous and context-dependent nature of psychosexual experiences (Brandberg et al., 2008; Dean, 2016; Ussher et al., 2015; Witte et al., 2025).

This has led to a growing recognition that psychosexual wellbeing should be understood as a dynamic and relational concept, rather than a fixed outcome. For this study, psychosexual wellbeing is therefore approached as an experiential and interpretive construct. Rather than treating it as a set of predefined outcomes, it is understood as something that is articulated and negotiated in women's own accounts.

2.3 Identity and embodied identity in health contexts

Identity and embodied identity provide a theoretical foundation for understanding how bodily changes may affect women's sense of self in health-related contexts. Identity is commonly defined as the way individuals understand and define themselves in relation to their bodies, social roles, and personal histories (Giddens, 1991). Within psychological literature, identity has increasingly been conceptualised as a dynamic construct, shaped through ongoing interactions between the body, the self, and the social world (McAdams & McLean, 2013). A key development in this field is the concept of embodied identity, which emphasises that identity is not separate from the body, but fundamentally grounded in bodily experience. The body is not merely an object that individuals possess, but a lived and experienced entity through which they engage with the world (Merleau-Ponty, 1962). As such, changes to the body may disrupt established identities and require individuals to re-evaluate their sense of self.

In the context of BPM, this perspective is particularly relevant. Within many Western contexts, breasts function as highly symbolically charged markers of gendered embodiment. Their preventive removal in the absence of cancer may therefore have implications that extend beyond physical appearance (Fang, 2013; Hallowell et al., 2004). Women may experience changes in how they perceive themselves, as well as how they believe they are perceived by others.

Empirical studies support this view, showing that women may experience shifts in identity following BPM. Some describe feeling less feminine or less attractive, while others report a redefinition of femininity in which womanhood is understood less in relation to physical characteristics and more in terms of personal strength, resilience, or control over one's health (Dempsey et al., 2022; Zeighami Mohammadi et al., 2018). Within many socio-cultural contexts, womanhood is closely tied to bodily features such as the breasts, which are often associated with femininity, sexuality, and motherhood. As a result, their removal may not only alter body image but also challenge broader understandings of what it means to be a woman (Fobair et al., 2006; Hallowell et al., 2004). These findings suggest that identity is not simply lost or preserved but actively reshaped in response to bodily change.

2.4 Identity negotiation as an analytical perspective

While the concept of embodied identity helps explain why bodily changes may affect women's sense of self, it provides less insight into how women actively respond to, interpret, and manage these changes over time. To better understand these processes, the concept of identity negotiation offers an additional analytical perspective. Identity negotiation refers to the ongoing process through which individuals interpret, adjust, and redefine their identities in response to changing circumstances and social interactions (Swann, 2005).

In the context of BPM, identity negotiation therefore concerns the ways women make sense of bodily changes and integrate these experiences into a coherent sense of self (Mathieu et al., 2025). Rather than assuming that identity is either preserved or disrupted, this perspective emphasises the active and continuous process through which women negotiate meanings surrounding femininity, sexuality, attractiveness, motherhood, and bodily normality following surgery. This process may take different forms. Some women may frame surgery as a proactive and empowering choice, incorporating it into a narrative of strength and control. Others may struggle to reconcile changes in their bodies with their previous sense of femininity or attractiveness (Mathieu et al., 2025; Piot-Ziegler et al., 2010).

Importantly, identity negotiation is not only an internal process but is shaped by social interactions and cultural expectations. Norms surrounding femininity, sexuality, and the female body influence how women interpret their experiences and how they believe they are perceived by others (Cash & Pruzinsky, 2002). For example, a study conducted in Middle Eastern contexts has shown that breasts are often strongly associated with motherhood, marital intimacy, and feminine identity, which may intensify feelings of bodily loss or concerns about social acceptance following BPM (Khakbazan et al., 2014). As a result, identity negotiation may unfold differently depending on an individual's social and cultural context, including factors such as cultural norms, relationship dynamics, and personal values. As such, identity negotiation is both a personal and socially embedded process.

Using identity negotiation as a sensitising concept allows this study to move beyond static notions of identity and instead focus on how women describe ongoing changes, tensions, and adaptations in their sense of self following BPM.

2.5 Interrelation between psychosexual wellbeing and identity

The literature suggests that psychosexual wellbeing and identity are closely interconnected and mutually influencing one another (Dean, 2016; Ussher et al., 2015). Changes in body image, sexual functioning, and intimacy may shape how women perceive themselves, while existing identity frameworks influence how such changes are experienced and interpreted. Rather than representing separate domains, the two are best understood as processes that develop jointly in relation to bodily change.

In the context of BPM, this interrelation becomes particularly evident. Women's experiences vary considerably, reflecting differences in personal meanings attached to the body, relational contexts, and broader socio-cultural norms (Dean, 2016; Witte et al., 2025). As a result, psychosexual wellbeing cannot be understood independently from identity, nor can identity be understood without considering embodied and relational experiences. This study therefore approaches psychosexual wellbeing and identity as dynamically interrelated processes that are continuously interpreted and negotiated. Rather than assuming fixed outcomes, it focuses on how women describe and make sense of these changes in their own words.

By adopting this perspective, BPM is understood as an embodied intervention that initiates changes in the body, which in turn shape psychosexual experiences and identity processes influenced by individual, relational, and socio-cultural contexts. In doing so, this study contributes to existing literature by moving beyond a primary focus on measurable outcomes and offering a more nuanced understanding of lived and embodied experiences as articulated by women themselves in online spaces. Furthermore, the study also contributes to broader discussions within healthcare management and person-centred care by highlighting the importance of recognising psychosexual and identity-related experiences within preventive cancer care trajectories. Greater attention to these dimensions may support healthcare professionals in developing more responsive counselling, expectation management, and psychosocial support for women considering or recovering from BPM.

The interrelations between the main concepts of this study are summarised in Figure 1. The model illustrates how BPM leads to bodily changes that shape both psychosexual impacts and identity, which are continuously interpreted through processes of identity negotiation. This conceptualisation provides the foundations for the methodological approach outlined in the next chapter.

Figure 1

Conceptual model of the interrelation between BPM, psychosexual impacts, and identity.



3. Research methods

This chapter outlines the methodological approach used to answer the research question. It describes the qualitative research design, the characteristics of the dataset, and the procedures used for data selection and analysis. Particular attention is given to how relevant posts were identified and systematically analysed using reflexive thematic analysis. The chapter further addresses ethical considerations, as well as matters of validity and reliability with the use of online data.

3.1 Research design

This study adopts an exploratory qualitative research design to examine how women with a BRCA mutation describe their lived experiences of the psychosexual impacts of BPM. Such an approach is particularly suitable in contexts where limited research exists on subjective and experience-based dimensions of a phenomenon, such as the psychosexual and identity-related consequences of BPM. Exploratory qualitative research aims to generate a deeper understanding of how individuals interpret and make meaning of complex experiences within their social and personal contexts, rather than testing predefined hypotheses or measuring predetermined variables (Green & Thorogood, 2018). This is especially relevant for psychosexual wellbeing, which is shaped by emotional, relational, embodied, and identity-related processes that are often difficult to capture through standardised quantitative instruments alone.

The study is based on the analysis of naturally occurring online data derived from Reddit, a large-scale online discussion platform that hosts millions of users worldwide. As of recent estimates, Reddit has over 121 million daily active users and more than 100,000 active communities, known as subreddits, which are organised around specific topics of interest (Reddit, 2025). Reddit users are generally younger and digitally engaged, with previous research indicating a predominance of users from Western countries, particularly the United States (Britt et al., 2023). Communities on Reddit range from general discussion forums to highly specialised health-related subreddits focused on hereditary cancer risk, BRCA mutations, BPM, and breast reconstruction experiences.

Reddit differs from other social media platforms in that it is structured around topic-based communities which allows for discussions between users, rather than personal networks, and

users typically participate under pseudonyms. This relative anonymity reduces the visibility of offline identities and may lower barriers to self-disclosure (Barak et al., 2008). As a result, Reddit has been identified as a valuable data source for studying sensitive and stigmatised topics, including health-related experiences, sexuality, and identity (Suler, 2004; Ziebland & Wyke, 2012).

The choice for Reddit as a data source is therefore closely aligned with the aim of this study, which is to explore how women describe and interpret the psychosexual impacts of BPM. Given the sensitive and intimate nature of psychosexual wellbeing, the semi-anonymous and peer-based environment of Reddit offers a unique opportunity to access rich, experience-based narratives that may not be captured through traditional research methods with pre-defined categories.

3.2 Data source and data collection

The dataset used in this study consists of 100 Reddit posts and 537 associated comments related to BRCA gene mutations. The data were collected prior to the start of this research project by the extended research arm, dr. CAM van Diepen, using Reddit's DevPlatform Actions Infrastructure and provided in the form of a Microsoft Excel file. The dataset includes posts from publicly accessible Reddit communities specifically focused on BRCA1 and BRCA2 mutations, hereditary breast and ovarian cancer risk, and experiences related to BPM and reconstruction.

As the data were pre-collected, no additional data extraction procedures or interactions with Reddit users took place as part of this study. Instead, the focus was on systematically selecting and analysing relevant posts within the existing dataset.

3.3 Sampling and selection criteria

Data screening was conducted in Microsoft Excel. All posts were reviewed and assessed for relevance based on predefined inclusion and exclusion criteria. In this study, the term "post" was used to refer to both original Reddit posts and individual comments. Original posts often introduced experiences or concerns, while comments frequently contained additional reflections, elaborations, or personal experiences relevant to the research question.

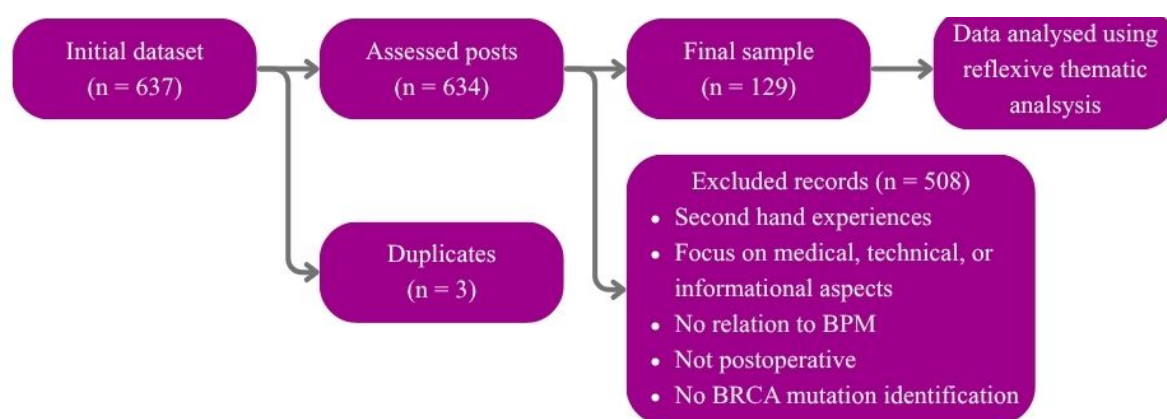
Posts were included if they contained first-person and clearly experience-based accounts of self-identified women with a BRCA mutation discussing the psychosexual, embodied, or identity-related impacts of BPM. These included experiences related to reconstruction, flat closure, body image, sexuality, intimacy, femininity, and postoperative adaptation. Users were included when they explicitly identified themselves as carrying a BRCA mutation, but also when BRCA status could reasonably be inferred from contextual information within the post, such as references to hereditary cancer risk, genetic testing, prophylactic surgery decisions, or participation in BRCA-focused subreddits and discussions. Since the study focused on preventive surgery, posts were only included if the users had not yet developed breast cancer at the time of surgery.

Posts from women with breast cancer but without a BRCA mutation were excluded as well as posts from users who had not yet received a confirmed BRCA diagnosis or had not yet undergone BPM at the time of posting. Furthermore, posts were excluded if they described second-hand experiences, focused exclusively on medical or technical information without reference to lived experiences, concerned non-BPM, or did not contain postoperative or decision-making experiences relevant to the research question.

During the screening process, irrelevant and duplicate posts were systematically removed and stored in a separate worksheet to ensure transparency and traceability of selection decisions. In addition, an audit trail (Appendix 1) was maintained throughout the screening and analytic process to document inclusion decisions, coding developments, and theme refinement. The remaining posts constituted the sample for analysis, consisting of 129 posts. The different stages of inclusion and exclusion are summarised in a flowchart presented in Figure 2.

Figure 2

Flowchart of data selection process.



3.4 Data analysis

The data were analysed using reflexive thematic analysis, following the approach outlined by Braun and Clarke (2019). This method is embedded within an interpretivist epistemology, which assumes that meanings and experiences are socially constructed and interpreted rather than objectively measurable (Braun & Clarke, 2019). This is particularly suitable for identifying and interpreting patterns of meaning across qualitative datasets, while acknowledging the active role of the researcher in the analytic process.

The analysis followed an iterative and reflexive process. First, all included posts were read multiple times to achieve familiarisation with the data and to gain an overall understanding of how psychosexual experiences were described. During this phase, initial impressions and reflections were documented in analytic memos (Braun & Clarke, 2019).

Following familiarisation, the dataset was organised within Microsoft Excel. Posts were structured in a way that allowed for systematic comparison across cases, and relevant excerpts were identified for further analysis. As an initial step in organising the data, posts were inductively grouped into preliminary subtopics based on recurring patterns observed in the dataset. This step functioned as a form of data reduction and helped to structure the subsequent coding process (Braun & Clarke, 2019).

Subsequently, an inductive coding process was conducted (Appendix 2). Although coding remained primarily data-driven, the concepts of psychosexual wellbeing, identity, and identity negotiation functioned as sensitising concepts that informed interpretation without determining coding categories beforehand (Blumer, 1954). Segments of text were assigned descriptive codes capturing key aspects of women's experiences, with particular attention to how bodily changes, sexuality, intimacy, and self-perception were described. Coding remained flexible and iterative, allowing codes to be refined, merged, or expanded throughout the analysis (Braun & Clarke, 2019).

In the next phase, codes were compared across posts and grouped into broader categories, which informed the development of overarching themes. These themes captured recurring patterns in how women described the psychosexual impacts of BPM, including both challenges and adaptive responses. Themes were continuously reviewed and refined to ensure internal coherence and clear distinctions between them (Braun & Clarke, 2019).

The final themes were defined and named in relation to the research question and theoretical framework, ensuring that they captured not only descriptive patterns but also the underlying meanings attributed to psychosexual experiences and identity-related changes (Braun & Clarke, 2019).

3.5 Ethical considerations

This study is based on publicly accessible Reddit data. According to ethical guidelines for internet-mediated research, the use of publicly available online data without informed consent may be considered acceptable when appropriate measures are taken to protect user privacy (British Psychological Society, 2021). Ethical approval and permission for the use of Reddit data were obtained by the extended research arm prior to data collection, including explicit approval from Reddit for the use of the platform data for academic research purposes.

Although the dataset was originally collected and stored by the extended research arm, additional steps were taken in this study to ensure anonymity. Usernames and other directly identifying information were not retained in the working dataset. During the analysis, all data were further anonymised by removing or generalising potentially identifying details. In addition, all quotations were paraphrased to reduce traceability through search engines, which was later verified by conducting a reverse search on several quotations.

Despite Reddit's publicly accessible content, the study treats users as individuals discussing potentially sensitive health-related experiences. Therefore, careful consideration was given to the ethical handling and representation of the data. The anonymised working dataset was securely stored during the research process and will be destroyed after project completion, following completion of the project.

3.6 Validity and reliability

In qualitative research, validity is often conceptualised in terms of credibility, transparency, and reflexivity rather than statistical generalisability (Leung, 2015). At the same time, it is important to acknowledge the contextual nature of the dataset. Because Reddit users participate anonymously, background information was only available when provided by the user itself. As a result, the study cannot make claims about how representative the dataset is of the broader

population of women with a BRCA mutation who underwent BPM. Existing research does suggest that Reddit users are more commonly younger and digitally engaged individuals from predominantly Western contexts (Britt et al., 2023), which provides important context for interpreting the findings.

Several strategies were applied to ensure the rigour and transparency of the study. First, a systematic and transparent approach to data selection and analysis was applied. All inclusion and exclusion decisions were documented throughout the screening process, and a structured audit trail was maintained. This audit trail included detailed records of data screening decisions, coding iterations, theme development, and analytic reflections. Analytic memoing was additionally used throughout the coding process to document emerging interpretation, uncertainties, and reflexive considerations. As a result, the analytic process can be traced from raw data to final themes, enhancing the transparency and dependability of the findings.

Second, reflexive thematic analysis acknowledges the interpretive role of the researcher (Braun & Clarke, 2019). Throughout the analytical process, reflexivity was therefore actively practiced through continuous reflection on how my positionality, assumptions, and interpretive choices may have shaped coding and theme development. This included the use of analytic memos during coding and repeated discussions of emerging interpretations, emphasising that themes are not simply derived from the data but are actively constructed through interpretation.

Finally, consistency in the analytic procedure was supported by repetitive engagement with the data. The dataset was read multiple times, codes were systematically reviewed and refined, and themes were repeatedly checked against the dataset to ensure coherence and meaningful representation of the data as a whole.

4. Results

This chapter presents the findings of the thematic analysis addressing the research question of how women with a BRCA mutation describe the psychosexual impacts of BPM on Reddit. Following the screening and selection process described in the methodology chapter, posts containing lived experiences of psychosexual wellbeing, embodiment, identity, and relational experiences were included in the analysis.

Five overarching themes were identified through reflexive thematic analysis (Braun & Clarke, 2019): (1) trading cancer-related fear for peace of mind, (2) mourning the loss of the familiar body, (3) learning to live in a reconstructed body, (4) reclaiming control through preventive surgery, and (5) negotiating femininity, motherhood, and attractiveness. Together, these themes illustrate the complex and highly variable ways in which women described the psychosexual impact of BPM. Experiences ranged from grief, bodily alienation, and emotional distress to empowerment, relief, and renewed feelings of control over the future.

4.1 Trading cancer-related fear for peace of mind

A prominent theme throughout the dataset concerned the reduction of cancer-related anxiety following BPM. Many women described living with BRCA as a persistent psychological burden characterised by fear, hypervigilance, repeated screening, and anticipation of future illness. Within these narratives, surgery was frequently framed as a difficult but necessary intervention that provided emotional relief and a greater sense of safety.

Several women described feeling consumed by the anticipation of cancer prior to surgery, particularly in the context of extensive family histories of breast or ovarian cancer. They often referred to a constant awareness of risk that shaped their daily lives and future planning. For some women, BPM marked the first time they felt able to mentally disengage from the possibility of developing cancer.

“I was a bit older (35) when I had my surgery, 6 months after I tested positive for BRCA and a year after losing my 4th aunt. I’ll say this – it really helped me finally reach a headspace where I wasn’t constantly looking over my shoulder, waiting for cancer to show up.”

Similarly, another woman described feeling as though her body represented an inevitable future illness before surgery. She explained that her high estimated cancer risk caused her to feel like a ticking time bomb, while surgery immediately relieved a longstanding emotional burden.

“The journey will have its ups and downs, however when I woke up this afternoon, it felt like a huge weight has been lifted off of me. I’m glad that I won’t have to have regular screenings anymore or feel that pang of anxiety with every new lump that forms.”

For many women, the emotional relief experienced after surgery outweighed the physical consequences of BPM and reconstruction. Women frequently acknowledged ongoing numbness, scarring, discomfort, or altered sensation while simultaneously describing the procedure as worthwhile because of the reduction in cancer-related fear.

“I’m now 8 months post implant exchange surgery and couldn’t be happier. Sure, there’s no feeling and some scars. I wake up every morning and flip each implant before I brush my teeth. But I never ever think about cancer. It’s incredibly freeing.”

Others similarly framed surgery as emotionally difficult but ultimately necessary for achieving peace of mind. The reduction in anxiety was also closely connected to broader perceptions of future health and survival. Several women described realising only after surgery how strongly fear and medical surveillance had shaped their quality of life. Women frequently reflected on the emotional exhaustion associated with repeated MRI scans, mammograms, biopsies, or ongoing monitoring.

“I ended up getting a double mastectomy and I knew I would probably feel relieved but didn’t think it would have such a positive influence on so many aspects of my life. Everything just feels different, mostly in a good way.”

Although relief was a dominant pattern within this theme, posts also demonstrated that peace of mind rarely eliminated grief or physical discomfort entirely. Instead, women frequently described BPM as a trade-off in which bodily loss and emotional hardship were accepted in exchange for reduced cancer-related anxiety.

4.2 Mourning the loss of the familiar body

Alongside relief, many women described profound feelings of grief, bodily estrangement, and emotional distress following BPM. Surgery was experienced not only as a preventive medical

intervention, but also as a disruption of familiar embodiment, sensuality, and bodily identity. Women frequently reflected on the emotional impact of losing a familiar and embodied part of themselves, particularly in relation to bodily continuity, physical sensation, and everyday experiences of inhabiting their bodies.

Loss of sensation emerged as one of the most commonly discussed bodily changes. Many women described mourning the absence of physical feeling in their breasts and nipples, particularly the loss of erotic sensation. Even among women who were satisfied with their reconstructive outcomes aesthetically, altered sensation remained emotionally significant.

“Aesthetically, I did direct to implant and kept both skin and nipples. My boobs look better than they did before. From a sensation perspective it’s not the same. First year I barely registered sensation but that has improved: I can tell all touch now although my nipples haven’t gotten back their erotic feeling.”

Similarly, several women explained that the emotional difficulty of losing sensation remained present despite otherwise positive surgical outcomes. For these women, grief was not necessarily connected to dissatisfaction with the surgical decision itself, but rather to the loss of bodily familiarity and sensual experience.

Many women additionally described experiences of bodily estrangement during the early postoperative period. They frequently reported feeling emotionally disconnected from their reconstructed bodies immediately after surgery, particularly when confronted with scars, swelling, asymmetry, or unfamiliar physical sensation. Women often described shock or emotional destabilisation when first seeing their altered bodies.

“Recovery from the 1st surgery was not painful but mentally very challenging. There’s nothing that can prepare you for a part of your body looking so different.”

Others described distress related to ongoing physical changes that occurred throughout the healing process, during which the reconstructed body often remained unfamiliar and unstable for extended periods of time.

“It’s been 5 weeks since my DTI mastectomy and I’m having a real emotional dip [...] I feel kind of mutilated. They feel hard and don’t look as amazing as like two weeks past surgery.”

For some women, complications and revision procedures intensified these feelings of bodily distress. In these accounts, women described dissatisfaction and self-consciousness when

complications altered the expected appearance of reconstruction outcomes or prolonged recovery.

“My breasts did not accept the donor area fat and turned a lot of it into giant lumps that resemble visible tumors on the surface of my breast skin. I’m extremely self-conscious wearing a swimsuit or low-cut top.”

Despite these experiences of grief and bodily disruption, many women continued to frame surgery as necessary or worthwhile. Across the dataset, emotional loss and perceived medical necessity frequently coexisted within women’s accounts of BPM.

4.3 Learning to live in a reconstructed body

Many posts described adaptation to the postoperative body as an ongoing and gradual process rather than a single moment of acceptance. Women frequently explained that both physical and emotional adjustment took considerably longer than anticipated, but that over time their reconstructed bodies became increasingly familiar and integrated into daily life. Rather than returning to a pre-surgical state, women often described developing a “new normal” in relation to their bodies.

Several women described initially feeling disconnected from their reconstructed breasts because implants felt unfamiliar in movement, texture, or sensation. Over time, however, many explained that this sense of unfamiliarity gradually diminished as they became more accustomed to their postoperative bodies.

“It takes a while to get used to implants [...] They don’t feel or move like regular boobs, but truly with clothes on they look exactly the same as my original set. Even naked I think my brain has finally connected the dots and understands these are my new boobs now.”

Women additionally identified several factors that supported adaptation, including physical therapy, online peer support, patience, and gradual re-engagement with daily activities. Returning to sports, work, childcare, or exercise often contributed to a renewed sense of bodily confidence and normality.

“The further along I got in physical therapy I started to feel more connected to my new boobs and realized I made the right decision for me.”

Many women described adaptation as a process of relearning bodily normality in which numbness, tightness, implants, or altered sensations slowly became part of daily life. However, experiences of adaptation varied considerably. While some women eventually described high levels of comfort and acceptance, others continued to experience ongoing discomfort, emotional ambivalence, or awareness of bodily difference.

Some women additionally expressed surprise that reconstruction outcomes appeared more aesthetically satisfying or natural than anticipated, which positively influenced postoperative adjustment.

“My new breasts look great, almost exactly the same as before. I have more sensation than I thought I would have and I’m doing all the sports as before without any issues or discomfort.”

Importantly, adaptation was rarely described as linear. Women frequently emphasised that emotional wellbeing and physical healing fluctuated over time and that recovery was often slower and more unpredictable than expected.

“Things will keep changing for a while. The feeling changes, the way they feel to touch changes, and eventually, you and your new boobs will find a way of fitting together.”

These accounts demonstrate that adaptation following BPM was understood as a long-term embodied process involving continuous renegotiation of comfort, identity, and bodily normality. But experiences of adjustment were not uniform across the dataset. Some women described eventually incorporating their reconstructed bodies into everyday life with increasing ease, whereas others continued to describe persistent awareness of bodily difference or unresolved emotional discomfort related to postoperative changes.

4.4 Reclaiming control through preventive surgery

Another important theme concerned the experience of agency, empowerment, and control in relation to hereditary cancer risk. While paragraph 4.1 focused primarily on relief from cancer-related fear, this theme specifically reflected how women framed BPM as an active and intentional decision through which they reclaimed autonomy over bodies perceived as vulnerable to future illness.

Women frequently described surgery as a proactive response to family history, genetic risk, and ongoing medical surveillance. Rather than waiting for cancer to develop, women often emphasised the importance of taking action while still healthy.

“Best decision I ever made for my health [...] You have an opportunity to advocate for your health and make a decision that could potentially save your life.”

Similarly, several women described surgery as strengthening their sense of self-advocacy and ownership over healthcare decisions. In these accounts, empowerment was associated with actively making difficult choices rather than passively living with uncertainty.

“Being on the other end of surgery, I am a better advocate for myself and a healthier person mentally and physically.”

Many women framed surgery as an act of self-preservation and personal strength despite the emotional and physical difficulty associated with BPM.

“There is nothing like going through these choices and surgery to save your own life.”

Feelings of agency were also closely connected to future planning and family responsibilities. Women frequently described wanting to remain present for their children or future families, which shaped both the timing and interpretation of surgery.

Several women additionally described making strategic decisions regarding reconstruction methods, fertility planning, or timing of surgery in order to maximise long-term control over their health and recovery trajectory.

“I decided to go flat to avoid multiple surgeries and get back to normal as quickly as possible. I’m much happier than if I had tried to reconstruct.”

Although BPM was often described as emotionally difficult, many women simultaneously framed the procedure as an act of empowerment and self-preservation. Within these narratives, surgery became associated not only with reducing cancer risk, but also with reclaiming ownership over the future.

4.5 Negotiating femininity, motherhood, and attractiveness

The psychosexual impact of BPM was closely intertwined with broader questions surrounding femininity, motherhood, and attractiveness. Women frequently reflected on how surgery affected their sense of womanhood, reproductive identity, and bodily self-perception.

One recurring issue concerned breastfeeding loss and reproductive sacrifice. Several women described grieving the inability to breastfeed future children following BPM, even when they remained confident in their surgical decisions overall. Within these accounts, breastfeeding was often associated with motherhood, bonding, or expectations surrounding the maternal body.

“Not being able to breastfeed has been emotionally more difficult than I expected, but I still don’t regret choosing to have my surgery before kids.”

Motherhood additionally shaped the timing and interpretation of surgery. Some women chose to undergo BPM before pregnancy to reduce future anxiety, while others delayed surgery specifically because they hoped to breastfeed.

“Breastfeeding didn’t go very well and only lasted a few months, and surgery scheduling/recovery is SO much more complicated with childcare in the mix. I wish I had gotten surgery out of the way before getting pregnant.”

Experiences of femininity and sexuality were similarly negotiated through women’s own changing understandings of attractiveness and womanhood. Several women described fears that surgery would negatively affect their femininity, attractiveness, or sexual identity, particularly in relation to nipple loss, scarring, or altered sensation. At the same time, some women described reconstruction as positively influencing body confidence and femininity.

“Keeping my nipples makes me feel like a woman and I even feel sexier because my breasts are bigger.”

Others described gradually reconciling feelings of bodily loss with evolving understandings of femininity and attractiveness that became less dependent on their pre-surgical bodies.

“It’s worth it [...] Sometimes it’s weird looking at myself, especially as I didn’t do nipple sparing but I’d still do it again.”

Relational support additionally shaped how women navigated postoperative changes and bodily insecurity. Several women described feeling reassured by supportive partners who continued to affirm their attractiveness and femininity following surgery.

Across the dataset, psychosexual wellbeing following BPM extended far beyond surgical recovery alone. Women's experiences were deeply connected to broader negotiations of embodiment, reproductive futures, femininity, sexuality, and self-perception.

5. Discussion

The aim of this study was to explore how women with BRCA1 or BRCA2 mutations described the psychosexual impact of BPM on Reddit. Building on existing literature regarding hereditary cancer risk, embodiment, and psychosexual wellbeing, this study applied a qualitative research design using reflexive thematic analysis (Braun & Clarke, 2019) to analyse online patient-generated accounts shared on Reddit. By examining women's lived experiences in an anonymous digital environment, the study sought to answer the following research question: *How do women with a BRCA gene mutation describe their lived experiences of the psychosexual impacts of bilateral prophylactic mastectomy on Reddit?*

The findings demonstrated that psychosexual experiences following BPM were highly variable, emotionally complex, and often contradictory. Women simultaneously described relief and grief, empowerment and bodily alienation, as well as adaptation and ongoing loss. While many women framed surgery as liberating because it reduced cancer-related anxiety, they also described significant disruptions to embodiment, femininity, sexuality, and reproductive identity. Over time, however, many women developed new understandings of their bodies and identities through processes of adaptation and renegotiation.

This discussion chapter interprets these findings in relation to existing literature and broader theoretical debates surrounding psychosexual wellbeing, embodiment, preventive healthcare, and hereditary cancer risk. The discussion synthesises the findings into three broader interpretative areas: the coexistence of relief and grief after BPM, adaptation and the renegotiation of embodied identity, and autonomy, femininity, and reproductive decision-making. Together, these themes provide insight into the multidimensional psychosexual consequences of BPM and demonstrate the value of online patient narratives for healthcare management research.

5.1 Relief and grief as coexisting experiences

One of the central findings of this study was that BPM was simultaneously experienced as emotionally relieving and emotionally painful. Women frequently described surgery as reducing persistent cancer-related anxiety and uncertainty, while at the same time confronting them with grief, bodily loss, and emotional distress. Rather than presenting BPM as either

empowering or traumatic, the findings demonstrate that these experiences often coexisted within women's narratives.

Many women described living with BRCA as a constant psychological burden characterised by fear, hypervigilance, and anticipation of future illness. Surgery was therefore commonly framed as a way to regain peace of mind and reduce the emotional burden associated with ongoing cancer surveillance. These findings align with previous literature demonstrating that women with a BRCA mutation often experience chronic uncertainty and anxiety throughout the broader BRCA trajectory, particularly in relation to ongoing surveillance, anticipatory fear, and future cancer development (Dean, 2016; Timmermans & Buchbinder, 2010). Other studies similarly found that BPM can significantly decrease cancer-related distress and improve psychological wellbeing among women at high hereditary risk (Brandberg et al., 2008; D'Alonzo et al., 2018; Razdan et al., 2015).

The current findings further support Dean and Davidson's (2018) argument that women with hereditary cancer risk actively seek strategies to manage uncertainty and regain psychological stability. They frequently described surgery as worth it, despite physical pain, numbness, or bodily change because it removed the constant fear of cancer. Several women described finally being able to stop anticipating illness or looking over their shoulder after surgery. In this sense, BPM appeared to function not only as a preventive medical intervention, but also as a psychological strategy aimed at restoring emotional security and reducing anticipatory fear. Previous qualitative research similarly describes preventive surgery as a means through which women attempt to regain control over uncertainty and reclaim a sense of psychological stability (Hallowell et al., 2004; Piot-Ziegler et al., 2010).

At the same time, the findings demonstrate that relief did not eliminate grief or emotional hardship. Women often described simultaneously mourning the loss of sensation, familiarity, or bodily normality while remaining confident in their decision. This coexistence of emotional relief and bodily grief was one of the most striking patterns within the dataset. Women frequently framed surgery as a trade-off in which emotional and physical sacrifices were accepted in exchange for reduced cancer anxiety and a perceived safer future.

Existing literature recognises the coexistence of emotional relief and bodily grief as a common experience among women undergoing BPM, particularly within hereditary cancer contexts where preventive surgery involves sacrificing a healthy body part to avoid a future illness that may never occur (Dean, 2016; Piot-Ziegler et al., 2010). The current findings reinforce this

emotional ambivalence by demonstrating how women openly articulated both reassurance and loss within the same narratives.

The nature of the Reddit platform may also have contributed to the visibility of these emotionally ambivalent narratives. The relative anonymity of online discussion forums can provide space for individuals to disclose complex or conflicting emotions that may be less readily expressed during clinical consultations or in face-to-face research settings (Barak et al., 2008; Ziebland & Wyke, 2012). As such, the data may offer particularly rich insight into the coexistence of relief, grief, and uncertainty surrounding BPM.

The tension between reassurance and loss reflects broader literature surrounding hereditary cancer risk and liminality. Timmermans and Buchbinder (2010) describe women with a BRCA mutation as patients-in-waiting, occupying an uncertain position between health and illness. Similarly, Dean (2016) found that many women with a BRCA mutation experience themselves as living in anticipation of disease rather than in a state of full health. Within the present study, BPM appeared to partially resolve this uncertainty by replacing future-oriented fear with a sense of action and protection. However, surgery simultaneously introduced new emotional and embodied challenges, suggesting that the transition from risk surveillance to postoperative recovery does not fully eliminate psychological complexity.

Importantly, women's experiences of grief were not limited to aesthetic dissatisfaction alone. They described emotional pain associated with numbness, altered bodily sensation, physical complications, and the confrontation with a changed body. These findings support earlier qualitative work by Piot-Ziegler et al. (2010), who argued that BPM can disrupt women's sense of bodily continuity and familiar identity. The current study therefore demonstrates that relief and grief should not be conceptualised as opposite outcomes, but rather as intertwined emotional responses to prophylactic mastectomy.

Overall, the findings suggest that psychosexual wellbeing following BPM cannot be understood through simplistic positive or negative outcomes alone. Instead, women's experiences were characterised by emotional ambivalence, in which feelings of safety, empowerment, grief, and bodily loss continuously coexisted and interacted.

5.2 Adaptation and the renegotiation of embodied identity

A second major finding concerned the long-term process of adapting to the reconstructed body and renegotiating embodied identity after BPM. Women frequently described reconstruction and recovery not as a return to their pre-surgical selves, but as a gradual process of becoming familiar with a changed body and developing a new sense of bodily normality.

Many women described initial feelings of estrangement from their reconstructed breasts. Altered sensation, numbness, scars, asymmetry, and changes in physical movement often created a sense of bodily unfamiliarity, particularly during the early postoperative period. Previous research has similarly shown that reconstruction following BPM may alter women's experiences of bodily familiarity, physical movement, and sensory embodiment, particularly during the early postoperative period (Cash & Pruzinsky, 2002; Fobair et al., 2006). In the present study, women frequently described not only altered appearance, but also difficulty recognising or emotionally inhabiting their postoperative bodies during the adjustment process.

The findings can further be understood through Merleau-Ponty's (1962) concept of embodiment, which conceptualises the body as central to how individuals experience themselves and interact with the world. Women in this study did not only describe physical changes, but also disruptions in how they emotionally inhabited and recognised their bodies. Feelings of numbness or altered sensation therefore represented more than cosmetic concerns alone. They also reflected changes in embodied self-experience. Several women described difficulty emotionally connecting to reconstructed breasts during the initial recovery period, suggesting a temporary disruption in bodily continuity.

At the same time, many women also described adaptation as a gradual and ongoing process through which reconstructed breasts slowly became integrated into daily life. They frequently explained that over time their new boobs began to feel more familiar, while numbness or tightness became less psychologically noticeable. This supports previous longitudinal findings demonstrating that body image and satisfaction after reconstruction can evolve positively over time (Dempsey et al., 2022; Fang et al., 2013). Importantly, however, women rarely described adaptation as a complete return to their pre-surgical body. Instead, they appeared to negotiate a revised sense of normality that incorporated scars, altered sensation, and bodily difference into everyday identity.

This process of adaptation can additionally be interpreted through theories of narrative identity. McAdams and McLean (2013) argue that individuals construct coherent identities by

integrating major life experiences into personal narratives. Within the present study, women frequently described reframing reconstruction outcomes and bodily changes over time. Some became proud of their scars or viewed reconstructed breasts as symbols of survival and resilience rather than solely as signs of loss. In this sense, adaptation involved not only physical recovery, but also psychological meaning-making and identity reconstruction.

Importantly, the findings also revealed substantial variability in women's experiences of adaptation. While some gradually developed acceptance and bodily familiarity, others continued to experience dissatisfaction, emotional alienation, or body dysmorphia years after surgery, particularly following complications or revision procedures. These findings reinforce earlier research suggesting that psychosexual outcomes after BPM are highly individual and shaped by both physical and psychosocial factors (Fobair et al., 2006; Ussher et al., 2015).

The characteristics of Reddit as a data source may also have contributed to the visibility of this variability. The platform's relative anonymity appeared to encourage women to share detailed reflections on both positive and difficult aspects of long-term recovery, including experiences of uncertainty, ongoing dissatisfaction, and changing perceptions of their bodies over time. Consequently, the data provided particularly rich insight into adaptation as an evolving process, rather than as a single postoperative outcome.

Overall, the findings suggest that adaptation after BPM should be understood as an ongoing embodied and identity-based process rather than a finite stage of recovery. Women did not simply recover from surgery, but continuously renegotiated their relationships with their bodies, femininity, and self-perception over time. Importantly, the findings also demonstrated that adaptation was rarely linear or complete. While some women gradually incorporated bodily changes into everyday life with increasing ease, others continued to experience fluctuating feelings of estrangement, discomfort, or emotional ambivalence long after surgery. Adaptation appeared highly unstable and context dependent, with moments of acceptance often coexisting alongside renewed confrontation with bodily difference during physical activity, daily chores, or postoperative complications. This highlights that psychosexual adjustment following BPM may remain an ongoing and dynamic process rather than a final stage of recovery.

5.3 Autonomy, femininity, and reproductive decision-making

The third major finding concerned the interconnected relationship between autonomy, femininity, and reproductive decision-making among women undergoing BPM. They frequently described how decisions surrounding surgery, reconstruction, breastfeeding, fertility, and motherhood became deeply intertwined with broader questions of identity, bodily autonomy, and future planning.

Many women framed BPM as an active and self-directed decision that allowed them to regain control over a body perceived as vulnerable to future illness. These findings align with previous research demonstrating that women with a BRCA mutation often experience preventive surgery as a proactive form of health management and self-protection (Howard et al., 2009). Women frequently described making deliberate decisions regarding reconstruction type, timing of surgery, and fertility planning in order to maximise long-term wellbeing and reduce future uncertainty. In this sense, BPM was commonly experienced as an act of autonomy rather than passivity.

At the same time, women's accounts demonstrated that autonomy was often closely connected to reproductive futures and family roles. Several women described choosing surgery before pregnancy in order to reduce anxiety during future motherhood, while others postponed surgery because they hoped to breastfeed future children. Feelings surrounding breastfeeding loss emerged repeatedly throughout the dataset and were often described as emotionally significant, even among women who remained confident in their surgical decision. These findings correspond with earlier work by Hayes et al. (2023), who demonstrated that women with a BRCA mutation of reproductive age frequently experience tension between cancer risk management and reproductive desires. Their findings specifically highlight concerns surrounding breastfeeding loss, fertility timing, bodily autonomy, and anticipatory guilt regarding future motherhood, all of which strongly resonated with the current dataset.

Importantly, women's narratives demonstrated that reproductive decision-making involved ongoing negotiation between personal wellbeing and socially embedded expectations surrounding femininity and motherhood. Several women described grieving the inability to breastfeed while simultaneously prioritising long-term survival and future presence within their families. This demonstrates how BPM decisions extended beyond medical risk reduction alone and became embedded within broader understandings of womanhood, caregiving, and maternal identity.

Experiences of femininity and attractiveness were similarly complex and highly variable across posts. Importantly, unlike women undergoing breast cancer treatment, women choosing BPM undergo surgery in the absence of active disease. As a result, psychosexual consequences are not weighed against immediate cancer treatment itself, but rather against the anticipation of a possible future illness. Several women in the present study appeared highly aware of this distinction and reflected on whether bodily loss, numbness, or altered femininity felt justified without ever having developed cancer.

Previous research has shown that breast cancer treatment and BPM can significantly affect body image, sexuality, and feminine identity (Fobair et al., 2006; Ussher et al., 2015). Within the present study, some women feared that surgery would negatively affect attractiveness, sexuality, or feelings of femininity, particularly in relation to nipple loss, scarring, or flat closure. Others, however, described reconstruction as positively influencing confidence or attractiveness, particularly when aesthetic outcomes aligned with personal body ideals.

These findings support Zeighami Mohammadi et al.'s (2018) argument that feminine identity following breast-related surgery is not fixed, but continuously reconstructed through coping strategies, social interactions, and changing self-perceptions. Similarly, Swann's (2005) theory of identity negotiation suggests that identity is shaped through ongoing interactions between self-perception and perceived social recognition. Women in this study frequently described renegotiating femininity through reconstruction decisions, changing body image, motherhood expectations, and relational experiences.

Relational support also played an important role within women's experiences of autonomy and psychosexual adjustment. Supportive partners, family members, and online communities frequently reduced anxiety surrounding bodily change and helped women navigate feelings of vulnerability or insecurity. Previous research demonstrates that emotional reassurance, partner responsiveness, and open communication about bodily insecurity and sexuality can significantly influence psychosexual adjustment following breast-related surgery (Manne & Badr, 2008; Reese et al., 2017). Women in the present study similarly described supportive partners and peer communities as important sources of validation and emotional normalisation.

Additionally, Reddit itself appeared to function as an important space for experiential knowledge-sharing and emotional validation. Women openly discussed intimate concerns surrounding sexuality, reproduction, bodily dissatisfaction, and emotional distress in ways that may be more difficult within traditional healthcare settings. This supports previous research

demonstrating that online support communities can foster empowerment, connection, and psychosocial support among individuals experiencing health-related uncertainty (Barak et al., 2008; Ziebland & Wyke, 2012). The relative anonymity of Reddit may have further encouraged openness surrounding sensitive psychosexual experiences, consistent with Suler's (2004) online disinhibition effect.

Overall, the findings suggest that BPM involved much broader negotiations than surgical risk reduction alone. Women's experiences reflected ongoing attempts to balance autonomy, femininity, reproductive identity, bodily integrity, and future wellbeing within the context of hereditary cancer risk.

5.4 Synthesis

Taken together, the findings of this study contribute to existing research by highlighting the complexity, variability, and emotional ambiguity of psychosexual experiences following BPM. While previous research has often focused on measurable outcomes such as anxiety reduction, body image satisfaction, or quality of life, the Reddit narratives demonstrated how these experiences frequently coexist in contradictory ways.

Beyond confirming earlier findings, this study extends the existing literature by showing that psychosexual wellbeing following BPM is not a stable outcome but an ongoing process of embodied identity negotiation. Rather than experiencing a linear transition from vulnerability to recovery, women continuously navigated tensions between relief and grief, empowerment and vulnerability, as well as bodily disruption and adaptation. These experiences were shaped not only by bodily changes resulting from surgery, but also by interpersonal relationships, reproductive aspirations, and broader socio-cultural understandings of femininity and womanhood.

Additionally, this study contributes to the growing body of literature using online patient-generated narratives to explore sensitive healthcare experiences. Reddit provided access to emotionally detailed accounts that may not always emerge within clinical settings or structured interviews. The anonymity of the platform appeared to encourage open discussions surrounding sexuality, body image, numbness, grief, and reproductive concerns.

For healthcare management, these findings demonstrate the importance of recognising psychosexual wellbeing as a central component of hereditary cancer care rather than a secondary consequence of surgery. The results suggest that psychosexual counselling and expectation management should become more structurally integrated within hereditary cancer care pathways, including genetic counselling, reconstructive consultations, and long-term postoperative follow-up. Professionals such as breast surgeons, clinical geneticists, nurse specialists, psychologists, and reconstructive surgeons may particularly benefit from greater awareness of the emotional ambivalence and identity-related consequences associated with BPM.

The results also suggest that women may benefit from more comprehensive preoperative counselling, realistic expectation management, long-term psychosocial support, and greater acknowledgement of emotional ambivalence throughout the surgical journey.

5.5 Reflexivity

Within reflexive thematic analysis, knowledge production is understood as an active and interpretative process, in which the researcher inevitably shapes the analysis through their theoretical positioning, embodied experience, and engagement with the data (Braun & Clarke, 2019).

My positionality as a female researcher played a role in how the data were approached and interpreted. As someone who has lived experience of having breasts and is socially positioned within dominant Western constructions of femininity and embodiment, I was not a neutral observer of the material. Instead, I approached the dataset with an embodied familiarity with some of the themes discussed by women, particularly those relating to body image, femininity, and sexuality. This proximity to the topic may have facilitated deeper empathetic understanding of the women's narratives but may also have influenced what I recognised as meaningful, emotionally salient, or analytically important within the data.

In addition, my academic background in psychology influenced my analytic lens throughout the research process. My training had familiarised me with interpreting narratives in relation to underlying cognitive, emotional, and behavioural processes, which supported my engagement with the complexity of women's accounts. However, it also required continuous reflexive awareness of the potential to over interpret or to impose psychological meaning where it was

not explicitly present in the data. I therefore aimed to remain attentive to this influence by grounding interpretations closely in the data and through the use of analytic memoing and the audit trail, in which coding decisions, interpretative reflection, and theme development were systematically documented throughout the analytical process.

5.6 Strengths and limitations

This study has several important strengths. First, the use of Reddit data enabled access to naturally occurring patient narratives shared outside formal clinical environments. This allowed women to discuss sensitive experiences, including sexuality, grief, body image, and reproductive concerns, in relatively candid ways.

Second, the study contributes to a relatively underexplored area within hereditary cancer research by specifically focusing on psychosexual wellbeing rather than primarily biomedical or surgical outcomes. By centring women's lived experiences, this study provides a richer understanding of how BPM affects embodiment, identity, and emotional wellbeing, which may support healthcare professionals in developing more realistic counselling practices and more holistic approaches to hereditary cancer care.

Last, the use of reflexive thematic analysis, supported by continuous analytic memoing and an audit trail to safeguard analytic rigour, allowed for nuanced interpretation of contradictory and emotionally complex experiences. Rather than reducing psychosexual outcomes to positive or negative categories, the analysis captured the coexistence of empowerment, relief, grief, and bodily disruption.

Despite these strengths, several limitations should also be acknowledged. First, Reddit users do not represent all women with BRCA mutations undergoing BPM. The platform may overrepresent younger, digitally literate individuals who feel comfortable sharing experiences online. As a result, the findings may not fully capture the experiences of older women, women with limited digital literacy, or individuals from cultural contexts in which discussing sexuality or preventive surgery online is less socially acceptable. The findings likely best reflect a digitally engaged subgroup of women with a BRCA mutation, thereby limiting the transferability of the findings.

Second, the anonymous nature of Reddit limited access to demographic and contextual information. Important factors such as ethnicity, socioeconomic background, healthcare access, relationship status, cultural context, time since surgery, and type of reconstruction were often unavailable, making it difficult to place women's experiences in their personal and clinical context. As a result, the themes reflect recurring patterns of meaning rather than a fully representative picture.

Finally, online narratives reflect self-reported experiences that could not be independently verified, including users' BRCA status, reconstructive procedures, or postoperative experiences. Additionally, individuals who post on online forums may be more likely to share particularly emotional, positive, or negative experiences. Consequently, the dataset may overstate the intensity of psychosexual responses to BPM, while more neutral experiences remain underrepresented.

5.7 Conclusion

This study explored how women with a BRCA mutation described the psychosexual impact of BPM on Reddit. The findings demonstrated that psychosexual experiences following BPM are highly variable, emotionally layered, and frequently contradictory. Women described surgery as simultaneously relieving and distressing, empowering and disruptive, as well as medically reassuring while emotionally challenging.

Although many women experienced substantial reduction in cancer-related anxiety and described surgery as worthwhile, these benefits frequently coexisted with grief surrounding bodily loss, altered sensation, disrupted femininity, and reproductive sacrifice. Over time, many women described processes of adaptation in which they gradually renegotiated embodiment, identity, and sexuality within the context of a reconstructed or altered body.

The findings highlight the importance of understanding psychosexual wellbeing as a central component of hereditary cancer care. For healthcare practice, this suggests a need for more comprehensive and realistic preoperative counselling that openly addresses embodiment, sexuality, numbness, breastfeeding loss, emotional ambivalence, and long-term adjustment. Given that women in this study rarely described relief as eventually replacing grief, but instead as continuing to coexist with it, healthcare professionals could explicitly communicate during follow-up that ongoing grief does not signal regret or a wrong decision. Normalising this

ambivalence directly may help prevent women interpreting their own continued grief as evidence that they should not have undergone surgery.

In addition, healthcare professionals may benefit from revisiting psychosexual concerns throughout long-term follow-up, for example through structured check-ins at follow-up appointments or referral to psychosexual support services. Since women's adaptation to BPM often unfolds gradually and concerns such as grief or body image disruption may only surface well after surgery, addressing these issues solely during preoperative counselling risks leaving later emerging difficulties unrecognised and unsupported. Greater interdisciplinary collaboration between surgical teams, psychologists, nurse specialists, and genetic counsellors may further support more holistic hereditary cancer care.

In addition, the study demonstrates the value of patient-generated online narratives for healthcare management research. Platforms such as Reddit provide insight into experiences that may remain underreported within clinical consultations, particularly regarding intimacy, identity, and emotional vulnerability.

Future research could further explore how psychosexual experiences following BPM differ across cultural contexts, age groups, relationship statuses, or reconstruction choices. Given the recurring grief around breastfeeding loss observed in this study, reproductive identity in particular merits closer attention. Longitudinal interview studies could also help examine how emotional ambivalence, bodily adaptation, and identity renegotiation evolve over time. Additionally, future studies could investigate how psychosexual support can be more effectively integrated into hereditary cancer care pathways, for example by examining both patient and healthcare professional perspectives on communication surrounding sexuality, embodiment, and reproductive concerns.

Overall, this study demonstrates that BPM is not solely a preventive medical procedure, but also a deeply embodied and emotionally significant life event that reshapes how women experience their bodies, identities, relationships, and futures.

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Appendices

Appendix 1: Audit trail

Methodological approach: Reflexive thematic analysis (Braun & Clarke, 2019)

In this audit trail, I show the step-by-step choices and thought processes I went through while screening, coding, and analysing the data. It tracks how my thinking shifted as I moved from raw data to codes, subcodes, and final themes.

Phase 1: Getting familiar with the data

What I did: I started with an Excel file containing 100 original posts and 537 comments underneath (n = 637). I read through everything multiple times to fully immerse myself in the women's stories.

My thought process: While reading, I realised early on that I could not just look at original posts by themselves. I noticed that the comment sections often held much deeper, more emotional, and more intimate reflection. My main takeaway here was that the community aspect of Reddit, where women reply to and comfort each other, was where the most honest data about sexuality and intimacy lived. I decided I had to keep posts and comments together as a single conversation during my initial review.

Phase 2: Selection of relevant conversations

What I did: Keeping the original posts and comments grouped together, I performed a first-round filter to separate relevant conversations from irrelevant ones.

My thought process: My main challenge here was drawing a clear boundary line of what was relevant for my research question and what was not. Many threads were purely technical or medical. I realised that these technical questions were only useful to my research if the women explicitly connected them to an emotional or psychosexual frustration about their changing body image or womanhood. If a thread was 100% mechanical, I discarded it. I also had to make sure I was only including unaffected women, as the psychology of a preventive surgery is fundamentally different from a curative cancer journey. This phase successfully narrowed down my focus.

Phase 3: Highlighting and generating global codes

What I did: I went through all the individual posts and comments within my selected relevant data one by one. I highlighted the specific experience-based posts that could help answer my research question and copied these into a separate worksheet to create a clean, focused sample. This process yielded my final sample of 129 highly relevant posts. I then assigned each of these highlighted segments one or more broad global codes.

My thought process: When assigning these broad codes, my goal was to categorise the data based on the primary psychological or somatic driver behind the women's experiences. I established the global codes for the following reasons:

- Adaptation and becoming familiar with the reconstructed body: Created to capture the slow, non-linear process of women learning to coexist with their new breasts and integrating them into their daily self-image.
- Disruption and reconstruction of femininity: Created to address specific concerns regarding how the removal of breasts challenged their gender identity, feelings of attractiveness, and sexual confidence.
- Emotional turbulence before and after surgery: Created to capture the intense emotional roller coaster, panic, and psychological instability women experienced during the immediate preoperative and acute postoperative phases.
- Empowerment, agency, and proactive health management: Created because many narratives focused heavily on the pride and control women felt by actively choosing surgery to save their own lives rather than being passive victims of genetics.
- Fertility, motherhood, and breastfeeding loss: Created because younger women faced unique gendered grief, specifically surrounding the inability to breastfeed future children or having to plan surgery around pregnancy timelines.
- Mourning bodily loss and altered embodiment: Created because women expressed deep grief over losing their natural breast tissue, dealing with physical numbness, and feeling disconnected or estranged from their own flesh.
- Reconstruction outcomes and bodily authenticity: Created because women's psychosexual wellbeing was heavily dictated by whether they felt their new breasts or flat closures looked real, met expectations, or suffered from medical complications.
- Relief and reduced cancer anxiety: Created because a vast majority of women explicitly noted that the primary emotional outcome of surgery was a massive weight being lifted regarding their cancer fears.

- Trade-offs and sacrifice: Created because women explicitly framed their journey as an existential bargain, since they were willingly sacrificing physical sensation, comfort, and energy in exchange for long-term survival.

Phase 4: Developing detailed subcodes

What I did: Once I had my highlighted segment organised under these global codes, I looked much deeper into the specific quotes within each category to develop precise subcodes. This allowed me to break down the large topics into fine nuances.

My thought process: Here, my thinking shifted from what the women were feeling to how they were actively processing it. For instance, under the broad category of Mourning bodily loss, I initially looked at descriptions of physical numbness. But looking closer at the posts, I realised that numbness meant two completely different things depending on the context: some women were actively grieving the loss of erotic touch, while others were working hard to normalise it as a necessary trade-off for survival. I chose to split these into distinct subcodes like Loss of erotic sensation and Normalisation of numbness, to capture that psychological active processing.

Phase 5: Building the overarching themes

What I did: For the final step of my analysis, I looked at how my global codes and their detailed subcodes connected to each other. I clustered them together to build the 5 final overarching themes of my thesis.

My thought process: This phase required the highest level of conceptual thinking. I had to step back from individual codes and ask myself what the bigger story was. I spent a lot of time mapping out how different aspects of a woman's life collided. For example, I realised that surgical recovery could not be isolated from family life, as a woman's grief over breastfeeding loss or her desire to be a healthy role model for her children directly impacted how she navigated her new body image. This led to the creation of the theme Negotiating femininity, motherhood, and attractiveness.

Phase 6: Final review and reflexivity

What I did: I reviewed the entire coding tree to ensure my themes made sense and truly represented the dataset. I carefully paraphrased all the quotes used in my results chapter and verified that the original Reddit users could not be tracked down through search engines.

My thought process: My final reflection focused on how my background in psychology shaped my expectations. From a psychological standpoint, I actually anticipated that choice and autonomy, such as opting for flat closure, could function as deeply empowering strategies for women trying to reclaim control over their health. The data confirmed this expectation, showing that women felt comfortable, proud, and satisfied with their decision to go flat. My final intellectual adjustment was making sure that my psychological training helped me remain fully open to these diverse expressions of empowerment, ensuring that standard societal norms surrounding breasts and femininity did not cloud my analysis of their positive psychological outcomes.

Appendix 2: Coding tree

