

Information needs and lived experiences of BRCA carriers regarding medically induced menopause after oophorectomy: a qualitative analysis of patient-driven online discussions on Reddit to support person-centred care

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AI and submission statement

Generative AI software was used to improve the quality of my writing, as permitted by the provided guidelines. This was done to enhance the academic tone and refine sentences to improve my writing. Reflecting on these writing refinements helped me grow my academic vocabulary with commonly used terms and helped me improve the structuring of my arguments that I had developed myself. The content of the figures was my own; however, the lay-out of the figures was also generated with generative AI software. The original data and the final sampled dataset were not submitted with the study due to the agreement that was made with Reddit, which does not allow for this.

Preface

Acknowledgements

I would like to thank Leonie Witte for her guidance during this project, which has helped me develop my academic skills and shown me the joy that research can bring and the impact it can have on others. Her belief in me, openness, and leadership have given me an experience that I look back on with both pride and contentment. Her research on BRCA and passion for women's health have inspired me and taught me a lot about this topic and the work that still needs to be done.

Furthermore, I would like to thank Cornelia van Diepen for her teaching on person-centred care and the effort she put in to provide me with the data from Reddit. This research project would not have been possible without her vision and efforts.

Abstract

Background: Women carrying a BRCA1/2 mutation are commonly advised to undergo premenopausal risk-reducing oophorectomy, which triggers an abrupt, medically induced menopause (MIM). MIM reaches across physical, emotional, relational, and identity-related domains. However, information and follow-up care are frequently experienced as insufficient, and little is known about how BRCA carriers themselves articulate their information needs in naturalistic peer-driven settings.

Aim: To explore the information needs of BRCA carriers regarding MIM and how these emerge from the lived experiences they articulate online, and to examine what these accounts suggest about gaps in person-centred counselling and follow-up care.

Methods: A qualitative infodemiology study was conducted using publicly available discussions from a BRCA-related Reddit community. Purposively selected against explicit inclusion and exclusion criteria, 49 threads and 58 standalone comments were analysed through reflexive thematic analysis. An integrated framework developed for this study, combining an empowerment model for menopause management with a model of person-centred clinical communication, informed the interpretive phase of the analysis.

Results: Four themes were constructed. BRCA carriers experience MIM as a single, impactful transition in which body and identity change together; they undertake substantial self-led work to build the preparation and care they need; the clinical relationship is the decisive site at which empowering, person-centred care succeeds or fails; and decision-making about oophorectomy is ongoing, weighing MIM against cancer-risk reduction across the trajectory. Information needs emerged from the work of anticipating, weighing, and managing the transition while retaining a sense of control over it.

Conclusion: Information needs centre on accessible, tailored, anticipatory information addressing the symptomatic, long-term, and identity dimensions of MIM, alongside support for the weighing of MIM against ovarian cancer-risk reduction that BRCA carriers do individually and for joint decisions about hormone replacement therapy, timing, and the sequence of risk-reducing surgeries. Care should establish a clear clinical home for menopause expertise across the BRCA trajectory and integrate the active role BRCA carriers already take on, rather than treat their self-led work as a reason for formal care to step back.

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1. Introduction

Medical research has long paid less attention to women and female-specific conditions, contributing to gender-based knowledge gaps and health disparities (World Health Organization, 1995, 2009). In response, women's experiences of health risks, navigation of uncertainty, and decision-making regarding their health have been a growing focus in research and practice. Timely access to meaningful information in such contexts helps women make sense of their situation, anticipate consequences, and feel supported. Because of this, informational support is increasingly recognised as central to empowerment and person-centred care, especially in complex care situations. Person-centred care responds to an individual's needs, values, and preferences. It is realised through the clinical relationship and the communication within it, where people are kept informed and supported as they share in decisions about their own care (Gagliardi et al., 2019; McCance & McCormack, 2025; Ramlakhan et al., 2019).

These information needs are particularly evident in trajectories of women carrying a BRCA1/2 mutation. BRCA mutations are hereditary oncogenetic conditions that are associated with substantially increased lifetime risks of breast (45-72%) and ovarian (11-44%) cancer (Kuchenbaecker et al., 2017; Young et al., 2017). Many BRCA carriers are diagnosed at a relatively young age, when they are still healthy. This means diagnosis introduces risks to their future rather than current disease. This state has been described as 'virtual' illness, and is characterised by prolonged uncertainty and impactful repeated decision-making needs while symptoms are absent (Dean, 2016; Dean & Fisher, 2019; DiMillo et al., 2013; Fisher et al., 2017; Samson et al., 2014). Living with this risk has been linked to various biopsychosocial challenges, in particular the fear of cancer development, concerns about fertility and bodily integrity, and experiences of anticipatory loss that affect well-being and identity.

Against this backdrop, BRCA care trajectories are complex and organised around risk management, which often involves irreversible preventive strategies. One of those strategies is premenopausal prophylactic oophorectomy that results in immediate and permanent menopause (Nederlandse Vereniging voor Obstetrie en Gynaecologie, 2024; Witte et al., 2025). Throughout this study, medically induced menopause (MIM) refers to this oophorectomy-induced menopause rather than menopause arising from other treatments. The decision to undergo a prophylactic oophorectomy is preference sensitive and emotionally demanding due to its physical and psychological consequences, making it a particularly loaded strategy for reducing ovarian cancer risk (Witte et al., 2025). Research on BRCA carriers' care experiences and preferences shows they value information that supports management of uncertainty, emotional well-being, and understanding of the broader impact of risk-reducing strategies on daily life. However, gaps persist in tailored and anticipatory information provision in formal care (Witte et al., 2025, 2026).

Within the context of complex risk-reduction management, MIM in BRCA carriers represents a critical yet insufficiently addressed disruptive transition. Research on BRCA carriers undergoing oophorectomy and on life after preventive strategies more broadly has shown that MIM has a broad and multifaceted impact on well-being beyond vasomotor symptoms and sexual difficulties (Campfield Bonadies et al., 2011; Chapman et al., 2015; Finch et al., 2011). BRCA carriers report effects on intimate relationships, sexual identity, emotional balance, and daily functioning after oophorectomy. Feeling unprepared for the extent and persistence of these changes was often emphasised by BRCA carriers (Campfield Bonadies et al., 2011; Finch et al., 2011). This indicates that care addressing only the biomedical domain is insufficient, and that BRCA carriers need help contextualising their experiences and new

“normal” and anticipating how symptoms and their sense of self may change over time (Campfield Bonadies et al., 2011; Chapman et al., 2015; Finch et al., 2011). Despite unmet information needs being consistently reported, the existing literature relies mostly on clinical outcomes and structured assessments built on clinician- or researcher-defined categories (Campfield Bonadies et al., 2011; Finch et al., 2011; Witte et al., 2025, 2026). As such, they primarily capture biomedical dimensions of the experience. Patient narratives offer a way to counter this, because they show how people make sense of their conditions and lived experiences, and what this implies for their healthcare needs. Since such narratives are not confined to retrospectively defined categories, they are a valuable knowledge source both for research and for improving person-centred care (Hartog et al., 2020; Nembhard et al., 2024; Novak et al., 2020; Pedersen, 2016). However, little is known about how BRCA carriers themselves articulate and interpret their information needs in relation to their lived experiences of MIM in more naturalistic, peer-driven contexts. In particular, limited attention has been paid to how elements of their experiences, such as uncertainty, practical consequences, and psychosocial concerns, come together in their own accounts and are interpreted in daily life. This matters because what BRCA carriers want to know about MIM shifts across the stages of their journey and reaches beyond biomedical fact to personal and social knowledge (Dean et al., 2017). Focusing on the knowledge they seek out and generate themselves is therefore a justified way to address the gap.

Research on health information seeking suggests that when information provision is experienced as insufficient, difficult to apply, or hardly reflective of lived reality, online environments may provide spaces where individuals articulate, share, and interpret experiential knowledge and informational concerns (Deng & Liu, 2017). This appears to extend to BRCA, where peer-based online environments give women functional spaces to combine experiential disclosure with practical exchange, and where participants engage in both self- and community-care by sharing experiences and knowledge (Wellman et al., 2025). The interactions in these environments are especially relevant for topics that may be difficult to bring up in clinical settings but matter for MIM. Examples include sexuality, identity, and the lived impact of preventive interventions. These topics are hard to disclose because their sensitive and intimate nature contrasts with the clinical environment. Stigma surrounding these topics can also be a factor. The anonymity of online settings may alleviate these barriers.

Studying such environments therefore provides access to patient-generated experiential knowledge that may remain underrepresented in clinical settings and structured research. Through analysing discussions on Reddit, an online discussion platform, this study aims to explore how BRCA carriers articulate their experiences of MIM and how related information needs emerge within these narratives. In doing so, it provides insight into these experiences, information needs, and patient-driven sense-making processes that complement existing literature. This focus is relevant to healthcare management because BRCA carriers’ accounts of where information and support fall short indicate how counselling and follow-up provision around oophorectomy could be designed and delivered more responsibly across their care trajectories.

1.2 Objective and research questions

The aim of this study is to explore the information needs of BRCA carriers regarding MIM, and to understand how these emerge from their lived experiences as articulated by themselves. To do so, this study goes beyond clinician/researcher-defined information domains by using an infodemiology approach to examine the patient-driven discussions on Reddit. Infodemiology is the study of health information patterns in online environments (Eysenbach, 2009). Reddit, a peer- and topic-based social media platform organised into user-moderated communities, is a

relevant setting for this study because it allows pseudonymous, lengthy, and detailed inputs and discussions, while offering accessible information and support. These characteristics invite free and vulnerable expression from users (Proferes et al., 2021). Furthermore, the platform's peer-based and asynchronous nature supports the exchange of experiential knowledge, practical advice, and personal reflections across care trajectory stages. In line with the identified knowledge gap, analysing BRCA carrier narratives of MIM on Reddit may better capture how experiences and information needs are described, including dimensions of MIM that are harder to visualise in clinical practice and structured research. Through this analysis, this study seeks to contribute to a more grounded understanding of care trajectory gaps and to inform more responsive and person-centred counselling and follow-up care for BRCA carriers experiencing MIM.

The main research question is therefore:

What are the information needs of BRCA carriers regarding medically induced menopause, and how do these emerge from their lived experiences as expressed on Reddit?

With the following sub-question:

What do the narratives of BRCA carriers regarding medically induced menopause suggest about potential gaps in person-centred counselling and follow-up care?

1.3 Reading guide

The remainder of this thesis is structured as follows. Chapter 2 presents the integrated theoretical framework that combines an empowerment model for menopause management with a model of person-centred clinical communication, and serves as the sensitising lens for the analysis. Chapter 3 sets out the qualitative methodology, including the infodemiology approach, the Reddit data source, the sampling and selection procedure, the reflexive thematic analysis, the ethical considerations, validity, and limitations of this study. Chapter 4 reports the four themes constructed from BRCA carriers' accounts of MIM. Chapter 5 discusses these findings in relation to the theoretical framework and existing literature, reflects on the study's strengths, limitations, and researcher reflexivity, and concludes by answering the research questions and outlining implications for person-centred care, healthcare management, and future research.

2. Theoretical framework

The integrated framework developed for this study provides the analytical lens for examining Reddit discussions of BRCA carriers on MIM, focusing on their information needs and lived experiences. Its main anchor is Hickey et al.'s empowerment model for menopause management, which this study extends from natural menopause to MIM (Hickey et al., 2024). Stemming from participatory care paradigms, the model conceptualises empowerment as acquiring knowledge, decision-making capacity, and confidence, which supports women in self-navigating their menopause experiences. To better understand how support is shaped in care, this study complements the empowerment model with Epstein and Street's (2007) model of patient-centred communication. The communication model describes the core functions of patient-centred communication in clinical care. It contributes a valuable perspective by shifting attention toward broader communicative processes needed beyond biomedical information exchange to provide holistic and tailored healthcare. In this study, empowerment is approached

as the broader goal of care, while communication helps to explain processes that may support or constrain that goal. The integrated framework is visualised in Figure 1 and shows how these models work together.

This study uses the framework as a sensitising lens in the data-driven analysis to interpret how information needs are expressed and embedded within lived experiences of MIM among BRCA carriers.

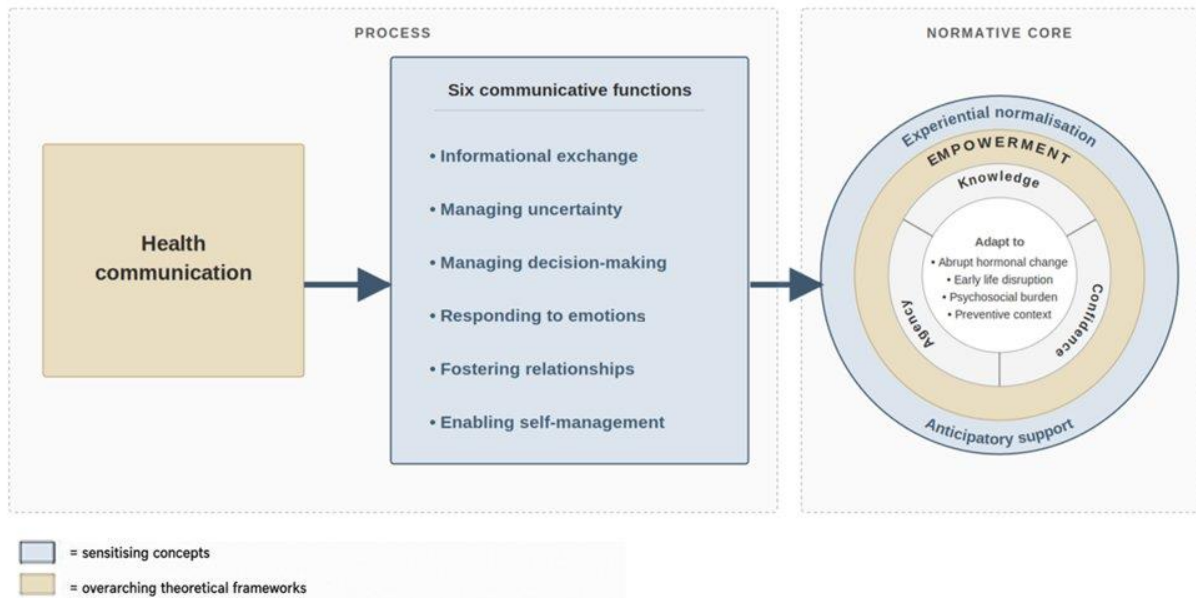


Figure 1. Integrated framework for understanding BRCA carriers' lived experiences and information needs in MIM.

Note. Adapted from Epstein and Street (2007) and Hickey et al (2024).

2.1 Empowerment in MIM care

The empowerment model frames menopause care as an ongoing process in which women's lived experiences and concerns are acknowledged, and shared decision-making is actively supported (Hickey et al., 2024). This process enables women to build confidence and knowledge, and to more actively take part in the management of their menopause care. The model was developed in response to critiques of biomedical paternalism. Consequently, it challenges more traditional approaches that prioritise clinical outcomes while giving limited attention to relational support, experiential validation, and shared decision-making. This model was chosen because it fits the present study particularly well. The model is, to current knowledge, the only empowerment model developed specifically for menopause. It treats information as tied to confidence and self-management rather than as a set of separate facts, which suits a study concerned with how information needs are embedded in lived experience and connected to person-centred care. The model's person-centred orientation, in which the woman is supported as an active partner, also forms the link to the communication perspective in section 2.2.

Because the model was recently proposed (Hickey et al., 2024), its direct empirical application is still emerging. At the same time, mechanisms that align with empowerment processes are demonstrated in empirical studies on menopause care in a broader sense. A randomised controlled trial of 140 postmenopausal women by Khademi et al. (2025) drew on Longwe's empowerment framework (Longwe, 1991), defining empowerment as gaining control over health-related decisions and structuring it across levels of awareness, participation, equity,

access, and control. This is a broader and more structural account than Hickey's, but rests on the same premise that women move from passive recipients to active agents in their own care. The study's empowerment-programme improved quality of life (measured with the WHOQOL-BREF; World Health Organization, n.d.) and menopausal self-care behaviours with large effect sizes ($\eta^2 = 0.23$ and 0.42 , respectively), alongside smaller gains in general health and internal health locus of control. Similarly, a quasi-experimental study of 186 menopausal women compared three kinds of self-care education interventions (Kafaei-Atrian et al., 2022). One empowerment-intervention built also on Longwe's empowerment model, another intervention strengthened women's confidence in their ability to manage menopause through skill-practice and encouragement, and one intervention integrated both approaches. All three improved menopause-specific quality of life over time, with reductions of roughly four to six and a half points on the MENQOL (Hilditch et al., 1996), a 0-78 scale on which lower scores indicate better quality of life. The group began near 32 to 34, indicating a moderate level of menopause-related impact at the outset. Because the three interventions had similar effects, the gains appear to stem from a mechanism they share rather than from any single programme. That mechanism, the strengthening of women's confidence, knowledge, and capacity to manage their own health, is similar to Hickey et al.'s definition of empowerment. Complementing these quantitative works qualitatively, Sillence et al. (2025) showed that menopause apps can help women build knowledge about menopause and draw on it to feel more informed in their care, reflecting the same knowledge and confidence that empowerment depends on.

For this study, the model is extended from menopause in the broader sense to the context of BRCA carriers experiencing MIM, which is characterised by impactful attributes such as abrupt hormonal change, early life disruption, and psychosocial and informational challenges (Campfield Bonadies et al., 2011; Chapman et al., 2015; Finch et al., 2011). Hickey et al. (2024) developed their model for natural menopause and place induced and early menopause outside its immediate scope. However, extending the model to MIM is justified because the empowerment-process it describes does not depend on how menopause begins. It can be argued that the features that set MIM apart make the empowerment-process more pressing rather than less. Because MIM is brought on abruptly and early, women may have the sense to prepare for it in a shorter timeframe and with few non-BRCA peers undergoing the same change, increasing the need for knowledge, confidence, and agency regarding MIM. This unfolds against a baseline of chronic uncertainty, as BRCA carriers, especially younger ones, describe living with the persistent threat of cancer as an unending and unresolved process (DiMillo et al., 2013). Empowerment in MIM can therefore be seen as dealing with the uncertainty by building knowledge, confidence, and agency alongside it.

When viewed through the empowerment lens, Reddit posts by BRCA carriers discussing MIM can then be understood as expressions of constrained empowerment and as attempts to attain it. Recurrent questions about effects on sex lives and identity, the severity and duration of symptoms, and early osteoporosis, cognitive decline, and cardiovascular risk point to areas where current care trajectories provide limited anticipatory guidance and experiential insight. From this perspective, two sensitising concepts are derived from the model. *Experiential normalisation* builds on the model's emphasis on normalising menopause, and refers to coming to understand what is normal or to be expected. Importantly, MIM can be seen as practically unavoidable and as something to learn to live with due to oophorectomy being the only recommended way to reduce ovarian cancer risk, as there is no reliable screening alternative. Working out a new normal, as set out in the introduction, is then necessary and may be supported by coming to feel that what one experiences belongs to this transition rather than signalling that something has gone wrong. Such normalisation may take shape between women in peer settings, including the Reddit discussions this study examines, where they encounter others going through the same change. Anticipatory support, in turn, follows from

the model's emphasis on information given ahead of the transition and on the likely course of symptoms, and refers to being prepared for what MIM brings. It names something BRCA carriers themselves indicate they want in order to face risk-reducing management (Campfield Bonadies et al., 2011; Dibble et al., 2022; Witte et al., 2025, 2026).

2.2 Health communication and its function in MIM

The second component of the framework is Epstein and Street's (2007) model of patient-centred communication, which identifies six core functions: exchanging information, managing uncertainty, making decisions, responding to emotions, fostering healing relationships, and enabling patient self-management. The authors explicitly frame these as the functions of patient-centred communication in how they organise care around the patient's understanding, participation, and emotional experience rather than around clinical tasks alone. This connects to person-centred care as set out in this study, as the six functions operationalise how the clinical relationship and the communication within it create person-centred care. The functions are closely tied to the development of empowerment, since they concern how far patients come to understand their situation and take part in their own care. They are relevant to this study because their presence or absence, as it surfaces in the lived experiences of BRCA carriers, makes potential gaps and needs in the care around MIM visible.

The importance of these communicative functions in cancer populations was validated by empirical research. A study of cancer patients found that patient-centred communication, through increased trust and health literacy, was associated with less cancer information avoidance (Lu et al., 2024). Adding to this, another study showed better psychosocial outcomes in a cancer survivor population through a more participatory physician communication style that fostered self-efficacy, trust, and perceived control (Arora et al., 2009). These studies support the model's central premise that both behavioural and cognitive processes closely aligned with empowerment are shaped through communication.

The relevance of the model's perspective extends to the context of BRCA carriers experiencing MIM. Across care trajectories, BRCA carriers' needs extend beyond biomedical facts and include support in making sense of the impact of preventive interventions on daily life and emotional well-being (Witte et al., 2025, 2026). In care phases most relevant to experiencing MIM, for example when approaching decisions about risk-reducing surgery, BRCA carriers seek experiential insight, guidance in decision-making, emotional support, and practical coping strategies (Dean et al., 2017). In studies that looked at BRCA carriers undergoing oophorectomies specifically, these needs surface in that they often feel unprepared for the extent and persistence of MIM symptoms and the impact on sexuality, identity, relationships, and daily functioning (Campfield Bonadies et al., 2011; Finch et al., 2011). These findings indicate that gaps in clinical communication are not only in purely factual information exchange, but also in how individuals are supported in interpreting and applying information in their lives.

Furthermore, needs evolve throughout BRCA care trajectories. BRCA carriers in later stages may shift from seeking information to sharing from their own experiences in the hope of helping others navigate similar situations (Dean et al., 2017). This shift can be understood as an extension of empowerment, in which experiential knowledge is mobilised to support others. Such connection among women is part of the empowerment model, because it encourages women to turn to others going through menopause for discussion and support (Hickey et al., 2024). This is another connection between the empowerment and communication perspectives, as what Hickey et al. frame as connection among women corresponds to the relationship-fostering and other functions in Epstein and Street's model that exist in that relationship. Engagement of this kind is especially relevant in online contexts, where social relationships can function as coping resources by providing emotional support, affirmation, and

assistance in interpreting symptoms and risks alongside biomedical information (Corrarino, 2013; House, 1981). Similarly to offline realities, the way BRCA carriers build online peer communities in relation to what they seek and provide mirrors the communicative functions in Epstein and Street's (2007) model. This makes *informational exchange, managing uncertainty, managing decision-making, responding to emotions, fostering relationships, and enabling self-management* relevant sensitising concepts for this study. Read through this lens, the lived experiences BRCA carriers share on Reddit can be interpreted in terms of how these functions are met or fall short, which speaks to gaps in the person-centred counselling and follow-up care they receive. Questions and uncertainties voiced on Reddit reflect information needs and the management of uncertainty, while expressions of feeling unprepared or in distress may point to gaps in emotional responsiveness. Discussions of coping and treatment may relate to decision-making and self-management, and the relational contact formed on Reddit to the fostering of relationships.

2.3 Integration of the framework

The framework conceptualises empowerment for BRCA carriers experiencing MIM as the broader, normative aim of care, with communication as an important process through which the aim may be supported or constrained. By combining both perspectives, information can be understood as emerging from the dynamic interaction between lived experience, support, and sense-making, rather than as static or existing in predefined categories.

Applied to Reddit discussions, the framework may enable identification of where information needs on MIM-related topics are concentrated, how they are articulated and prioritised, and how they relate to gaps in care. Through this process, empowerment visualises the needs BRCA carriers experiencing MIM have in managing their situations, while communication shows how these needs are supported or unmet in care trajectories. The framework may then support a more nuanced understanding of how care trajectories could be better aligned with person-centred counselling and follow-up.

3. Methods

3.1 Study design and methodological rationale

This study adopts a qualitative design to examine how BRCA carriers narrate and make sense of their experiences of MIM in the context of prophylactic oophorectomy, and how information needs take shape within peer-driven discussions on Reddit. The study is situated within the field of infodemiology, which treats online communication as a meaningful source of health-related insight when the aim is to understand patterns in naturally occurring discussions (Eysenbach, 2009; Mavragani, 2020).

A qualitative design suits this study, given that it is exploratory and centrally concerned with lived experience and how BRCA carriers interpret it, rather than an approach measuring predefined variables (Green & Thorogood, 2018). An exploratory approach is warranted because the information needs surrounding MIM in this group are not well established in advance, meaning the analysis must let them surface from how BRCA carriers themselves raise and discuss information needs in order to develop a better understanding of them. Qualitative methods allow participants' own categories, language, and contextualised accounts to guide analysis rather than forcing experiences into pre-specified response options, which is what questions about illness interpretation, lived impact and information-seeking require (Pope & Mays, 2020). Qualitative approaches have already yielded meaningful experiential insight into how BRCA carriers deal with the consequences of risk-reducing oophorectomy (Hickey et al., 2021), and have similarly illuminated how women experience surgical menopause following oophorectomy more broadly (Siyam et al., 2018), supporting the appropriateness of this approach for the current population and research question.

Web-based platforms are used in infodemiology to access patterns of health communication that are hard to reach through conventional recruitment and data collection (Eysenbach, 2009; Mavragani, 2020). Reddit has 100+ million daily active users and 100,000+ active communities (Reddit, Inc., 2026), making it one of the largest social discussion platforms to exist (Business of Apps, 2026). Reddit has a pseudonymous design and topic-specific subreddits that allow users to post detailed accounts, receive threaded responses, and return to update their experiences later, making it an insightful place for experientially oriented studies. In this study, Reddit functions as a naturally occurring environment where BRCA carriers can formulate and revisit MIM-related experiences and information needs in interaction with peers, affording an experiential and process-oriented understanding that formal data collection cannot easily replicate. Comparable qualitative analyses of data from Reddit and online message boards on topics other than BRCA demonstrate that these environments yield contextualised, patient-generated accounts of health-related concerns that extend beyond what clinician-directed research captures (Chew et al., 2019; Cousineau et al., 2006; Garg et al., 2020; Nicmanis et al., 2023).

Because the aim is to understand how BRCA carriers interpret MIM rather than to draw conclusions about the wider BRCA population, the study's contribution is best judged by its transferability. This translates to the conceptual insight the study offers into the experiences and information needs of BRCA carriers experiencing MIM and the extent to which readers can assess its applicability to their own settings (Mays & Pope, 2000). The study's value therefore lies in surfacing these experiences and information needs in a way that can inform more person-centred counselling and follow-up care.

3.2 Data source and context

The extended arm of the supervisor used Reddit's DevPlatform Actions Infrastructure to collect 1002 publicly available BRCA-related posts and comments. Access to the data was granted after thesis plan approval. No interaction with users has occurred at any point in this study.

Drawn from BRCA-related subreddits, the data consist of pseudonymous threaded discussions among individuals navigating hereditary cancer risk and its management (for themselves or others). Threads are structured by original posts where someone shares an experience, opinion, or question, and others can respond with comments. The dataset represents context-specific articulated experiences from self-selected, digitally engaged users.

3.3 Sampling and data collection

The unit of analysis is the Reddit thread, comprising an original post and its associated comments. Threads preserve the interactional context of peer discussions, which is analytically important given that exchanges between users can form a primary site of experiential knowledge-sharing in this population. The full dataset comprises 1002 threads organised in Microsoft Excel, with each thread as a separate entry.

Prior to applying the inclusion and exclusion criteria, a keyword-guided familiarisation was conducted across the full dataset. Keywords (formulated as full words or short phrases) reflected both clinical terminology and lay expressions commonly used online (Kim et al., 2016), covering six domains: surgery, menopause, symptoms, sexuality and bodily change, hormonal management, and experiential or information-seeking expressions. This process mapped how MIM experiences appeared across the data and surfaced initial awareness of user variation. The full set of keywords, together with the analytical notes and personal reflections recorded during familiarisation, is provided in the reflexive audit trail (Appendix 1).

Subsequently, duplicates, where the original post appeared more than once with no differing comments or none at all, were removed. After this, all 997 remaining threads within the available dataset underwent a full read and were assessed for their relevance based on the inclusion and exclusion criteria detailed in Table 1. To preserve contextual reading, non-relevant comments (based on inclusion and exclusion criteria) were retained but not coded during the analysis. This was done to retain analytically relevant material that would otherwise be lost solely due to the nature of the original post, and to apply the inclusion and exclusion criteria consistently at the individual contribution level.

During the full read, comments from excluded threads that were relevant based on the inclusion and exclusion criteria were included as standalone units of analysis, while the surrounding thread was not. The thread was left out because its discussion responded to the excluded original post rather than to the relevant comment, and so did not meet the inclusion and exclusion criteria. A comment was kept on its own only when it was self-contained, meaning it could be understood without the rest of the thread. This comprehensive purposive sampling strategy is detailed in Figure 2 and resulted in a sample of 49 threads and 58 standalone comments, together totalling 107 units of analysis. This approach is consistent with comparable Reddit studies, which analysed final samples of roughly 70 to 300 threads using similar strategies (Garg et al., 2020; Nicmanis et al., 2023).

INCLUSION CRITERIA	EXCLUSION CRITERIA
Threads (original posts) + comments (from excluded threads):	Threads (original posts) + comments (from excluded threads):

• Author identifies* as a BRCA carrier • Discusses MIM experiences or the post-prophylactic** oophorectomy period	• Unrelated to MIM or the post-prophylactic oophorectomy period • Discusses menopause*** but origin unclear or explicitly not MIM • Discusses chemical menopause (e.g., from cancer treatment) without a subsequent oophorectomy framed as a new MIM onset*** • Discusses post-oophorectomy recovery period**** only without reference to MIM or longer-term post-oophorectomy experiences. • Discusses HRT***** outside the context of MIM • Author explicitly identifies as a non-BRCA carrier • Author does not identify* as a BRCA carrier • Post concerns oophorectomy linked to ovarian cancer diagnosis**
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***BRCA carrier identification:** Explicit statement of BRCA carrier status, or reasonable inference from trajectory markers such as discussion of risk-reducing mastectomy, DIEP flap reconstruction, family members with a BRCA mutation, prophylactic surveillance protocols, or active identification with the BRCA Reddit community as a participant. Community membership alone (e.g., posting in a BRCA-related subreddit) is not sufficient without at least one additional trajectory marker.

****Prophylactic oophorectomy:** An oophorectomy is considered prophylactic unless the author explicitly states an ovarian cancer diagnosis, or a positive ovarian cancer status is declared in the trajectory described prior to the surgery.

*****MIM and relevant post-prophylactic oophorectomy content:** MIM is considered present when surgical onset is explicitly stated, or when menopause is framed as a new experience beginning after prophylactic oophorectomy, as evidenced by the phrasing of questions, symptom descriptions, or treatment discussions. Posts or comments discussing menopause as an ongoing continuum predating the oophorectomy, or where onset cannot be attributed to the surgery, are excluded. Where MIM onset is present alongside a prior cancer treatment history, inclusion requires that the author frames the oophorectomy and its menopausal consequences as a distinct and new experience rather than a continuation of treatment-related menopause.

******Post-prophylactic oophorectomy recovery content:** refers to experiences of the period following surgery that are attributable to post-operative recovery (e.g., acute surgical pain, wound care, or infection).

*******HRT:** hormone replacement therapy

Table 1. Inclusion and exclusion criteria.

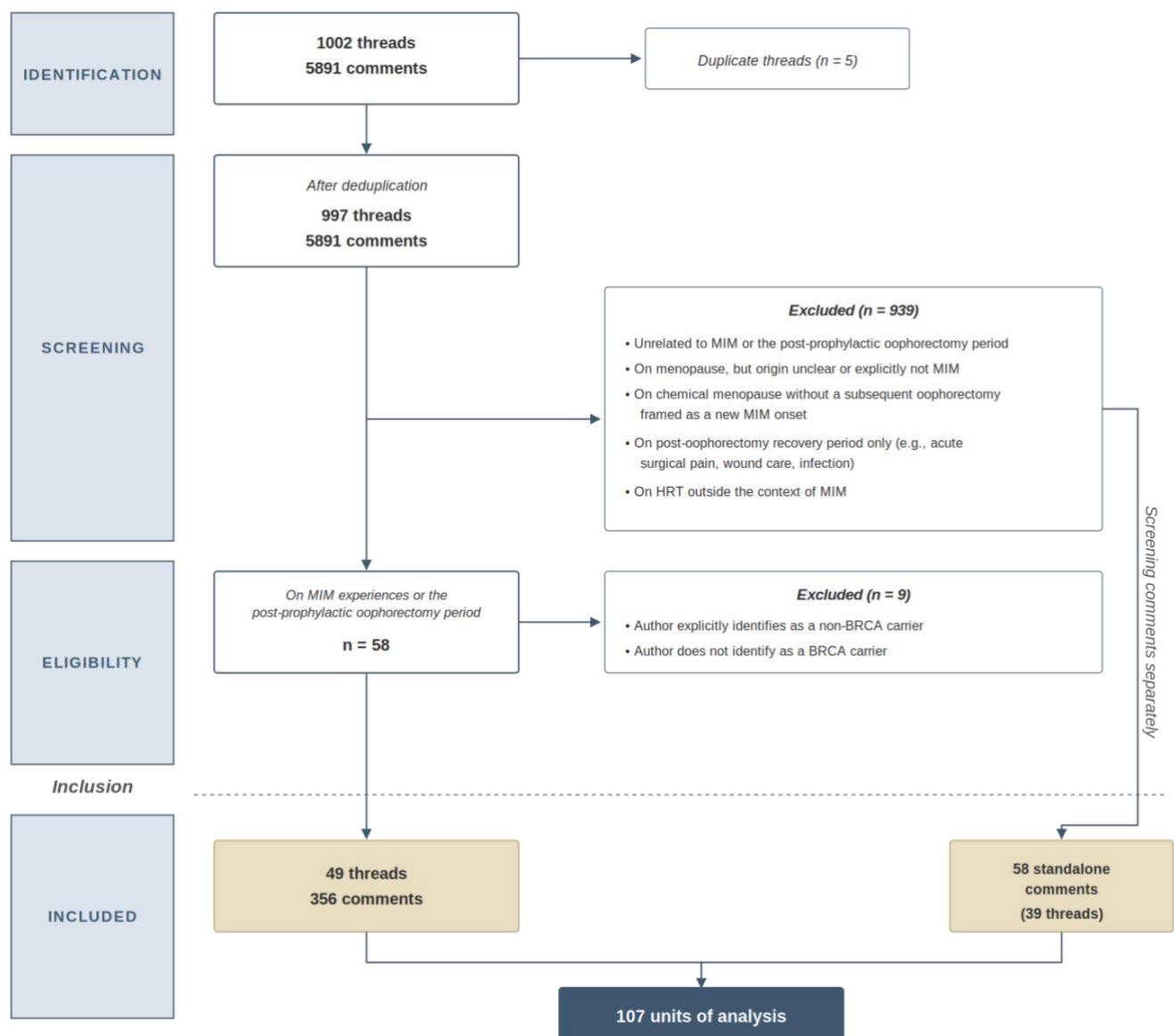


Figure 2. Data selection flowchart. See Table 1. for details on inclusion and exclusion criteria.

3.4 Data analysis

The analysis was carried out in Excel and followed the six phases (familiarisation, generating initial codes, constructing candidate themes, reviewing and developing themes, defining and naming themes, and producing the report) of reflexive thematic analysis (RTA) as described by Braun and Clarke (2006). RTA is grounded in an interpretivist epistemology in which knowledge is constructed through the researcher's active engagement with the data. The theoretical framework, and its sensitising concepts more specifically, inform interpretation during theme construction rather than direct initial coding, consistent with Braun and Clarke's (2006) guidance that theoretical frameworks function as analytical resources rather than as deductive schemes. RTA was selected over phenomenology or grounded theory for its flexibility to work with sensitising concepts while remaining open to data-driven patterns (Braun & Clarke, 2006).

The process began with repeated reading of the final sample alongside analytic memoing, building the depth of familiarisation and creating engagement with the data, which helped inform decisions during the following inductive coding phase. Initial coding was inductive and

data-driven, applied closely to included threads and standalone comments with attention to both what BRCA carriers expressed about their MIM experiences and their information needs. This covered the consequences they described, the needs they raised, the support they sought or offered, and the ways they made sense of their situation in daily life and care. The codes were interpretive formulations, formed through engagement with the data (Braun & Clarke, 2019).

Codes were subsequently grouped into working clusters around shared topics, serving as an intermediate 'work-in-progress' step toward theme development that was added to the standard six-phase methodology of RTA. Final themes were meaning-based interpretive constructions unified by a central organising concept that was devised from the pattern in the data rather than imported from the framework. Themes can therefore be seen as more than topic summaries and could only be named after analysis (Braun & Clarke, 2023). The move from working cluster to theme thus required an interpretive stance and looking beyond what users said about a topic to what a pattern of meaning revealed about how BRCA carriers narrate and make sense of MIM. Seeing and extracting these patterns, and interpreting what they collectively show about the BRCA carriers in the subreddit, is what RTA is designed for. Accordingly, RTA was chosen over more code-driven approaches to answer the question regarding information needs that emerge from experiences.

Theme development then followed a recursive process. Candidate themes were reviewed against coded extracts and the full sample, and as the analysis progressed, revised, merged, or split (Braun & Clarke, 2006). The theoretical framework's sensitising concepts entered only at this stage to inform interpretation. Defining themes took place once they demonstrated internal coherence, clear distinction from one another, and grounding across the full sample.

The code-to-theme development proceeded as follows: 381 codes were initially formed and resulted in 115 final codes after refinement in the inductive coding stage; the refined codes were grouped into 23 working clusters based on topic and early pattern recognition; the working clusters were then grouped into eight candidate themes based on data-driven patterns; the final four distinct themes were identified through candidate theme refinement. An overview of the final themes and the working clusters belonging to each is provided in Figure 3. Furthermore, the results of the analysis are reported in the results section, organised by the final themes. An audit trail documenting analytic memos, notable coding decisions, and the code-to-theme development with rationale for revisions was kept and is provided in Appendix 1. Through the audit trail, the interpretive process becomes transparent and traceable (Braun & Clarke, 2019; Mays & Pope, 2000).

3.5 Ethics, validity, and limitations

Reddit posts are publicly accessible, yet they often contain personal and vulnerable disclosures that come with ethical obligations that extend beyond the question of legal access (Harris et al., 2024; Heilferty, 2011). The extended arm of the supervisor obtained ethical approval from Reddit for the use of the data. Identifiable information was removed prior to analysis, quotations were paraphrased for non-retrievability, thread titles were not quoted directly, and retrievability was tested before reporting (Reagle, 2022). The dataset was stored in an institutional OneDrive environment protected by a password- and two-step authentication (Microsoft Authenticator) and will be destroyed upon project completion.

The quality of the analysis is considered against the criteria Mays and Pope (2000) set out for qualitative research. Validity rests on analytic rigour that is established by a strict selection procedure as detailed in Table 1, prolonged engagement with the data, a recursive movement

from codes through clusters to themes, and the integral place of reflexivity in an interpretive analysis where the researcher's situated reading is treated as a resource (Braun & Clarke, 2019, 2023). Regarding reflexivity specifically, I want to disclose that I am a medical student with clinical experience and I am also a 30-year-old woman. This places me professionally in the healthcare context more than a medically lay person and personally in the age range in which BRCA carriers make surgical decisions in their care trajectories, including about oophorectomy. It may influence how I interpret BRCA carriers' MIM experiences and their experiences with healthcare encounters. Furthermore, I integrated the framework for this study, making it difficult to keep it entirely out of mind before its intended use in the RTA. Knowing this can help me reflect proactively and understand my analytical decisions more than would be possible without this reflexive approach.

Several limitations to validity follow from a data-driven analysis of naturally occurring Reddit data: self-reported accounts from posters whose demographic information is unverifiable, no follow-up questions could be asked, and triangulation (comparing results from more than one data collection method) and fair dealing (deliberate inclusion of other perspectives to prevent a single viewpoint from standing as the sole account) were beyond reach (Mays & Pope, 2000). Self-reported accounts are not in themselves a limitation. This is because qualitative research of this kind, interview-based work included, depends on participants' own descriptions of their experience, the truthfulness of which can only be assumed in either setting. Reliability is not understood here in the positivist sense of replicability and inter-coder agreement, which is incompatible with RTA and this study being a single-researcher project, but as transparency and traceability, supported by an audit trail and clear exposition of setting and methods (Braun & Clarke, 2023; Mays & Pope, 2000). Representativeness of the data is limited by the findings being a reflection of BRCA carriers active on the subreddit rather than the wider population. Reddit's user base tends to skew younger, more educated, and of higher socioeconomic status (Goodwin et al., 2023; Hargittai, 2020; Proferes et al., 2021; Shatz, 2017). Moreover, the platform's audience skews geographically, as around 43% of its daily active users were based in the United States in late 2025 (Reddit, Inc., 2026). A further consideration is that posting is prompted, so experiences that do not lead someone to post or comment may be underrepresented relative to those that do. The findings therefore offer analytical insight into digitally articulated MIM experiences and information needs rather than a representative account of all BRCA carriers. Although a representative account is not the aim, transferability is supported by the transparent and traceable description of the setting, methods, and analytic process, which provides enough detail to allow others to assess how far the findings apply to other contexts (Mays & Pope, 2000).

4. Results

4.1 General overview of the analysis

This study analysed BRCA carriers' accounts of MIM as they were expressed on Reddit to gain insight into BRCA carriers' experiences of MIM, their information needs that emerge from these experiences, and what the experiences and needs suggest about potential gaps in person-centred counselling and follow-up care. The four data-driven themes that structure this section were developed through RTA (Braun & Clarke, 2006, 2023) and were the end point of the analysis. In the analysis, the framework's sensitising concepts functioned as interpretive lenses that informed the interpretation of patterns in the dataset from the point of candidate theme to final theme development. Figure 3 shows the final four themes together with their corresponding working clusters to give an overview of the dataset.

The themes can be understood as patterns of meaning, capturing how BRCA carriers articulate MIM in relation to their lived experiences and to the information they need or seek, with the expressed needs varying at different points in trajectories. The themes present MIM as a change BRCA carriers live through with their body and identity at once, with HRT availability mediating the experience of this change; the self-led work BRCA carriers undertake to empower themselves and construct the MIM care they need; the clinical relationship as most meaningful in shaping HRT availability and MIM management, contested between obstacle and gateway; and the ongoing weighing of MIM against ovarian cancer risk that shapes the surgical decision-making across BRCA care trajectories.



Figure 3. Hierarchical coding structure of themes and working clusters from the RTA of BRCA carriers' accounts of MIM as expressed on Reddit.

4.2 Theme 1: The inseparable bodily and identity changes in MIM

BRCA carriers see MIM as a transition in which body and sense of self move together, with each shaping the experience of the other. Changes in weight, sex life, mood, appearance, physical health, and the felt sense of staying like oneself surface across the data as connected concerns held together in one experience.

Before surgery, BRCA carriers describe concerningly anticipating these changes. Many also minimise their concerns even as they raise them in the subreddit, particularly those about weight, appearance, and sex, for example by framing their concerns as superficial relative to the preventive medical work being done and feeling guilty for having them. For younger BRCA carriers in their thirties and early forties, the timing intensifies what they anticipate. They describe worry about how MIM will unfold at this stage of life and a desire to gain a sense of control over the transition.

'I want to know what my life will look like after surgery. I mean physically, emotionally, and mentally? My main concern is MIM. Please do not mind my nervousness about aging skin, changing moods, weight gain, and if HRT will do something for feeling like myself. My goal is being there for my kids when I go into MIM.'

After surgery, identity change continues in lived form. BRCA carriers name self-doubt and emotional turbulence as logical parts of a sudden hormonal transition rather than as a personal failure. The disconnect from non-BRCA peers becomes lived isolation, with BRCA carriers noticing how MIM shapes their lives in ways that differ from peers, and how people in their own social circles, and even clinicians, struggle to recognise what they are going through.

'More women in my circle are now experiencing perimenopause, which makes me feel relieved in that I am not so different from them anymore. But their experience is still different than what we go through as BRCA carriers. I am also so happy that I went to a menopause specialist recently and that has helped a lot. She just had a lot more experience than my own gynaecologist with younger women going into menopause'

Where formal care and offline peers of BRCA carriers do not engage with the identity dimension, the subreddit peer community steps in. BRCA carriers with experience in MIM report how they experienced anticipated changes and that some of the ones they worried about beforehand turned out milder than expected. They also validate worries about sex, weight, mood, and appearance as warranted, contesting the invalidation pattern.

'When I got my hormones balanced, which took some time, I began to feel normal. My skin is not aging rapidly, my libido is good, and I am no longer tired all the time. I had to titrate my HRT a lot, but it worked out.'

The embodied dimension of MIM appears with felt weight across several specific symptoms. Hot flashes are named as a defining, impactful symptom needing active management. BRCA carriers on HRT sometimes describe them as the only remaining burdensome symptom, while those who cannot take HRT describe hot flashes as the standout of an unmanaged symptom set. Libido loss is named as a symptom that genuinely disrupts daily life, with vaginal dryness mitigated incrementally through local oestrogen and lubricant. The opposite also holds true in some accounts of no real

impact on sex life, sometimes naming partner support as a reason. Weight gain is anticipated before surgery and approached afterwards as a site for active self-management. Mental health impacts of MIM have been described on multiple occasions, especially for BRCA carriers with pre-existing vulnerability. Across these symptoms, the physical embodied and identity dimensions are inseparable rather than merely linked. How BRCA carriers look, feel, and function is bound up with whether they still feel like themselves, so bodily change is lived as a change in the self rather than as physical symptoms with a separate emotional reaction.

'I feel so horrible and not like myself. Did I make a mistake? It is so hard now to take care of my little kids, and I no longer have help. I need my old life back, but I feel stuck.'

HRT availability and adequacy in mitigating MIM are described as the main factor in how much of the body and identity change BRCA carriers live through. Where HRT is initiated around surgery, and the regimen is effective, MIM is described as not impactful or barely noticeable.

'Before surgery, I got a prescription for oestrogen from my doctor so I could start soon after. Until now, it has made me feel good, which makes me so relieved!'

Iterative titration is framed as normality rather than failure, and BRCA carriers often describe arriving at a settled new normal. When a regimen ends up working well, they describe MIM as milder than they had feared. Where HRT is unavailable, delayed, or inadequate, this gets connected, before and after oophorectomy, to significant body and identity changes of MIM. One BRCA carrier describes MIM without HRT as having led to suicidal ideation. Another names retrospectively that caring for young children would have been impossible without HRT. The lost HRT path, where breast cancer history blocks access, appears as a hard aspect of the BRCA journey and as a kind of grief alongside the ovarian cancer risk itself.

'I have had breast cancer, which responds to oestrogen, so I cannot have HRT. I need to have an oophorectomy at 40 and will go through MIM without HRT. Making peace with this has been very hard.'

Body and self in MIM present as moving together in one lived change. Anticipatory support, experiential normalisation between BRCA carriers with and without MIM experience, and emotional and relational responsiveness surface as the means by which BRCA carriers find this dual recognition. When this process is not supported enough in formal care, BRCA carriers seem to construct it with each other.

4.3 Theme 2: Self-led empowerment work to construct MIM care

BRCA carriers describe doing substantial work themselves to build the MIM care they receive. Many name feeling unprepared by clinicians for the lived effects of MIM, with some recognising the gap before surgery and others naming it only retrospectively after experiencing MIM. The recognised gap, together with the limits of single clinical encounters and the impact BRCA carriers expect MIM will have on their lives, drives a wide range of self-led work to obtain the care and symptom management they feel they need.

Before oophorectomy and around the HRT regimen specifically, BRCA carriers take on anticipatory information work to know how to prepare for MIM. BRCA carriers also describe wanting practical guidance on managing MIM through lifestyle and non-HRT strategies, and on managing residual symptoms when HRT alone does not cover everything. Needs for HRT-specific information to enable self-led empowerment work

are particularly substantial. BRCA carriers seek information on dosing, forms, combinations, specific hormones, eligibility, safety, and evidence on long-term protective effects against cognitive, bone, and cardiovascular decline. When formal clinical preparation does not help enough with the information work, BRCA carriers describe turning to peer voices for what they need to know about going through MIM and how to prepare for clinical encounters to make the most out of them.

'I came on here to find reassurance for what menopause will be. HRT is also very confusing to me, and my doctor only adds to the confusion. So, that leads me to do my own research, but now I don't know what to do. The doctor said oestrogen, and I think that I cannot take progesterone since I have not had a mastectomy until now. How can I know if I need testosterone? MIM really terrifies me... can anyone give me some advice? I would be helped a lot by this. There are still some appointments before surgery so I want to show up prepared with meaningful questions to ask.'

They use peer MIM experiences for preparation, with BRCA carriers who are anticipating MIM or are new to it learning from what others wished they had known or how others worked through trial and error. The subreddit peer community, in doing so, functions as a deliberate counter to the limits of what clinical encounters cover, giving BRCA carriers access to shared experiences and practical knowledge that formal care does not consistently provide.

'I hope you all want to let me know what you think assisted you, made things difficult, came as a surprise, or would explain to another about life after surgery. I would appreciate it. Thank you in advance for your guidance.'

Peer accounts surface as a source of both reassurance and fear, depending on what is shared, with both being named as part of building a realistic picture. BRCA carriers also recognise and applaud one another's MIM journeys, particularly those navigating MIM with added life responsibilities such as caring for young children, marking this navigation as substantial work.

A smaller, but analytically distinct group engages with the evidence base itself in response to information and clinical encounters that feel inadequate or contradictory. They recognise a lack in research and look up evidence to support decision-making that feels less supported by available evidence.

'Can someone give me the details of studies that look at the long-term consequences of MIM with HRT as compared to natural menopause? I am debating delaying my oophorectomy a bit longer than was advised.'

The way BRCA carriers position themselves in the subreddit illustrates a pattern of feeling a responsibility and need to take on an active role in their care trajectories around oophorectomy and MIM to increase the chance of a good experience and outcome. This pattern also appears in the non-information-related self-led work BRCA carriers undertake. They make surgical decisions actively as part of constructing the MIM care path. BRCA carriers describe double mastectomy (in data often called DMX) and hysterectomy as cancer-preventive procedures and also as structural preconditions for HRT access, with double mastectomy in particular named as the gateway to clinicians' openness on HRT. Hysterectomy decisions are weighed for how they will shape HRT options afterwards. For BRCA carriers, these decisions are seen as informed planning and as reframing of surgical choices they were going to make for cancer prevention, now with the MIM care path explicitly weighed in. The surgical decisions illustrate the anticipated impact and the lengths BRCA carriers will go to in order to make their MIM experiences something they can handle.

'I am planning for my oophorectomy in a few years, around 40. I already did a mastectomy to secure HRT for myself as an option.'

Additionally, BRCA carriers take on an active role in shaping the regimen and daily experience of MIM itself. Their active and informed engagement with their own HRT plans, using knowledge built over time, is named as part of how the regimen ends up unfolding well. Drawing on partners and family is part of managing MIM practically and emotionally, and lifestyle interventions through exercise, diet, supplements, and sleep are named as further ways to maintain perceived control over outcomes.

'I focused on lifestyle to manage my symptoms and I was quite successful in that, even before HRT. I stopped drinking alcohol, which helped for my intense hot flashes, and I started exercising. I still cannot have any oestrogen so I take vitamins and calcium, next to investing time and effort into strength training and cardio for my health in MIM.'

Empowerment is exercised actively by BRCA carriers, more than it is something they receive. Normalising experiences (before and after oophorectomy), through sharing of these experiences in a supportive online peer community, assists BRCA carriers in building knowledge, working the decision-making process, and growing confidence through their own and each other's work. Within this theme's self-led and peer-driven empowerment work, formal care offers a more limited contribution. The work is inherent to the MIM journeys described in the dataset, but most visible when formal care does not deliver what BRCA carriers need.

4.4 Theme 3: Constrained empowerment in the contested clinical relationship

The clinical relationship appears as the most meaningful factor in shaping HRT availability and MIM management. The clinical experiences BRCA carriers describe vary widely across clinicians, sometimes within a single carrier's own trajectory. The theme holds both accounts where empowerment is blocked and accounts where it is actively pursued and gained through the clinical relationship.

On the obstacle side, clinicians' knowledge experienced as outdated surfaces in accounts of HRT being refused or hesitated on by default. Hesitancy and delay after surgery are described as periods where BRCA carriers wait and advocate while MIM symptoms develop unmanaged. Conflicting advice across clinicians leaves BRCA carriers to navigate uncertainty on their own. Feeling unheard by clinicians who do not engage with the MIM dimensions of the oophorectomy trajectory comes up as bound up with regret, frustration, and unmet care needs.

'I want to have a salpingectomy soon and delay oophorectomy until about 45. I am looking for a gynaecologist who is open to this delay and will not dismiss me as if oophorectomy is just something to get over with. I fear the effects of MIM, but I am also scared of ovarian cancer. It is an impossible situation. Can someone recommend a good gynaecological oncologist who listens? The previous one I had just said to take HRT and did not address my issues.'

Across these obstacles, BRCA carriers describe empowerment constrained at the point of clinical encounters, with knowledge contested, decisions imposed, and confidence in care undermined.

On the gateway side, BRCA carriers describe clinician openness to HRT and active support as translating into relief and a smoother care path. Some BRCA carriers find this initially. Others seek it through second opinions or by switching to menopause specialists after unhelpful initial

clinical contact. Personalised, tailored HRT care plans that go beyond protocol are described as central to a good MIM experience. Self-advocacy in clinical conversations operates as a way to override hesitancy or denial, and BRCA carriers feel their agency is restored when decisions about timing, surgical options, or HRT path are worked out together with the clinician rather than imposed.

'I did the oophorectomy and have a mastectomy on my agenda. I was feeling bad for two years in MIM. I was at my limit and went online to find someone specialised in menopause. Because of my screening regimen with a mastectomy on the way, she agreed I was eligible for HRT. My life was never the same.'

Peers actively coach each other on how to engage in the clinical conversation. Advice circulates on discussing HRT planning before oophorectomy, on using the clinician's guidance when it is available, on seeking out clinician guidance independently when the initial contact does not offer it, on advocating for oneself, and on titrating HRT iteratively with the clinician over time. The advice draws explicitly on peer experience of what worked and what did not. In the advice, BRCA carriers position themselves and one another as informed participants in the clinical conversation rather than as only passive recipients of clinical decisions.

'I know it is scary, but hold on. Keep a good relationship with your clinician and go to them when you have troubles mentally or physically. Be patient with yourself and understand that dosing HRT takes time.'

'Quality of life is everything. It is important for a doctor-patient relationship to be true and open. However, when a doctor is stuck in one way of thinking, I believe you should find a new doctor. The field of medicine is always changing.'

Some obstacles exist beyond individual clinicians. BRCA carriers name the absence of a clinical home for their menopause care outside oncology as a structural gap, with care for residual or longer-term MIM concerns not consistently picked up by either oncology or general gynaecology. Care is described as insufficiently personalised at the system level. This lack makes concerns and questions go unaddressed, amplifying the MIM impact. The experiences of physical recovery from oophorectomy are compounded by the simultaneous hormonal shift of MIM and the surgical recovery system not being built around this overlap. Even with HRT in place, BRCA carriers describe continuing to seek help for residual MIM issues that do not have a clear clinical home.

'MIM management is not on the research agenda, so no one really knows what to do. But there are things you can do, such as going to a menopause specialist regularly before and after surgery. Gynaecologists are not the experts on MIM they make it out to be due to their focus on natural menopause.'

Across this theme, empowerment is described both as constrained and as actively pursued, often within the same BRCA carrier's account. The clinical relationship is where the communicative functions that lead to supportive and empowering care are most acutely tested, and where the absence of those functions is consequential for what MIM becomes.

4.5 Theme 4: Ongoing decision-making across the BRCA-MIM trajectory

The surgical decision about oophorectomy is present in the data as ongoing rather than as an one-time event. This process has cognitive, affective, and behavioural dimensions that are touched upon across the BRCA care trajectory. BRCA carriers describe weighing MIM-related

concerns against the ovarian cancer risk reduction that oophorectomy provides. Immediate symptoms, long-term health effects, life timing, and fertility considerations all enter this weighing as dimensions of quality of life. Fear, delay, regret, and reaffirmation surface across the process both before and after the surgical decision is formally made.

Many BRCA carriers frame the quality of life impact of MIM as worthwhile because cancer risk reduction is at stake, and BRCA carriers within the subreddit peer community coach one another in this perspective. The coaching emphasises the cancer comparison and the temporary nature of symptoms. Personal and relational motivations are factors that influence the framing, including wanting to be alive for family and fearing ovarian cancer more than MIM, at times tied to family history.

'At 36, I have an oophorectomy planned, due to lack of screening options and overall medical advice. My worries are the same as yours in being scared to not be there when my kids grow up. I think about them and being alive for them to motivate me.'

Long-term health concerns about cognition, bone, and cardiovascular function, tied to MIM, also influence weighing. Family history of decline amplifies the concern for some BRCA carriers. Beyond its bearing on immediate symptoms, HRT is weighed for how well it will protect long-term health, particularly in oestrogen-less form. For BRCA carriers whose breast cancer history limits HRT options, the lack of protection worry is described as more acute and as part of what makes the long-term risk side of the weighing heavier. Long-term health risks are described as shaping the timing decision for oophorectomy itself. Through this, some BRCA carriers delayed or declined oophorectomy specifically because these risks are weighed as higher than the cancer-reduction benefit in their own assessment.

'I will be doing a salpingectomy now and my oophorectomy after menopause because of my kind of mutation and lack of ovarian cancer family history. (...) I delayed the surgery due to MIM-related risks (heart disease, osteoporosis, dementia and arthritis), which I consider to be higher. I can live with this decision.'

BRCA carriers describe fear about MIM that information alone does not always address. The clearest instance is a fear of permanency, with the impact of MIM on quality of life feared to be lasting. Because the oophorectomy and the MIM that follows are irreversible, a poor outcome feels like it cannot be undone, keeping the decision-making ongoing past the point of consent. This fear is amplified by past hormonal experiences or pre-existing health vulnerabilities, and persists for some even once an HRT plan is in place.

'I have my oophorectomy next week, and my HRT plan stands after I did my mastectomy already. I still am having trouble with the idea of going into MIM at this age. I have dealt with mental illness earlier in life, and therefore I am scared about the effects that MIM may have on this.'

Active decision-making follows these considerations. Some BRCA carriers delay oophorectomy until the latest recommended age-range, delay until after natural menopause, or cancel oophorectomy entirely due to being deemed not eligible for HRT or fear of MIM impact, distinct from long-term health reasons.

'I had planned my oophorectomy for over a few months, but I have decided to only do a salpingectomy. The chances of me getting ovarian cancer are one in five, and this goes down even by taking my tubes out. I have experienced chemical menopause, and the quality of life problems are just too great for me.'

The sequencing of BRCA surgeries, meaning the order and timing in which risk-reducing surgeries such as mastectomy and oophorectomy are undergone, is worked out to optimise risk and life timing across domains. In the considerations, fertility enters the timing decision for those still planning families. When BRCA carriers decide on doing premenopausal oophorectomy, feelings of regret after surgery are described in cases of limited HRT effects, felt clinical pressure for surgery, or impactful MIM.

'I can tell you from experience that MIM sucks for some because our bodies are not always ready. Everyone is different of course, and my doctor said I would be okay. Let me tell you.. I regret my oophorectomy. I wish I delayed it until after regular menopause. Earlier hormonal shifts have been hard on me too.'

Variability across BRCA carriers is named as a limiting factor to anticipating. MIM surfaces as more intense than chemical, natural, or postpartum hormonal shifts for most BRCA carriers, but also as mild or manageable for others. In sharing variable experiences and naming variability specifically, BRCA carriers emphasise it to one another. BRCA carriers describe disclosing their own mild MIM experiences to comfort those in earlier stages of their journeys. This is done to counter-balance the dominant narrative of impact, but with the disclaimer that experiences vary from person to person, highlighting the unpredictability factor that comes into play when weighing options.

'I was very afraid of MIM, but I can gladly say that it has been okay, apart from a few symptoms such as trouble sleeping, some manageable hot flashes and difficulty finding words sometimes. I understand that everyone has their own unique experience, so do with my information what you want.'

Decision-making about oophorectomy stretches across the BRCA-MIM trajectory, before and after the point of consent. Managing uncertainty and managing decision-making, as communicative functions in the framework, are present here as ongoing work that BRCA carriers carry in substantial part themselves and weighs on them between clinical encounters.

5. Discussion and conclusion

The aim of this study was to investigate the information needs of BRCA carriers regarding MIM and how these emerge from the lived experiences they articulate on Reddit. An integrated framework developed for this study, combining Hickey et al.'s (2024) empowerment model for menopause management with Epstein and Street's (2007) model of person-centred clinical communication, informed the interpretive phase of the RTA. From the empowerment model came the sensitising concepts of anticipatory support and experiential normalisation, treated as routes toward empowerment in MIM, meaning the knowledge, decision-making capacity, and confidence a BRCA carrier needs to self-manage MIM and make informed decisions about it. From Epstein and Street came the six communicative functions of clinical care, the relational mechanisms through which that empowerment is supported or withheld. The four data-driven themes give a general answer to the main research question: BRCA carriers experience MIM, before and after oophorectomy, as an impactful and deeply individual transition of body and identity, and their information needs emerge from anticipating, weighing, and managing that transition in a way that lets them keep perceived control over it. The following sections discuss the three main findings, taking up the way BRCA carriers experience MIM as a transition they seek to control, the information needs that emerge from it, and the gaps in their person-centred care. A synthesis then draws the findings together, after which the study's strengths and limitations, a reflection on the research process, and its conclusions will be presented.

5.1 MIM as a body-and-identity transition BRCA carriers seek to control

In this study, BRCA carriers made sense of MIM as one transition of body and identity rather than as separate symptoms, speaking of the changes to health, vitality, daily functioning, and the sense of staying like themselves as connected concerns. The transition also reached forward, as alongside immediate symptoms, BRCA carriers raised the longer-term decline in cognitive, bone, and cardiovascular health. A future not yet lived thus already shaped how they saw their bodies, health, and well-being. HRT was an integral part of the transition rather than a later treatment question, and since the recommended oophorectomy and its timing have to be agreed to by BRCA carriers themselves, they approach MIM as theirs to control.

The way body and identity held together is where the present study extends existing evidence. The symptomatic and long-term effects of risk-reducing oophorectomy are documented in BRCA carriers (Campfield Bonadies et al., 2011; Chapman et al., 2015; Finch et al., 2011, 2012; Hall et al., 2019; Hickey et al., 2021). However, that evidence reports them as adjacent domains rather than facets of one transition, even where it links sexual change to identity or notes body image among carriers' concerns (Campfield Bonadies et al., 2011; Hickey et al., 2021). A likely reason is research methods, as the quantitative studies measured symptoms and sexual function as separate domains (Finch et al., 2011; Hall et al., 2019), and the reviews and survey are framed by topic or confined to one domain such as the psychosexual (Campfield Bonadies et al., 2011; Chapman et al., 2015; Hickey et al., 2021). Reading BRCA carriers' MIM experiences shared in personal detail on Reddit for meaning rather than measuring them against predefined categories lets body, identity, relationships, and daily life surface as the one experience they describe MIM to be. Pearce et al. (2014) approached this for surgically induced menopause, but in women with benign gynaecological conditions looking back, whereas the BRCA carriers here speak preventively and across the trajectory. This means the integration appears in anticipation as much as in hindsight.

A clear contrast nonetheless runs through the present findings, since lived impact varied and some BRCA carriers described MIM as mild. This is unsurprising alongside existing evidence

describing natural menopause as a phenomenon that is uniquely experienced by every woman, a reminder that it should not be overmedicalised (Hoga et al., 2015; O'Reilly et al., 2023). Even so, studies of BRCA carriers after oophorectomy report a dominant pattern of impact (Finch et al., 2011; Hall et al., 2019), with variation falling mainly within the psychosexual domain (Hickey et al., 2021). That dominance fits the abrupt onset, earlier life stage, and place in a cancer-risk trajectory with elective elements that sets MIM apart from natural menopause. The present findings echo the pattern but surface more of the variation around it, where milder experiences reassure others approaching the decision. Much of the milder experience reflects HRT, especially when it is organised around oophorectomy. This matches research that links HRT to better symptoms, sexual function, and quality of life (Finch et al., 2011; Gordhandas et al., 2019; Hickey et al., 2021; Siyam et al., 2017).

HRT carries this weight because it is BRCA carriers' main means of having perceived control over the transition, not only of relieving symptoms, and some go to considerable lengths to secure it. The clearest instance is risk-reducing mastectomy used to reach HRT. Because breast cancer risk is the recognised constraint on HRT (Finch et al., 2012), some sequence that surgery to become eligible. This willingness to undergo even major surgery is one expression of a wider active role. BRCA carriers feel responsible for their health and well-being in MIM, and this shows as self-led work to shape how it will be lived. BRCA carriers' work entails preparing through information work and consistently anticipating its impact while aware that experiences may vary, keeping a healthy lifestyle, structuring surgical decisions around MIM rather than cancer prevention alone, and weighing anticipated impact against the protection oophorectomy offers. The role is not unique to the present findings. Women after oophorectomy take a self-directed part in managing menopause and securing HRT (Siyam et al., 2018), and the weighing of menopause against ovarian cancer risk is documented when BRCA carriers decide about oophorectomy (Gaba et al., 2022). Across their wider trajectory, BRCA carriers are recognised as managers of their risk who want to be equal partners in their care, and this decision-making is ongoing work bound up with managing uncertainty rather than a one-time event (Dean, 2016; Dean & Fisher, 2019; DiMillo et al., 2013; Witte et al., 2025, 2026). What this study adds is the forms the active role and weighing take once BRCA carriers face MIM, seen most clearly in the mastectomy-for-HRT route. The extended and specified insight into these forms, and BRCA carriers' MIM experiences more generally, comes from the subreddit being a place where they have informal, low-threshold exchanges that motivate them to share in intimate detail. In this context, BRCA carriers set out their own reasoning, providing novel access to the motives behind their decisions rather than to their outcomes alone, with the mastectomy-for-HRT route as the most visible example.

5.2 Emerging information needs in MIM and their empowering function

The information needs of BRCA carriers regarding MIM emerge from the lived experience and the position they take within it. Because MIM is lived as one multidimensional transition that reaches forward, the needs span that whole frame. BRCA carriers want to understand the immediate symptoms, the longer-term decline in cognitive, bone, and cardiovascular health, the bearing on identity, and the disruption to daily life, along with how these can be eased. Because they also hold themselves responsible for how MIM turns out, a second strand concerns the decisions over HRT, timing, and surgical sequencing, weighed against their own circumstances. What unites the two groups of information needs is their use. BRCA carriers want information they can act on, to prepare for and mitigate MIM and to weigh the decisions it brings, the same self-led work and anticipation described in 5.1.

That women need information for menopause is established, yet prior research has addressed it only in part. In research on women's experience of natural menopause, women report wanting information that prepares them for what menopause can involve, especially long-term, but deeming the available information insufficient (O'Reilly et al., 2023). Furthermore, for induced menopause, clinical guidance recommends that women be informed about menopause before its induction (National Institute for Health and Care Excellence, 2015). Where prior research on BRCA carriers undergoing oophorectomy specifies what that information on menopause after oophorectomy should contain, it stays close to symptoms and sexual function (Finch et al., 2011; Hall et al., 2019), the clinical management of surgical menopause (Finch et al., 2012), and HRT with its effects on quality of life and breast cancer risk (Siyam et al., 2017). Other existing evidence assessed information needs closer to the present findings' scope, but for BRCA carriers in their trajectories more broadly, by treating information as instrumental support for managing uncertainty and for sharing in care decisions (Dean et al., 2017; Witte et al., 2025, 2026). For MIM specifically, the present findings broaden the scope of information needs by showing that they follow the whole lived MIM experience rather than a narrower, symptom-focused set of topics. They form both before and after oophorectomy in BRCA carriers' own framing and are as multidimensional as the experience, reaching across symptoms, long-term health, identity, and daily life and into the decisions BRCA carriers must make. Much is anticipatory, voiced before oophorectomy to prepare for what is to come. That these needs are not merely pre-surgical anxiety is borne out both by BRCA carriers in the present findings who have had the surgery and by earlier evidence of BRCA carriers wanting, in hindsight, more preparation for life after it (Campfield Bonadies et al., 2011). Hickey et al.'s (2024) empowerment model clarifies what the information needs are for: information on the impact of MIM builds the knowledge and confidence to face it, while information on the decisions ahead supports decision-making capacity, and together these make up empowerment. Information is thereby the means by which their active role becomes perceived control over how MIM is met and decided.

The more complete insight into BRCA carriers' information needs is established through this study's data source being Reddit. Because BRCA carriers write at every trajectory stage, the subreddit works as a marketplace of informational exchange, one of the communicative functions in the theoretical framework through which empowerment in MIM is built. Those further along or having overcome certain problems share their experiences to give (anticipatory) informational support to BRCA carriers with questions on MIM. The informative sharing of experiences, together with treating such questions as valid and ordinary, leads to experiential normalisation. This, together with the pseudonymous, low-threshold setting, makes the subreddit a rich data source for information needs. Importantly, as the information needs appear as they form in the subreddit, in anticipation as much as in hindsight, they are visualised in a way that is less accessible through fixed questions of interviews and questionnaires.

5.3 Gaps in person-centred MIM care and how BRCA carriers meet them

What BRCA carriers need from their care follows from the two findings above. As BRCA carriers anticipate and live MIM, they give its impact considerable weight and take responsibility for managing it. To do so, they want to be informed about the whole MIM experience they may encounter and about actionable related topics that present options to mitigate MIM. Care that met this would treat MIM's impact with the priority BRCA carriers give it and engage them as partners in decision-making regarding MIM, before oophorectomy as much as after. Against that standard, two gaps run through the narratives. The first is in the

clinical encounters around oophorectomy, where the care plan, including the surgery, HRT, and day-to-day management of MIM, is decided. The clinical relationship most shapes whether care needs are met, and BRCA carriers describe it as contested. Clinician knowledge is experienced as outdated, HRT is refused or delayed, and advice at times conflicts. Additionally, feeling unheard by clinicians who do not engage with the menopausal side of the trajectory runs alongside regret and care that falls short. The second gap is more structural. MIM care has no settled place in the system, falling between oncology and gynaecology. Through this, who has responsibility for MIM care is unclear and the provision of care is spread unevenly across the trajectory, from the preparation before oophorectomy to the residual and longer-term concerns that follow. The two gaps leave BRCA carriers feeling unsupported, their concerns unaddressed, and symptoms unmanaged, potentially exacerbating the burden of MIM and its effects on quality of life.

Faced with the first gap, BRCA carriers intensify their earlier self-led work and try to build the care they need. They become their own advocates, press for HRT, and turn to more specialised opinions when the clinician in front of them does not engage, much as women after oophorectomy did in prior research where doctors lacked knowledge of menopause and hormones (Siyam et al., 2018). This is visualised in the subreddit peer community, where BRCA carriers advise one another on what to ask and how to be heard, the active uptake of the very advice that carriers in earlier research, looking back, would give themselves and others (Campfield Bonadies et al., 2011). The furthest they go is the risk-reducing mastectomy used to reach HRT. Earlier this appeared mainly as a way to meet the HRT-eligibility requirement, but read as a question of care it is something carriers must negotiate within the clinical relationship: they undergo major surgery partly to bring a (future) reluctant clinician to act on their own prioritisation of HRT and by extension quality of life. That they go this far measures both how far their self-led work reaches and how real the barrier in their care is.

The peer community does more than help BRCA carriers negotiate their clinical encounters. Because BRCA carriers share their care experiences openly in the subreddit to feel understood and supported, this study could see both what they say about the care they received and how the support they build for themselves works. Across the narratives, the peer community takes up the six communicative functions the framework assigns to person-centred care (Epstein & Street, 2007). It builds relationships and belonging, fosters the exchange of information addressed earlier, responds to the emotional and identity weight of MIM, helps BRCA carriers deal with its uncertainty, supports their decisions, and backs their self-management of symptoms and recovery. The empowerment clinicians are expected to foster is, in this setting, instead built between carriers (Hickey et al., 2024). That such self- and community-care passes between BRCA carriers online is documented (Dean et al., 2017; Wellman et al., 2025). Yet, the present study reads it against what care itself should do, and in carrying these functions at every stage the peer community also stands in for the settled place MIM care lacks, the structural home the second gap describes.

What the peer community provides is, in effect, a statement of what counselling and follow-up for MIM should provide in its place: preparation and information, attention to its emotional and identity dimensions, support in dealing with its uncertainty and the decision-making it brings, and a backing of self-management. These recommendations are largely in line with earlier research on BRCA carriers after oophorectomy. Fuller and more compassionate counselling after oophorectomy, and clearer management of its quality-of-life and sexual symptoms, are already called for (Campfield Bonadies et al., 2011; Chapman et al., 2015; Finch et al., 2012; Hickey et al., 2021). On the structural side, Gaba et al. (2022) call for more deliberate centralisation of care into specialist multidisciplinary services, as BRCA carriers in such settings reported better care and HRT access. Additionally, research on surgical menopause

outside of the BRCA context adds the case for supporting the well-being and identity changes it brings (Pearce et al., 2014). Across BRCA care more broadly, Witte et al. (2025, 2026) argue for less fragmented, more person-centred care provision that guides communication and counselling responsive to lived experiences and evolving. Importantly, MIM care and more validation for MIM symptoms is named among those needs. From the decision-making side, Dean and Fisher (2019) add that support should extend across the trajectory rather than concentrate at the point of a risk-reducing decision. Where prior research recommends what better MIM care should include, the present adds a first-hand account, from BRCA carriers themselves, of how gaps in this care are experienced and worked around. In the support BRCA carriers build for one another, the findings demonstrate what care that meets the full range of person-centred functions can look like in practice, read as a model rather than as evidence that formal care can deliver it.

5.4 Synthesis of main findings

The study's main findings largely support what existing research has established about MIM, from its symptoms and the benefit of HRT to the self-directed role BRCA carriers take and the shortfalls in their care. In several respects they also extend it. A close reading of BRCA carriers' self-led narratives shows MIM as one integrated transition of body and identity, shaped by individual circumstances rather than the separate domains earlier measures captured, and surfaces more of MIM's variation than dominant-pattern studies record. The information needs that follow span that whole experience, including how BRCA carriers see their role in it, and arise as much in anticipation as in hindsight, beyond the narrower content prior research specifies. Read against the fuller picture of what BRCA carriers experience and build for themselves, the whole range of person-centred functions that care should cover comes into view, with the structural gap where MIM care has no settled place.

Together, the extended insights also underline one connected process. The MIM transition BRCA carriers experience, the information they seek, and the care around them are all directed at keeping perceived control over MIM. This is partly supported by formal care, partly withheld, and partly secured by BRCA carriers for themselves out of a responsibility for their own outcomes that the gaps in care intensify. Reaching these insights rests on this study's data source. On the subreddit, BRCA carriers gather at every point in the trajectory, so anticipated, current, and retrospective accounts of their lived MIM experiences and emerging information needs stand alongside one another. The richness of these accounts stems from the function the subreddit peer community has for BRCA carriers and the low threshold to share in it. Because it is BRCA carriers themselves, not a researcher's frame, who shape what becomes prominent there, the weighing they bring to MIM becomes visible as they collectively live it, as do the contested clinical relationship and the functions their care leaves unmet.

5.5 Strengths and limitations

This study has three main strengths. The first is this study's contribution to an underexamined area in existing evidence. As general menopause research expands, qualitative evidence on the experience of MIM after risk-reducing oophorectomy remains thin, even more so for BRCA carriers, as they are an overlooked group within oncology and genetic pathways (Hickey et al., 2021; Witte et al., 2025, 2026). The contribution is grounded in the ecological validity of this study's data. This is because the naturally occurring and unsolicited accounts of lived MIM experiences, written by BRCA carriers in the conversational context of the threads where they share in intimate detail, are well matched to a question about information needs emerging from lived experience. The second strength concerns the credibility of the data, since rather than

treating any first-person account as eligible, a strict selection procedure included only accounts where the poster could reasonably be established as a BRCA carrier experiencing MIM, strengthening confidence that the analysis reflects the intended population as far as the context allows. The third strength concerns the steps taken to support the quality criteria Mays and Pope (2000) set out for assessing the validity and traceability of qualitative research: a clear exposition of methods, with detailed inclusion and exclusion criteria and a transparent audit trail, supported traceable analysis; the interpretive engagement integral to RTA supported reflexivity; and the deliberate retention of all eligible accounts, including those running counter to the dominant patterns, addressed disconfirming cases.

This study also has three main limitations. The first concerns the same set of quality criteria. Because the data is naturally occurring posts, no standard or verifiable demographic data about posters was available, no follow-up questions could be asked, respondent validation and fair dealing were impossible, and the data-driven design placed triangulation beyond reach. The second concerns representativeness. The findings reflect BRCA carriers active on the BRCA subreddit specifically. This stems partly from the Reddit user base not being a neutral mirror of the wider population, overrepresenting younger, more highly educated individuals and those of higher socioeconomic status (Goodwin et al., 2023; Hargittai, 2020; Proferes et al., 2021; Shatz, 2017). For the current topic of menopause, the skew matters because research indicates that the engagement with hormone therapy decisions is itself shaped by health literacy and socioeconomic position (Torres & Marks, 2009). Moreover, comparable to what is reported about the United States geographical skew of Reddit (Reddit, Inc., 2026), many posters in this dataset referred to a United States location, insurance system, or healthcare context, so the experiences described here may transfer less well to other care contexts. Self-selection compounds this, since BRCA carriers may be more inclined to post when something is unresolved, such as distress or a difficult decision. As such, the platform likely overrepresents those BRCA carriers with unmet or more elaborate information needs and underrepresents BRCA carriers whose MIM experiences are milder or whose needs were already met. The third limitation is the cost of the selection rigour indicated earlier as a strength, since strict criteria meant excluding insightful accounts in which BRCA-carrier status or MIM experience, though suspected, was too ambiguous to confirm.

5.6 Reflexivity

By using RTA and its interpretive properties, my position as a researcher and the person behind it were integral to the analysis rather than a bias to remove (Braun & Clarke, 2006, 2019, 2023). I am a 30-year-old woman and a medical student with clinical experience, at a life stage close to many carriers in the data who are anticipating MIM. This proximity shaped the analysis in multiple ways. My clinical background gave me sensitivity to patterns in clinical communication, which sharpened the reading of the data but also risked framing clinician hesitancy as a failing rather than as BRCA carriers' own experiences. My identification with women facing choices in a similar age range made the more distressing accounts resonate strongly and could have drawn interpretive weight toward the narrative of severe impact. On the other hand, it did help me to hold space for the context BRCA carriers described. My theoretical position, using a self-integrated framework, may have unintentionally shaped what I read as important in the data, leading to inductive coding not being assumption-free. I worked with these tendencies through memoing and an audit trail that made my interpretive moves visible to myself, and through deliberately retaining the (milder) counter-experiences in the analysis.

5.7 Conclusion

BRCA carriers experience MIM, before and after oophorectomy, as an impactful transition of body and identity they want to control within a risk-reducing trajectory with elective elements. The information needs that emerge from this experience are for accessible, tailored information that prepares BRCA carriers for the full range of what MIM can involve on multiple dimensions for their life stage and how this can be mitigated. This includes possible immediate symptoms, longer-term health effects, and its bearing on identity, alongside information that supports decisions about HRT, timing and surgical sequencing and that recognises both the joint decision-making and BRCA carriers' individual weighing that variability of MIM and contexts call for. From these narratives, the clinical relationship emerges as the decisive site at which these needs are met or not. In it, BRCA carriers experience shortfalls in person-centred counselling and follow-up by not being prepared consistently for what MIM can involve across its dimensions and not being sufficiently supported in decision-making across MIM's variability. The absence of a structural clinical home for MIM care across the trajectory exists next to the relational gap. Together, they risk BRCA carriers feeling unsupported and MIM being experienced as unnecessarily impactful, with MIM effects on quality of life and health insufficiently mitigated.

From these findings, the central healthcare-management implication is the need to design the premenopausal oophorectomy trajectory to hold a clear place for MIM care before and after surgery, supported by the specialised expertise needed to inform BRCA carriers and jointly develop personalised plans that aim to mitigate the impact of MIM as fully as possible. What that care should attend to follows from the present findings. It should prepare BRCA carriers for the body-and-identity dimensions of the transition, not only its symptomatic ones; it should actively support the individual weighing they do alongside the joint clinical decisions they make; and it should recognise and integrate the active role BRCA carriers already take in their risk-reducing trajectories rather than treat self-led work as a sign that formal care can step back. This direction is consistent with the broader move toward person-centred care for BRCA carriers.

For further research, patient-led data from Reddit, used in the way this study did, is well suited for questions in healthcare management where formal evidence has repeatedly signalled a persistent gap. This is because such data can surface the experiential dimensions that help explain why the gap persists and what would address it. To extend the present findings, future work could combine this approach with other research methods for example interviews with topic lists informed by this study, to reach BRCA carriers beyond the Reddit population and across wider healthcare contexts and socioeconomic positions. This would test whether the patterns identified here hold beyond a self-selecting online sample and to inform care designs for BRCA carriers in different settings. Beyond extending the present findings to other contexts, the information needs themselves warrant study, returning to the challenges set out in the introduction of this study. One question is when and where in the risk-reducing BRCA trajectory structural and informational MIM care is best placed, so that BRCA carriers are prepared for what MIM can involve without being over-burdened at an already decision-dense point in their care trajectories. Because the present sample is self-selecting, underrepresentation of BRCA carriers with milder MIM experiences and/or less unmet or elaborate information needs is possible. Therefore, it remains open who would benefit from fuller information provision and who it would over-burden. A further question is the form this information provision should take, given the value BRCA carriers give to peer support and the constraints of formal care. Addressing these questions would help translate the identified information needs into the

tailored and anticipatory information provision that has not been consistently available in formal care.

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Appendix 1. Audit trail of analysis

1. Familiarisation with the data (RTA stage one)

Familiarisation – full data set (search with key words)

Surgery (“oophorectomy”, “ovaries removed”, “ovaries out”, “ovaries”, “RRSO”):

MIM can impact health (heart/bones/cognitive) later in life, wondering about/scared of quality of life/impact on life effects after surgery, weighing oophorectomy risk to early menopause risk and asking guidance from others. HRT experienced and anticipated as helpful for MIM, sometimes not allowed by doctors because of increased breast cancer risk leading to frustration of BRCA carriers and decision-making regarding breasts. Doctors can be hesitant to start HRT, leading to poorly managed MIM. HRT right combination/dosage after surgery can be difficult. MIM experience is diverse, symptoms after surgery are noticed, hot flashes mentioned repeatedly.

Menopause (“menopause”, “surgical menopause”, “early menopause”, “sudden menopause”):

Wanting to know what to expect from MIM, dealing with MIM experienced as hard/impactful/acute disruptive, MIM experienced as doable/not impactful, symptoms (night sweats, brain fog, hot flashes) experienced and positive effects of HRT experienced/anticipated, sex drive/weight/emotional/mental state negatively affected by MIM. Concerns about long-term effects of MIM on bones/heart/cognition, doctors open/pro HRT expressed as helpful for guidance and experience of MIM, Doctors do not want to perform oophorectomy ‘too early’ because of MIM leading to concern/uncertainty about timing of surgery, doctors do not always understand difference between MIM and natural menopause. Surgical menopause is not experienced the same as chemical menopause. Anticipation of MIM influences prophylactic oophorectomy decisions.

Symptoms (e.g. “hot flashes”, “night sweats”, “brain fog”, “mood swings”, “can’t sleep”, “period”, “bleeding”, “trouble sleeping”):

Self-management can help adjust to MIM and gives sense of control over long-term effects. HRT dosages/forms/combinations get titrated on symptoms, hot flashes and sweats are frequently mentioned impactful symptoms, variety of other symptoms are also mentioned as burdensome, cognitive function/mood/sleep are affected by MIM. Symptoms can present shortly after surgery. Not having a period or PMS was an upside, testosterone used for libido/sleep/energy/brain fog. Chemical menopause experience primed concerns for MIM. Users try to get up to date on research regarding HRT safety for BRCA carriers

Sexuality and bodily change (e.g. “low libido”, “vaginal dryness”, “pain during sex”, “sex life”, “body feels different”, “don’t feel like myself”, “aging”):

Not feeling like their old self, mental state and libido/desire changed, vaginal dryness described as impactful, sex lives are affected by MIM in a negative way. posters seem unprepared for

these symptoms, worrying about faster aging because of MIM resulting in negative health effects.

Hormonal management (e.g. “hormone”, “hormone therapy”, “HRT”, “estrogen”, “progesterone”):

No new insights/patterns than above.

Experiential or information-seeking expressions (“is this normal”, “what to expect”, “anyone else”, “my experience”, “need advice”):

Posters want to know what to expect to prepare themselves/did not always know what to expect looking back, MIM experiences are personal, sharing experiences to ask about others’ experiences too, experiences are shared to help others, advice to advocate for yourself.

Familiarisation – final sample

Analytical notes

- BRCA carriers describe how they are affected by MIM, what helped them and how they reflect on their experiences. The accounts are personal and open, and little seems intentionally (vaginal, sexual, identity, mental health). They also share tips and tricks in dealing with doctors, HRT, overall things they had to overcome.
- HRT is a very important element in their journeys. Limitations regarding getting HRT prescriptions are not the same for everyone and differ by healthcare setting and clinician based on how they look at the risk of using HRT (some are pro, others are against, some do not know). Medical assistance in managing MIM should be provided by doctors who understand BRCA and MIM as a unique/specific context, which risks are relevant, and how they should be weighed. Guidance from doctors is sought after and varies. Hysterectomy and mastectomy decisions to provide better HRT options are discussed/questioned/explained.
- Dealing with MIM is described as personal and done proactively. It seems like this is done to gain some perceived control over their MIM experiences. BRCA carriers are worried about how MIM will affect them. MIM experiences vary from not too bad to impactful based on symptoms and effect of HRT. HRT kinds, dosages, and combinations vary and getting it right is not always easy. MIM experiences are mostly discussed as surprising, either better or worse than expected based on symptom severity or symptom types. BRCA carriers who have been going through MIM and are now at a ‘good place’ seem to describe it as finding a balance in their new normal that worked for them.

Personal reflection

- I feel for these women and I identify with them as being a woman in the same age-range where they have to make choices resulting in MIM in the near future. I feel frustrated in how they feel unprepared. Similarly, I feel like they are unprepared for something that their doctors should guide them in. My medical training has an influence on this where I feel obligated to support patients with information and

making an effort to understand them as individuals. Also the lack of knowledge on HRT is something I am frustrated about because I recognise this gap in my own professional experience and I feel like these women suffer because of this.

- Regarding the analysis I feel contentment and relief about the number of sampled units, given the data-driven character of the study. I feel like there is a lot to find in the data. As I read, I stayed close to what posters had actually written, while staying aware that my enthusiasm, my identification with these women, and my investment in the project shaped what I had noticed. Rather than treating that influence as something to remove, I worked it as part of how I read the data. The number of units to analyse helps me in this.

2. Inductive initial coding (RTA stage two)

Initial inductive coding resulted in 381 codes

Analytical notes (coding decisions)

- Before starting: Given the research questions, I will be coding sections that describe experiences of MIM by BRCA carriers as matching inclusion and exclusion criteria. The focus is on sections where MIM experiences are shaped and signal an information need that exists, was overcome, might be helpful in overcoming for others etc.
- BRCA carriers who describe elements of their own MIM experience where they, in any way, signal those elements as important information to share, is seen as information that they share to close an information gap proactively. This is regardless of if the information was asked for directly or not.
- Specific standard menopause symptoms mentioned are not included in codes since they differ for every poster and in themselves do not hold much analytical weight, based on the research questions. If symptoms stand out in the description of an experience of MIM in how it is shaping it, they are coded.
- BRCA carriers' descriptions of the outcomes of/ or specifications of surgical decisions to avoid MIM are not coded. Specific reasoning behind the decisions that are linked to the experience of MIM are coded.
- Expressions of delaying oophorectomy without going into specific concerns or motivations regarding MIM are not coded. Wanting the timing of surgery to be optimal is not substantive enough, since that is logical and standard practice. How that timing is determined and decided is coded.
- At coding thread 29 I feel I am too zoomed-in/detailed in codes, so I am taking a more analytical approach for focus and feasibility.
- Individual life experiences and background unrelated to BRCA may influence MIM experiences. Because every person has their own complex life and no questions can be asked to posters, these experiences are not coded.
- Content by BRCA carriers describing perimenopause before surgery but describe MIM as a new experience is coded.
- Coding all hormone replacement therapies as HRT unless something specific indicates naming a specific hormone for the meaning of the code.
- Breast cancer history in codes refers to BRCA carriers' own history and not family history of breast cancer. When the matter is family history of any condition this is indicated clearly by 'family'.

- Risk-reducing double mastectomy is coded as DMX, since this is the term BRCA carriers in the data use consistently. In the context of the data, it is discussed mostly as a preventive measure taken to be able to have HRT (this happens a lot).

Analytical notes

- Knowing what to prepare for regarding MIM seems to be important to be confident and feel in control when it happens.
- HRT is seen as a standard necessity to manage MIM and information about it/a plan is appreciated beforehand.
- The data consists of BRCA carriers anticipating future MIM and BRCA carriers who have already experienced MIM or are currently dealing with it. BRCA carriers with MIM experience seem to help by giving perspective on MIM to lessen worries or provide functional advice. They do this through explaining how they have dealt with impactful elements. Moreover, BRCA carriers share lessons they learned throughout their journey.
- At times, posters emphasise questions on what they should be asking their doctor. It could signal that they feel responsible for the result of their own care. This may reflect worry that they could negatively affect their own care by not being sufficiently informed.
- Long-term health risks of MIM appear to be dementia/cognitive decline, cardiovascular disease, and osteoporosis.
- BRCA carriers mostly feel like HRT does not increase breast cancer risk for them, based on growing evidence and positive opinions in the medical field. They seem to prioritise quality of life.
- There is a divide between BRCA carriers who felt supported and who did not, which seems to be correlated to how they experienced MIM.
- BRCA carriers do seem to worry how elements of different life domains are affected by MIM, based on what their life looks like before surgery. Indicating that an individual approach and person-centred focus is in order.
- Intimate/vulnerable elements of the MIM experience such as sexuality are discussed as elements that are important in quality of life and feeling like self. It seems to be known that MIM can affect sexuality. In what way sex is affected appears as an information need.
- Themes that come up: quality of life and longevity, autonomy, guidance and support.

Personal reflection

I feel disappointed in not being able to identify posters of interesting content as BRCA carriers when I suspect them to be, leading to me not coding their accounts. Same in menopause experiences where it appears to be MIM, but it cannot be confirmed (appears less). I also feel quite excited about how rich the data is and that the choice for Reddit as a data source pays off. During coding I notice my perfectionistic tendencies, which makes coding a long process where I sometimes have trouble keeping attention. Purposefully, I took a more deliberate analytical stance when I noticed it to not get lost in details. Furthermore, I am frustrated about how a lot of BRCA carriers seem to be let down by their providers when they describe MIM symptoms without any treatment. I may be focussed on how they describe wanting quality of life directly and indirectly. I have the desire to improve care and this may lead to me using this as a lens for the coding unintentionally. The other side of this is my sense of pride for BRCA

carriers in how they face their trajectories head on in the face of uncertainty and the impactful risks they seem to be juggling.

3. Code refinement (RTA stage two)

Code refinement resulted in 115 codes

Analytical notes

- For refining codes it works well to identify the common element of the codes I may cluster together, including the motivation that is shared in the codes. Motivation means what comes forward as the message of the coded content in what it, for example, says about how something is framed or experienced. It appears that the posts and comments function in getting information across about the MIM experience or about care/information/support needs that exist or are filled. Therefore, the shared motivation of data and corresponding codes is an important driver for the refinement of codes.
- There are no set specific refinement decisions as were in the initial coding. I printed the codes and sorted them as a puzzle. I started putting the codes that were alike by each other and then followed with more motivation-based grouping, as described above.
- One code goes in on the fear-inducing effects of experiences that are shared by BRCA carriers living MIM after surgery. This is mentioned once explicitly, however appears more often when posters voice worry in a somewhat anxious way and a shared lived experience feeds into it. The context of Reddit and how threads appear in my data, does not provide whole conversations. The response to the shared experiences can thus only be imagined.
- One code explicitly goes in on not having a clinical home for menopause-related care for BRCA carriers, but this comes back in more accounts as a message. The main pattern is not getting the specialised care they feel they need.
- Some codes are more prevalent than others, showing potentially a 'stronger' pattern. The goal is to see and notice the patterns that come through strongly, but analytically distinct patterns should not be absorbed when they are standalone or add a meaningful layer to a pattern that already exists (fertility connected to timing for example).
- What autonomy in the context of this data seems to be: ability to decide what should be prioritised, timing decisions and weighing in life domains where this feels important, taking control of care trajectory and self-management aside from hormones, becoming knowledgeable on evidence and treatment options for MIM, making decisions on HRT, getting enough information to fully understand the decision that is made and stand behind it completely.
- What guidance and support for BRCA carriers should do or be: up-to-date on research, provide preparation for MIM, contain specialised knowledge, help in weighing risks, recognise the complexity lives behind diagnoses.
- Refining was more analytical than expected. Figuring out the motivation driving each code and not only looking at the topic touched was more work. However, this improved the analytical quality of the refined codes.
- The way risk-reducing mastectomies show up structurally as a gateway to HRT is more than I expected. Mastectomy is therefore not only breast-cancer prevention, but also a HRT precondition.

- Code regarding grief over the lost HRT path due to breast-cancer diagnosis is a different register than other HRT-denied codes, due to it naming the loss itself as one of the hardest things to cope with in the BRCA journey. Could matter analytically for how the care gap is described. Other HRT-denied accounts describe consequences and frustration of HRT-denial more.
- Variability matters more than I anticipated. Some codes describe MIM as severely impactful, others as mild and unexpected. The impactful narrative is still the main pattern noticeable. However, counter-experiences are part of the full picture and including them preserves rigour of the analysis. They seem to function in how BRCA carriers among each other try to create the full picture, with BRCA carriers further along helping to create it for BRCA carriers newer to/ anticipating the MIM experience.

Personal reflection

I want to stay consistent and precise. However, going through the process of refinement, I notice a learning-curve regarding actively losing some detail for the sake of refinement. Even so, it still was difficult to do. Keeping the framework out of my analytical process for now was difficult too. I am already seeing bigger patterns and having the framework in mind unintentionally at times. To counter this, I am keeping my attention on the data in front of me and building the refined codes from what is actually there, holding the framework's larger patterns to one side for now rather than reading them back into the codes. Also focusing at the stage where I am at is a good way to deal with it, leaving the other stages ahead of me for now. The initial emotions and frustration are more present in the background, because at this stage the data is not new to me anymore. This RTA stage is more of a technical process than before, which leaves me less room for the feelings I had before. Nonetheless, I still identify with BRCA carriers as individuals in my age-range by thinking about how it must be to undergo such major life altering processes. Some codes are intense and make me think about BRCA carriers' realities, such as one about MIM experience without HRT leading to suicidal ideation. Moreover, the care gaps being visible in many experiences as I work through many codes, still frustrates me. I know my healthcare training is part of why I read it as something clinicians should do better, but it also surfaces in the data clearly. The more hopeful accounts affect me too. The BRCA carriers who advocate, seek a menopause specialist, find a personalised plan, name their partners or gynaecologist as the difference between coping and not coping provide glimpses of what care could look like if it were better. A personal goal is to not let the positive accounts get drowned out by heavier accounts in the working cluster forming. Importantly, I do not feel that my closeness to this material has kept me from abstracting as this stage asks. If anything, staying with how these accounts affect me is part of how I notice what the codes are doing.

4. Creating working clusters (intermediate stage)

Working cluster forming resulted in 23 working clusters

Analytical notes (not tied to specific WC)

- I kept going with the printing codes and puzzling on a physical table I had done for code refinement. This grouping is more topic-based and worked well with the refined codes

that were still close to the data, easy to interpret and kept what the original inductive codes had as the core elements.

- Not specifically foregrounding salpingectomy with delayed oophorectomy as a new way to delay oophorectomy. The method is interesting, but it is already studied and increasingly applied to delay oophorectomy. The delaying oophorectomy itself or surgical sequencing and the context around this in BRCA carriers' accounts is the focus.
- Other surgical choices, such as the pattern of risk-reducing mastectomy for HRT accessibility, is recognised in the analysis and appears novel. WC8 and WC20 both indicate that it determines whether HRT is on the table for BRCA carriers. This pattern became most visible in this stage of the analysis.
- Working the refined codes into the WC revealed two parallel tracks in BRCA carriers' accounts of MIM experiences. One is experiential (HRT working or not, MIM with or without HRT, regimen complexity). The other is more relational (clinician openness of hesitancy, advocating for HRT, peer advice on securing HRT). Being aware of them in forming the WC.
- Anticipated vs lived experiences split cleanly enough to create separate clusters in more than one instance. WC1 represents anticipated bodily and identity changes, while WC15 is the lived identity work in MIM. WC14 is the anticipatory information cluster, while WC4 is how information gaps are experienced now and retrospectively. How BRCA carriers position themselves in where they are in the trajectory shapes how they frame their accounts and warrants separation.
- Counter-experiences are present in the data and they are retained in the clustering. WC16 includes codes where sex life is unchanged. WC17 is the most direct variability and counter-experience cluster where MIM is experienced as mild. WC19 includes how peer accounts can also generate fear, which is counter to how the dominant pattern shows them as helpful.
- WC23 surfaces as a cluster on system gaps that is structurally different from how barriers exist in clinical encounters (WC9). The system around clinicians and encounters seems to not be built for BRCA carriers in MIM, which influences the micro level. The distinct levels are important because they pertain directly to the research question regarding person-centred counselling and follow-up care.
- WC3 is a relatively smaller, but distinct cluster. BRCA carriers at times want more than information, they work evidence themselves when they feel it is insufficient or contradictory. They appear as epistemically different from information seeking and is kept in mind for later empowerment framing.

WC	Name of WC	Analytical notes
1	Anticipating self and body change	The codes name the anticipated changes to self, identity, and body that BRCA carriers worry about before MIM. Sex life and intimacy are under threat, and changes in weight, mood/mental health, appearance and aging come together in a fear of not feeling like themselves.
2	HRT information needs	Covers the substantial information seeking around HRT specifically. BRCA carriers ask about dosing, forms, combinations, specific hormones, eligibility, evidence on HRT safety for BRCA carriers, duration limits, whether

		HRT actually delivers, what to do with residual symptoms, and age-specific evidence. The shared practical concern is creating a regimen that fits their own body. The epistemic concern is needing clarity on a treatment that sits at the intersection of menopause care and cancer risk.
3	Pushing back on evidence base	The codes describe a different kind of relationship to HRT information than the practical info seeking elsewhere. They experience the evidence base itself as a source of stress, call for more research, and engage with the evidence themselves when formal evidence is unclear/contradictory.
4	Gaps in clinical preparation	A gap is experienced between what BRCA carriers say they need for MIM preparation and what clinicians provided, both before and after oophorectomy. Some name the gap in real time and others look at this retrospectively. The aspect of being unprepared for the time and effort it takes to adjust is also mentioned.
5	HRT making MIM manageable	Codes where HRT is central to making MIM liveable. Some describe starting HRT immediately after surgery as the key to a smooth transition and others find that a delay in starting HRT eventually delivers substantial improvement. HRT has led to essentially removing MIM experience in multiple cases.
6	Clinician openness and self-advocacy	The counter-side of negative clinical experiences. Clinician openness translates into relief and a smoother path. Personalised care is secured by seeking second opinions and specialised care, advocating for self to override hesitant clinicians. Agency feels restored in joint decision-making.
7	Peer coaching on clinical conversations	Codes show peers actively coaching each other on how to engage the clinical conversation about HRT taking into account what they learned from their experiences. Some name importance of discussing HRT planning beforehand, and others say to use clinician guidance. Self-education on menopause and HRT comes up too.
8	Surgical decisions as HRT gateway	Surgical decisions, especially risk-reducing mastectomies, are seen as a gateway to HRT access. Mastectomy is framed as a form of cancer prevention but more so as a structural precondition for HRT later. Hysterectomy decisions shape HRT options going forward because having a uterus means needing to take progesterone.
9	Clinician obstacles to HRT	Codes describe clinical experiences where HRT is hesitated, denied, delayed, or not validated. Included outdated knowledge and imposed delays or short-term use, conflicting advice, and a felt loss of not being heard. RC20 here and not in the WC on HRT complexity due to the clinician imposed element that sets its tone. RC29 also here and not in WC on self-advocacy and clinician openness due to frustration being the main focus and not the desire for self-advocacy.
10	MIM without HRT as severely impactful	This is the opposite side of the codes compared to other code where MIM was mitigated by HRT availability. When

		it is not available, some describe it as impactful or unbearable. Impact can go as far as leading to suicidal ideation for one BRCA carrier. Retrospective recognition of what MIM would be like, deeming it unmanageable. This gets anchored in personal context such as caring for children.
11	Decision making around oophorectomy	Codes show that BRCA carriers make active decisions in delaying or revision decisions about oophorectomy. Delay happens due to MIM-related fear, cancelling entirely, regret after the fact. Also Sequencing with other surgeries and timing menopause, also in relation to fertility. The active role of BRCA carriers seems bound to their status (own interpretation of early pattern)
12	Weighing MIM burden vs ovarian cancer risk	How BRCA carriers position MIM in relation to cancer risk is described in the codes. MIM is framed by some as worthwhile because ovarian cancer risk is at stake. Peers also coach this perspective. Personal and relational motivations anchor the framing, and many describe actively weighing MIM-related risks against ovarian cancer risk-reduction as a central element in decision-making.
13	Long-term health concerns	Codes name long-term health effects (cognitive, cardiovascular, bone) as serious concerns that shape anticipation and surgical decisions. Family history strengthens the worry for some. Other BRCA carriers hold this concern more generally, worry about HRT not being sufficient protection, or link the concerns to surgical timing fix. RC65 here due to long-term health concern appearing as main focus of the content and not the delay itself. Compared to RC94. RC62 also specifically on HRT in connection with long-term risk so best to place it here.
14	Anticipatory information needs	In essence about wanting information before MIM happens. BRCA carriers ask what to expect, what bodily and hormonal changes to anticipate, how MIM and HRT decisions hang together and what to bring to the clinical conversation. The motivation that runs through the codes is gaining a sense of control and calming anticipatory anxiety. information seeking is a practice of preparation.
15	Lived identity and peer validation	Covers the lived dimension of identity and self once MIM is experienced. Feeling shame and guilt about having MIM concerns, body image affected by the aging process coming from MIM, and MIM pictured as identity-disruptive due to young age of onset. Peer validation pushes back on dismissing their own concerns and self-doubts integral to the sudden transition.
16	MIM impact on sex life and intimacy	This cluster describes MIM impacting sex life, libido, and vaginal comfort in concrete, embodied ways. Mitigation through local oestrogen/lube named as partial and incremental. Libido loss is a standout and debilitating symptom, bleeding as separate disruptive symptom and the counter-experience where MIM does not significantly affect sex life is also in the codes.
17	Variability and counter-experiences	Codes name how MIM compares to other hormonal states and how it varies between BRCA carriers. More

		intense than chemical, natural, or postpartum for some. Mild, doable, unexpectedly different for others. Variability is often a message to others.
18	Self-management and active regimen role	BRCA carriers' own active role in shaping how MIM goes is the common topic of the codes. Lifestyle is a way to have control over outcomes. Active and informed engagement with own HRT regimen based on gained knowledge.
19	Peer and non-clinical support	BRCA carriers appear to use non-clinical support resources. Peer MIM experiences are used for preparation, online peer support limits isolation and online sources extend the knowledge base. Support for each other takes form in applauding others' MIM journeys. Peer accounts also generate fear. Support in real life in form of psychological or family support/supportive partner are part of MIM regimen.
20	Complexity and loss of HRT regimens	Brings together the lived complexity of HRT once it is in play. Some describe titrating and adjusting as normal iteration. Others go in on what happens when regimen is not working, the situation of HRT allowed for limited time, denial due to breast cancer history, and grief over lost HRT path.
21	Specific MIM symptoms	Codes go in on specific MIM symptoms and weight gain dimension. Hot flashes need active management and are impacting, MIM symptoms overwhelm on multiple levels at once, mental health is affected requiring additional care and weight gain is deemed as important to manage with lifestyle and HRT due to its impact or difficulty (to manage). RC not placed in WC on self-management and active regimen role due to specific focus on weight gain and the difficulty pertaining to the symptom
22	Anticipatory fear about MIM	Another cluster on anticipatory fear about MIM, however now it is distinct from information needs. Fear is on permanence, fear is amplified by past hormonal experience of health vulnerabilities, exists despite plan, fear of surgical regret (oophorectomy).
23	System-level care gaps	Gaps in the care system beyond individual clinician encounters, located in the structure of the system itself. The lack of a clinical home for MIM care in the trajectory, care not being personalised, recovery from surgery compounded by MIM unexpectedly, and ongoing help-seeking despite HRT are captured in the codes and indicate the gap.

Personal reflection

Working the codes into clusters helped me see the dataset zoomed-out again more. It was easier than refining codes, because it felt closer to sorting than constructing. Even so, I caught myself wanting to over-merge. I reminded myself of the RTA steps and how the deeper theme-forming and interpretation came later. What came up again is how much uncredited work BRCA carriers do. They research, advocate, switch providers, join online communities, and function in their lives through symptomatic MIM, all to have the MIM experience and care they need. Where advocacy, switching providers, or finding the right specialist is described, I feel as

though it is something that is somewhat positive, but experiences stained by denial and dismissal are something I feel should not be happening. My medical training helps me see the contrast in these two groups. Grief over how HRT is lost as an option and what it stands for, a certain hopelessness, touches me. The mourning BRCA carriers do in relation to MIM and how they feel they can succeed or fail is something I would not wish on anyone. The variability cluster pulled me the other way. It reminded me that framing of the 'gap in care' may be dominant narrative, but it is not the only one. Some BRCA carriers do fine in MIM, have HRT that simply worked, and have unchanged sex lives. I feel positive in my set goal in having the variability stand out appropriately next to the dominant narratives. I am excited about how risk-reducing mastectomy came into view as a route BRCA carriers take to get to HRT access. It proves to me how Reddit is indeed a very rich data source through its distinct attributes.

5. Searching for and reviewing themes (RTA stages three and four)

Searching for themes resulted in eight candidate themes

Analytical note (not tied to specific CT)

- Deliberately not naming candidate themes due to not wanting to limit their meaning in the review process. Patterns in the theme are what defines them at this stage and not the name I give them.
- Through forming candidate themes with the sensitising concepts I can see how the communicative functions and empowerment exist in the subreddit. They appear to be represented well and the framework fits the data.
- BRCA carriers seem to share their experiences, their needs, their self-led work to help each other figure out how to live with MIM. The accounts also have a function to gain support and to be understood as a basis for why BRCA carriers share in the subreddit, besides helping others.
- Experiential normalisation between BRCA carriers with more MIM experience to those with less experience is also validating the feelings, concerns, and questions that come up or the problems they see before them, not only physical effects of MIM after its onset.

CT (numbers)	Candidate theme	Analytical notes from reviewing candidate themes
1	BRCA carriers do information work themselves to prepare for MIM. They ask what to expect, dig into HRT options and dosing, engage the evidence base when they feel it is inadequate, and want to come to clinical discussions in real-life with questions. The clearly visible pattern is calming anticipatory anxiety and gaining felt control before a known impactful event (possibly) WC about connection between clinical guidance	This theme holds on its own looking at data and other forming themes/clusters. The work exists through BRCA carriers doing preparation in information seeking. The analysis of the theme holds as earlier constructed. The calming of anxiety and gaining control sits closest to knowledge dimension of empowerment and to the sensitising concept of anticipatory

	and feeling prepared makes the gap visible. The information work that follows is what BRCA carriers do to fill it, mostly self-led because clinical preparation does not arrive timely.	support, with both being constructed by BRCA carriers themselves when care does not deliver. The information work is done to fill this gap. CT1 connects with CT3 (agency) since both describe self-led work.
2	The clinical relationship is the most meaningful factor in shaping HRT availability and how MIM unfolds. This relationship in the data appears as contested more than dependable. There are experiences of delay, denial, conflicting advice, and limited validation on the side that is experienced negatively. Openness, personalised care, and joint decisions on the other side. One WC extends the theme from individual to system-level context. Across the CT BRCA carriers go into clinical encounters not knowing which side of care they will meet. However, they advise each other how to work this to get the care they need.	The clinical relationship comes through in the data as the most meaningful factor in shaping HRT availability and MIM's unfolding. Codes show it as contested and not dependable. On the good side care provides openness, personalised care, and joint decision-making. On the other side, care provides denial, delay, conflicting advice and insufficient validation. Empowerment reads as both constrained and as attempts to attain it, both visible across the codes. The core of empowerment (agency, confidence and knowledge) is what BRCA carriers appear to want in order to self-manage their MIM. The way empowerment is described in the theoretical framework is thus represented clearly here. The communicative functions are packed densely here too (more how they are/are not represented in care than CT3), most notably fostering relationships, information exchange, managing decision-making, and responding to emotions. The layers of care gaps, with at the most macro level a system that has not built a place for MIM care specifically, can be identified in the data. The obstacle and gateway sides are two halves of the same contested pattern and not separate themes.
3	Codes come from doing substantial work outside of, or alongside, the formal encounter in care for making MIM unfold how they want. Choosing risk-reducing mastectomy or hysterectomy to unlock HRT access, restructure lifestyle, build peer/content networks, and sometimes go outside formal approval. Again, a compensation for what care does not	A lot of work is done outside of the clinical encounter to make MIM livable and something to be able to control. Surgical and non-surgical decisions are as named in the CT. Enabling self-management (sensitising concept) is happening, the clinical scaffolding for it not really. Self-management can be linked to the

	deliver. They piece a form of care together which unifies.	broader aim of empowerment (managing MIM). Regarding this, the other communicative functions are represented too in the peer community, used by BRCA carriers, for the MIM experience and care they strive for (for themselves and others). Experiential normalisation comes up too. Peers are a normalising reference, especially when there is no good clinical alternative. Overlap in CT1 because both describe BRCA carriers compensating for the system.
4	Codes come together where HRT functions as a determining factor for if MIM will be livable or unlivable. HRT being available leads MIM to be unnoticeable or manageable. No HRT means most times MIM will have great impact (severe). It can even become life threatening. Across the theme, HRT is not one issue but the issue the data and discussions behind the codes seem to organise around when it is mentioned. HRT weight is in a way existential.	HRT carries the heaviest weight in the data. Makes MIM severely to not at all impactful, depending on its presence. (original inductive codes and data on suicidal ideation, caring for young children, HRT being unavailable due to breast cancer is hardest part of journey). In between is the lived complexity of HRT. Titrating, time limits, denial due to breast cancer history. Almost all of the six communicative functions are present because HRT is the organising issue around MIM. Empowerment effectively hangs on HRT being available, especially for breast cancer subset. Sharing of how BRCA carriers experience MIM, especially when further along in it, is a form of giving anticipatory support and experiential normalisation to others of what the effects are like, this comes through mostly rather implicit. concerns from others are in turn asking for this (CT5 and CT1). In this CT it is quite purely on the lived effects of MIM on body and self. Strong as a theme, likely to consolidate with CT5 and CT6 at the next step due to mediation of embodied dimensions.
5	These codes show pattern of describing MIM as something that rewrites how a BRCA carrier feels about oneself. The anticipatory codes name worry about sex life, weight, mood, appearance, and not feeling like	MIM rewrites in anticipated and lived ways how BRCA carriers feel. (Original codes and data describe sex, weight, appearance and self being affected with body image and shame as a

	oneself. The lived data has shame about MIM concerns, body image after surgery, experience of being out of sync with non-BRCA peers, and self-doubt as part of the transition. MIM is an identity change next to a hormonal one is what this theme defines. Peer validation creates confidence (or tries to).	consequence.) Through the framework's sensitising concepts (communicative functions), responding to emotions is most directly invoked and missing in clinical encounter it appears. Through normative core of the framework and its sensitising concepts, confidence is threatened limiting empowerment. Peer validation shores up where clinicians fail. This is in line with CT6. Anticipating MIM effects also represented in CT7 and CT8, however they are more connected to long-term, weighing and surgical decision-making, and fear.
6	MIM as a lived embodied dimension. Vaginal dryness, hot flashes, libido loss, weight gain, impact on mental health. Some symptoms get mitigated (lube, local oestrogen, exercise, psychiatric care) and there are also others that persist. No impact is also reported. A thread in the theme is that the body is where MIM gets lived most concretely and self-management is where BRCA carriers go to if clinical support lacks.	Embodiment of MIM comes in concrete daily ways. Symptoms are similar to those described in CT5 describes and mitigation is possible, but limited in experiences. Others do not report any impact. The sensitising concept of enabling of self-management is a function that happens self-organised. The practice test of empowerment comes from the body being the place where self-management is exercised. Connection with CT5. Will probably merge next.
7	Codes and data bring together the ongoing cognitive and affective work BRCA carriers do as they weigh MIM against ovarian cancer risk. They reframe MIM as worthwhile, but anticipatory fear is taken into the calculation (fear of permanence, fear amplified by past hormonal- or health experiences, fear despite HRT-plan). In this theme, it comes through that weighing is not purely rational. Variability across BRCA carriers means the same weighing produces different conclusions for different women.	Ongoing cognitive and affective work that is personal and not purely rational. BRCA carriers' reality is not having everything available yet, but going off of what is known, including past experience, vulnerabilities, and fears. Sensitising concepts managing uncertainty and managing decision-making both are represented most visibly. Responding to emotion from BRCA carriers who have dealt with the same or are further in the process to help the weighing comes through as well. Responding to emotion is sometimes also what they appear to need from other peers in the community. Variability sits in this theme as an analytical reminder that the same weighing produces

		different conclusions and realities for different BRCA carriers. Continues with CT8. The weighing produces the decisions, these decisions get revisited based on continued weighing.
8	Long-term health concerns and surgical decision-making are what defines this CT. Codes and data they are from show that they are connected and long-term health concerns shape decision-making. Family history amplifies worry. Delaying, canceling, regretting oophorectomy and aligning timing with natural menopause are consequences of the decision-making when MIM is anticipated to be impactful for multiple reasons. That decisions are revisited based on contexts that shift over time and long-term considerations is coming through in the data.	Surgical decisions are made and remade, in the data BRCA carriers look back on decisions and reflect on them. This process is influenced by concerns for MIM, also long-term. The concerns are affected by personal fears (as comes through best in CT7) that have a number of reasons. Decisions (delaying, canceling) and the consequences of them are therefore personal and may not be what care recommends. Yet, they want to make their own decisions and appear to want support for doing that. The sensitising concept of decision-making capacity in empowerment is clearly visible here. Managing decision-making (and also uncertainty) are the health communication sensitising concepts. Anticipatory support is most directly connected to the long-term concerns because they represent an anticipated future and oophorectomy decisions act on them. Continues with CT7.

Personal reflection

I feel happy that these women are helping each other out and also frustrated that they have to. My wish to bring these BRCA carriers' stories into view pulls me toward what is lacking in their care, and I worked with that pull by deliberately keeping the fuller picture in view, including the accounts where current care settings were described as empowering and tied to good MIM experiences. I feel for them and admire their strength and perseverance. The work they put in motivates my analytical process. Rather than guard against identifying with the posts and the BRCA carriers behind them, I let that identification inform how I read, while staying aware of it. However, I do identify with these BRCA carriers in how I can feel energised sometimes in clinical settings by patients that are brave and take ownership of their care and situations to change it for the better. As a woman in the age range of these BRCA carriers, I stayed conscious of this closeness. During the review of the candidate themes, it felt like the analysis was coming together and it kept getting easier to feel in control over the analysis. Using the sensitising concepts helped to feel this way. Forming candidate themes felt like a relief and the point where the analysis came to life the most for me. Getting to the interpretive stage feels more natural to my thinking process.

6. Final theme review, defining and naming themes (RTA stages four and five)

Forming final themes resulted in four themes

Analytical notes (not tied to any specific theme)

- Deliberately not naming reviewed themes until the final stage.
- The sharing of the experiential reality of MIM in intimate detail across themes shows the overarching experiential-normalisation function of the subreddit.
- Theme 3 indicates most directly what care does or should do for BRCA carriers to have the care they need (Theme 2 more implicitly, and Theme 1 shows the experience that clinicians should understand).
- Theme 1 and Theme 3 feel more difficult to capture fully. There are many aspects that are relevant and connect to each other and other themes. How the MIM experience unfolds and how BRCA carriers are cared for in healthcare settings influences both the self-led work and the decision-making process/weighing they do.
- The communicative functions are not included in the names of the final themes. They appear as more instrumental and process-steering towards the empowerment in BRCA carriers' MIM experiences. This is in line with how the framework is visualised in Figure 1 of this study.

CTs (per final theme)	Analytical notes from forming reviewed themes	Naming final themes + definition and reasoning
4,5,6	Theme 1: Merge due to the divide between identity change/work and bodily symptoms not lasting in the review. Weight, sex life, and mental health sit in together at once. HRT (CT4) mediates the change that unfolds for BRCA carriers. The main pattern describes MIM as lived (and anticipated) through the body and felt as identity change at the same time. Through the framework, it is where empowerment meets the lived body because confidence is threatened and self-management is tested in practice. Responding to emotions surfaces most directly here as a sensitising concept, often missing in the clinical care of BRCA carriers regarding MIM. Experiential normalisation is consistently in the data through peer-validation that BRCA carriers use to push back on dismissal of MIM concerns.	The inseparable bodily and identity changes in MIM <i>Definition:</i> BRCA carriers describe MIM as a transition in which body and identity move together, with each shaping how the other is felt. HRT availability shapes the unfolding of this multi-dimensional change in daily life. <i>Analytical reasoning:</i> the name evolved from an earlier short data-led form (MIM as lived in body and self) to the fuller phrasing that conveys the meaning of the theme that came up in the review: that change in both elements is part of one transformative experience. Empowerment is tested practically here, but has its anchor more elsewhere (theme 2).

1,3	Theme 2: Merge because information work and active agency surface in the review as facets to the same compensatory pattern. Information seeking, surgical decisions to secure HRT, lifestyle work, peer networks, and sometimes off-label HRT run together. The pattern describes BRCA carriers doing substantial self-led work to construct the care they feel they need, for themselves and others in the peer-community. As such, BRCA carriers take on all six communicative functions. It appears as empowerment in action, especially where clinical care does not deliver. Empowerment (ability to self-manage MIM) and anticipatory support appear to be built peer-to-peer and helped by the sharing of BRCA carriers at different trajectory stages.	Self-led empowerment work to construct MIM care <i>Definition:</i> BRCA carriers doing substantial information, surgical, lifestyle and community work to build the care they actually receive, especially when formal care does not deliver. <i>Analytical reasoning:</i> empowerment, as pertaining to BRCA carriers having/attaining it, is most fitting in the name of this theme. This is because the data show BRCA carriers exercising the three empowerment dimensions (knowledge, decision-making capacity, confidence) most vividly in this theme. Self-led carries the compensatory framing.
2	Theme 3: Remains unmerged. Analytical density and its centrality for the research sub-question on person-centred care argue for keeping it intact. CT3 seems a partial consequence of CT2, but not continuous enough (self-led work is not only the result of clinical care experiences). The clinical relationship being described as contested rather than dependable is the main pattern in this theme. Obstacles (denial, delay, conflicting advice) and gateways (openness, personalised care, joint decisions) appear to be two sides of the same contested pattern. The WC on the system-level care gaps extends this contested care phenomenon to the system, which seems to lack a structural place for MIM care in the trajectory of BRCA carriers (undergoing oophorectomy). Empowerment exists in this theme as both constrained and as attempted to be attained. Especially fostering relationships, managing decision-making, and responding to emotions cluster densely here as the communicative functions of care.	Constrained empowerment in the contested clinical relationship <i>Definition:</i> the clinical relationship as the main factor shaping HRT availability and MIM management, contested between obstacle and gateway, with empowerment represented as both blocked and actively pursued. <i>Analytical reasoning:</i> as this theme is connected to the Theme 2, by how the clinical relationship influences self-led work, naming empowerment directly seems fitting. Calling it constrained shows the dominant pattern. The clinical relationship being contested held during review as a way to describe it. The value BRCA carriers place on having a good clinical relationship is represented by that term too.
7,8	Theme 4: Merged because in the review weighing (note: as part of the self-led work pattern it is in theme 2) and decisions regarding oophorectomy are continues in the data. CT7 seems to produce the CT8 decisions, and	Ongoing decision-making across the BRCA-MIM trajectory <i>Definition:</i> The surgical decision about oophorectomy as ongoing rather than once-and-done work,

	these get revisited based on continued weighing. The pattern describes the oophorectomy decision not as made once and held, but as ongoing cognitive, affective, and behavioural work across the trajectory. Decision-making capacity as empowerment is exercised actively here. Managing uncertainty and decision-making are represented in this theme as the communicative functions. Responding to the emotional element of weighing is also visible, as is the normalisation of the experiential elements BRCA carriers bring into weighing and the reasoning behind it (empowerment sensitising concept). Anticipatory support is most directly relevant because long-term concerns are anticipated futures, yet they (feel they) have to decide on them now. Variability is something BRCA carriers remind each other of, and comes through in the weighing as what can lead to different individual outcomes.	with cognitive, affective, and behavioural dimensions that revisit themselves across the BRCA trajectory. <i>Analytical reasoning:</i> The naming of this theme is most directly data-led because the ongoing decision-making is the main pattern, rather than any single framework element. Managing uncertainty and managing decision-making do not anchor the name. Variability is in the theme, but more part of the internal structure than its anchor.
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Personal reflections

- I felt a bit insecure when forming Theme 1 and Theme 3 as they were more difficult to capture fully, given the many relevant aspects that are also connected to other themes. Taking a step back and thinking of the main points of the themes and where they differ helped me feel secure in my analytical choices. The reflections at earlier points of the process still hold (feeling for BRCA carriers, applauding and admiring their sense of community and fierceness, identifying with them as an age-range peer, and as a soon-to-be clinician with some prior insight into what they go through in the healthcare system.) I feel this was something I carried into the interpretation, and I questioned it as I worked, checking the patterns I was constructing against what the accounts actually said rather than assuming the reading was already there to be found. Looking back on the process, I feel like I stayed close to the data and did the analysis in a logical way. The analysis grew to more interpretive in the later stages, as was intended. In the recursive process I noticed how deeply I had immersed myself in the data and come to know it well, which helped me read across the accounts and construct the themes. Staying this close also meant the themes I build remained answerable to what BRCA carriers had actually written rather than to anything I may have assumed.