The “Double Whammy”: a cooperative inquiry exploring how women navigate the biographical disruption of perimenopause and rheumatoid arthritis

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Abstract

Background

Biographical disruption offers a robust framework for understanding how chronic illness affects people's lives, yet it often overlooks how gender shapes these experiences. Drawing on a feminist perspective, this study addresses a critical gap in research by exploring how women with rheumatoid arthritis (RA) navigate perimenopause (PM). This intersection is significant, as RA is most commonly diagnosed around the same age as PM onset (40–50 years) and affects women three times more often than men. The dual challenge can profoundly impact physical, emotional, and social wellbeing, disrupting daily life, identity, and future expectations. However, little is known about how women manage these experiences when they occur together.

Method

Guided by feminist-informed phenomenology, this study sought to understand women's lived experiences while acknowledging how intersecting gendered inequities shape health and meaning-making. Data were collected through cooperative inquiry, a participatory action research method that fosters shared reflection and dialogue. It was then analysed using reflexive thematic analysis underpinned by phenomenological epistemology. This iterative process enabled the identification and interpretation of themes that illuminated how women navigate and make sense of the intertwined experiences of RA and PM.

Results

Three overarching themes were identified: 'Biopsychosocial distress of a new reality', 'Coping through resilience strategies and accepting change', and 'Navigating the health system'. Participants described a *"double whammy"* of bodily disruption, emotional strain, and social

constraint. Despite these challenges, they also developed adaptive, relational forms of coping that fostered new ways of flourishing. Flourishing was not the absence of suffering, but the capacity to find meaning and connection through it.

Conclusion

The study extends biographical disruption theory by demonstrating that disruption is a dynamic, ongoing and dialectic process through which women continually reconstruct meaning and identity. Recognising women's embodied expertise and the centrality of gender is essential for improving healthcare practice and broader understandings of living well within disruption.

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Preface

My interest in the topic of perimenopause stems from my own lived experience of feeling misunderstood and invisible. At the time, I was working in a demanding corporate role that offered little understanding or accommodation for what I was going through. The stress and lack of support during this period also contributed to significant strain in my personal life. These experiences prompted a period of reflection and ultimately inspired a career change, leading me to pursue a Master's in Health Psychology, with the goal of becoming a health psychologist specialising in women's health and ageing. For my practicum I worked with Arthritis NZ/Mateponapona Aotearoa, developing menopause resources for their community. Through facilitating a workshop with women on menopause and arthritis, and later working as a support worker with the Arthritis Assist team, I became aware of the complex and often overlooked intersection between RA and PM and the lack of research in this area. These personal and professional experiences became the catalyst for this study.

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Abbreviations

RA: Rheumatoid arthritis

PM: Perimenopause

EM: Early menopause

DMARDs: Disease-modifying anti-rheumatic drugs e.g. methotrexate

NSAIDs: Nonsteroidal anti-inflammatory drugs

HRT: Hormone Replacement Therapy – this was used over Menopausal Hormone Therapy (MHT) as it was what the participants used in their discussions

UK: United Kingdom

WHI: Women's Health Initiative

US: United States

CI: Cooperative Inquiry

Reflexive TA: Reflexive thematic analysis

Figures

Chapter 1: Introduction and overview of the literature

Introduction

This study draws on several complementary theoretical frameworks to explore women's experiences of rheumatoid arthritis (RA) and perimenopause (PM). These include Bury's concept of biographical disruption, Cluley's alternative concept of biographical dialectics, Leder's phenomenological framing of illness as dys-appearance, Frank's illness narratives, Lazarus and Folkman's transactional model of coping, and feminist and critical disability scholarship, including Butler and Garland-Thomson, which highlights the ways gender shapes women's health experiences. Together, these perspectives provide the theoretical lens for this study. In this chapter, I provide a brief overview of these frameworks before reviewing the literature.

In terms of terminology, this thesis adopts Kleinman's (1988) distinction between illness and disease for RA: illness refers to the subjective, lived experience of a condition, while disease denotes the underlying pathological changes in biological structure or function. While PM is neither an illness nor a disease, it is a natural biological transition that can produce physiological and psychological challenges. Consequently, the lived experience of PM can, at times, resemble aspects of illness or disease. Throughout the thesis, I aim to acknowledge PM as a normal life stage rather than a pathology, while allowing some conceptual flexibility when discussing the overlapping experiences of RA and PM, particularly in relation to how women navigate the dual demands of chronic health conditions.

In this thesis, I primarily use the term *women* to describe participants and to discuss existing research, as the study focuses on cisgender women and much of the literature in this area

specifically addresses women. However, I recognise that not all people who experience perimenopause or who have ovaries identify as women. Wherever possible, I have aimed to use inclusive language to acknowledge the diversity of gender identities affected by PM. The use of the term *women* in this thesis therefore reflects both the composition of the study sample and the focus of much of the existing literature, while recognising that further research is needed to understand the experiences of people of other genders during PM.

Theoretical frameworks

Women's health in midlife is shaped by the complex interplay of biological, psychological, social, and cultural factors, however, the lived and embodied dimensions of these experiences often remain underexplored within dominant biomedical frameworks. The concept of biographical disruption offers a useful lens for understanding this complexity by framing illness as unsettling everyday life, identity, and future expectations. Bury (1982) introduced this term through his research with people diagnosed with RA, showing how illness can unsettle established self-narratives. Such disruptions can provoke existential questions—"Why me?", "Why now?", "What is to become of me?" and even "Who have I become?"—reflecting the profound impact on self-understanding. For women, experiences of health-related disruption are often shaped not only by physical changes but also by gendered social expectations and roles that intensify the challenges to identity and everyday life that come with illness or embodied changes such as PM. Feminist work in health highlights how gender social expectations and roles intensify the challenges for women (Riley et al., 2018), but in the original study Bury did not foreground gender as a shaping force within biographical disruption even though most of his participants were women. Thus, Bury absented important elements of the biographical experience for women.

Building on Bury's (1982) foundational concept of biographical disruption, the notion of biographical dialectics (Cluley et al., 2023) offers a more dynamic understanding of how individuals live with ongoing and fluctuating health conditions. Rather than viewing disruption as a single event followed by resolution, biographical dialectics conceptualises illness as an ongoing negotiation between disruption and repair – where stability is continually challenged and re-established. This cyclical process acknowledges that periods of adaptation or acceptance are often temporary, as new symptoms, changing bodily capacities, or shifting social contexts can reignite uncertainty. In this sense, biographical dialectics captures the temporal and embodied oscillation between control and loss, coherence and fragmentation, that characterises life with chronic or transitional conditions. This perspective therefore highlights the importance of understanding women's experiences not as linear journeys toward adjustment, but as fluid, relational processes of ongoing biographical work.

Leder's phenomenological account of illness offers a further valuable lens for examining women's health, highlighting how disruptions in embodiments can profoundly shape lived experience, identity, and social participation. In *The Absent Body* (1990), Leder explains that in states of health the body tends to "disappear" from conscious awareness, enabling an effortless sense of capacity and engagement with the world. By contrast, illness produces what he terms "dys-appearance", where the body obtrudes into consciousness through pain, fatigue, or dysfunction, becoming a source of disruption rather than an invisible medium of action. This bodily intrusion undermines a person's sense of reliability and control, destabilising identity and producing what later scholars describe as an "uncanny" or "unhomelike" embodiment (Madeira et al., 2020; Svenaeus, 2000). In subsequent work, Leder (2016) further explains how illness triggers existential distress through loss of agency, disruption of roles, and feelings of being

excluded from the flow of everyday life (using a punishment metaphor). Framed through Bury's (1982) concept of biographical disruption, Leder's work highlights how illness unsettles not only physical functioning but also temporal orientation, social roles, and expectations for the future.

Complementing Leder's phenomenological perspective, Frank (2013) emphasizes the importance of illness narratives in making sense of bodily change. In *The Wounded Storyteller*, he argues that chronic illness shapes identity and social relationships, and that narrating one's experiences can help restore agency and coherence. His framework of the Five Dramas of Illness—quest, restitution, chaos, mystery, and tragedy—provides a lens for understanding the diverse ways people interpret and communicate bodily disruption. Ketokivi's (2008) concept of the wounded self also illuminates how chronic illness or bodily change can destabilize identity, continuity, and agency, highlighting the emotional and relational dimensions of living with health challenges. The wounded self is often drawn to others who share similar experiences, seeking connection, understanding, and social recognition as part of reconstructing a new sense of self. Together, these concepts foreground both the narrative reconstruction of identity and the relational processes that support coping, showing how sharing experiences and forming connections can foster coping.

Lazarus and Folkman's (1984) transactional model of coping, which includes problem-focused and emotion-focused coping, provides a useful framework for understanding how women in midlife manage health-related stressors, particularly those that are ongoing, embodied, and socially constructed. The model conceptualises coping as a dynamic process arising from the interaction between an individual and their environment, shaped by cognitive appraisal and available resources. Within women's health, this model helps explain how women interpret and respond to conditions that challenge their sense of control, identity, and social roles. However,

feminist scholars have noted that women's coping is not merely an individual psychological process – it is also constrained and enabled by gendered expectations, social support networks, and structural inequities within healthcare (Fricker, 2007; Hunter, 2019; Ussher, 2006). Thus, while the transactional model underscores women's agency and adaptability, it also highlights how coping must be understood within a broader sociocultural context that shapes the meanings of illness, resilience, and endurance in women's lives.

Feminist and critical disability perspectives also offer important insights into women's health, particularly in understanding the embodied, social, and identity-related consequences of illness and bodily change. Butler's work (2004; 2015) highlights how gendered norms shape which experiences of women's bodies are recognised, with deviations from these norms—through illness, ageing, or reproductive transitions—often dismissed, contributing to epistemic injustice. Garland-Thomson's (2011) "misfits" framework extends this understanding by emphasising how biographical disruption arises not only from bodily changes but from the misalignment between bodies and social environments, showing how structural and cultural expectations amplify distress when women's bodies no longer "fit." The strict definitions of what women "should be" reinforces traditional contrasts, such as normal versus abnormal, abled versus disabled, and desirable versus undesirable (Olafsdottir, 2013). Together, these perspectives underscore that women's health is simultaneously embodied, social, and political, and that disruptions to the body are intertwined with disruptions to identity, roles, and social recognition.

As highlighted in much of the research on women's health, women frequently encounter epistemic injustice within healthcare (Fricker, 2007), where their testimony about their own bodies and symptoms is dismissed, minimised, or deemed unreliable. In women's health contexts

this can potentially manifest through “medical gaslighting,” fragmented specialist care, or the failure of health professionals to integrate overlapping conditions into a holistic understanding of the patient’s experience. Leder (2016) points out in his book *The Distressed Body* that being objectified in medical settings, by bodies becoming abnormalities to be managed, magnifies suffering. So, for women facing health stigma and gendered expectations, this lens helps show not just what distress is, but why many feel their distress is discounted or invisibilised. Such injustices compound the challenges of biographical disruption, leaving women not only to live with complex symptoms but also to fight for recognition and legitimacy within healthcare and social settings.

Carel and Kidd (2014) further examine how people with illness are vulnerable to epistemic injustice in healthcare. They argue that testimonial injustice occurs when patients’ accounts are undervalued due to biases, such as assumptions of emotional instability, while hermeneutical injustice arises when gaps in collective understanding prevent patients from expressing their experiences effectively. Women are especially affected because societal expectations around caregiving and emotional labour can lead to their health concerns being dismissed or misunderstood. Carel and Kidd suggest that adopting a phenomenological approach, which values women’s lived experiences, can help redress these injustices by ensuring that women’s voices are heard and respected in medical contexts.

Taken together, these frameworks—biographical disruption, biographical dialectics, phenomenological framing of illness as *dys-appearance*, illness narratives, a transactional coping model, feminist and critical disability scholarship, and epistemic injustice—highlight that women’s health in midlife cannot be understood purely in biological terms. Rather, it involves the ongoing negotiation of identity, relationships, and credibility within systems that often fail to

accommodate or validate their lived realities. This chapter will therefore begin by critically examining the qualitative literature on women's experiences of RA, before proceeding to consider the research on PM and finally exploring the limited literature on chronic conditions and PM.

What is rheumatoid arthritis?

Rheumatoid arthritis (RA) affects 2.5 percent of New Zealanders and approximately one percent of the population worldwide (Arthritis Foundation, 2021; Arthritis New Zealand, 2018). RA is a chronic disease that causes inflammation around the body and commonly presents with pain and swelling in the joints (Arthritis New Zealand, 2025). RA can occur at any age but most often develops between the ages of 30 and 50 and affects more women than men. RA has been framed as a "women's health issue" as three to one people with RA are female (Milne, 2020). Women with RA also experience higher disease activity and pain and more difficulties in performing daily activities than their male counterparts (Ahlstrand et al., 2015; Sokka et al., 2009).

The development and progression of RA encompasses a range of genetic, hormonal, and environmental factors, with stress increasingly recognised as an important contributor to disease onset and activity (De Cock et al., 2022). Anecdotally, women often report that their RA emerged following periods of stress, trauma, illness, or significant life events such as childbirth (National Rheumatoid Arthritis Society, 2024). Empirical research supports these observations: Bengtsson et al. (2009) highlight the role of stressful work events in increasing RA risk, while Germain et al. (2021) show that cumulative stress is significantly associated with disease onset among women.

Once established, RA typically leads to progressive deterioration of physical functioning, creating limitations in activities of daily living and reduced functional independence. The fluctuating and unpredictable nature of symptoms—termed episodic disability—means that periods of relative stability are interrupted by increased pain, fatigue, stiffness, or reduced mobility (Campbell et al., 2022). These physical limitations often have a profound impact on women's psychological health and social functioning (Barker & Puckett, 2010), while long-term RA is also associated with increased early mortality, particularly from cardiovascular complications (Emery et al., 2002; Marder et al., 2015). Taken together, these findings indicate that both the onset and progression of RA are shaped by complex interactions between biological and environmental factors.

Medically, RA is diagnosed with blood tests and X-rays to help doctors assess disease progression. Identifying the condition early allows clinicians to recommend the most appropriate treatment and anticipate the likely progression. Women are typically referred to a rheumatology specialist, as timely diagnosis and prompt intervention greatly reduce the risk of long-term joint damage. Management of RA often involves non-drug interventions such as physiotherapy, hydrotherapy, and occupational therapy, which aim to improve joint mobility and alleviate pain. In addition, pharmacological treatments are commonly used to prevent the immune system from damaging the joints. These medications include disease-modifying anti-rheumatic drugs (DMARDs), biologic therapies, corticosteroids, and nonsteroidal anti-inflammatory drugs (NSAIDs) (Arthritis New Zealand, 2018).

Overall, these studies have been conducted outside of Aotearoa New Zealand but involve populations with comparable gender roles, life expectations, and healthcare systems, providing a relevant and robust evidence base. However, most of this research relies on quantitative

measures, offering limited insight into the lived experiences of women, particularly in the New Zealand context. Having considered the biological aspects of RA, it is now important to explore how these intersect with psychosocial experiences, drawing especially on qualitative research, as outlined in the following section.

Psychosocial experiences of living with RA

The lived experience of RA extends far beyond its medical diagnosis and biological symptoms, profoundly affecting women's psychological, social, and emotional worlds. While RA is clinically defined by joint inflammation, pain, and disability, research shows that each woman's experience is shaped by her emotions, identity, social roles, and cultural background. The experience is significantly gendered and women often describe the hardest part of living with RA as the frustration of being unable to perform simple daily tasks such as opening a jar, fastening a bra, or putting on shoes (Arthritis New Zealand, 2025). Constantly needing to ask for help, pace activities, and reserve energy "for a bad day" takes a cumulative toll, leading to frustration, feelings of uselessness, and fear for the future (Arthritis New Zealand, 2025).

RA also significantly constrains women's social and economic participation. The condition reduces opportunities for employment and income, while limiting engagement in key social roles such as parenting and caregiving (Cutolo et al., 2014; Dures et al., 2016; Feddersen et al., 2017). Many women are forced to give up or reduce their working hours (Kirkeskov & Bray, 2023), often at the cost of their financial security and sense of identity. Codd et al. (2022) found that women with inflammatory arthritis described the condition as an "invisible burden" in the workplace, with disclosure of their diagnosis often triggering anxiety and fear of losing their jobs. Milne (2020) powerfully illustrates this in the account of one woman—a top performer in a

contract-based role—who was forced to resign when her hands and feet became too inflamed to care for her preschool child, yet who still faced the ongoing financial costs of childcare as she was too disabled by her arthritis thereby facing significant financial difficulties.

The bodily changes caused by RA, such as inflammation and deformity in the hands and feet, can fundamentally alter women's relationships with their own bodies, creating a sense of a non-compliant or "betraying" body, or transforming a private body into one that feels publicly scrutinised (Plach et al., 2004a). This experience reflects Leder's (1990) notion of the dys-appearing body, in which the body—ordinarily taken for granted in health—becomes obtrusive and demanding of attention through pain, dysfunction, or loss of control. In this state, the body is no longer an invisible medium of action but becomes a visible and problematic presence, disrupting the sense of bodily integrity and identity. The disabilities literature highlights how social norms construct the healthy, autonomous body as the ideal, positioning illness and impairment as deviant or deficient. Feminist disability scholarship extends this critique, arguing that the "universal" ideal body is often implicitly male, rendering women with chronic illness or disability doubly problematised – deviant both from able-bodied norms and from patriarchal ideals of femininity (Garland-Thomson, 2005; Inckle, 2014). This altered embodiment can contribute to self-stigmatisation, poorer body image, and diminished self-esteem, as women navigate the tension between lived bodily reality and social ideals of femininity and capability (Han et al., 2023; Mitton et al., 2007; Van Alboom et al., 2021).

RA is also often experienced as an "invisible" illness, especially for women, because many of its symptoms—such as fatigue, pain, and stiffness—are not outwardly visible despite their debilitating impact (Daker-White, 2013; Plach et al., 2004a). This invisibility can result in misunderstanding and disbelief from others, compounding emotional distress and isolation (Bay

et al., 2020; Toye et al., 2019). Conversely, when symptoms or assistive devices make the illness visible, women may experience stigma and discomfort as their private suffering becomes publicly exposed (Mitton et al., 2007; Plach et al., 2004a). Women with RA therefore must continually negotiate a tension between invisibility and unwanted visibility, balancing their embodied realities with social expectations, and often needing to self-advocate to have their needs recognised and validated (Carel & Kidd, 2014; Fricker, 2007).

These challenges evoke a wide range of difficult emotions that have been well-documented in phenomenological research on women (Hwang et al., 2004; Iaquinta & Larrabee, 2004; Mitton et al., 2007). Adding a cultural dimension, the small group study on Korean women by Hwang et al. (2004) identified self-esteem and negative feelings as two key themes experienced by women with RA. Further to this, US women often describe grieving for their former selves and for the lives they once led (Iaquinta & Larrabee, 2004) and Mitton et al. (2007) in a study on British women identified themes around inner strength, depression and failure.

Other qualitative studies also consistently show that RA disrupts both men and women's emotional well-being and sense of self, evoking grief, frustration, fear, anger, and loneliness alongside reduced agency and social withdrawal. In a Swedish study by Östlund et al. (2014) the 48 men and women with early RA described a range of emotions linked to participation restrictions in daily life, including sadness and grief over lost abilities, fear of deterioration and mistrusting their bodies, and anger or irritation when unable to meet work or social expectations. Shame and embarrassment were also reported when limitations became visible to others, highlighting the emotional burden of reduced participation and loss of valued roles. Adding to

this, a later Swedish study by Bay et al. (2020) showed that loneliness can be burdensome for both men and women when living with RA.

Interestingly, the study by Lempp et al. (2006), which focused primarily on women, found that while living with RA led to some variations in illness experiences among younger patients, these differences did not appear to be related to ethnicity. This suggests that, within the populations studied, ethnicity may not be a defining factor in shaping the lived experience of RA, highlighting the potential universality of certain psychosocial and embodied impacts of the condition. However, there are no studies examining the experiences of Māori women with RA in Aotearoa New Zealand, indicating a significant gap in the literature and raising questions about how cultural, social, and systemic factors unique to this population may influence illness experiences. Although McGruer al. (2019) found that Māori participants living with osteoarthritis experienced whakamā (shame) and frustration – emotions that may similarly characterise the experiences of Māori women with RA.

Collectively, these studies illustrate that living with RA profoundly affects emotional well-being and identity, particularly for women. Across diverse cultural contexts, RA is experienced as an emotionally taxing and identity-disrupting condition that evokes grief, fear, anger, shame, and loneliness. Women often describe mourning their former selves and struggling to maintain valued roles in family, work, and social life. The studies consistently highlight how the loss of bodily control and participation restrictions diminish self-esteem and agency, creating a sense of isolation and frustration. While experiences vary across gender and culture, the emotional themes show striking similarity – suggesting that RA not only disrupts physical functioning but also deeply challenges one's sense of self and belonging. These emotional and identity challenges reflect what Bury (1982) conceptualises as biographical disruption, where

chronic illness fractures taken-for-granted assumptions about the body, self, and future, requiring individuals to reconstruct meaning and continuity in their lives. Although no studies to date have specifically explored these experiences in Aotearoa New Zealand, the populations studied in Western countries are broadly comparable in terms of gender roles, social expectations, and healthcare systems, indicating that these findings are likely relevant and informative for the New Zealand context.

The social context of RA for women further compounds experiences of disruption. Women often face intensified responsibilities—paid work, caregiving, and household management—that heighten pressure to meet social and gendered expectations (Barns et al., 2015; Feddersen et al., 2019; Parton et al., 2022; Plach et al., 2004). Pain and physical limitations ripple across their lives, disrupting relationships, straining family dynamics, and eroding their ability to fulfil socially valued roles. Bury's (1982) concept of biographical disruption provides a useful framing for understanding these experiences, as illness interrupts not only the continuity of everyday life but also the sense of self. Both Sanderson et al. (2011) and Barns et al. (2015) demonstrate how biographical disruption unfolds in the lives of women with RA – anderson et al. emphasise its ongoing and dynamic nature, showing how the condition requires continual renegotiation of identity and daily routines, while Barns et al. illustrate how RA challenges roles as mothers and partners, drawing attention to bodily limitations and fuelling efforts to sustain "normalcy." From a feminist disability perspective, these disruptions are further complicated by gendered expectations of the ideal female body and social roles, revealing how patriarchal and ableist norms intensify the challenges of illness and shape women's strategies for coping, adaptation, and self-redefinition.

Frank's (2013) work on *The Wounded Storyteller* deepens this understanding by showing how narrative becomes a means of restoring coherence and agency in the wake of bodily and biographical disruption. His framework resonates strongly with the ways women with RA describe bodily betrayal, shifting identities, and the search for meaning amid chronic pain and unpredictability. Qualitative studies (e.g., Barns et al., 2015; Feddersen et al., 2019; Sanderson et al., 2011) often reflect the chaos and quest narratives Frank describes, as women's accounts oscillate between despair over bodily decline and acts of resilience, adaptation, and advocacy. In this sense, the "wounded storyteller" not only conveys suffering but also resists cultural silencing and the biomedical framing of illness as purely physical, instead asserting the social, emotional, and moral dimensions of living with RA.

Motherhood, in particular, amplifies these tensions, as societal ideals of caregiving, competence, and productivity collide with the embodied realities of chronic illness. Qualitative research in the United Kingdom (UK) and Australia has shown that mothers with chronic conditions often struggle with daily caregiving tasks and experience a diminished sense of control over their mothering roles, increasing their reliance on others for support (Mitton et al., 2007; Parton et al., 2022). This aligns with feminist disability scholarship, which highlights how gendered expectations around the "ideal mother" create additional moral and social pressures for women managing illness (Garland-Thomson, 2005). The literature suggests that women face an intensified burden: the physical and emotional demands of chronic illness alongside the expectation to perform unpaid care work seamlessly. Much of this research focuses on younger mothers with young children, highlighting a gap in understanding the experiences of older mothers who may be navigating additional challenges, including perimenopause. While some participants in Parton et al.'s study were likely experiencing perimenopause, the analysis did not

explicitly examine how midlife hormonal transitions intersect with chronic illness. Most existing studies focus on single conditions or assume normative gender roles, overlooking the compounded impact of managing multiple, intersecting health challenges.

Feddersen et al. (2019) also show how women actively negotiate these disruptions by juggling and reordering identities as mothers, workers, and patients. Their work highlights the moral and gendered pressures to suppress illness identities in order to maintain social legitimacy and self-worth. This struggle is further reinforced by the ideology of healthism, which positions health as a personal responsibility and moral virtue, often equating wellness with discipline, control, and productivity (Crawford, 1980; Riley et al., 2018). Within this framework, illness can be perceived as a form of personal failure, compelling women with RA to manage or conceal symptoms to meet societal expectations of the "good mother" and "productive worker." In this way, RA becomes not only an embodied condition but also a socially negotiated one – eeply entwined with the norms of femininity, productivity, and care that shape how women narrate, experience, and manage their illness.

The chronic unpredictability of symptoms demands constant adaptation, particularly as women navigate the competing expectations of motherhood, work, and self-care. Internalised gender norms further intensify this emotional labour, as women strive to uphold ideals of competence and caregiving despite pain, fatigue, and physical limitation (Barns et al., 2015; Feddersen et al., 2019; Parton et al., 2022). As a result, women with RA experience heightened stress that arises not only from the physiological burden of disease but also from the social and moral pressures attached to their roles. This sustained stress is both embodied and relational – shaped by cultural expectations and, in turn, influencing disease activity through biological pathways linking stress and inflammation (Cutolo & Gotelli, 2023; Eudy et al., 2018). These

overlapping physiological and psychosocial demands mean that coping becomes an ongoing, dynamic process of managing symptoms, emotions, and identities in everyday life.

Coping and managing RA

Alongside the psychosocial difficulties, studies reveal that women with RA often cultivate resilience and personal growth. Iaquinta and Larrabee (2004) describe this as "grieving while growing," where loss coexists with transformation. Similarly, the concept of "shifting normalities" (Sanderson et al., 2011, p. 631) captures how women learn to adapt, redefine what counts as "normal," and reconstruct meaning in the face of limitation. These adaptive processes align closely with Lazarus and Folkman's (1984) transactional model of coping, which conceptualises coping as a dynamic process shaped by the interaction between individuals and their environments. Within this framework, women continually appraise and respond to stressors, drawing on both problem-focused strategies—such as managing symptoms or adjusting routines—and emotion-focused strategies that support psychological resilience and acceptance. More recent work shows that women actively seek ways to reclaim agency, integrate illness into their identities, and develop new capacities for living well despite persistent symptoms (Barns et al., 2015; Parton et al., 2022). Together, this literature paints a nuanced picture: while RA brings profound emotional, social, and embodied challenges, it can also foster reflection, adaptation, and resilience in the ongoing negotiation of life with chronic illness. However, this framing raises critical questions: what kind of resilience is being valorised, and with what consequences for women living with RA? While resilience may indeed offer women practical strategies for navigating daily challenges, it also risks shifting responsibility onto individuals, implicitly blaming them for struggling with what is, in reality, a profoundly disruptive and socially entangled illness.

Managing RA effectively involves a combination of medical treatments, lifestyle modifications, and psychological interventions in alleviating symptoms and improving quality of life for individuals with RA (Arthritis New Zealand, 2025). Toye et al. (2019), in their qualitative evidence synthesis of 77 studies, conceptualise living life with RA as "precarious" (p. 9), characterised by uncertainty, loss of autonomy, and the continual negotiation of identity. The study produced a useful conceptual framework for coping and managing RA. The framework suggests that flourishing with RA entails a continual balancing act between autonomy and reliance – ccepting the body's constraints while embracing the legitimacy of seeking help as part of an ongoing process of adaptation and growth. Their analysis demonstrates that RA extends beyond physical impairment to disrupt everyday life, social roles, and self-concept. From a gendered perspective, these disruptions are particularly salient for women, whose identities are often tied to caregiving, motherhood, and social participation, making the illness especially challenging in relation to normative expectations of femininity and strength.

Building on prior qualitative work, Parenti et al. (2020) synthesised findings from 21 studies to explore how RA affects daily living and how individuals, particularly women, adapt to its challenges. Their meta-analysis generated a health psychology model organised around two central categories—"impact on life domains" and "confronting the illness"—intersected by the cross-cutting themes of "health" and "independence and normality."

Figure 1: *The model of the experience of living with rheumatoid arthritis (Parenti et al., 2020)*

This model (Figure 1) highlights not only the ways in which RA constrains women's ability to sustain valued roles and the importance of taking a bio psychosocial approach, but also the strategies they may use to adapt, such as seeking independence, normalcy, and control. In both this model and Toye et al.'s framework (2019), resilience is often framed as a key resource in coping with RA. Parenti et al. (2020) highlights resilience as a key coping strategy, and research shows that women with RA often demonstrate remarkable adaptability and personal growth despite ongoing challenges (Chavare & Natu, 2020). However, it is important not to overvalorise this resilience, as studies also emphasise the crucial role of social, familial, and community support in helping women manage the emotional, physical, and practical impacts of the condition (Hwang et al., 2004; Parton et al., 2022). Accessing social support through family involvement and the redistribution of household responsibilities can help women manage daily

demands while maintaining a coherent sense of self (Prodinger et al., 2014). Nonetheless, as discussed earlier, such support is contingent on the family's willingness and capacity to provide it, which is not always forthcoming. Another important group of people and organisations that women with RA engage with is the healthcare system, as discussed in the next section.

Navigating the healthcare system with RA

Living with chronic pain and an episodic disability presents considerable complexity (Campbell et al., 2022). The media reports that Aotearoa New Zealand is almost 500 GPs short (Steyl, 2024) and "rheumatologist staffing levels of 1.0 FTE/100,000 population was associated with 80% of patients meeting the recommended 6-week time to DMARD treatment" with longer wait times in rural areas (Taylor et al., 2024). This means that there are delays in referrals from a GP to a rheumatologist and there are longer waiting times for follow-ups whereas patients with active RA should be monitored 3-monthly (Grainger et al., 2024). Research in Norway also shows that health services may be gendered as women with RA in their study were referred to specialists later than men (Palm & Purinszky, 2005). This is supported by recent findings from a Canadian study by Campbell et al. (2022), which highlight how gendered treatment within the healthcare system. This pattern is evident across health systems in global north countries, such as Norway and Canada, and is likely transferable to contexts like Aotearoa New Zealand, where longstanding critiques highlight persistent inequities in gendered healthcare (Ministry of Health, 2019). The healthcare system negatively affects women living with episodic disabilities and chronic pain. Delays in diagnosis and gendered approaches to treatment have both material and psychological consequences for women with rheumatoid arthritis, including financial impacts, such as job loss or reduced work capacity, and psychological effects, as worsening symptoms contribute to heightened distress and diminished wellbeing.

Digital health technologies, such as mobile applications, are increasingly promoted as tools to support patients in managing chronic conditions by tracking symptoms, improving self-understanding, and facilitating more effective engagement with healthcare providers (Lupton, 2013, 2017). For people living with RA, such technologies hold the potential to help individuals monitor fluctuations in pain, fatigue, and mobility, and to use this information to negotiate care within a complex healthcare system. However, the evidence to date suggests that most existing apps are poorly designed, lack clinical validation, and fail to adequately address the lived realities of users (Grainger et al., 2017; Healthify, 2025). Consequently, while apps are often presented as empowering, their limitations mean that they rarely fulfil this promise, leaving a notable gap for high-quality, evidence-based digital tools that could genuinely facilitate self-management and patient–provider communication.

Summary

In summary, RA is a profoundly challenging condition, compounded by social and structural contexts that shape how illness is experienced and managed. Women are disproportionately affected, not only because they are more likely to develop RA, but also because they often experience more severe symptoms and face societal expectations to prioritise caregiving and work, which can leave their own needs overlooked. The onset of RA frequently occurs between the ages of 30 and 50, a life stage when women are juggling multiple roles in work, family, and household responsibilities. The convergence of RA and social roles produces a compounded sense of strain (Barns et al., 2015; Parton et al., 2022) and evidences profound biographical disruption across biological, psychological, and social domains. Conceptually, the literature demonstrates that the body “dys-appears” (Leder, 1990) through pain, fatigue, and functional limitations, disrupting everyday routines and relationships. Narrative approaches

(Frank, 2013) reveal how women make sense of these embodied disruptions, reconstructing identity and agency through stories that integrate loss, adaptation, and resilience. Coping strategies are diverse and fluid, encompassing personal, relational, and social resources, while feminist and critical disability scholarship highlights how gendered and ableist norms intensify these challenges and shape what is considered a "normal" or acceptable body. Taken together, this evidence base supports a view of RA in midlife as not merely a medical condition but a socially and culturally embedded experience of ongoing disruption, where embodied suffering, narrative reconstruction, and adaptive coping intersect to shape women's lived realities.

For many, this period also coincides with PM, which brings fundamental embodied changes, adding an additional layer of complexity to living with RA. Together, these intersecting factors highlight the compounded challenges women face, providing a bridge to examining how RA interacts with other life-stage transitions such as PM.

What is perimenopause (PM)?

Menopause marks the stage at which menstruation permanently ceases, typically occurring between the ages of 48 and 52, though in Western contexts it may arise anytime from the early 40s through to the late 50s (Dillaway, 2020). It is clinically defined as having occurred after twelve consecutive months without a menstrual period. The years preceding this transition are referred to as the menopausal transition or perimenopause (PM), a period that may span several years. PM is characterised by fluctuating and gradually declining levels of reproductive hormones—primarily oestrogen and progesterone—which give rise to a range of physiological and psychological changes (World Health Organization, 2024). There are up to 34 symptoms of PM which include vasomotor symptoms (hot flushes and night sweats), sleep disturbance, mood

changes, fatigue, cognitive concerns, low libido, genitourinary symptoms, arthralgia and myalgia (Magraith et al., 2022 Todd, 2025). However, every woman's experience of PM is different (Hickey et al., 2022). Some women will go through PM with little or no disruptions while others will experience severe disruption. There is variation across the globe, which suggests social and cultural context are important, for example Hunter et al. (2009) found that Southeast Asian women living in the UK reported experiencing more symptoms associated with PM than their counterparts living in Delhi.

Historically, menopausal women were considered to have decaying bodies with diagnoses of "hysteria" or "sexual frenzy" (Hagège, 2020). In Western cultures, Anleu (2014) argues that menopause has increasingly been framed not as a natural life transition but as a condition requiring medical intervention, portraying the female body as inherently unstable and prone to suffering. Hormone replacement therapy (HRT) was first introduced in the mid-20th century as a treatment for the symptoms of PM, based on a biomedical model that defined menopause as an oestrogen deficiency. Initially, HRT was promoted not only for symptom relief but also as a way to sustain women's youth, sexuality, and femininity, reflecting cultural ideals that positioned women's value in terms of fertility and appearance (Watkins, 2007; Wilson, 1966).

Following the Women's Health Initiative (WHI) study in 2002, which raised concerns about HRT and highlighted potential risks such as breast cancer and cardiovascular disease, women faced a more restrictive prescribing culture and heightened uncertainty about treatment decisions (Writing Group For The Women's Health Initiative Investigators, 2002). In this context, Breheny and Stephens (2003, 2008) examined how women navigated these decisions, showing that choices about HRT were shaped not only by biomedical information but also by

moral and social considerations. Women who reported few menopausal symptoms often positioned themselves as morally disciplined, aligning with cultural ideals of self-control and healthy living. Alongside these findings, women who resisted HRT—framed as risky—constructed this decision as responsible and virtuous, emphasising personal prudence and caution. These studies illustrate that, in the years immediately following the WHI study, women's engagement with HRT was deeply embedded in social norms and moral expectations, with treatment decisions reflecting broader cultural narratives about femininity, responsibility, and bodily management. However, in recent years HRT has been re-established as a safe and effective treatment for many women. This resurgence reflects both updated clinical evidence and the increase in the public awareness of menopause symptoms, often through celebrity endorsement which has been referred to as the 'Davina Effect' (Jermyn, 2023).

Psychosocial experiences of living with PM

PM is therefore not just a biological transition but also a personal, emotional, and sociocultural experience. Women frequently report feelings of discontinuity, as the bodily and hormonal changes of PM disrupt established routines, roles, and identities (Sergeant & Rizq, 2017; de Salis et al., 2018). A recent narrative review of women's lived experiences of perimenopause by Wood et al. (2025) reveals that many women encounter emotional disturbances—including mood swings, anxiety, and irritability—during this transitional phase. These symptoms can be distressing and may disrupt women's sense of identity and social relationships. Most of these studies have been conducted outside of Aotearoa New Zealand, yet they involve populations with broadly comparable cultural and healthcare contexts, including similar gender roles, life expectations, and access to medical care. This suggests that the findings provide a reasonably robust evidence base for understanding women's experiences of PM in

comparable settings. The review further highlights that such negative experiences are often compounded by stigma and gendered cultural stereotypes surrounding ageing and menopause, which can intensify psychological distress and feelings of marginalisation.

Women's psychological experiences of PM therefore occur within a broader sociocultural context that shapes how these changes are understood and felt. For instance, dominant cultural values that equate femininity with sexual attractiveness and uphold a slim body ideal can render PM-related weight gain particularly distressing, reinforcing feelings of loss and diminished self-worth (Cleghorn, 2021; Vincent et al., 2023). Such norms align with Butler's (2004, 2015) work by demonstrating how gendered expectations are performative, producing ideals of femininity that constrain women's bodies and behaviours. Consequently, PM has often been portrayed as a period of decline—a loss of fertility, desirability, and "womanhood"—rather than as a natural life transition or a potential period of growth. This framing has reinforced stigma around aging bodies, contributed to women feeling diminished or invisible (Ussher, 2006). In effect, PM has been interpreted through a lens that reflects societal anxieties and stigma about aging and gendered expectations (Wood et al., 2025).

This Western view of PM reproduces a form of "postfeminist healthism" that, intersecting with neoliberalism, places a moral importance on maintaining good health—as these constructs of health intersect with cultural ideals of femininity—and shapes how women are expected to manage PM by emphasising individual responsibility, self-improvement, and personal choice centred around consumerism (Riley et al., 2018). Riley et al. highlight how this postfeminist healthism discourse can marginalise women who do not conform to these health ideals, potentially leading to feelings of inadequacy or failure. By centring individual responsibility, such discourses risk obscuring the biological, structural and relational conditions

that shape women's health experiences—including working on the body such as dieting to lose weight, socioeconomic positioning, access to healthcare, and the availability of social and emotional support—particularly as they navigate the challenges of PM.

These experiences reveal how the instability of the body unsettles one's sense of continuity and self-coherence. As Leder (1990) describes, when the body becomes unpredictable or symptomatic, it moves from the background of experience to the foreground, demanding attention and altering one's orientation to the world. Women experiencing PM often report feeling estranged from their bodies—uncertain, out of control, or "not themselves"—as the boundaries between body and self become blurred (Sergeant & Rizq, 2017). This sense of loss of self is further intensified by societal expectations that women maintain productivity, emotional composure, and a youthful appearance, making the experience of change feel like personal failure rather than a natural transition. Within this framework, PM can be understood as both a psychological and existential process of adjustment – one that involves mourning previous bodily capacities while negotiating new ways of being-in-the-world.

Simpson et al. (2025) provide valuable insights into the lived experiences of women during PM in the UK, highlighting how bodily, emotional, and social changes intersect to shape their daily lives. From the perspective of biographical disruption (Bury, 1982), the study illustrates how PM unsettles women's taken-for-granted assumptions about their bodies, identities, and life trajectories, creating a need to renegotiate routines, roles, and future expectations. The findings also align with a biopsychosocial lens, as they demonstrate the interconnected influence of biological changes (hormonal shifts, physical symptoms), psychological responses (emotional distress, adaptation), and social contexts (relationships, work, and cultural expectations) on women's experiences. Together, these frameworks show that

PM is not only a biological transition but a profound, multi-dimensional disruption that reshapes selfhood and daily life.

The social context also shapes the narratives through which individuals make sense of their experiences. In a study of 48 UK mothers (de Salis et al., 2018) a woman's identity in PM was driven by three narratives: menopause as a natural biological process; menopause as a struggle with uncertainty conveying emotional turmoil, loss of identity and a renegotiation of roles; and finally as a transformative and liberating experience with an opportunity to refocus on goals and wellbeing. While some women followed a predictable "rite of passage" where transformation emerged from distress, this was not universal and there is also a perception that menopause should often be kept hidden. Dillaway (2020) also suggests that uncertainty and change are normal at this stage of life. These comments and the findings indicate that PM does not occur in isolation but is shaped by broader sociocultural influences, including dominant discourses circulated in media, particularly within Western cultures. Importantly, Indigenous perspectives, including Māori understandings of wahine and mana wahine are explored in a later section.

The media is an important site for sharing social understanding around PM. The growing awareness around perimenopause and its empowering potential is reflected in the rise of 'menopause talk' in media and everyday conversations among women in Western societies. (Orgad & Rottenberg, 2023). High-profile figures such as Michelle Obama have contributed significantly to this shift; her public reflections on experiencing hot flushes during personal security events, alongside her critique that "we're living like it's not happening," highlight how social norms still demand that women conceal menopausal symptoms as if they are private failings rather than shared, universal experiences (Walters, 2020). Similar findings are reflected

in Aotearoa New Zealand through podcasts, TV shows, radio programmes, news articles and on social media (Baghurst, 2024; Bezzant, 2024; Newshub, 2023). In New Zealand, public figures like Hilary Barry and Anika Moa are contributing to reducing the stigma around menopause, while some women describe the accompanying media attention as ‘a little exhausting’(McFall, 2024; McLachlan, 2021; Nissen, 2024). This talk and increase in awareness can mean that women are often exposed to conflicting and confusing views which can shape their understanding of PM and available treatments.

The UK television programme hosted by Davina McCall illustrates how media coverage can simultaneously raise awareness of PM and promote its medicalisation (Orgad & Rottenberg, 2023). By emphasising HRT as an individualised, neoliberal approach, the show encourages the perception that medical interventions are essential for managing the impacts of ageing and PM, supporting women in sustaining a sense of their younger selves (Beilis, 2022). While these studies were conducted in the UK, the media produced by Davina including YouTube videos and a documentary available on streaming services, means they are readily available for a New Zealand audience (Times Radio, 2023). This construct of PM as a biomedical issue or disease construction is also promoted by pharmaceutical companies (Big Pharma) and through menowashing, the practice of marketing products or initiatives related to menopause without scientific evidence, to encourage aspirational ageing by inducing insecurities and stigmatisation (Brettkelly, 2024; Harvey, 2013; Orgad & Rottenberg, 2023a).

Indigenous perspectives

In contrast to many Western perspectives, several cultures regard PM positively, associating it with personal transformation, empowerment, and a sense of liberation (Ussher et

al., 2019). For instance, Mayan women, whether experiencing symptoms or not, celebrate the end of menstruation as a release from pregnancy and an elevation in social status (Stewart, 2003). Similarly, in some Indigenous contexts where older women are accorded respect and authority, PM may be understood as a meaningful life transition associated with changing reproductive roles, and women have reported fewer or less distressing menopausal symptoms (Chadha et al., 2016).

Notably, research indicates that while Māori experience menopausal symptoms similar to those of Pākehā (New Zealanders of European descent), the use of HRT is uncommon, as symptoms are not generally understood through a biomedical lens (Lawton et al., 2008). This perspective reflects Te Ao Māori, which encompasses Māori ways of understanding health as holistic and interconnected, as articulated through the Te Whare Tapa Whā model. This framework emphasises the balance of four interconnected dimensions: taha tinana (physical), taha hinengaro (mental and emotional), taha whānau (social), and taha wairua (spiritual) (Durie, 1985). Consequently, PM can be approached not merely as a biological event but as a multifaceted life transition encompassing all these aspects. Māori women in Aotearoa New Zealand may draw on holistic and culturally embedded frameworks when making sense of PM, rather than approaches grounded primarily in dominant Pākehā biomedical models of health. These understandings can be informed by concepts such as *mana wahine,* which emphasise strength, leadership, and relational roles within whānau and wider communities. Metaphors like *ruahinetanga* depict postmenopausal women as cultural leaders, providing a perspective that stands in stark contrast to Western interpretations of menopause as a time of decline or dysfunction (Bullivant Ngāti Pikiao et al., 2022). Panelli and Tipa (2007) highlight the centrality of place in Māori understandings of health, arguing that wellbeing is embedded in relationships

with whenua (land), whānau, and the wider environment. Their work challenges Western biomedical framings that abstract the body from place, instead emphasising the lived, embodied, and relational dimensions of health that are grounded in Māori worldviews.

Coping and managing PM

Women employ a range of coping and management strategies to navigate PM, reflecting both practical and psychosocial approaches. Common strategies reported in the literature include lifestyle modifications such as dietary changes, exercise, mindfulness, and sleep hygiene, alongside the use of hormone replacement therapy (HRT) or other pharmacological interventions to manage symptoms like hot flushes, mood swings, and sleep disturbances (Hickey et al., 2022; Johnson et al., 2019). Psychosocial coping often involves seeking social support, sharing experiences with peers, and accessing educational resources, which can validate women's experiences and reduce feelings of isolation (Hunter, 2019; Ussher, 2006). Qualitative studies highlight that women's coping is shaped by personal beliefs, cultural narratives of ageing and femininity, and broader societal expectations, which can both enable and constrain strategies for managing symptoms (Sergeant & Rizq, 2017; de Salis et al., 2018). Coping with PM is rarely linear or static; it is an ongoing negotiation as women respond to fluctuating symptoms alongside the demands of work, family, and social life. This aligns with Lazarus and Folkman's (1984) Transactional Model of Stress and Coping, which views coping as a dynamic process in which individuals continually appraise stressors and adjust strategies—both problem-focused and emotion-focused—to manage changing physical and emotional challenges.

Social support—through emotional encouragement and practical guidance—enhances individuals' capacity to cope with stress and can alleviate both psychological and physical

symptoms. Hayfield et al. (2024) report that partners, friends, and family members lacking shared experiential knowledge were perceived as less capable of providing adequate support. As social support from various sources increases, physical and emotional symptoms tend to decrease. Importantly, many women increasingly turn to what has been described as a *menopause sisterhood* by Hayfield et al. 2024. Women in the study described social support as emerging from shared embodied experiences with other women, particularly within workplace settings. In this sense, perimenopausal experiences were not merely physical or hormonal events but were deeply shaped by social and cultural contexts.

In addition, digital health technologies are increasingly being utilised to support women navigating PM, particularly in managing symptoms and enhancing coping strategies. These technologies encompass mobile applications, wearable devices, and online platforms that offer personalised interventions, symptom tracking, and accessible information (Lupton, 2017). While they can extend support beyond traditional healthcare interactions, their effectiveness is often maximised when paired with the emotional validation and shared understanding that women find within these peer-based "sisterhood" networks.

Medicalisation of menopause

Recent scholarship has examined the uptake and framing of HRT through a post-feminist lens, highlighting how its increasing acceptance reflects both biomedical advances and shifting cultural attitudes toward midlife women's bodies (Hickey et al., 2024). HRT is now recognised as an effective intervention for alleviating menopausal symptoms and supporting women's wellbeing, and many women actively seek it to manage their changing bodies. From a post-feminist perspective, however, this uptake can also be read as aligning with neoliberal ideals of

self-management and individual responsibility, where women are encouraged to actively "work on themselves" to maintain youthfulness, attractiveness, and productivity (Riley et al., 2018). In this framing, HRT becomes not only a medical tool but also a cultural instrument, reinforcing norms that link successful ageing to appearance, performance, and self-optimization, while positioning women as responsible for managing both the biological and social consequences of ageing.

Hickey et al. (2024) advocate for an empowerment model that recognises the multifactorial nature of menopause, encompassing psychological, social, and contextual factors, not just biological ones. They emphasise the importance of providing women with accurate, consistent, and impartial information, enabling them to make informed decisions about their care. In Aotearoa New Zealand, numerous women experience menopausal symptoms that affect their wellbeing, work engagement, and potentially their economic participation (NZIER, 2023). As a result, many turn to HRT to validate these experiences and to avoid feelings of embarrassment or being undermined (Hagège, 2020). It can therefore be argued that HRT occupies a contested yet prominent role in shaping cultural expectations and biomedical responses to PM.

Navigating the healthcare system

Despite women's efforts to seek support and answers, the healthcare system often appears ill-prepared to address their concerns effectively. An online survey of over 5,000 women in the UK experiencing menopausal symptoms found that 44 percent waited more than a year for a diagnosis, highlighting persistent delays in care (Newson & Lewis, 2021). Similarly, a United States (US) survey revealed that women often felt dismissed and received little helpful advice from medical professionals (Richardson et al., 2023). Earlier research by Daly (1995) also noted

that doctors frequently lacked the time to understand patients' concerns; some women were treated for depression with antidepressants rather than receiving HRT, and participants reported feeling dismissed and unsympathetic. Marginalised groups, including non-binary and transgender people, face additional barriers due to limited evidence and a lack of culturally safe services (Hickey et al., 2022). These issues are reflected in Aotearoa New Zealand, where around 70 percent of women experience significant menopausal symptoms, yet only 40 percent consult a doctor about them (Healthify, 2025a). The situation may improve, however, as the Aotearoa New Zealand Women's Health Strategy highlights the need to "prioritise pathways, treatments, and services to manage health conditions that only affect, or more commonly affect women, such as menopause and autoimmune disease" (Ministry of Health, 2023, p. 55).

Summary

PM represents a complex transition in which biological, psychological, and social factors intersect to shape women's lived experiences. Research consistently shows that PM disrupts daily routines, interpersonal relationships, and self-perception, highlighting its profound biopsychosocial impact. From a biographical disruption perspective, these changes challenge temporal continuity and identity, while Leder's notion of dys-appearing bodies emphasises how bodily symptoms—such as hot flushes and sleep disturbances—draw attention to bodily vulnerability. Women's narratives from the studies offer insight into how they make sense of these changes and strive to restore coherence and agency, and a feminist lens underscores how gendered expectations amplify distress and shape coping strategies. Coping often involves a combination of lifestyle adaptations, social support and medical interventions. Women must also navigate healthcare systems, where they may face inconsistent information, dismissive attitudes, or limited access to individualised care. However, most studies focus on otherwise healthy

women, limiting understanding of how PM intersects with chronic conditions like RA. Given that RA disproportionately affects women in midlife, it is important to consider the dual experience together, including how women manage overlapping symptoms and negotiate support from healthcare providers.

PM, chronic health conditions and RA

Although PM and RA frequently co-occur, there is surprisingly little qualitative research examining their intersection. Existing studies tend to focus primarily on early or chemically induced menopause leaving a gap in understanding for women experiencing these conditions together during midlife. Studies examining women who experience early menopause (EM) because of chronic or serious illness highlight how gendered norms surrounding femininity and fertility shape the meaning of this transition. Parton et al. (2017) demonstrated that medically induced menopause, occurring alongside cancer treatment, intersected with cultural ideals that equate womanhood with reproductive capacity, producing feelings of loss and perceptions of being an "incomplete woman" (p. 1109). Such experiences reveal how illness and menopause are not discrete events but mutually reinforcing disruptions that challenge embodied identity and expectations of continuity. Extending this perspective, Johnston-Ataata et al. (2020) showed how the affective and psychological dimensions of EM were mediated by the extent to which women and their social networks subscribed to, or resisted, these normative constructions of femininity. Viewed through the lens of biographical disruption (Bury, 1982), these findings illustrate how the co-occurrence of chronic illness and reproductive transition destabilises women's sense of self and life trajectory, compelling an active reworking of identity in the face of altered bodily and social meanings.

Building on the discussion of PM in the context of chronic illness, hormonal changes appear to play a significant role in both the onset and progression of RA (NRAS, 2024). Disease onset often coincides with periods of hormonal fluctuation in women, such as PM. Observational studies indicate that women who experience EM—whether spontaneous or medically induced before the age of 40—are at an increased risk of developing RA (Jiang et al., 2024). While the evidence is largely observational rather than experimental, it suggests that reproductive and hormonal transitions are relevant to the timing and course of the disease. Further research has documented changes in RA activity during PM, with some women reporting worsening symptoms during this period (Mollard et al., 2018; Shah et al., 2020), and improvements during hormonally distinct phases such as pregnancy (Cutolo & Gotelli, 2023; Eudy et al., 2018).

The overlap of perimenopausal and RA symptoms further compounds these challenges. Both experiences can include fatigue, joint pain, and functional limitation, and for some women, a decline in oestrogen—an anti-inflammatory hormone—may exacerbate RA symptoms. This convergence of symptoms can complicate diagnosis and management, blurring the boundaries between menopause-related changes and disease activity. The recent study by Petford et al. (2024) bridges a critical gap by centring women's lived experiences at this intersection, revealing that PM often exacerbates disease burden and affects how symptoms are perceived, managed, and communicated with healthcare providers. Their national survey of nearly 800 UK women with RA found that 80 percent reported worsening RA symptoms during menopause, with 10 percent describing their arthritis as much worse; 47 percent had used hormone replacement therapy (HRT), among whom 80 percent experienced improvements in menopausal symptoms, and 30 percent reported moderately or greatly improved RA symptoms. Notably, 93 percent had never discussed PM in relation to RA with a healthcare professional. Participants described

overlapping symptoms, confusion about their origin, and receiving conflicting advice regarding HRT, highlighting the need for enhanced education among rheumatology teams and more integrated, holistic care approaches.

Taken together, these findings illustrate how the intersection of PM and RA has the potential to heighten symptom burden and amplify biographical disruption. Despite this, there is currently no qualitative literature exploring how women experience these intersecting transitions, representing a significant gap in understanding the psychosocial and embodied impact of overlapping PM and chronic illness. Recognising this intersection is therefore essential for understanding women's lived experiences and informing care that supports identity continuity, psychosocial wellbeing, and effective symptom management.

Research rationale for the present study

As already outlined, there is currently no research that directly examines the intersection of RA and PM, despite the clear significance of both for women's health and wellbeing. This absence is striking given that both conditions commonly occur in midlife and that hormonal changes are known to influence immune function, inflammation, and pain sensitivity. Studies have investigated the effects of chemically induced menopause – such as that caused by cancer treatment or surgical intervention (e.g., Johnston-Ataata et al., 2020; Parton et al., 2017). Yet there has been little attention to naturally occurring PM, despite it affecting the majority of women diagnosed with RA during midlife. This gap implies that women's everyday, lived experiences of navigating hormonal change alongside chronic illness have been overlooked within both rheumatology and menopause research. Given that biological, emotional, and social changes converge during this period, the lack of inquiry represents a significant omission in

understanding how women manage health, identity, and care within this critical life stage. Arguably, if chemically induced menopause is considered important to study, it is equally, if not more, important to explore how PM impacts women living with RA—a condition affecting many in midlife—because of its profound implications for daily life and health management.

Society often values women primarily for their work and caregiving roles, yet both RA and PM can introduce fatigue, brain fog, and joint pain, making it increasingly difficult to meet these expectations. Fears of ageism and ableism in the workplace may lead women to conceal symptoms, overcompensate, or rely heavily on medical interventions, which can contribute to burnout. At the same time, perimenopause challenges cultural ideals of youth, femininity, and sexuality (Cleghorn, 2021), while RA may further restrict mobility, independence, and body image. Postfeminist healthism adds an additional layer of pressure to maintain productivity and self-care (Riley et al., 2018). Consequently, women managing both conditions often feel invisible or dismissed, as societal norms marginalise ageing women and people with disabilities. These challenges are amplified when RA and PM co-occur, each bringing its own forms of disruption, stigma, and uncertainty, creating a compounded experience that is both physically and socially demanding.

Research on RA and PM highlights gendered expectations of resilience and caregiving (Chavare & Natu, 2020; Hwang et al., 2004; Iaquinta & Larrabee, 2004; Süss et al., 2021). Women are positioned as emotionally strong caretakers, yet both conditions introduce pain, fatigue, and bodily disruption. The pressure to "soldier on" despite these challenges reinforces the gendered burden of care and career responsibilities, making it difficult to seek support or rest. Both RA and PM are medicalised differently – RA as a chronic illness requiring biologic treatment, and PM as a hormonal transition often managed with HRT (Arthritis New Zealand,

2025; Hickey et al., 2022). Studying their intersection is therefore crucial to understanding how women navigate overlapping biological, social, and emotional demands during midlife.

The literature reviewed suggests that navigating either PM or RA presents significant challenges, as both involve complex physical, emotional, and social adjustments. These difficulties are amplified when women must manage both simultaneously. However, there is currently no research that explores how women navigate these dual experiences when engaging with the health system. Given the highly specialised and fragmented nature of contemporary healthcare—where rheumatologists typically manage RA and general practitioners or endocrinologists oversee PM—there are likely to be gaps in communication, coordination, and holistic care. Women managing both RA and PM may encounter significant barriers to integrated, person-centred care. In effect, a large group of women is navigating overlapping biological, emotional, and social transitions within a healthcare system ill-equipped to recognise or address the intersection between them – highlighting a crucial gap in the existing knowledge base and the need for further qualitative inquiry.

Therefore, the intersection of RA and PM presents a profound challenge to how women make sense of themselves in relation to cultural expectations of gender, ageing, health, and productivity. Both conditions invite a re-evaluation of identity and embodiment, requiring women to navigate not only fluctuating physical symptoms but also the psychological and social ideologies that frame their experiences. Despite the shared themes of bodily change, uncertainty, and adaptation, to date I could find no published work specifically focusing on exploring how women live through and interpret this illness and transition together. Existing studies have examined the psychological and social implications of RA and PM separately, and some have considered the impact of RA on motherhood, but the lived experience of negotiating midlife and

PM with a chronic condition remains unexplored. This absence raises important questions about how women sustain a sense of self and continuity amid overlapping disruptions – how they discern and manage symptoms, engage with healthcare systems, and seek meaning and support in the face of limited understanding.

Exploring these questions through a feminist phenomenological lens allows for a deeper appreciation of the embodied and relational dimensions of this dual experience, illuminating how women inhabit and interpret their changing bodies within broader sociocultural narratives. Therefore, understanding how women with RA navigate midlife and PM is the driver for this research which includes the following questions:

1. How do women with RA, who are also navigating PM, make sense of the challenges of this dual experience?
2. What coping strategies or solutions or new ways to flourish can be generated when such women are supported to enquire into their experiences together?

Chapter 2: Methodology and method

This chapter outlines the methodological approach taken in this study. It begins by introducing the theoretical framework that underpins the research, explaining how phenomenology, feminist theory, and CI together shape its philosophical foundations and design. The chapter then details the study's design, including participant recruitment, data collection, and analysis processes, and discusses ethical considerations and reflexivity. Collectively, these sections demonstrate how the chosen methods align with the study's aim to explore women's lived experiences of navigating PM alongside RA.

Phenomenological approach

This research is grounded in a phenomenological orientation, which prioritises the exploration of lived experience and the meanings individuals ascribe to their everyday realities. Phenomenology offers a methodological and epistemological lens through which to investigate how women make sense of the concurrent experiences of PM and RA. It is particularly well-suited to inquiries that seek to explore the embodied, affective, and social dimensions of health and illness. As Willig (2013) outlines, phenomenological research aims not simply to describe experiences, but to understand how individuals interpret and engage with those experiences from their own situated perspectives.

Adopting a phenomenological approach allows this study to understand how a woman experiences her body, identity, and emotions as she undergoes hormonal changes and manages chronic pain or mobility limitations from RA. This intersection is not merely physiological; it is lived and negotiated in the context of women's identities, daily functioning, and interactions with health systems. The framework enables a focus on how meaning is constructed around

symptoms, bodily changes, and clinical encounters. It also invites reflection on the complex ways women navigate shifting senses of agency and selfhood in relation to their bodies during this transitional life stage.

Phenomenology, particularly as articulated in psychological contexts, often aligns with a critical realist ontology (Langdridge, 2007). That is, while such research acknowledges the existence of a material world, it contends that our access to it is always mediated through subjective, embodied experience (R. Shaw, 2019). As Larkin et al. (2011) emphasise, individuals are viewed as situated, meaning-making agents, whose experiences are shaped by sociocultural contexts, life events, and corporeal realities. From this standpoint, the aim of phenomenological research is to elucidate not only what is experienced, but how it is experienced and understood – treating experience as a dynamic and interpretive process (Willig, 2013).

Phenomenologists argue that subjectivity and perception are inseparable from the world we encounter; hence, illness cannot be reduced to its biological dimensions alone. As Finlay (2011 p.33) suggests through the notion of the "body-world of illness," disruptions to the body reverberate through one's experience of the world. Illness transforms the body from a taken-for-granted medium of engagement with the world into an object of scrutiny and concern. Medical objectification can exacerbate this alienation. Mazis (2001) describes how biomedical practices often intensify disembodiment through their decontextualised and technologically driven gaze, further estranging individuals from their lived bodily realities.

Merleau-Ponty's (1962) phenomenology of embodiment complements this perspective by recognising the ways in which bodily changes fundamentally reshape one's engagement with the world. This approach is also complementary to the wider conceptual framework outlined in Chapter 1, particularly the concepts of biographical disruption and dialectics, which highlight

how challenging embodied experiences can interrupt normative and desired ways of being in an iterative, ongoing process. When the body becomes unreliable or painful, it moves from a backgrounded presence to a foregrounded obstacle, aligning with Leder's notion of dys-appearance and prompting a renegotiation of self, social roles, and future trajectories. As Carel (2016) argues, such disruptions are not only physical but ontological, requiring a reconfiguration of meaning, identity, and belonging.

Through a phenomenological lens, this research explores how women experience and make sense of the convergence of menopause and RA, with particular attention to how these experiences affect their embodied identities, interpersonal relationships, and health-seeking behaviours. This approach allows for a rich, contextualised understanding of how women live through and reflect upon the intersection of a chronic illness such as RA during a life stage transition.

Feminist-informed phenomenology

Integrating a feminist lens within a phenomenological framework provides a means of examining the embodied experience of gender in relation to structures of power, identity, and cultural meaning. Simone de Beauvoir's assertion that "one is not born, but rather becomes, a woman" (2015) encapsulates a foundational premise within feminist thought: that gender is not an innate biological condition, but an ongoing process shaped by cultural and social norms. By attending to the gendered nature of lived experience, it becomes possible to explore how normative expectations—particularly those surrounding ageing, productivity and emotional labour—profoundly influence how women interpret and respond to the overlapping experiences of PM and RA.

This perspective also enables a critical engagement with the concept of postfeminist healthism (Riley et al., 2018), which interrogates the ways in which health, wellness, and bodily regulation are framed within contemporary neoliberal contexts and normative constructs of ideal femininity. Women are frequently positioned as individually responsible for managing their bodies, emotions, and productivity, often through consumerist or biomedical logics. Such framings can obscure the structural conditions and social inequalities that shape health experiences and access to care.

In this research, attention to social positionalities is therefore central to understanding how lived experience is shaped and interpreted. Social categories such as gender, ethnicity, class, sexuality, and dis/ability afford individuals particular vantage points from which to perceive the world, while also shaping how they are understood by others. These positions are always intersecting and relational. Drawing on black feminist scholarship, it is essential to recognise that gender is always racialised and situated within broader hierarchies of power (Collins, 1989; Collins & Bilge, 2020; Crenshaw, 1991; Hull et al., 1982). A feminist lens therefore foregrounds intersectionality by acknowledging how intersecting social categories mediate the experience and interpretation of symptoms, as well as the quality of care received. Feminist scholars have also long critiqued the medicalisation of women's health, including menopause, arguing that biomedical models can pathologise natural transitions or minimise the significance of women's subjective accounts (Hickey et al., 2022; Ussher, 2006). By resisting such reductionist framings, I sought to use feminist-informed phenomenological research to elevate women's narratives, re-centring their voices in contexts where they have historically been marginalised.

Within this framework, acknowledging positionality becomes both an ethical and epistemological imperative – it shapes what can be known, how it is known, and whose

experiences are legitimised as knowledge. The crisis of representation brought these issues to the forefront, questioning the long-held assumption of researcher objectivity. Haraway (1988), for example, argues that all knowledge is situated – produced from specific social and cultural standpoints that often reflect the positionalities and biases of predominantly white, male researchers. These critiques remain relevant today, evident in biomedical research that still treats the male body as the norm (Riley et al., 2018). In this study, reflexively considering both participants' and the researcher's positionalities is vital for understanding how women's experiences of PM and RA are narrated and situated within intersecting structures of gendered and embodied knowledge.

Therefore, taking a feminist-informed phenomenological approach, drawing on how phenomenology is used in psychology, allowed me to maintain a strong emphasis on individual meaning-making while simultaneously addressing broader sociocultural dynamics.

Study design

The study employed the in-depth qualitative research method of cooperative inquiry (CI). CI, developed by Heron and Reason (1997), is a participatory form of action research in which participants are positioned as co-researchers rather than subjects of study. Rooted in cycles of reflection and action, CI emphasises experiential knowledge, shared inquiry, and transformative practice, making it particularly suited to research that aims not only to understand experience but also to foster empowerment and change. A phenomenological approach informed by a feminist lens aligns closely with these principles, as it foregrounds lived experience, meaning-making, and the agency of participants in interpreting and reshaping their realities. Within this study, such

an approach provides a way to explore how women navigate PM alongside RA, acknowledging the relational, embodied, and situated nature of their experiences.

The epistemological stance of CI is often described as an extended epistemology, which expands conventional understandings of knowledge to include participatory, experiential, and practical ways of knowing alongside rational and empirical forms (Riley & Reason, 2024). Within this framework, knowing emerges through human relationships and everyday interactions, reflecting the dynamic interplay between thought, feeling, and action. Heron (1996) outlines four interrelated modes of knowing central to this approach: experiential knowing, which arises through direct encounter with people, places, and events; presentational knowing, expressed through creative or symbolic forms such as storytelling, art, or movement; propositional knowing, conveyed through concepts and theories; and practical knowing, realised through intentional action in the world. Of these, practical knowing holds particular significance, as it integrates the other forms into purposeful practice (Riley & Reason, 2024). When knowledge is grounded in lived experience, articulated through expressive forms, informed by conceptual reflection, and enacted in everyday life, its credibility and transformative potential are enhanced (Reason & Bradbury, 2006).

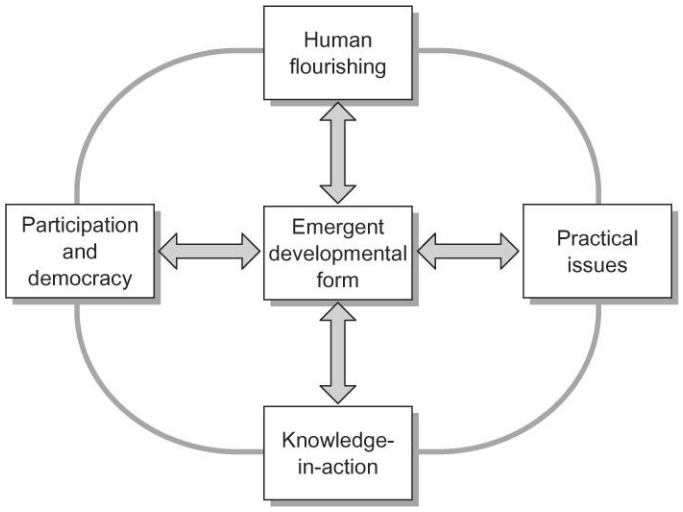

Figure 2: *Characteristics of action research (Reason & Bradbury, 2006)*

CI is guided by several core principles that distinguish it from traditional research approaches. Central to the method is co-ownership and participation, whereby all members act as both subjects and co-researchers, contributing to the framing of research questions, generation of data, and interpretation of findings. The inquiry unfolds through cycles of action and reflection, in which participants engage in everyday activities, reflect collectively on their experiences, and plan subsequent actions informed by shared insights. CI emphasises critical subjectivity, encouraging participants to acknowledge personal perspectives while engaging in reflexive critique and collective sense-making. Authenticity and validity are assessed through transparency, coherence, and resonance, focusing on whether the findings illuminate lived experience meaningfully for those involved rather than on replication or experimental control. Finally, CI integrates experience and action, aiming not only to deepen understanding but also to transform practice, relationships, and systems through the iterative inquiry process itself.

Based on my observations, women from similar backgrounds often find it easier to discuss their health concerns in a group setting. CI works particularly well with relatively homogenous groups, as this helps ensure the research remains grounded in participants'

perspectives and relevant to their context. In this study, small groups of women with shared experiences collaboratively explored issues of mutual concern over time, following the rhythm of creative inquiry that encourages deep reflection on matters meaningful to them. A central feature of CI is facilitation, which supports participants in examining their experiences and moving beyond individual knowledge to generate new, collective insights. This process fosters the creation of liberatory knowledge—knowledge that is practical and actionable, supporting the flourishing of participants in a particular time and place—rather than seeking universal, decontextualised truths (Riley & Reason, 2024).

Participant recruitment

Participants who were recruited had a diagnosis of RA, were aged over 40 and were noticing changes in their menstrual cycle (perimenopausal). This approach was used to include women who might be experiencing perimenopausal changes but were either unfamiliar with the term or reluctant to self-identify with it, given its association with stigmatising discourses surrounding age and gender (as discussed in Chapter 1). The research included a commitment to diversity – different ethnicities, socio-economic groups, sexually and gender diverse individuals including non-binary. Spontaneous EM was considered as an option, but there were no participants who came forward.

Participants were recruited online and through existing networks. Groups were leveraged for recruitment through Facebook menopause and arthritis groups including Arthritis NZ/Mateponapona Aotearoa, Rheumatoid Arthritis Online Support Group NZ, Menopause Support Group NZ, TOI Wā Hine Empowerment group. Posters and information were also emailed to menopause clinic, doctors/GPs and rheumatologists (Appendix A). I also went on

national radio, specifically RNZ's Afternoons with Jesse Mulligan to recruit participants (Appendix A). Plus, I was featured in Joint Support magazine, a twice-yearly publication by Arthritis New Zealand, and I wrote a blog post for Menopause Wellbeing that included information about my research (Appendix A). I also approached Pacific groups in the Porirua and Hutt areas of Wellington and met with The Pacific Health Service Hutt Valley.

Interested individuals were directed to a website (Appendix A) with a registration form which I used to check criteria and put participants into similar demographic groups. I contacted these potential participants to discuss the project with them and explain the cooperative inquiry method and what that entailed – it was important that it was something they wanted to do and that it would be an enjoyable experience. Participants were sent information and consent forms prior to the hui (Appendix B), which they read and signed before taking part in hour-long online recorded sessions.

Overview of participants

The names of the participants have been changed for publication of this study, and ages are as they were at the time of the data collection. All six participants identified as female and were over 40 years old with irregular periods. They all had children, a tertiary qualification, and were employed in either full-time or part-time work. One participant identified as Māori, while all the others identified as NZ European/Pākeha. The participants were split into two groups with three participants in each group. Registration highlighted a thematic split around the time of RA diagnosis; with three participants having had a recent diagnosis within the last two years, and the other three diagnosed over five to ten years ago. Given that CI is about learning together in groups of similar people, this distinction was a useful way to create the two groups. To provide a

sense of the participants, I give brief vignettes, based on the information provided by them, below (note pseudonyms used throughout). These vignettes were shared with the participants for review and approval.

Group 1

Jane is 49 years old and was diagnosed with RA about 18 months ago. She became perimenopausal four years ago and spent this time trying to get a diagnosis. Jane is single and has two children. She works as a teacher at a school in a city commuting in from a regional area. Jane takes NSAIDs and DMARDs for her RA and is on HRT for PM.

Ruth is 46 years old and was diagnosed with RA this year when she also became perimenopausal. She lives just outside of a city and is married with an eight-year-old son. She works in the travel industry and has a sister in the health system who has supported her journey. Ruth takes DMARDs for her RA.

Vanessa is 44 years old and has very recently been diagnosed with RA when she was hospitalised. She has just entered PM and works in education, managing a regional team. She has one son who is five years old and is married. She identifies as Māori and has little support from family and friends. Vanessa takes NSAIDs for her RA.

Group 2

Ann is 49 years old and was diagnosed nearly 14 years ago when she had young children. She has been in PM for a few years. She is based in a major city and works part time as a scientist at a university. Alison takes DMARDs for her RA.

Sarah is 55 years old and was diagnosed with RA 15 years ago when her youngest son was four years old. She believes this is around the same time she hit PM. She is married with four sons and is a primary school teacher. She has also survived breast cancer. Sarah has chosen to stay off medication and uses a probiotic diet alongside fasting to manage her RA.

Jenny is 51 and was diagnosed with RA five years ago, the same time she started going through PM. Her RA is well managed, but she still has flares. She works part time and is married with children. Jenny takes DMARDs for her RA and is on HRT for PM.

Procedure

Two CI groups were recruited (see above), and each group met four times, over a six-eight week-long period. All sessions, which I gave the term 'hui', took place on Zoom for an hour each and the agreed time depended on availability which was often in the evening, recognising that marginalised women often have little time and flexibility to participate in research. Hui is a Māori word for a gathering or meeting for a specific cause and felt appropriate for this research in Aotearoa New Zealand. The sessions followed a plan drafted before the start and agreed with my supervisor (Appendix C). My primary role was to provide space for discussion and gently guide participants to speak from lived experience rather than sharing their observations of others. Minimal encouragers and active listening skills were often utilised, allowing dialogue to be relatively free-flowing. All sessions were digitally recorded (with consent) for transcription and analysis.

Initial hui

The intentions and aims of the first hui were to develop rapport and provide participants with an understanding of what to expect from partaking in the research, such as the nature and structure of the hui and between-hui tasks. A key consideration at this first hui was the importance of providing a relaxed, conversational space in which a shared concern and purpose could be established (Riley & Reason, 2024). The cycle of action and reflection in CI was explained and questions about the research process were invited. Other principles of CI were also discussed, such as the positioning of participants as experts, and the position of the author as facilitator and co-researcher. Group members were assured that there would be no "right or wrong" response. It was outlined that the purpose of the research was to explore lived experience, rather than to determine a particular 'result' as might be the aim of quantitative research. Ground rules were then set out and each participant was invited to introduce themselves and explain what drew them to the project (Appendix D).

To prompt initial discussion, Care-full Conversation Cards were used to support collective reflection and facilitate open dialogue within the inquiry groups (see Appendix E). The Care-full Conversation Cards—a tool developed by PhD researcher Ajuli Muller to foster meaningful conversations about women's bodies, health, and wellbeing—provided a structured yet flexible means of initiating discussion. They functioned as both an icebreaker and a catalyst for exploring embodied and emotional aspects of participants' experiences. Cards featuring prompts such as pain, confusion, self-esteem, and embarrassment encouraged participants to share initial reflections, while others, including guilt, death, and mental health, invited deeper consideration of more complex or sensitive topics. The use of these cards aligned with the phenomenological and CI framework by fostering relational trust, enabling participants to articulate lived experience in their own terms, and creating a shared interpretive space from

which deeper collective meaning-making could emerge. After each hui I would share the Zoom recording with the participants with an outline of what was discussed for reflection and actions they had agreed to take before the next hui.

Subsequent hui

Each hui would begin with a whakataukī, a traditional Māori proverb, and the participants sharing any reflections they had from the previous hui or new insights related to past topics that they had noticed. Between hui actions were then discussed, which often led to a starting place of the current hui. I would often ask questions to elicit specific details from participants related to taken-for-granted assumptions or rules they had discussed relating to their experiences and prompt discussion from the rest of the group.

Final hui

As well as the typical format followed for hui, discussed above, the final hui concluded with a mind, body, place, space, relationships, identity game. I then asked them to describe their experiences as if it was a journey and to add any take-home points of learning. Finally, I then thanked the participants for their contributions and explained next steps around data sharing, sending a koha in the form of supermaket vouchers and final publication.

The two CI groups created deep inquiry through cycles of action and reflection and engagement with critical thinking activities which enabled the participants to develop understanding of their experience as well as new and creative ways of looking at things. While CI offers a participatory and empowering framework well-suited to exploring women's lived experiences of PM and RA, it also presents certain challenges. The method’s emphasis on collaborative reflection and shared ownership of knowledge aligns with feminist and Indigenous

values, particularly in supporting culturally responsive, embodied, and relational research (Riley & Reason, 2024). However, practical and ethical considerations must be acknowledged. The process can be time and energy intensive, which may burden participants managing fluctuating health conditions such as RA and the symptoms of PM. Furthermore, despite its collaborative intent, power dynamics between researchers and participants may persist, particularly in cross-cultural contexts.

Reflexive Thematic Analysis

To analyse the data, I adopted Reflexive Thematic Analysis (Reflexive TA) as outlined by Braun and Clarke (2006, 2019, 2021). Reflexive TA enables the identification and interpretation of patterns of meaning across qualitative data. This flexible approach was selected for the present study because it aligns theoretically with a phenomenological framework and the use of CI, enabling an in-depth exploration of women's lived experiences of managing RA alongside PM. This was crucial in a study of RA and PM, where experiences are embodied, relational, and shaped by cultural narratives of gender, health, and ageing.

Reflexive TA acknowledges the active role of the researcher in knowledge production, emphasising reflexivity and the recognition that themes do not "emerge" passively but are generated through a process of interpretation. This was particularly important in the present study, with my positioning as a researcher alongside my co-researchers and the broader feminist and critical realist lens which shaped how the data was engaged with and understood.

Reflexive TA also sits comfortably within a feminist lens. Feminist approaches value women's voices, highlight the significance of lived and embodied experience, and challenge dominant medicalised or pathologising framings of health. By treating participants' accounts as

meaningful in their own right, rather than as data to be objectified or measured, reflexive TA supported a more situated and respectful analysis. It also allowed space for ambivalence and contradiction, recognising that women's coping strategies may reflect both agency and constraint within social and cultural structures. In this way, reflexive TA enabled the analysis to move beyond symptom description, to consider how RA and PM intersect with broader issues of gender, identity, and power. Ultimately, reflexive TA provided an interpretive framework that was not only consistent with the study's phenomenological approach with a feminist lens but also directly supported the thesis aim: to understand how women navigate the challenges of PM while living with RA.

The analytic process followed Braun and Clarke's six phases of thematic analysis: (1) familiarisation with the data through immersive reading and re-reading of transcripts, (2) systematic coding of interesting and meaningful features, (3) generating initial themes by collating codes and considering conceptual connections, (4) reviewing and refining themes against the data set, (5) defining and naming themes to capture their essence, and (6) producing a narrative account that situates the themes within the context of women's experiences of RA and PM. This process worked well for this specific study as it followed on from the workshop I undertook with Gareth Terry (see below) and meant I was able to put the literature into the context of doing.

Approach

"Thematic analysis is a flexible analytical method that enables the researcher to construct themes—meaning-based patterns—to report their interpretation of a qualitative dataset" (Terry & Hayfield, 2021, p.3). I attended a workshop on reflexive TA run by Gareth Terry at Massey

University before I started my data analysis. Data were analysed using Braun and Clarke's six-phase approach to reflexive TA (Braun & Clarke, 2021):

1. Data Familiarisation

   Braun and Clarke (2013) suggest that repeatedly reading the data helps researchers develop a critical perspective and generate initial ideas that can later be refined into codes and themes. Following this approach, I engaged in multiple readings of the hui transcripts, identifying excerpts of potential significance, and recording preliminary observations, interpretations, and emotional responses in a research journal. This journal also served as a space to document my reflections on both the content of the data and the analytic process itself. Transcriptions were prepared using a playscript format for clarity, with "…" indicating a long pause, "[...]" showing deliberately omitted data, and other notations employed as appropriate to convey participants' speech and interactions accurately, e.g. question marks showing the participants framed their talk as a question.

2. Generating codes

   A code is a label applied to a segment of data to capture its essential meaning and its relevance to the research question (Terry & Hayfield, 2021). Consistent with the view that coding is a flexible, interpretive process rather than a rigid or purely technical step, I employed a data-driven, "bottom-up" approach, generating codes directly from the dataset itself without reference to pre-existing literature. This approach allowed the codes to emerge organically from participants' accounts, reflecting the nuances and complexity of their lived experiences. Coding was carried out using a spreadsheet – identified key words and "chunked" the data to code, for example by using a "/" to mark when there

was a change in topic or shift in the way they were talking that implied something new was being discussed. The coding process was iterative, with repeated engagement with the dataset allowing codes to be refined and revised multiple times. In instances where data extracts encompassed more than one concept, multiple codes were applied to capture the full range of meanings.

3. Theme construction

   Codes that reflected similar, related, or overlapping ideas were clustered together to develop initial themes, using a Miro board to visualise and organise these relationships (see Appendix F). According to Terry and Hayfield (2021), a theme represents a patterned meaning across the dataset, capturing something important in relation to the research question. This grouping process was iterative, and several rounds of review led to the reshuffling and refinement of some clusters. A small number of codes did not initially align with any emerging themes and were temporarily placed in a 'miscellaneous' category. This allowed them to be revisited later in the analysis to determine their relevance. If too many codes accumulated in this category, it was also a way of showing that the analysis might not be fully capturing the breadth of participants' experiences. Reflexivity was central to this stage – for example, women found it easier to talk about PM than RA, I ensured that this wasn't due to my framing by checking through the data to see if there were counter examples. I could therefore be truer to what they were saying rather than what I thought they might be saying.

4. Theme development

I examined the initial themes to assess how well they related to one another and to the supporting data extracts. Some initial themes were expanded into subthemes and then taken back into a key theme as reflexive TA has a flatter hierarchy than some other forms of qualitative analysis (Terry & Hayfield, 2021). This led to a reconfiguration of the initial themes, with some combined or refined, ensuring that each theme was both distinct and relevant to the research question while remaining conceptually connected.

5. Revising and defining themes

   For each theme, I developed a written definition outlining its core concept, scope, and boundaries. In collaboration with my supervisor, we reviewed theme names to ensure they accurately reflected the meaning of the data while remaining concise, clear, and meaningful (Braun et al., 2022; Terry et al., 2017). Some theme names incorporated participants' quotations, which I revisited and adjusted as needed to capture the essence of the theme effectively. To visualise the relationships between themes, I created a mind map (see Appendix G). Although these analytical steps are presented sequentially, the process was iterative and recursive, requiring me to move back and forth between stages as interpretations developed (Braun & Clarke, 2006, 2019). I recognised that my analysis represents one interpretation of the data; other researchers with different perspectives might produce alternative readings (Vaismoradi et al., 2013). However, by attempting to adher to best practice principles of reflexive TA—through a detailed, iterative process that engaged deeply with reflexivity and remained attentive to participants' voices—I was able to address key quality criteria for a reflexive TA study.

6. Writing up

In reflexive TA, writing is an integral part of the analytic process, serving as a tool for refining ideas and interpretations (Braun et al., 2022). During this phase, I worked to weave together the analysis, selected data extracts, and relevant literature to construct an illustrative and interpretive narrative (Terry et al., 2017). All data extracts are presented verbatim as they appeared in the original transcripts. My aim was to move beyond simple description of the data and develop a coherent argument that directly addressed the research questions. This phase built directly on the analysis outlined in the next chapter, where themes were developed, refined, and interpreted to capture the complexity of women's experiences of navigating PM alongside RA using extracts and evaluations.

Considering reflexivity

This study was conducted from a phenomenological perspective, informed by feminist theory and a critical realist ontology, recognising that my experiences shape how I interpret phenomena (Braun & Clarke, 2013; Langdridge 2007). My experiences as a cisgender woman who has undergone PM and lives with some arthritis resonated with the literature and guided my interest in women's health, shaping both my research focus and interpretations. At the same time, I am conscious of my social privilege as a Pākehā, middle-class woman in New Zealand, with relatively unproblematic access to healthcare – a reality not shared by those with marginalised identities (Ministry of Health, 2019). I have also studied physical and mental health issues and work as a support worker for Arthritis NZ/Mateponapona Aotearoa. Reflexivity was therefore central throughout, enabling me to acknowledge how my positionality and assumptions may have influenced the research process and analysis of findings.

Therefore, I was aware that my facilitation and interpretation of how women navigate PM with RA may differ from someone with a different relationship to health and healthcare. I have also facilitated several workshops in my previous career as a content strategist, which I recognised could both support and complicate the process, as I might inadvertently seek to align the findings with my prior expectations. Aware that my own subjectivity may influence the analysis, I regularly discussed and reviewed the facilitation of groups and the analytic process with my supervisor to help ensure that my interpretations did not unduly shape the findings.

I also recognised that being in a slightly older age bracket than my participants (3-12 years older), helped to enable rapport to develop quickly as I was recognised as an expert in RA and someone who had gone through PM. Participants would often ask for my view on particular topics or if I knew of other research findings. However, I made frequent strides to 'check' that my understanding of their responses were accurate, and that I had not heard their experience through my own interpretation. I found that participants were extremely adept at clarifying or explaining their position further when provided the opportunity.

To achieve reflective awareness in this study, I kept a free writing journal which I utilised both before and after meeting with groups, to identify and observe my own assumptions, beliefs, critiques, and reflections of the topics discussed and participants' responses to them. I approached each workshop with an open curiosity, positioning myself as a naïve enquirer eager to learn from and understand the participants' experiences. Working for Arthritis NZ/Mateponapona Aotearoa, I understood acronyms and rarely needed to clarify much of what was said regarding their treatment regimes.

In both my observations of the participants during the sessions and in the direct feedback they provided, it was clear that they valued the opportunity to share their experiences. CI

provided a space to explore strategies and solutions for coping during this life stage. It was evident that it was something new and that they gained a lot from sharing with others going through something similar. Aside from occasions in which they had forgotten to complete between-workshop tasks, all participants engaged well in discussions and took their turn accordingly. The Care-full Conversations cards activity in particular was well-received by participants as an icebreaker to start initial discussions. Overall, a significant amount of laughter occurred during the workshops, and I observed a high level of comfortability within the space, which built up over time as the women got to know each other. Both groups thanked me for the opportunity to participate in the research. As several participants shared emotionally challenging experiences, I provided appropriate support following each hui – I emailed an information sheet with relevant contacts.

In reflecting on the structure of the CI, I initially planned for three meetings per group, in line with Riley and Reason's (2024) guidance that a minimum of three sessions is needed for exemplar projects. However, I decided to extend the process to four meetings for each group. This decision allowed for a deeper exploration of participants' experiences, particularly because they were navigating two interconnected issues – RA and PM. Holding a fourth meeting provided the opportunity to explore PM in more depth as RA had dominated much of the earlier discussions.

While adding a third group might have increased the breadth of perspectives, extending to four meetings enhanced the depth of understanding within each group, supporting richer, more nuanced data. The fourth session, in particular, enabled participants to reflect further and consolidate their thoughts. All the participants were happy to add a further session as they could see the value of the research. Overall, this approach emphasised the value of iterative, sustained

engagement in CI, reinforcing that depth and relational understanding were more important for this study than sheer breadth of perspectives.

Ethical issues

Throughout this research project, I designed and conducted all activities in accordance with the ethical principles outlined in the Massey University Code of Ethical Conduct for Research, Teaching, and Evaluation Involving Human Participants (2017) and the Code of Ethics for Psychologists in Aotearoa New Zealand. Ethics approval was granted for this project by the Massey University Human Ethics Northern Committee on date (see Appendix H), ensuring that all procedures adhered to the standards specified in my Ethics Application.

Ethical considerations included ensuring informed consent, confidentiality, and anonymity throughout the research process. Written consent was obtained from all participants before the project began, and ongoing verbal consent was sought throughout to ensure continued comfort and agreement. Confidentiality was maintained through the establishment of group ground rules, with all personal information kept confidential and stored separately from the research data. To preserve anonymity, participants were assigned pseudonyms, and any identifying details were removed from transcripts and reports.

Data protection and security were prioritised throughout the research process. All identifying information was stored separately from anonymised transcripts to maintain participant confidentiality. Research materials, including group transcripts and any recorded content, were securely stored on Massey University's OneDrive system, with access restricted solely to the researcher to prevent any potential breach of confidentiality.

Freedom from harm was another important consideration. The primary ethical concern in this research relates to the potential emotional or psychological distress participants may experience when discussing menopause. To minimise any risk of discomfort, a detailed informed consent process was undertaken, clearly outlining the study's purpose, procedures, and potential sensitivities. Regular check-ins were incorporated throughout the study to validate participants' feelings and to emphasise that experiencing discomfort was acceptable within the safe and supportive group environment. Participants were reminded that they could take a break or withdraw from the study at any time without consequence. Ongoing reflexive discussions with my supervisor were also used to monitor and manage any ethical or emotional issues that arose. Each group session concluded with a positive, affirming closure, and participants were provided with information and signposting to professional support services if needed.

Finally, cultural considerations were integrated throughout the research, acknowledging that one participant identified as Māori. Considering the small scale of the research, it will be emphasised that the findings cannot be generalised based on ethnicity to avoid the potential harm of misrepresentation. Paula Te Kahika (Chief Financial Officer) and Zechariah Reuelu (Community Development Pacific Peoples) at Arthritis NZ/Mateponapona Aotearoa were consulted to support the research.

Chapter 3: Analysis

The group discussions highlighted the complexity of participants' subjective experiences, encompassing bodily sensations, emotional responses, social contexts, and shifts in identity that shaped how they understood and managed RA while navigating PM. The women described experiences of biological, psychological, and social distress, alongside a range of coping strategies and efforts to make sense of and navigate the health system. From analysis of these accounts, three overarching themes were produced: 'Biopsychosocial distress of a new reality', 'Coping through resilience and accepting change', and 'Navigating the health system'.

"I didn't know my world could ever be like this" – Biopsychosocial distress of a new reality

This theme reflects the profound distress and disruption that the participants described while navigating the overlapping challenges of RA and PM. The findings show that both conditions generate a difficult new reality, one that affects bodily changes, social relationships, self-identity, and psychological wellbeing, resulting in an all-encompassing and interconnected biopsychosocial experience of distress.

This new reality was intensified by the ambiguity, uncertainty, and unpredictability that arose from the participants' biological changes. Central to the participants' accounts was the difficulty in understanding how to interpret their symptoms such as joint pain. The women described how the overlapping experiences of RA and PM created a sense of ambiguity, *"a double-edged whammy, for choice of what we can blame it on."* (Sarah, Group 2), in understanding what was happening to their bodies. For example, they often questioned whether fatigue, joint pain, mood changes, or sleep disturbances were caused by hormonal shifts related to PM, autoimmune activity related to RA or were simply a sign of ageing. As Ruth explains:

"Yeah, really sore toe joints, and then quite sort of sore hands, but then my shoulders are really sore, and I just felt so tired and so run down and just achy and exhausted, but not really being able to pinpoint what it was... I put everything down to old age. I just thought, 'oh, I'm just getting old, and it's just perimenopausal,' and I've heard you can get joint pain and just fatigue and all, and you could put anything down to anything just about. So how do you know what's RA? How do you know what's PM? What's just tired, you know, what's just aging? It's quite hard." (Ruth, Group 1)

Ruth, who is reflecting on experiencing her initial symptoms, struggles to *"pinpoint what is what"* and in this context, describes putting "everything" down to old age. The symptoms she experienced, joint pain, and fatigue, map against old age, PM and, as she puts it, just about *"anything"*. In this context of ambiguity, she is unable to determine the source of her experiences, nor how to interpret them, producing a confusing, ambiguous space that she summarises as *"hard"*.

Jane also describes the experience of living with RA during PM as creating a confusing ambiguous space, with the extra changes relating specifically to an aging stage *"so many changes at this stage of our lives"* and that *"as women"* is profoundly gendered:

"I don't know… how much of it you could say is the PM, and how much of it is RA, in terms of the fact that I think that we just go through so many changes at this stage of our lives, as women, physically, that, yeah, it's really hard to know." (Jane, Group 1)

One of the reasons why participants found it hard to know was that they often happen at the same time, research shows that most women are often diagnosed with RA in their 40s and 50s (Arthritis New Zealand, 2025), below Jenny talks about her experience:

“My symptoms, my arthritis symptoms started at the same time I was going through PM, there were a lot of blurred lines, and I couldn't really tell what was what, and still can't, because I haven't really got a non-PM frame of reference, but I pretty much know that the … the swollen joints and sore joints is arthritis. Well, that's what I tell myself, anyway. And the fatigue and, cognitive stuff is kind of anybody's guess, really.” (Jenny, Group 2)

For Jenny, because both RA and PM started at the same time, she's never had a moment where she can distinguish between the two to help manage the ambiguity. In this extract she evidences ongoing uncertainty, as she describes symptoms as *"pretty much know that... is arthritis"* which gives a sense of at least some confidence, but then immediately she undermines that, by reflecting *"that's what I tell myself"*. In the context of PM and RA having similar symptoms, participants could often be left with a sense that they would never know – as Jenny says, her fatigue and *"cognitive stuff"* is *"anybody's guess"*.

Another element of these biological changes is that it does not settle, so there is a constant sense of potential to be out of control or unsure of what is going to happen next physically, creating further psychological distress. Some participants spoke of a sense of detachment from their bodies, describing them as unpredictable, *“out of kilter”* (Ruth, Group 1), and feeling older than they were. While most symptoms remained invisible, participants also noted the confronting nature of visible bodily changes due to both RA and PM, which served as a reminder of disruption and loss of control, intensifying feelings of difference but also something *“to get back”* (Sarah, Group 2). This uncertainty and distress were described by Ruth:

“I guess I just feel less sure about myself because I'm not certain [of] my physical or cognitive functioning. It can be sort of unpredictable, because you just don't know quite

what's going to happen, I guess… yeah, I would say I feel quite detached from my body at this stage of my life." (Ruth, Group 1)

In the extract above, Ruth talks of feeling *"less sure about myself"* due to the unpredictability of both physical and cognitive functioning. This uncertainty disrupts the usual tacit trust in one's body. In everyday life, the body often recedes into the background—as discussed in Chapter 1, Leder (1990) calls this the "absent body"—because it operates silently, reliably, and without drawing attention to itself. But when illness—or in the context of this study —PM or RA symptoms intrude, the body ceases to be absent and becomes obtrusive, unpredictable, and alien. To feel *"detached from my body"* suggests Ruth is experiencing the body as not quite hers, as though it is an external object rather than the ground of subjectivity. Leder's (1990) terms—"dys-appearance" (when the ill body forces itself into awareness as problematic)—illuminates this alienation. This sense of alienation disrupts a person's sense of embodiment and embodied self, with potential to create an "uncanny body experience and an unhomelike being-in-the world" (Madeira et al., 2020) and thus, creating biopsychosocial distress that is a key theme in the accounts of the participants in this study.

Participants also talked about a sense of alienation and detachment from their embodied selves through the significant body change that came from weight gain associated with PM, *"I've had... lots of weight gain"* (Jane, Group 1). This, in turn, generates a great deal of distress, as illustrated by Sarah's account:

"It's probably the most detached... I know it's probably because I've gained weight, and I'm less active, but also, I think… just having your hormones all over the place and having… your pain threshold all over the place. It makes it really hard to navigate

sometimes. Yeah, it can be quite difficult. I think it makes me a little bit sad that I've kind of lost… I feel like I've lost control of that. And I don't feel like I have a lot of control over it at the moment. And I know it's something that I have to get back." (Sarah, Group 2)

Here Sarah's detachment is lived as a crisis of agency. Hormonal shifts, pain fluctuations, and weight gain pull the body out of tacit background into Leder's (1990) 'dys-appearance'. Sarah mourns a loss of control and aspires to *"get back"* a body that can again be trusted and to return to a socially acceptable self within normal expectations. This form of detachment resonates with Leder's notion of the body as both self and not-self, with the balance tipping heavily toward the not-self in the context of Sarah's experiences of PM.

This sense of loss is further experienced in a social context where the women describe a loss of the ability to do things with other people that were often part of their relationships and imagined futures: *"I wanted to be out mountaineering with my kids in their teenage years, not…you know, rocking myself to sleep on the couch, crying"* (Sarah, Group 2). The participants also spoke of grieving the activities they could no longer do, and the loss of spontaneity, which was not solely individual but also social, as women felt distanced from others who could not fully appreciate their struggles. Ruth describes how, through the CI conversations, the group realises that they share the experience of having withdrawn from social activities:

"... it sounds like maybe all three of us have been, you know, quite active socially, you know, and sports physical, you know. Outdoors, I mean, I'm not a sports person, but, you know, I've always been doing stuff outside and outdoors, and seeing friends and social, and then, when you withdraw from a lot of it." (Ruth, Group 1)

Ruth reflects on a previously active lifestyle centred around being outdoors, socialising, and engaging in physical activity, which contributed not only to wellbeing but also to identity and social connection. The withdrawal from these activities underscores a profound disruption – not just of leisure, but of valued roles and ways of being with others. This loss is felt socially, as opportunities for connection diminish, and psychologically, as the women grapple with a diminished sense of self shaped by what they can no longer do.

Several of the women also reflected on how living with PM and RA affected not only themselves but also their families, particularly their children. Jane, for example, noted how the unpredictability of symptoms and physical limitations—such as difficulty climbing stairs or walking distances—could influence children's awareness and experiences, shaping what they could do together as a family as they altered their behaviours. "*I can't take the stairs, sweetie. I've got to take the lift"* (Jane, Group 1). This also often created a sense of concern and distress as women recognised that their condition subtly altered their children's routines, activities, and perceptions of what was possible, "*I suppose that in a sense makes me sad, because I probably have got quite used to changing my behaviours, and I don't even know that I've changed my behaviors"* (Jane, Group 1). These reflections highlight that the social impact of RA and PM extends beyond the individual, influencing family dynamics, roles, and emotional wellbeing.

Overall, the participants' embodied experiences extended beyond the biological to affect their social interactions, including those related to work, highlighting the broader impact of living with unpredictable symptoms. For example, Sarah described attending a staff meeting, feeling *"quite ordinary"* upon arrival, only to suddenly struggle to *"get out of your chair"*:

"I think it's not really shame, but it's that ridiculous unpredictability of the whole thing. You know you can go and sit down in a staff meeting, and you're skipping into the room looking quite ordinary, and then you can hardly get out of your chair." (Sarah, Group 2)

The example above was distressing not only for Sarah's sense of self but also because it occurred within a social context that demanded she account for her altered bodily presence – risking being perceived as "odd" or "unreliable." This experience illustrates how bodily unpredictability can unsettle a woman's professional identity and challenge the maintenance of a coherent self within normative expectations of competence and control. Similarly, Ann reflected that being visibly tired or fatigued is often misunderstood or minimized by others, leaving them feeling unseen or invalidated, *"you say you're tired, and it doesn't mean anything to people"* (Ann, Group 2). These accounts underscore that the social dimension of their experience is shaped not only by the symptoms themselves, but by the gap between how participants feel and how others perceive them, revealing the intricate ways in which chronic illness and perimenopausal changes can challenge social engagement and belonging.

These experiences affect social confidence and participation, and, as Ann describes below, creates a difficulty in maintaining friendships:

"I actually found keeping those friendships up really hard because I was constantly cancelling. I didn't want to commit to anything... how long will people keep inviting me to go for a coffee? And then I'd just ring and say I can't, or you know you. All those doubts come in of 'are you really just a problem for other people?'... I think I lost the confidence of what to say to other people, make plans, because again, you don't want to be the one who's made the plans, and then not be able to follow through with them, and not be able

to do it out the other side, where, in actual fact, most of my friends they didn't care like they were fine with it. They didn't care not. They didn't care about me, you know. They didn't care about canceling rather than they didn't care about what was going on. I think a lot of people didn't know as well, necessarily, which wasn't something that I didn't hide it. It wasn't like I made a conscious effort to not tell people, but it wasn't necessarily something that came up in conversation." (Ann, Group 2)

Ann describes self-doubt, guilt, and a loss of confidence in making plans, fearing she may be perceived as a burden. Socially, the unpredictability of her symptoms leads to frequent cancellations, straining friendships and heightening her sense of isolation, even though she acknowledges that her friends were generally understanding. The limits in her ability to engage consistently in social activities reinforces a sense of detachment from her previous active life. Taken together, this illustrates how the overlapping conditions do not simply affect the body but reverberate across social connections, self-image, and emotional wellbeing, creating an all-encompassing experience of biopsychosocial distress.

The experience of social withdrawal was often compounded by a heightened awareness of how others might view them during symptom flares as illustrated by Sarah's experience:

"I'd been in tears, say, tying my shoes or whatever that morning, and then I was at school and we needed to unload compost, and it's like, well, I can't not be doing it when I'm, you know, the one with the gardening hat on, and I've kind of organized this all. So I was out there, I think I had, like, a… I, … you know, shovel and brush that you have for the fireplace, just doing the bit, thinking, well, at least [I can do something]... and, one of the parents, just jokingly, said, 'oh, come on, you weakling', and handed me the big shovel.

And it's like, you can't even… and that was the reality check for me, was oh my god, this is how people actually see me when I'm having a flare-up. This is what I'm… you know, how… I appear to them." (Sarah, Group 2)

Sarah describes how, as the leader of an activity, she was physically limited while helping at school and then made to feel publicly judged. She illustrates that chronic illness such as RA is not just a biological struggle – it reshapes social interactions and identity. Sarah is misunderstood due to the invisibility of RA and her distress is intensified by the awareness of how she appears to others and her perceived capability. Sarah's distress arises not only from physical limitations but from the pressure to conform to social norms. Thus, across family, work and community activities the participants reported a sense of social exposure that exasperated feelings of vulnerability, embarrassment, or inadequacy, particularly when flares are unpredictable and uncontrollable.

These struggles meant that disclosure was not a straightforward act for the participants in social situations, but a negotiation shaped by fear of stigma, due to concerns about being misunderstood or dismissed, and the desire to maintain a sense of normalcy. This sense of social exclusion echoes Leder's (2016) metaphor of punishment to describe feelings of social exclusion due to illness. For some of the participants in this study, silence served as a protective strategy against judgement, unwanted pity or fear of losing their job, but others did talk about it creating – see the coping strategies section below for further discussion. Ann (Group 2) alluded to the discomfort of talking about it, "*it's not something that I'd advertise if it came up in conversation."*. Vanessa (Group 1) reiterates this comment and explains how it's a *"very isolating journey"* because "*it gets dismissed quite easily"*:

"I think it is a very isolating journey...[people] don't really get it...But you know I haven't told a lot of people, and it's still taken a while because it doesn't really come up in conversation. 'Oh, yeah, I've just been so tired. I've actually just been diagnosed with an autoimmune disease.' Or if you say, 'well, arthritis', they just go, 'Oh, yeah, my Nana's got that in her knee, or, oh, yeah, my mum has got that in her hip.' So I tend not to even say it. Yeah, I suppose there's a few people who know, but it gets dismissed quite easily, and I think with a chronic, long-term condition people don't really understand, because they see you normally, or they see you at the school gate, and you're fine, and you're okay, but they don't see the other side of it, and what you're dealing with as well." (Vanessa, Group 1)

Above, Vanessa reflects on the isolation and misunderstanding that arises when women's experiences of RA and PM are minimised or dismissed in social interactions. She describes the difficulty of disclosing her condition, noting that arthritis is often trivialised or associated only with older relatives in ways that dismiss the difficulty of her situation, both of which undermine the seriousness of her experience. This lack of recognition from others contributes to a reluctance to share, reinforcing her sense of invisibility and solitude. Social interactions thus become fraught for Vanessa, as people only see her in moments when she appears *"fine"*, while the hidden struggles remain unacknowledged. In this way, Vanessa describes how RA is socially alienating, as the lack of understanding erodes empathy, validation, and support.

Several women also spoke about the tension they face in deciding whether to disclose their condition in workplace settings. On one hand, disclosure can bring understanding and support, but on the other, it risks stigma, judgement, or altered treatment from others. *"You don't want people to think you can't do your job"* (Ruth, Group 1). Jane (Group 1) describes how she's

finding it *"stressful"* to tell her work about her condition because she doesn't want to be judged, *"I don't know how they'll react"* and *"it can backfire on you as well"*. This meant that the women experienced a "luck of the draw" in terms of their work culture, as Jenny explains:

> *"But yeah, I'm definitely in a job now where people are more compassionate, I suppose, than where I was previously, and I did actively avoid telling people about anything really health related." (Jenny, Group 2)*

Jenny reflects on deliberately avoiding conversations about her health in a previous job, suggesting that disclosure felt unsafe or carried risks, perhaps of stigma, judgment, or being treated differently. The contrast she draws with her current workplace—where she perceives people as more compassionate—highlights how the social environment shapes disclosure decisions. Here disclosure discussions are helpful and can create opportunities for recognition, empathy, and practical support (see coping strategies section for further analysis).

The participants also reflected on the differences between disclosure in relation to RA and PM and highlighted the increasing recognition of PM as a legitimate topic for discussion within the workplace. Contrasting perceptions of PM and RA also stood out around how women connected in social environments. One participant spoke about how *"PM is inevitable, but RA is uncool"*. Sarah (Group 2) spoke about how *"You get people's sympathy with RA, but you kind of get connection with the PM"*. Other women in the study also found it easier to connect with women going through PM as awareness has increased and it is more accepted, *"and now I see it all the time, everywhere"* (Vanessa, Group 1), but that people don't understand RA and they *"get sick of hearing about it",* (Jenny, Group 2). Jenny goes on to describe the comparison with RA in more detail:

"I don't know if it's because of the age and stage, but it feels like a lot more people are openly talking about PM, and… there's a lot more discussion around it, and so everyone just sits there and chats about it over coffee, and it's fine. So, it sort of feels a lot more like a shared journey this time, rather than a solo, sort of isolating thing. It's almost like… I don't know, enveloping rather than isolating, if that makes sense."

(Jenny, Group 2)

Jenny compares the social interactions of RA and PM and how they can either intensify isolation or foster connection, depending on whether experiences are shared and validated by others. She notes that PM is increasingly part of everyday conversations, which helps to normalise the experience and reduce stigma. Now that there is more discussion about PM, Jenny no longer carries the burden privately but describes it as a shared journey, framed by solidarity and mutual understanding. Her description of it being "enveloping rather than isolating" reflects how supportive social interactions can provide comfort, reassurance, and a sense of being held within a community, rather than left alone with distress.

Above, I focused on the biological and social dimensions, while recognising their psychological consequences. Indeed, navigating these overlapping experiences had profound emotional and psychological effects. Many described a loss of their usual sense of self and a disruption of expectations for daily life, such as being able to engage fully with family or maintain previous levels of activity. This often translated into feelings of guilt for not being able to do the things they wanted or felt they should, alongside a loss of "get up and go" that intensified distress. Women also spoke of being caught in negative mental spaces, experiencing low mood, anxiety, and intrusive thoughts, including fears about death, which could leave them lying awake at night consumed by worry. Together, this evidences significant psychological and

emotional distress, and concerns for the future. Ruth describes her distress from the ongoing loss of self, "*new normal"*, that changed over time:

> *"What's that new normal? And will you ever go back to your old life, or a life without pain or feeling like you?" (Ruth, Group 1)*

Some women also described experiencing guilt as a pervasive aspect of their psychological distress, feeling torn between the demands of work, family, and self-care while managing the unpredictable symptoms of PM and RA. This guilt often arose from perceived shortcomings—not being able to socialise and see friends, relying on others for support, or feeling less capable than before—which compounded emotional strain and heightened self-criticism:

> *"You've got your normal, mum guilt, anyway. But just the guilt for saying no… It's not in my nature to say, no, I'll just sit at home, you know. I'm not just someone. I'm not sitting around watching TV or just relaxing at home. I mean there's no time for that. Right? There's always other things – parents to visit, you know, kids to look after, other things, work".* (Ruth, Group 1)

Ruth explains how her feelings of guilt are entangled with her identity loss. She highlights *"mum guilt",* which is compounded by guilt for saying no to activities that once defined her socially and physically active lifestyle. Socially, withdrawing from friendships, sports, and outdoor activities disrupts her sense of belonging and connection, intensifying the distress of it *"not being in her nature"* to say no. Being forced to rest and *"sit at home"* conflicts with her identity as a busy, engaged mother, partner, and friend. Together, these dimensions

create a sense of loss and frustration, where guilt not only arises from what she cannot do but also undermines her sense of self and role within her family and wider community.

All participants talked about feeling 'scared', *"I'm too scared to go on the next one [drug]"* (Vanessa, Group 1), and some spoke about their mental health which included depression and anxiety. This was more heightened in the group that had recently been diagnosed with RA as they worked through how to manage their diagnosis. The women in group 1 spoke about being at *"death's door"* (Ruth, Group 1) or *"I was pretty much a wreck"* (Jane, Group 1). Ruth went on to explain:

> *"And it did feel like my get up and go, got up and went, got up and left completely. And just that real, yeah. I suppose that I found myself in quite a negative space mentally and very much that, 'why me?', you know, because it's not in my family... It does feel a bit random, and I have, you know, found myself, and I'm normally okay at sort of catching myself when I have a bit of a 'woe is me' moment." (Ruth, Group 1)*

She describes a profound loss of energy and motivation—*"my get up and go… got up and left"*—which signals both physical exhaustion and its effect on mood. The expression of feeling in a *"negative space mentally"* and asking, *"why me?"* reveals a struggle to find meaning in what feels like a random and unjust diagnosis, particularly in the absence of family history. Although she notes an ability to *"catch herself"* when slipping into self-pity, the need to actively manage these thoughts underscores the ongoing psychological burden. This highlights how chronic illness not only disrupts the body but also erodes emotional resilience, contributing to cycles of frustration, sadness, and self-questioning. Ruth went on to talk further about even when

family told her that it's ok to do nothing she still struggled to reconcile the guilt, *"But it is quite hard to reconcile that guilt. Oh, I should be doing something, or I should be somewhere."*

From a psychological and emotional perspective, participants described a profound shift in their sense of self and emotional wellbeing before and after receiving a diagnosis of RA:

> *"I guess I always felt like I couldn't do these things everyone else can. I'm the only one who can't, and so I have to try and hide that away and get on and do it anyway, which…was isolating...in that…I withdrew from doing things, or from putting myself out there to do things that I thought I might not be able to do, because that was easier for me than having to stand up and say to somebody, I can't do this now, even though I was going to." (Ann, Group 2)*

Interestingly, Ann was diagnosed over ten years ago, but the guilt was still very real for her. Ann describes a pervasive sense of inadequacy and difference, feeling that she is unable to do what others can, which fuels self-consciousness and isolation. In an effort to maintain appearances and avoid perceived judgment, she withdraws from social activities or challenges, highlighting how chronic illness can restrict participation and reinforce feelings of separation from others. This self-imposed withdrawal reflects both emotional strain, as she navigates disappointment and frustration with her body, and psychological distress, through the internalised pressure to meet social expectations despite her limitations. It underscores how the intersection of physical limitations, social expectations, and internalised self-criticism contributes to sustained emotional burden and feelings of being "left out" or disconnected.

The women who had been more recently diagnosed also spoke about facing their own mortality and fear of death, particularly as RA can shorten life expectancy (Arthritis New

Zealand, 2025). This contributed to a deep sense of loss and emotional distress intensifying feelings of anxiety and uncertainty. The 'death' care-full conversations card prompted one of the participants to talk about her anxiety around death and how she's *"never thought like this before"*:

> *"What scared me the most was probably the thoughts of death. So that death card was probably the most [obvious] one for me because of to not being able to sleep because you're thinking about what happens if you die. 'Oh, what happens to everyone else anytime?' ...I've never thought like that before in my life. And it felt like it came out of nowhere." (Vanessa, Group 1)*

Summary of biopsychosocial distress of a new reality

In summary, the biopsychosocial impact on these women reflects a "double burden" of PM and RA, with overlapping symptoms that are often difficult to disentangle and contribute to heightened uncertainty. Participants described never knowing which condition was responsible for what they were experiencing. Unlike PM, which carries the hope that symptoms may ease once menopause is reached, RA offers no such resolution. As Jane (Group 1) explained, *"This is forever. This is not going away. It can't be fixed and it's for life"*, with low-dose medication or remission representing the best possible outcome rather than full recovery. The distress of this new reality encompassed not only the embodied challenges of chronic illness and PM but also the emotional strain and sociocultural contexts through which women made sense of, and lived with, these intersecting conditions. Prevailing social expectations and cultural narratives—such as viewing both perimenopause and RA as simply 'getting older'—exacerbated feelings of isolation and confusion, shaping how participants identified, recognised, and interpreted their

bodily experiences. This distress extended beyond physical suffering to include emotional and social dimensions, such as anxiety, frustration, guilt, grief over the loss of a once-familiar sense of self, and reduced participation in work, community life, and friendships. For these women, the convergence of RA and PM represented a profound biographical disruption (Bury, 1982), reshaping their sense of self and place in the world, intensifying feelings of invisibility, and amplifying the emotional, social, and existential strain of managing two life-altering transitions at once while juggling employment, caregiving, and family responsibilities.

"We get each other" – Coping through resilience strategies and accepting change

The women in this study described a variety of strategies for coping with the biopsychosocial distress arising from the overlapping challenges of PM and RA. They described cultivating resilience through powering on, confronting or reframing fears, and, in some cases, using medication to manage symptoms. They also described how acceptance of bodily changes, practices of gratitude, and meaningful connections with others helped them navigate daily life, demonstrating how coping is enacted across physical, emotional, and social domains.

All the participants described juggling busy lives, with family, work and social and how managing their condition is *"squeezed"* (Ruth, Group 1) or how they are *"a bit of a battler, I suppose, and I'm a bit of a just get on with things kind of person."* (Jane, Group 1). Participants described the conscious effort it took to reframe their circumstances, acknowledging limitations while finding ways to adapt daily routines and expectations by being *"more self-analytical"* (Sarah, Group 2). Sarah spoke about reframing her pain by learning to *"dig it in"* and making her *"affirmations louder and stronger"*. Coping was often expressed through a balance of pragmatism and perseverance – maintaining humour, minimising what could not be controlled,

and prioritising what mattered most: *"I guess it's made me a bit more determined with my head stuff, with my inner voice"* (Sarah, Group 2). Jane (Group 1) spoke about how:

> *"You just kind of do it, if that makes sense. I convince myself …that I can do things, and I don't know where that comes from, but I just dig deep and quite often just say, nope, you're going for a walk, you're going to go and do that. You can… you'll get through this bit, and I don't know, I think it gets built into you." suggesting that "it comes with age...you just sort of learn how to become resilient, and I think it's something that happens over a long period of time." Jane (Group 1)*

Jane's account shows how she actively convinces herself to keep going—whether by taking a walk or completing a task—using determination and self-talk to counteract feelings of limitation. This process of *"digging deep"* reflects both psychological endurance and a learned ability to adapt to adversity. Jane frames resilience not as an innate quality but as something developed gradually *"over a long period of time"*, suggesting that age and experience play a role in cultivating this coping strategy. By normalising perseverance and reframing difficulties as something she can endure, Jane demonstrates how resilience functions as a way of managing the ongoing biopsychosocial distress of RA and PM, enabling her to maintain a sense of agency and control.

Participants also described how they reframed or faced up to their fears. Jane spoke about *"facing the death side of this"* and making an appointment with her specialist to discuss it further as a way of coping with the implications of her RA diagnosis. She also talks about:

> *"[The] feeling [off] guilt is probably one that comes up where I have to remind myself that I'm okay. You know I don't have cancer, or you know it's only rheumatoid arthritis. I*

can live with it. It's fine. I'm managing it through medication or lifestyle trying to but yeah, it's sort of that flip side of having a strange thought, and then sort of pulling yourself back from it and going. Oh, it's not so bad, you know. It's okay. Take the drugs. That's what they're there for." (Jane, Group 1)

Jane describes how she manages her guilt by pulling herself back from intrusive or "strange" thoughts, reframing the situation as manageable, and relying on medication as both a biomedical and psychological resource. This strategy reflects Lazarus and Folkman's (1984) transactional model of coping, in which individuals appraise stressors and draw on cognitive and practical resources to restore equilibrium. It highlights how women actively manage the interplay between symptoms, emotions, and social expectations to maintain a sense of stability amid ongoing disruption.

Jane's reliance on medication also shows how medication was used as a coping strategy. For some women, medication—whether in the form of disease-modifying drugs, pain relief, or hormone replacement therapy (HRT)— as described as vital in sustaining daily functioning and providing a sense of control over otherwise unpredictable bodies. The availability of pharmacological relief offered reassurance, enabling women to continue with work, family, and social roles — as Jane said, *"Take the drugs. That's what they're there for"*.

Ruth (Group 1), described how the medication had helped her get things *"under control"*. Jenny also described how HRT has helped with her RA and that *"it does make a difference"*, with the potential to reduce her DMARDs. Jenny further explained how HRT has help with her moods and forgetfulness when *"things were out of whack"* and the difference this has made:

"Initially, it was probably the moods, I had minor hot flushes, but mainly the cognitive things like forgetting words and just general forgetfulness as well. And the emotional ups and downs too. I'm not really that teary. But yeah, you could tell when things were out of whack. And since I've been on HRT, that's all stabilized. So, I was at the point where I was thinking, I'm not going to be able to carry on working. I can't remember anything. So that's made a huge difference to me." (Jenny, Group 2)

Jenny's account shows that medication, specifically HRT, doesn't just manage symptoms but enables resilience and survival in multiple ways for her. She survives in the sense that she can continue earning an income and maintain her professional role, and she survives in the sense that she regains herself, reclaiming a sense of identity and stability that had been threatened by PM-related memory problems and emotional instability. Before treatment, these fears could have led to withdrawal, loss of identity, and further distress, echoing the first theme of women experiencing a loss of self. By finding an effective treatment, Jenny was able to restore balance in her daily life, continue with valued roles such as her job, and reclaim a sense of agency and continuity in her life – a tangible example of how women can negotiate strategies to regain their sense of self amidst the dual challenges of RA and PM. The negotiation between dependence and autonomy from medication reflects broader cultural and feminist debates around the medicalisation of women's health, where medication can simultaneously enable resilience and reinforce vulnerability. In this way, the role of medication emerged not as straightforwardly positive or negative, but as a site of negotiation in which women balanced relief, reliance, and the desire for self-determination in the face of bodily disruption.

Some women spoke about their love/hate relationship with the medication for RA due to the side effects but also how they couldn't get through without it due to the pain. The side effects

of certain medication were alluded to by Ruth (Group 1) sarcastically as "*that lovely drug"* with a negative impact on everyday life. They described how *"all your hair can fall out"* or *"your retina detaching"* from the side effects. Jane (Group 1) describes how the methotrexate taken for RA weakens the immune system and that she has had to "*take more drugs for more drugs"* to cope with the side effects. At the same time, participants also highlighted the limitations and uncertainties of medication. Concerns about the side effects, incomplete effectiveness, and long-term reliance meant that medication was not always experienced as an empowering solution.

Therefore, while medication is a solution for coping it produces its own problems. Some women spoke of deliberately coping without pharmaceuticals, emphasising self-management and lifestyle adaptations, such as exercise and nutrition, as strategies that fostered a stronger sense of agency. Sarah (Group 2) has used diet and raw foods to manage her RA and describes that as beneficial, whereas others (Ann, Goup 2) have found dietary change impossible due to other health conditions.

As well as medication, connection with others going through something similar—enabled through the inquiry—emerged as a powerful coping strategy to counter the participants' fears, with the women describing relief in finding others through the inquiry who *"understood"* and could validate their embodied struggles, sense of self and use of medication.

> *"I think there's something really nice about… saying even simple things like something is sore or something is tired to somebody who you know will actually understand what that means and how that feels to you." (Ann, Group 2)*

For Ann, simply expressing that *"something is sore or something is tired"* gains new meaning when shared with someone who has lived through similar challenges. In everyday

contexts, such statements might be brushed off or misunderstood, but within a space of shared understanding, they carry depth and resonance. This kind of empathetic connection allows participants to feel less alone in their struggles, counteracting the isolation and invalidation that often accompanies conditions like RA and PM. By articulating her pain or fatigue to someone who can *"actually understand,"* Ann is not just communicating symptoms – she is also seeking and experiencing recognition, solidarity, and reassurance. This process itself becomes a coping strategy, as it helps to alleviate the psychological distress of being unseen or dismissed. In this way, connection functions as a protective resource, reinforcing resilience by fostering belonging, shared meaning, and emotional support.

This connection was particularly important in the context of the isolation that participants had described (above). Narratives such as, *"and it's in some ways this is quite nice hearing it from other people, because, you know, as we said, we don't often talk about it with your colleagues, or day to day sort of life"*. (Ruth, Group 1) highlights how disclosure is entangled with broader sociocultural norms around women's health, where silence has often been expected. On one level, relationships with others and knowing *"there are other people out there as well"* provided essential comfort, validation, and practical help in managing the dual challenges of RA and PM. At the same time, maintaining these connections acted as a quiet form of resistance, pushing back against the isolation, stigma, and cultural expectations that women should endure health struggles silently. In this way, the connection women experienced through this research became more than a coping mechanism – it became an expression of agency rather than fatalism. As Sarah (Group 2) says: *"We get it, we get each other, it's been really good for me."*

Ann (Group 2) also explains how she is more accepting of her situation now she's more socially connected and can *"accept the limitations a bit more".* Amid the demands of daily life

and the challenges of navigating PM with RA, the participants described how acceptance can be a liberating and powerful coping strategy. When the weight of expectations felt unavoidable even in the difficult contexts outlined above, acknowledging small joys—such as supportive relationships, manageable symptom days, or personal achievements—helped cultivate acceptance. In particular, gratitude and ageing became lenses through which women could reframe their experiences, fostering acceptance of change and a sense of agency despite circumstances beyond their control. In this way, appreciation for what remained possible offered a quiet but meaningful source of strength and became *"liberating":*

> *"I just look out the window and think I get to turn on the tap and have drinkable water, and I get to look out the window and see the birds feeding, or I get, you know, just I guess, that gratitude... and that's what I'm going to try doing for the next week till we talk again. Just do those things... that seem to help as well." (Sarah, Group 2)*

Rather than resisting or focusing only on the distress caused by illness, Sarah shifts attention to small, positive aspects of daily life—clean water, birds outside the window—that remain accessible and meaningful. This doesn't deny the challenges of living with RA and PM but reframes her experience by anchoring it in what is still available and valuable. In this way, acceptance becomes liberating: instead of battling against limitations, Sarah cultivates a sense of peace and stability in ordinary moments. Ann (Group 2) reframes her experience by finding acceptance as she aged liberating:

> *"Part of it's probably just because I'm older and I don't really care so much what people think now. And in a way, it's almost… is it fair to say it's almost liberating? It's like, no… it is quite liberating."*

Acceptance did not signal passivity; rather, it represented an active process of adjusting to altered embodiment and shifting life trajectories. Women spoke of drawing strength from perspective-taking—reminding themselves that *"it could be worse"*—and of building acceptance through strategies such as pacing, conserving energy, asking for help and redefining what productivity or functionality meant in their everyday lives and that 'focusing on other things' was a distraction that also helped them to *"forget about it"* (Ruth, Group 1). Sarah (Group 2), describes how her school is supportive and how her *"teacher aide will help me"* while Ruth (Group 1) talks about appreciating *"what you can do"*. Ann (Group 2) also describes how *"coming to terms"* with her bodily changes makes her feel like a *"a totally different person"* by finding a way to cope through acceptance and compassion for herself.

All the participants talked about resilience and acceptance throughout the CI hui and how they needed to *"slog it out"* over time because *"this is not going away"* (Jane, Group 1) while they described holding on to things that they weren't able to talk about. In that way connecting with others going through something similar mattered.

> *"Yeah, I suppose that thing of resilience is important, because basically it's the only thing that I think really keeps you going. It's because this is, you know, this is forever. This is not going away. It can't be fixed and it's for life. Then I think resilience is really a key word there for me, because if I am not finding ways to be resilient, then I, you know, I'm going to fall apart. That's the reality. And so maybe some of having some strategies to help with resilience might be really good, because it's really this is, this is, yeah, this is like we...we are going to be with the you know, the old tortoise and the hare scenario. We are the tortoise, and we're just going to have to slowly slog it out. (Jane, Group 1)*

Jane highlights that because her condition is chronic and lifelong, *"this is forever… it can't be fixed"*, survival depends on cultivating resilience. Resilience here is not about "fixing it" in a short-term sense, but about developing the endurance to sustain herself over time – captured in her metaphor of the tortoise and the hare, where living with illness requires pacing, persistence, and long-term adaptation. At the same time, her words also point to acceptance as a key part of resilience. By recognising that RA is *"not going away"*, she shows a move away from denial or resistance toward acceptance of her circumstances. This acceptance is not resignation – rather, it opens up the space to focus on strategies and coping mechanisms that allow her to keep going, even if slowly. Together, resilience and acceptance create a framework where she can acknowledge the unchangeable aspects of her condition while still holding onto agency through coping strategies, endurance, and perspective. In this way, acceptance makes resilience possible, and resilience gives meaning and strength to acceptance.

Ann (Group 2), who was diagnosed over ten years ago, further noted how the guilt she once felt for not always being able to provide or keep up with others gradually gave way to recognition of the valuable lessons her children were learning. She described the unexpected positive impacts on her children and how it has taught them empathy, patience, and an understanding that people have different needs and capacities.

Summary of coping through resilience strategies and accepting change

In summary, this theme highlights how resilience was simultaneously empowering and constrained, *"it does take years to come to terms with how your life is now... it's a living with kind of thing"* (Jenny, Group 2). On one hand, acceptance allowed women to regain a measure of stability and control in the face of ongoing uncertainty. Thus, resilience and acceptance emerged

as both personal coping strategies and socially situated practices where connection mattered, revealing the complex interplay between agency, constraint, and gendered expectations in women's experiences of illness and transition. On one level, relationships with others provided essential comfort, validation, and practical help in managing the dual challenges of RA and PM. At the same time, maintaining these connections acted as a quiet form of resistance, pushing back against the isolation, stigma, and cultural expectations that women should endure health struggles silently. In this way, the connection women experienced through this research became more than a coping mechanism – it became an expression of agency rather than fatalism.

"You have to advocate for yourself" **– Navigating the health system**

For the women in this study, the difficulty in clearly attributing their symptoms often complicated their interactions with health professionals. This was further intensified by women's experiences of not being listened to, leaving them feeling dismissed or unheard. For many, this contributed to lengthy diagnostic delays, often lasting years, *"It took me a couple of years to get a diagnosis... I had to push and push"* (Vanessa, Group 1), often going back and trying other doctors, as Jane (Group 1) said describing her four year journey to diagnosis, *"Going to have to go back to the doctor. Try another one."*.

Some of the women were inclined to dismiss their RA symptoms as PM if they occurred at the same time, *"Oh, I feel a bit tired. It's probably just perimenopausal."* (Ruth, Group 1). Participants who were diagnosed with RA before reaching perimenopause often overlooked or misattributed their perimenopausal symptoms, as the boundaries between RA and PM were so blurred. It was only through conversations with other women that they began to recognise these

changes as part of perimenopause, highlighting how shared dialogue and relational knowledge play a crucial role in making sense of overlapping embodied experiences.

> *" And I must admit, it was when I was chatting with some friends over coffee. And they were, like, talking about, you know, how they were really tired, or the, you know, this and that, and… and I was like just mentally ticking off all these boxes, and it still didn't occur to me...until my periods became irregular, really, and then I sort of said to myself, oh, that's what it is, you know, like, that was something that was different to anything that I could have associated with arthritis. So, I probably was unconsciously in denial for a long time, I guess, because I wrote it off as just… every day is a bit weird and different." (Ann, Group 2)*

Ann initially attributed her experiences—fatigue and bodily changes—to everyday fluctuations or to RA, reflecting how overlapping symptoms can obscure recognition of PM. While this touches on ground already covered in Theme One regarding the loss of self and uncertainty around bodily changes, it is important to revisit it here because it directly connects to healthcare encounters. This delay in self-identification illustrates a gap in awareness, both personal and potentially within clinical contexts, where symptoms may not be proactively discussed or contextualised. Ann also reflects a form of unconscious denial, a coping mechanism that can arise when the healthcare system provides limited guidance on life-stage transitions like PM, especially in the context of chronic illness.

Participants frequently described challenges in accessing healthcare that addressed the interconnected nature of RA and PM. Many noted that doctors and specialists often lacked knowledge about how one condition might influence the treatment or progression of the other,

reflecting the siloed structure of medical care. Rheumatologists were highly skilled in managing RA with medication, and GPs or other clinicians were focused on PM or general health, but few were able—or willing—to integrate these perspectives. This left these women navigating a fragmented system, having to reconcile advice from multiple providers and make complex decisions about their care largely on their own.

> *"The rheumatologists are so specialized that they find it hard to break it down to a level that people can understand... They always get a bit frustrated when you ask lots of questions, but I found the rheumatology nurses really patient and really helpful... I've had far more luck, having really good conversations about what's actually happening in the body with the rheumatology nurses than I've had with the rheumatologists, because I think they're just a lot better at communicating with people." (Ann, Group 2)*

Ann highlights the challenges women face in navigating the health system, particularly when seeking information and understanding about their condition. Ann contrasts her experiences with rheumatologists and rheumatology nurses, noting that while doctors may be highly specialised, their communication often lacks accessibility and patience, leaving patients feeling dismissed or overwhelmed. In contrast, she describes nurses as more approachable, willing to explain complex processes, and responsive to questions. This reflects how women often rely on alternative professional relationships within the system to bridge gaps in understanding and support. It also illustrates a broader issue in chronic illness care: the tension between biomedical expertise and the need for relational, communicative care that validates patients' experiences and helps them make sense of their illness.

Participants described feeling frustrated and overlooked or dismissed when consulting with GPs or rheumatologists, perceiving that their experiences of PM alongside RA were poorly understood. Symptoms were often minimised, attributed solely to ageing or stress, or treated in isolation rather than in the context of overlapping conditions. Many expressed a need for healthcare professionals who could appreciate the complexity of navigating multiple, interacting health challenges, and who could offer guidance around women's health that validated both their physical and emotional experiences:

> *"The GP sort of wasn't quite sure, maybe, how to navigate it alongside RA as to what you know, didn't want to upset the, sort of, the current drug regime, knowing that it was still, you know, quite new, and it takes 3 or 6 months for it to take effect, and don't want to upset that, so we don't want to give you this." (Ruth, Group 1)*

Ruth's experience reflects the uncertainty and fragmentation women often encounter when navigating the health system. Ruth describes how her GP appeared hesitant to address perimenopausal symptoms because of her ongoing RA treatment. The GP's lack of clarity around how to balance HRT or other interventions with a newly established drug regime for RA highlights the siloed nature of healthcare, where different conditions are treated in isolation rather than holistically. This left Ruth in a position of uncertainty, as her needs relating to PM were effectively deprioritised out of caution for her RA treatment. Such experiences show how women are often caught between medical specialists, with clinicians uncertain or reluctant to integrate care across conditions, forcing patients to manage the burden of negotiating treatment trade-offs themselves.

"... when I spoke to my rheumatologist [about PM], an older male, it didn't even come up, you know, and I asked, and there was nothing to talk about. And even when I asked the rheumatologist nurse, thinking, well, you know, she's a woman, she might have heard, you know, I even think I said, you know, you must have had other patients bring this up. And it was sort of… not dismissed, but it just… there wasn't anything to talk about." (Ruth, Group 1)

Ruth illustrates how women can encounter silence and dismissal, which can be seen as medical gaslighting (see later), when trying to raise PM in the context of RA management. Ruth describes how her attempts to open conversations with both her rheumatologist and a rheumatology nurse were met with little engagement, leaving her with the impression that menopause was not seen as relevant or worthy of discussion. Even when framed as a common concern that other patients might share, her inquiry was met with a lack of acknowledgement, reflecting a gap in clinical awareness and responsiveness that left Ruth without the information she needed. This absence of dialogue highlights the systemic blind spot in healthcare, where PM and chronic conditions like RA are treated separately rather than as interconnected experiences. For the participants, this silence reinforces feelings of invalidation and isolation, as their attempts to seek support are left unanswered, forcing them to navigate these embodied challenges without adequate medical recognition or guidance.

Participants described how trying to access appropriate healthcare for RA and PM was made even harder by the practical realities of the system. Appointments were often sporadic, with long waits between consultations, and women frequently saw different clinicians who were unfamiliar with their history. This lack of continuity meant that they had to repeatedly explain

their symptoms and concerns, making the process frustrating and exhausting, and leaving them feeling unsupported in navigating their complex health needs.

> *"And I haven't even really had much consistency with rheumatologists, either. So because in [name] it's so hard to get anyone to the regions. I had a woman from [Australia] who was flown over to try and get rid of some of the backlog, because [my DHB area] was in such a bad state. And then I never saw her again. And then I had another woman who seemed really good. But then I saw her once, and then I think I had a phone call in about November. And then that's that. Nothing since." (Jane, Group 1)*

Jane, who lives in a rural area, describes a lack of continuity in care, with frequent changes in rheumatologists and inconsistent follow-up, which makes it difficult to build trust, communicate effectively, and manage a complex, chronic health condition. However, in Jane's last session, she described her excitement to the group after seeing a new rheumatologist who asked her about PM showing that there is some change in the sector, *"it was really good to talk to the rheumatologist, because for the first time, they actually bought up PM"*. The sporadic nature of appointments and the reliance on visiting specialists illustrate systemic barriers, particularly in regional areas, that can leave patients feeling unsupported and uncertain about their care.

Navigating the health system is further complicated by experiences of 'medical gaslighting'—a form of epistemic injustice (Fricker, 2007)—in which healthcare providers dismiss, minimise, or question a patient's symptoms and interpretations of their own body, leading individuals to doubt their perceptions, memory, or judgment. Participants, for example,

spoke about "*problems getting someone to listen to me"* (Jane, Group 1) and doctors often being dismissive of symptoms:

> *"Before I got diagnosed they just kept telling me... well, first of all, they told me I was depressed... I know what depression is. I know what anxiety is. I am not depressed. So I fought that off, and then we moved into the 'well, it's menopause'. And I was looking at other women going... 'they are not struggling to get through cooking dinner because they can't stand long enough to cook dinner' like they're not gripping onto the kitchen bench [like me]." (Jane, Group 1)*

Here, Jane describes how she 'fought that off' a diagnosis of depression and highlights the implications of how she struggles to cope in everyday life. She recounts being repeatedly told that her difficulties were due to depression or menopause, despite her awareness that her experience did not align with these explanations, producing an on-going battle for a diagnosis. She contrasts her embodied struggles with those of other women, noting the profound physical limitations she faced—such as being unable to stand long enough to cook dinner—highlighting the gap between her lived reality and the interpretations offered by medical professionals. Such experiences contributed to frustration, self-doubt, and a sense of being invalidated – underscoring difficulties navigating the health system.

Another participant described the gap between the biomedical management of RA and women's lived experience of PM:

> *"So, but you know that doesn't doesn't matter... I think it does make a difference definitely... because I was on methotrexate before for quite a while before I went on the HRT. And yeah, I did notice a difference. I did try and reduce my methotrexate, and that*

wasn't super successful. I ended up having to put it back up. But yeah, I would look at giving it another go as well. Yeah. But conversations about PM with the rheumatologist, they're not gonna happen. He's probably in his sixties. It's like, yeah, he's not interested." (Jenny, Group 2)

Jenny reflects on her efforts to adjust methotrexate while also noticing the impact of HRT, recognising the complex interplay between hormonal changes and disease management. Yet, despite this awareness, she emphasises that conversations about PM *"are not gonna happen"* with her rheumatologist, whom she perceives as uninterested or dismissive, as a normative feature of an older male doctor. This demonstrates not only a lack of holistic, integrated care but also a form of epistemic injustice (Fricker, 2007), where her knowledge of her own body and expertise in linking symptoms across conditions was marginalised within medical encounters, or as Jenny explains below, discounted:

"I have been taking HRT. The patches for probably two and a half years now, and I have found they have really helped my arthritis as well. And when I suggested this to the rheumatologist, he did kind of poo poo it. And yeah, so far, a bit of a non-believer." (Jenny, Group 2)

Once again, through medical gaslighting, Jenny's lived experience and insights about her body are dismissed or minimised by a healthcare professional. Despite personally noticing a positive impact of HRT on both PM symptoms and arthritis, her rheumatologist *"poo pooed"* the observation, signalling scepticism and a lack of validation. This dismissal undermines Jenny's expertise in understanding her own body, leaving her contributions to symptom management devalued and potentially limiting her ability to access efficacious healthcare. This can erode trust

in medical professionals, and create a barrier to integrated, holistic care, highlighting how women's knowledge of their own conditions is often marginalised within clinical encounters.

Ruth reflected on the persistent effort required to have her symptoms taken seriously, emphasising that medical professionals may not automatically recognise or validate the interplay of chronic illness and life stage transitions. The outcome of these experiences of limited and often neglectful healthcare encounters, was a need for self advocacy, as Ruth explains, *"you have to advocate for yourself as well. You have to really push your doctor, or your GP, or your rheumatologist."* This highlights the need for self-advocacy in healthcare when living with RA and PM. This need to "push" doctors underscores the presence of medical gaslighting or dismissal, where women's lived knowledge of their bodies is undervalued. This 'epistemic injustice', when someone is wronged specifically in their capacity as a knower, shows the diminished credibility given to patients' illness testimony, especially for women's pain as they navigate PM (Carel & Kidd, 2014; Fricker, 2007). These women experience a compounded biographical disruption – not only to the body and everyday life, but also to the assumed ease of moving through healthcare (Bury, 1982). "Getting care" becomes part of the illness work, intensifying the disruption in the context of normative expectations of medical health care.

Summary of navigating the health system

In summary, participants' experiences highlight how the overlapping symptoms of RA and PM complicated their interactions with healthcare professionals and contributed to delayed recognition and diagnosis. Women frequently described feeling dismissed, unheard, or minimised, with symptoms attributed to ageing, stress, or menopause rather than understood in the context of chronic illness. This often resulted in prolonged diagnostic delays, repeated

consultations, and the need to advocate persistently for themselves. Fragmented care, limited clinician knowledge of the interplay between RA and PM, and the siloed structure of healthcare left participants navigating complex decisions largely independently, sometimes relying on nurses or peer networks to bridge gaps in understanding. Experiences of medical gaslighting and epistemic injustice—where women's knowledge of their own bodies was devalued—further undermined trust in healthcare and exacerbated the emotional and practical burden of managing these intersecting conditions. Collectively, these accounts illustrate that the dual challenge of RA and PM constitutes not only a biographical and embodied disruption but also a disruption in access to supportive, integrated, and validating healthcare, highlighting the need for more holistic, patient-centred approaches.

Chapter 4: Discussion

This study provides new insights into how women navigate the overlapping experiences of PM with a chronic condition such as RA, focusing on the otherwise unexplored dual challenges they pose. It was guided by two key questions: how do women with RA make sense of the difficulties associated with PM, and what coping strategies or new ways of flourishing emerge when they reflect on these experiences collectively? By centering women's perspectives, the study highlights the embodied, emotional, and social complexities of the intersection between RA and PM, while also examining how participatory inquiry can generate practical and meaningful strategies for adaptation.

The analysis produced three themes that assist with addressing the research questions: 'Biopsychosocial distress of a new reality', 'Coping through resilience and accepting change', and 'Navigating the health system', and showed that their experience was shaped by biographical disruption. Below I start this discussion explaining how my findings relate to the research questions and then look at how it develops the literature on PM and RA, I then situate these findings within existing literature on biographical disruption, temporality research, psychosocial adjustment, and feminist and phenomenological perspectives on midlife health for women. I finish with sections considering the implications, limitations and future research recommendations from the study.

How do women with RA make sense of the difficulties associated with PM?

In this study, biopsychosocial distress shaped nearly every aspect of women's experiences, structuring how they perceived, interpreted, and responded to the intersecting challenges of RA and PM, and illustrating the profound disruptions they experienced across

bodily, emotional, and social domains. The intensification of their distress arose from the convergence of two profoundly challenging and unpredictable processes – each difficult in its own way and together producing an amplified sense of difficulty. The unpredictability, uncertainty, and ambiguity brought about by these intertwined biological changes compelled participants to confront a body that no longer functioned seamlessly, exemplifying Leder's (1990) notion of dys-appearance, wherein the once tacitly lived body becomes obtrusive through pain, fatigue, and dysfunction. This loss of bodily reliability disrupted their taken-for-granted sense of embodiment and self, leading to feelings of anxiety, frustration, guilt, and grief over the erosion of a once familiar identity.

One reason for the intensification of the participants' distress was the unpredictable symptoms of PM and RA, which were difficult to untangle and created additional uncertainty. While both contributed to distress, RA was more prominent in women's narratives, often dominating their focus due to its persistent pain, fatigue, and functional limitations. These symptoms, alongside the emotional challenges of PM, blurred the boundaries between illness and ageing—both frequently dismissed as natural consequences of "getting older"—creating a confusing and ambiguous space and heightening distress. In line with Bury's (1982) notion of biographical disruption, this dual experience unsettled the women's assumptions about their bodies, capabilities, and futures, producing what many described as a "double burden." They were compelled to continually renegotiate their sense of self and embodiment while managing the emotional and psychological demands of ongoing change.

The women in the study also made sense of the difficulties associated with PM and RA through ongoing negotiation of visibility, credibility, and recognition – processes that reveal the emotional labour of living with intersecting conditions. Their meaning-making emerged through

narrative attempts to reconcile fear, loss, and uncertainty with a reconfigured sense of self. Frank's (2007) dramas of illness provide a useful interpretive lens for understanding this process. The "drama of fear and loss" was evident in the women's stories as they grappled with the unpredictability of pain, fatigue, and cognitive changes, evoking profound vulnerability and anxiety about the future, including fears of decline or death. Making sense of these experiences involved acknowledging not only the loss of energy, control, and social participation but also confronting broader cultural narratives that equate ageing and dependency with failure (Butler, 2015).

Similarly, Frank's (2007) "drama of self" illuminates how chronic illness compels continuous identity work. The women's reflections on navigating "a new normal" show how they sought coherence amidst bodily and emotional disruption – redefining what it meant to live well, to be productive, and to remain themselves within constraint. Thus, meaning-making was an active, interpretive process through which participants reoriented their sense of identity and agency while living within the double burden of RA and PM.

While both RA and PM challenged bodily predictability and evoked a sense of loss, the participants interpreted these disruptions differently according to their temporality. They reframed their struggles by reflecting on how the temporal nature of RA and PM shaped their experiences. RA was understood as a chronic, enduring illness—something to be managed but never cured—whereas PM was framed as a transitional life stage that, although distressing, carried the promise of eventual resolution. When experienced together, however, these differing temporalities collided, producing conflicting meanings. For many of the participants, the coexistence of a temporary transition and a permanent condition intensified feelings of resignation and permanence, blurring the boundaries between what could be endured and what

must simply be lived with. Making sense of this duality involved negotiating between hope and acceptance – holding onto the idea that one aspect of their struggle might ease with time, while recognising that the other would remain an enduring feature of their embodied reality.

For the participants, an emerging 'new reality' was accompanied by a pervasive sense of isolation and invisibility. The study revealed how the women's embodied experiences frequently restricted their social participation, limiting engagement in work, family, and community life. Many described feeling that their symptoms and struggles were dismissed or minimised by others, particularly because they occurred within the socially devalued contexts of ageing, chronic illness, and femininity. Disclosure of their experiences was therefore rarely straightforward; instead, it was a continual negotiation shaped by fear of stigma, concerns about being misunderstood or dismissed, and a desire to maintain a sense of normalcy. Although PM has become increasingly visible in Aotearoa New Zealand through media campaigns, celebrity advocacy, and workplace wellbeing initiatives (Baghurst, 2024; Bezzant, 2024; Newshub, 2023), RA remains comparatively invisible. This imbalance in visibility created a complex dynamic for women navigating both conditions simultaneously. On one hand, PM is now more publicly acknowledged, allowing some women to speak more openly about their symptoms; on the other, RA continues to be marked by misunderstanding, with its fluctuating and often invisible symptoms—such as pain, fatigue, and stiffness—frequently questioned or minimised by others.

Consequently, the women found themselves managing dual and sometimes conflicting forms of visibility: the increasing openness surrounding PM alongside the persistent invisibility of chronic illness. Decisions around disclosure therefore became particularly fraught, as participants weighed which aspects of their experience to share and which to conceal to preserve social credibility and avoid stigma. These negotiations resonate with feminist critiques of

epistemic injustice (Carel & Kidd, 2014; Fricker, 2007), which highlight how women's embodied knowledge is frequently devalued or disbelieved, compelling them to continually legitimise their own experiences. From a phenomenological perspective, the women's sense-making emerged through this embodied negotiation of visibility and invisibility – here self-understanding was continually reconstituted in relation to others' responses, the social meanings of illness and ageing, and their own lived awareness of bodily change.

What coping strategies or new ways of flourishing emerged?

In terms of what coping strategies or new ways of flourishing emerged when they reflected on these experiences collectively, the participants described several patterns of adaptation and resilience that enabled them to re-establish coherence and agency within these overlapping disruptions. They spoke of juggling busy lives—family, work, and social commitments—while managing unpredictable symptoms that often left little space for formal support groups or self-care. Within these constraints, women cultivated resilience through persistence in the face of adversity, reframing fears (e.g. through processes of reflection, dialogue, and embodied awareness), and, for some, using medication and/or lifestyle changes to manage symptoms. Acceptance of bodily change, practices of gratitude, humour, and meaningful connection with others emerged as key strategies that enabled them to live well within uncertainty.

Viewed through Lazarus and Folkman's (1984) transactional model of stress and coping, their responses reflected an ongoing process of appraisal and reappraisal, oscillating between problem-focused coping—addressing the practical and bodily demands of illness—and emotion-focused coping, which sought to regulate distress through acceptance, humour, or connection

with others who understood their experiences. There was no singular or uniform way of coping; instead, women demonstrated a flexible, evolving repertoire of strategies shaped by fluctuating symptoms and shifting life circumstances. As Leder (2020) observes, chronic conditions demand multiple, fluid responses that change over time – resilience, in this sense, was not a fixed trait but an ongoing, adaptive process. As he says, "Probably the more strategies one has at one's disposal, the better."

Acceptance did not equate to resignation but reflected a form of embodied wisdom: learning to live well with, rather than against, the realities of illness and midlife transition. Resilience thus emerged as both personal and relational, grounded in women's capacity to reorient expectations, sustain connection, and find meaning amid disruption. Sharing experiences within the CI space deepened this process, allowing participants to validate one another's embodied knowledge and resist medical narratives that had previously silenced them. These collective dialogues fostered solidarity and mutual understanding, transforming isolation into empowerment.

Sharing experiences in a cooperative space allowed participants to validate one another's embodied knowledge and to resist the medical narratives that had previously silenced them. Through these dialogues, they co-created a sense of solidarity and mutual understanding, transforming isolation into collective empowerment. Many described learning from others' practical strategies—around exercise and nutrition, gratitude, and communication with clinicians—which fostered both confidence and agency. This collective sense-making enabled a reframing of distress: rather than viewing their bodies as deficient, women began to see themselves as resilient agents navigating intersecting transitions. In this way, flourishing was not defined by the absence of suffering but by the ability to find meaning, coherence, and connection

within it. This echoes Frank's (2013) conceptualisation of the "wounded storyteller," in which sharing experiences of illness enables individuals to reconstruct meaning and assert agency in the face of biographical disruption. Similarly, Ketokivi's (2008) notion of "the wounded self" illuminates how those who live with chronic illness or bodily disruption are often drawn toward others who share similar experiences of vulnerability. These relationships become sites of mutual recognition and validation, where individuals can witness and affirm one another's altered realities. It is therefore important that such spaces are made accessible and meaningful for women with RA who are navigating PM, enabling them to connect, share, and make sense of their experiences together.

When reflecting collectively on their experiences of PM and RA, the women described coping as an ongoing negotiation between acceptance, control, and the gendered expectations of health and femininity. Acceptance of bodily change and symptom unpredictability enabled them to regain a sense of stability within ongoing uncertainty, reflecting an adaptive resilience that allowed them to live well with rather than despite disruption. Yet these practices were shaped by the moral discourse of healthism, which positions women as responsible for managing risk and maintaining control (Crawford, 1980; Riley et al., 2018). Their discussions of medication—ranging from disease-modifying drugs and pain relief to HRT—highlighted how pharmaceuticals functioned as both coping tools and sites of negotiation, offering relief but also provoking ambivalence around dependency, side effects, and bodily autonomy. In particular, these ambivalent experiences resonate with feminist critiques of the medicalisation of menopause, which caution that while pharmacological interventions can support resilience and autonomy, drugs may not work or people may want to take a "natural" approach (Hickey et al., 2024; Perz & Ussher, 2008; Riley et al., 2018). Through shared reflection, women reframed these tensions,

recognising that flourishing did not depend on eliminating symptoms but on reclaiming agency and meaning amid constraint.

The findings show that when women reflected on their experiences collectively, resilience took on both personal and social dimensions, offering new ways of coping and flourishing. Acceptance allowed participants to regain a sense of stability and control amid ongoing uncertainty, while shared reflection highlighted the value of relational support. Connections with others provided comfort, validation, and practical guidance in managing the dual challenges of RA and PM, transforming social interaction into an active strategy for navigating illness. Maintaining these relationships also functioned as a subtle form of resistance, challenging isolation, stigma, and cultural expectations that women should endure health struggles silently. Through collective reflection, coping became more than managing symptoms – it became a way to assert agency, build solidarity, and reframe experiences of disruption as opportunities for growth and self-empowerment.

Finally, collective reflection also illuminated systemic barriers in healthcare. For the women in this study, the difficulty in clearly attributing their symptoms often complicated their interactions with health professionals. This was further intensified by women's experiences of not being listened to, leaving them feeling dismissed or unheard. The women recognised the need for self-advocacy in healthcare when living with RA and PM. Many noted that doctors and specialists often lacked knowledge about how one condition might influence the treatment or progression of the other, reflecting the siloed structure of medical care. Rheumatologists were highly skilled in managing RA with medication, and GPs or other clinicians focused on PM or general health, but few were able—or willing—to integrate these perspectives. Consequently, women were left to navigate a fragmented healthcare system, reconciling conflicting advice from

multiple providers and making complex care decisions largely in isolation. This shift from passive patient to informed agent represents another form of flourishing – one rooted in collective knowledge, embodied expertise, and the reclamation of voice and agency within systems that have historically marginalised women's experiences.

Developing the literature

Knowledge about the experience of PM alongside RA, and how women cope with it, remains limited. The little existing research has primarily focused on women who experience EM due to chronic illnesses such as cancer (Johnston-Ataata et al., 2020; Parton et al., 2017). This study further extends the work of Parton et al. (2016) and Johnston-Ataata et al. (2020), who show how bodily transitions tied to gender and ageing disrupt women's sense of identity, social roles, and relational positioning. While both studies illustrate the challenges of navigating PM and bodily change in contexts shaped by illness or medical intervention, the present research advances this literature by introducing the dimension of chronic illness intersecting with a life stage transition – specifically, the convergence of RA and PM. In doing so, it highlights how the interaction between an ongoing, unpredictable illness and a temporally bounded life-stage transition creates a compounded form of biographical disruption, where women must continually negotiate meaning and coherence in the face of shifting bodily capacities and emotional distress.

Building on this, the study advances existing literature by moving beyond research that treats PM or RA in isolation. While previous studies have documented the embodied, emotional, and social challenges of each condition separately (Plach et al., 2004, 2004a; Wood et al., 2025), this research shows how their co-occurrence creates unique and compounded disruption. By revealing how women experience conflicting temporalities – the chronic, enduring nature of RA

and the transitional temporality of PM – the findings offer new insight into the dynamic identity work women undertake. This temporal clash amplifies existential and emotional uncertainty, often resulting in social exclusion. Consistent with the literature on biographical disruption (Bury, 1982; Charmaz, 1995; Williams, 2000), the women's narratives show how chronic illness reshapes participation in work, family, and community life. This study extends these accounts by revealing that exclusion is not merely a by-product of physical limitation but is deeply shaped by gendered and cultural meanings attached to ageing, illness, and femininity.

As Parton et al. (2017) and Johnston-Ataata et al. (2020) argue, women's experiences of menopause are socially negotiated within gendered norms of control, productivity, and composure. The present study builds on this work by demonstrating that when PM intersects with chronic illness, these gendered expectations intensify women's struggles to reconcile femininity with fluctuating health and bodily change. The findings highlight how discourses of strength, care, and competence both constrain and sustain women's efforts to maintain coherence and agency amid ongoing disruption, underscoring that these experiences need to be understood as part of gendered social contexts.

While gendered norms shaped much of the women's experience, stress also emerged as a key mediating factor in how they navigated the dual challenges of RA and PM. For those with long-standing RA, physical or psychological strain frequently triggered flares, amplifying pain, fatigue, and functional limitations. Social responsibilities such as caregiving, bereavement, and work further compounded this burden, consistent with research showing worsening symptoms during PM (Shah et al., 2020; Mollard et al., 2018) and the cumulative effects of stress (Lempp et al., 2006; Toye et al., 2019). This study extends the literature by showing how women interpret and respond to these compounded stressors through the lens of everyday disruption,

supporting Williams' (2000) argument that chronic illness emerges not only from discrete pathological events but from interruptions to ordinary routines, roles, and identities. Here, stress is not merely psychological but a manifestation of biographical disruption itself, shaped by gendered expectations of resilience and caregiving.

Much existing research on PM or chronic illness focuses on individual coping or emotional adjustment (Hickey et al., 2022; Parenti et al., 2020; Toye et al., 2019), yet this study highlights how collective reflection and peer connection foster new forms of adaptation and identity reconstruction. The participants reflected on how the increasing visibility of PM in public discourse contrasted sharply with the persistent invisibility of RA. By engaging in group discussions, sharing experiences, and reflecting collectively, participants not only validated each other's embodied experiences but also navigated the tension between these visible and invisible aspects of their health. These insights offer a new perspective on adaptation in the context of intersecting chronic illness and life-stage transitions and advances the literature by situating coping and resilience within social, and culturally embedded processes rather than treating them as purely individual psychological phenomena.

Finally, the study deepens the insights of Petford et al. (2024) by providing a phenomenological account of how systemic and gendered gaps in healthcare are lived and made sense of by women navigating PM alongside RA. While Petford et al. (2024) demonstrate at a population level that menopause can exacerbate disease burden and remains largely absent in rheumatology care, this research reveals the emotional and epistemic consequences of that omission. Women's narratives exposed how symptom misattribution, diagnostic delay, and fragmented care pathways left them feeling dismissed, confused, and responsible for distinguishing between perimenopausal and RA-related changes. These experiences expose the

limitations of siloed biomedical models that treat reproductive ageing and chronic illness as separate domains, reinforcing what feminist scholars identify as epistemic injustice in women's health (Carel & Kidd, 2014; Fricker, 2007). By illuminating how women attempt to bridge these gaps—through self-education, peer dialogue, and advocacy—this study adds qualitative depth to Petford et al.'s findings, underscoring the need for gender-responsive and integrated models of care that legitimise women's embodied knowledge.

Ulitmately, this study offers new insights from Aotearoa New Zealand into how women with RA navigate PM. It builds on international qualitative research exploring women's lived experiences of RA – several of which have adopted phenomenological approaches and focused particularly on motherhood (Barns et al., 2015; Feddersen et al., 2017, 2019; Hwang et al., 2004; Mitton et al., 2007; Pach et al., 2004, 2004a; Parton et al., 2022) – yet none have examined the intersection with PM. It also extends existing qualitative studies on the lived experience of PM (e.g., de Salis et al., 2018; Sergeant & Rizq, 2017; Simpson et al., 2025; Wood et al., 2025), which have rarely considered the added complexities of chronic illness, except in cases of EM and cancer (Johnston-Ataata et al., 2020; Parton et al., 2017).

Connecting to theoretical frameworks

This study makes an important empirical and theoretical contribution by examining an area that has received little attention – the intersection of PM and RA. Whereas previous research has tended to treat PM and chronic illness as distinct phenomena, this study demonstrates how their coexistence produces a qualitatively different experience marked by intensified physical, emotional, and social disruption. Crucially, it highlights how gender shapes these experiences, influencing how women interpret bodily change, negotiate social roles, and manage care within

systems that often marginalise their knowledge and concerns. In doing so, it connects women's lived realities to broader theoretical debates about biographical disruption, temporality, and coping – frameworks that must be reinterpreted through a gendered and embodied lens.

Extending Bury's (1982) theory of biographical disruption, this study shows that when chronic illness intersects with a major life transition such as PM, the result is a compounded and enduring form of disruption that remains largely unacknowledged in current literature. While Bury's original formulation captured how illness interrupts taken-for-granted assumptions of health, it did not fully consider the gendered moral pressures of healthism or the social discourses that define women's bodies through control, discipline, and productivity. For women and people with ovaries, the embodied changes of PM are entwined with these expectations, producing disruptions that are simultaneously biological, social, and moral. Reinterpreting biographical disruption through feminist and intersectional lenses reveals that illness and life-stage transitions are not discrete events but entangled processes shaped by gendered norms, biomedical authority, and cultural visibility.

From this perspective, intersectionality (Crenshaw, 1991) operates not only through social categories such as gender, age, and health status but also through temporal and embodied experiences. The disruptions of PM—linked to ageing, fertility, and femininity—intersect with the chronic, unpredictable course of RA, producing a unique form of compounded disruption that reshapes identity, social participation, and relationships. This intersectional reading highlights how the participants' experiences cannot be reduced to a single axis of disruption (for example, "illness" or "menopause") but must be understood as entangled processes mediated by social expectations, biomedical discourses, and degrees of visibility. While PM has gained increasing

visibility in public discourse, RA remains largely invisible, creating conflicting dynamics of recognition and invalidation that intensify women's sense of disruption.

The concept of biographical dialectics (Cluley et al., 2023) further illuminates how women navigate these intersecting challenges. Rather than achieving a stable "new normal," participants' narratives reflected ongoing cycles of adaptation and constraint, where solutions to one problem often generated new challenges. This study extends biographical dialectics by showing how PM acts as another agent in the dialectic, amplifying the tension between disruption and continuity and complicating identity work. In doing so, it demonstrates that dialectical processes are shaped not only by fluctuations within a single illness but also by the intersection of a life-stage transition. The recurrent pattern that Cluley et al. (2023, p. 7) describe —"issue, problem, answer"—was evident in how participants balanced bodily limitations, social expectations, symptom management, and self-preservation, revealing how identity is continually reconfigured amid chronic illness, hormonal change, and structural constraints in healthcare.

Taken together, these insights extend biographical disruption theory beyond its original focus on illness as an isolated life event, showing instead how intersecting life transitions such as PM produce ongoing and uneven forms of disruption that are deeply gendered and relational. Meaning-making and coping occur within these intersections – through relational validation, collective reflection, and the reconstruction of self in response to overlapping bodily and social changes. This compounded disruption also foregrounds temporal complexity, generating conflicting experiences of resolution and recovery.

This study therefore contributes to growing scholarship on the temporality of illness and embodiment by revealing how women with RA and PM inhabit overlapping and sometimes contradictory temporalities – one indefinite and cyclical, the other transitional and bounded. As

Charmaz (1983, 1991) argues, time is integral to self-construction: the struggle to manage illness is also a struggle to control the meaning and direction of one's life. The women's accounts vividly illustrate this tension as they negotiate both illness time (the unpredictable rhythms of RA) and menopausal time (the hormonal and biographical transitions of midlife). Their sense of self and agency is continually reworked through these overlapping time frames, underscoring Charmaz's insight that temporal orientation—past, present, and future—is central to how illness shapes identity.

Building on the temporality of illness, the study shows how institutions and social expectations regulate temporal experience, imposing rigid timelines of recovery, productivity, and control. In contrast, concepts such as crip time (Kafer, 2013; White, 2023) and timescapes (Adam, 2005) offer alternative ways of understanding how women "bend" time to sustain livable rhythms, resisting pressures to stabilise or "return to normal." From this perspective, PM and RA can be seen as intersecting temporal embodiments—one signalling transformation and closure, the other extending indefinitely—producing a uniquely gendered and complex temporality of change

Deleuze's (1994) philosophy of time and becoming deepens this analysis by conceptualising temporality as multiple, non-linear, and continuously shifting. Rather than viewing bodily change as a deviation from normalcy, Deleuze's framework understands the body as always in flux – an ongoing process of transformation and emergence. This perspective unsettles biomedical discourses that assume recovery, stability, or ageing "on schedule." Within the context of PM and RA, these normative temporalities produce subtle forms of oppression, as women are encouraged to manage symptoms, maintain productivity, and perform stability within bodies that resist such control. Recognising temporal multiplicity instead allows for a more

compassionate and realistic understanding of embodied change – one that resists logics of blame and acknowledges the fluid, contingent nature of living with ongoing bodily uncertainty.

These temporal and embodied disruptions are further compounded by the gendered politics of recognition. Butler (2004, 2015) reminds us that gendered norms determine which experiences of women's bodies are socially legible. Deviations from normative femininity—through illness, ageing, or reproductive transitions—are often dismissed or silenced, producing what Fricker (2007) terms epistemic injustice. This includes both testimonial injustice, where women's accounts are disbelieved or minimised, and hermeneutical injustice, where dominant frameworks fail to provide the interpretive resources to make sense of their experiences. Garland-Thomson's (2011) "misfits" framework further demonstrates that disruption arises not only from bodily change itself but from the misalignment between bodies and the environments that demand conformity. For women navigating PM alongside RA, this misfitting is acutely felt: their bodies no longer "fit" within cultural scripts of productivity, youthfulness, and femininity, intensifying distress and invisibility.

These theoretical perspectives are reflected in the empirical findings, which show how medical gaslighting further undermines women's authority over their own bodies when navigating intersecting conditions such as RA and PM. For instance, one participant's observation that HRT alleviated both menopausal and arthritic symptoms was dismissed by a male rheumatologist – illustrating a broader pattern in which women's embodied knowledge is devalued in clinical encounters (Carel & Kidd, 2014; Fricker, 2007). In this context, medical encounters become sites of struggle where women must continually assert credibility and legitimacy – an additional form of labour that compounds the emotional and physical demands of managing illness. Such experiences extend Bury's (1982) notion of biographical disruption

beyond the personal to include institutional disruption, where the expectation of care itself is fractured.

Accessing efficacious healthcare thus becomes an integral part of managing illness, requiring women to navigate systems that frequently overlook the intertwined complexities of life-stage transitions and chronic conditions. As Leder (2016) argues in *The Distressed Body*, when medical practice objectifies the body as an abnormality to be managed, suffering is magnified rather than alleviated. These encounters expose the structural limitations of healthcare systems organised around discrete biomedical specialisms that rarely integrate women's insights across overlapping conditions. This dynamic aligns with Foucault's (2019) notion of the medical gaze, wherein clinical authority transforms the patient's body into an object of scrutiny, sidelining subjective experience. The result is a loss of trust and a barrier to holistic care – an expression of the gendered nature of epistemic injustice in medicine.

In the context of RA and PM, these dynamics converge to produce a compounded form of epistemic and social invisibility, where both chronic illness and midlife transition are misunderstood or minimised. This study therefore underscores the value of integrating feminist, intersectional, and epistemic frameworks to understand how women and people with ovaries navigate these complex intersections. It also highlights that midlife illness is profoundly shaped by gender: healthcare systems such as rheumatology cannot adequately serve the roughly 50% of the population whose bodies and experiences diverge from the "standard" male model.

Finally, this study advances understandings of coping and adaptation by moving beyond individualistic frameworks to foreground the phenomenological and relational dimensions of how women live with illness. Drawing on Lazarus and Folkman's (1984) transactional model, women's strategies encompassed both problem-focused coping (e.g., managing pain, seeking

medical advice) and emotion-focused coping (e.g., reframing expectations, seeking validation). Bury's (1991) later work on biographical disruption extends this view by emphasising the enduring, evolving nature of chronic illness and the active work required to navigate it. He distinguishes between styles—the interpretive and communicative ways individuals make sense of illness—and strategies, the practical adaptations that sustain continuity in daily life. Viewed phenomenologically, these styles and strategies reflect not only behavioural adjustments but also shifts in meaning and self-understanding, as women sought to re-establish coherence amid disruption. Their coping behaviours thus embodied both pragmatic adaptation and interpretive labour – ongoing efforts to reconcile bodily change with a livable sense of self.

Collective reflection and peer connection emerged as particularly significant in this process. Through shared dialogue, women were able to re-author disrupted identities, validate previously marginalised experiences, and create new interpretive resources for living with the intersection of PM and RA. In these spaces, meaning-making became a collective, embodied act, affirming women's experiential knowledge as legitimate and valuable. These findings extend existing literature by showing that coping is not merely a psychological or behavioural process but also a socially and relationally embedded one. Moreover, they highlight how the relative visibility of PM—now increasingly discussed publicly—contrasts with the invisibility of RA, shaping what can be expressed, shared, or normalised in collective contexts. This demonstrates that coping and identity reconstruction are contingent on cultural narratives of visibility, legitimacy, and gendered embodiment.

Implications and suggestions for future research

The findings of this study have significant implications for education, healthcare practice, policy, and future research. Women navigating the dual challenges of RA and PM described complex, overlapping disruptions that are often unrecognised or insufficiently addressed within current healthcare systems. Their accounts reveal how the convergence of chronic illness and midlife transition amplifies physical, emotional, and social challenges, while gendered assumptions within clinical settings can deepen feelings of dismissal or invisibility. In the absence of clear information or open discussion from clinicians, women frequently normalise or misattribute symptoms, delaying access to appropriate support.

The invisibility of PM in rheumatology and the under-recognition of autoimmune symptoms in menopause care highlight the persistence of biomedical silos that overlook women's embodied experiences in their entirety. Addressing these gaps requires not only better clinical education and interdisciplinary collaboration but also more creative, relational solutions – such as co-designed peer-support programmes, integrated midlife health pathways, and spaces that foster narrative sharing and embodied knowledge exchange. Such approaches move beyond purely informational or online interventions, instead validating women's lived expertise and encouraging partnership in care.

For Arthritis NZ/Mateponapona Aotearoa, the primary national charity supporting people with RA, these findings provide actionable insights for supporting women managing RA during PM. The research underscores the importance of recognising the compounded bodily, emotional, and social disruption these women experience, and suggests opportunities for targeted educational resources, case studies, awareness campaigns, and support programmes that validate women's lived experiences and provide practical strategies for managing fluctuating symptoms.

Insights from the study also point to the need for advocacy around integrated healthcare pathways, encouraging communication and coordination between GPs, rheumatologists, and other relevant specialists. Workshops and tools to support healthcare navigation could empower women to advocate for themselves, coordinate care across multiple providers, and address barriers such as misattribution of symptoms or gendered dismissal. Arthritis NZ/Mateponapona Aotearoa could also use its menopause and arthritis podcast to disseminate these findings, increasing awareness of the dual challenges women face, validating their lived experiences, and providing practical guidance for managing the intersection of RA and PM.

From a feminist and phenomenological perspective, the findings reveal the consequences of a biomedical model that fragments women's health into discrete body systems and life stages. Participants often had to identify, interpret, and manage the intersections between RA and PM themselves, developing personal coping strategies such as reframing, self-advocacy, and seeking connection. While these strategies demonstrate resilience, they also reflect systemic gaps: women's individual efforts fill spaces where coordinated care should exist, and reliance on self-management risks reinforcing neoliberal expectations that women privately manage their own health burdens. Improving New Zealand's health system responsiveness therefore requires a more integrated, gender-sensitive approach. Health professionals need training to recognise how perimenopausal and RA symptoms intersect and to validate women's embodied knowledge in clinical encounters within a broader gender inclusive framework. Interdisciplinary collaboration between rheumatology and primary care is essential to avoid diagnostic delays and fragmented treatment pathways. Incorporating routine discussions of PM into chronic illness consultations, and vice versa, could support earlier recognition, improved management, and better quality of life.

None of the participants reported using digital health tools or online platforms to support their self-management, revealing an important gap in current practice. While digital technologies are increasingly used to assist women navigating PM (Lupton, 2017), few tools address the intersecting experiences of RA and PM, and existing RA apps are often poorly validated and disconnected from women's lived realities (Grainger et al., 2017; Healthify, 2025). Future research could explore the potential of co-designed digital tools that integrate hormonal and inflammatory symptom management, facilitate peer support, and enhance communication with healthcare providers (J. Shaw et al., 2018). Grounded in feminist participatory health design (Henwood & Marent, 2019; Lupton, 2017), such tools could strengthen women's agency, visibility, and personalised care while addressing the gendered gaps that shape these overlapping health experiences.

Future research should also work towards developing a feminist framework that integrates biographical disruption with biographical dialectics, recognising that disruption is not a single event but an ongoing, evolving process. Such a framework would account for how chronic illness and life-stage transitions are continuously negotiated in relation to gendered bodies, roles, and social expectations. Building on feminist and phenomenological perspectives, this approach would move beyond linear models of disruption and adaptation to consider how women's experiences of chronic illness and PM are shaped by intersecting discourses of gender, embodiment, and health. Research could also evaluate the effectiveness of coping strategies, peer support, and self-management interventions to inform targeted programmes. Examining healthcare providers' perspectives and interdisciplinary practices may reveal barriers to integrated care, while studies addressing health inequities could identify structural factors shaping access. Finally, phenomenological and narrative research with diverse populations—

including Māori, Pasific, and rainbow communities—could deepen understanding of how they navigate PM with a chronic condition such as RA.

In sum, addressing the double burden of RA and PM demands both structural reform and cultural shift: from lack of information and understanding to improved education, from fragmented to integrated care, from individualised coping to collective responsibility, and from women as passive patients to active knowledge holders whose lived experiences can transform the health system itself. The women's narratives demonstrate that meaningful improvement lies not only in clinical interventions but also in relational and epistemic change – recognising women as experts in their own embodied experiences and integrating their insights into care design and delivery. These insights can help to further inform Aotearoa New Zealand's Women's Health Strategy (Ministry of Health, 2023) by emphasising the importance of recognising intersecting chronic illness and midlife transitions, addressing systemic gaps, and promoting equitable, culturally responsive care.

Limitations

Several limitations should be acknowledged. The study involved a small and relatively homogenous group of participants, which limits the diversity of perspectives represented, particularly in relation to ethnicity, socioeconomic background, and cultural understandings of health and ageing. The inquiry comprised two small groups with three participants in each, which allowed for rich, in-depth dialogue but also constrained the breadth of collective reflection. Having an additional group—particularly one composed of women with different cultural or social backgrounds—could have further diversified the relational dynamics and generated additional layers of insight into how PM and RA are experienced and made sense of

across different contexts. Although Māori and Pasifika people's groups were approached, and one of the participants identified as Māori, the study could not recruit enough Māori participants for them to form their own inquiry group and to explore PM and RA experiences as Māori.

As the research was conducted primarily through online methods rather than in-person cooperative meetings, opportunities for deeper relational engagement and embodied exchange were somewhat constrained. Additionally, my own positionality as a woman experiencing PM and living with arthritis inevitably shaped the research process. While reflexivity was central to the inquiry—enabling a more empathetic and embodied understanding of participants' experiences—it may also have influenced interpretation through shared assumptions or emotional resonance. These limitations do not diminish the study's value but highlight the importance of future research engaging more diverse voices, including additional inquiry groups, in-person participatory dialogue, and continued reflexive attention to researcher embodiment and standpoint.

Conclusion

This study has illuminated the deeply embodied, emotional, and social complexities of navigating PM alongside RA, revealing how their convergence generates compounded and enduring forms of disruption. By centring women's lived experiences, it has shown that the intersection of a chronic illness and a midlife transition is not simply additive but transformative – reshaping identity, meaning, and everyday life. Through a phenomenological and feminist lens, the research advances biographical disruption theory by showing that disruption is rarely discrete or resolved but unfolds dialectically and intersectionally across time, bodies, and relationships. The women's accounts revealed how adaptation and disruption coexist, where efforts to restore

stability continually encounter new constraints, underscoring that disruption is not only personal but also structural – shaped by healthcare systems, gendered expectations, and temporal norms that privilege control, productivity, and self-management. Integrating feminist and critical realist perspectives illustrated how social and cultural forces mediate women's embodied experiences of illness and midlife, influencing how time, change, and wellbeing are lived and understood. The study also redefines coping as a relational and meaning-making process rather than an individual act, showing how women cultivate resilience through acceptance, relational support, and collective reflection that transforms isolation into solidarity.

Collective reflection emerged as a powerful form of flourishing – one that validated women's embodied knowledge, challenged epistemic injustice, and enabled participants to reclaim voice and credibility in the face of medical and social marginalisation. In this sense, flourishing was not defined by the absence of suffering but by the capacity to find coherence, connection, and purpose amid ongoing change. Taken together, these findings call for a shift away from fragmented biomedical models toward more integrated, gender-responsive, and relational approaches to care that recognise women as active agents in their health journeys, attend to the intersecting temporalities of RA and PM, and value lived experience as a legitimate source of knowledge. Ultimately, this research contributes both empirically and theoretically to understanding how women live with and make sense of overlapping embodied experiences, demonstrating that biographical disruption is not merely an interruption but an ongoing, dynamic process through which women continually reconstitute meaning, identity, and agency in the face of bodily uncertainty, and offering a framework for recognising women's embodied expertise as vital to transforming both healthcare practice and broader cultural understandings of what it means to live—and live well—within disruption.

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Appendices

Appendix A: Public recruitment activities

- RNZ: Afternoons with Jesse Mulligan
  https://www.rnz.co.nz/national/programmes/afternoons/audio/2018994527/getting-insight-into-how-women-with-rheumatoid-arthritis-experience-PM

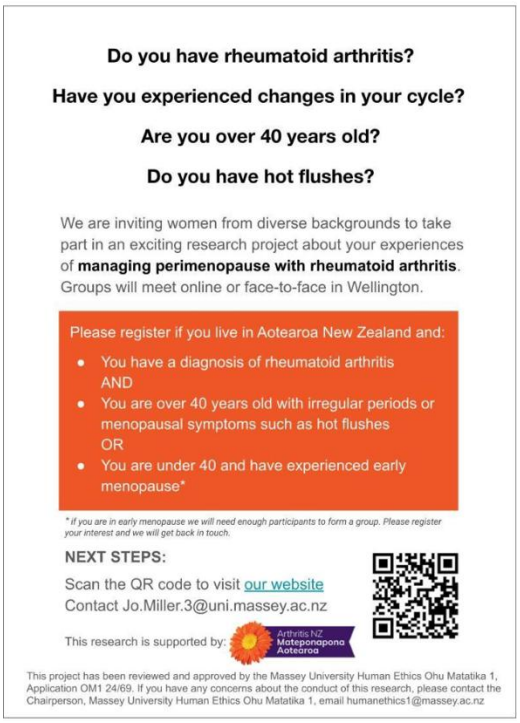
- Arthritis NZ/Mateponapona Aotearoa: Joint Support magazine

  https://www.arthritis.org.nz/assets-prod/downloads/Research-Reports/ArthritisNZ_JointSupport_Autumn_2025_WEB-2.pdf?v=1755309104

- Menopause Wellbeing: Blog

  https://menopause.sexualwellbeing.org.nz/blogs/perimenopause-and-arthritis-whats-the-connection/

- Poster



- Website https://sites.google.com/roarcontent.co.nz/navigatingchange/

Appendix B: Information and consent forms

A cooperative inquiry project to understand how women with rheumatoid arthritis navigate perimenopause

Participant Information Sheet

Thank you for your interest in this project. The information below summarises the research and describes what being a participant will mean for you.

It is important that you understand what the project is about so if you have any questions or would like to speak to me, please use the contact details at the end of this document

About the Project

Rheumatoid arthritis (RA) affects around 2.5 percent of the population in Aotearoa New Zealand and occurs 3 times more frequently in women than men. Most women are diagnosed with RA in their 40s to 50s which is around the same time they experience perimenopause. Perimenopause is the transition to menopause when hormone levels decline and symptoms like hot flushes and irregular periods start. Perimenopause and RA each bring significant challenges, but when they occur together, we know little about the combined experience or effective ways to manage it.

We want to know about your experiences of going through perimenopause with rheumatoid arthritis – how it affects your life, your body, how you think about yourself and what you do to cope. I am interested in what happens when I bring a group of similar people together to explore what going through perimenopause with rheumatoid arthritis is like. Does thinking together help people find ways of coping better? I hope that this will be a fun and interesting experience for those who participate in this project, and that our findings will help people with rheumatoid arthritis during this transitional life stage.

About the researcher

My name is Jo Miller. I am a master's student at Massey University studying health psychology and this research is for my thesis requirements. I am a Scottish born, Pakeha New Zealander, who is postmenopausal. I take HRT as I am on the cusp of osteoporosis and suffer some arthritis pain in my

hands and knees. I care about women's rights and health. My previous research explored victim blaming in New Zealand, and as part of my studies in health psychology I did a placement with Arthritis New Zealand. This is a passion project for me, I am excited – if a little nervous – to create the opportunity for women to talk about their experiences of managing arthritis and the transition to menopause.

Who Can Take Part?

To take part in this study you must meet the following criteria:

- Must reside in Aotearoa New Zealand
- Have a diagnosis of rheumatoid arthritis
- Aged over 40 with irregular periods and/or menopausal symptoms
- Or aged under 40 and have gone through spontaneous early menopause

I am especially keen to hear the perspectives of people who are often left out of research, including:

- sexually or gender diverse/takatāpui
- ethnic minorities
- Indigenous women/wāhine Māori
- women of colour

What's Involved?

If you participate in the study, I will include you in a group of 3-4 people. You can ask to be put in a group, or you can suggest an existing group, such as a group of your friends.

The group will meet face-to-face or virtually on Zoom/Teams fortnightly for up to 3 meetings, depending on your preference. Groups will meet 3 times because it is the smallest cycle of action and reflection over an extended period that enables decent research. Together we will reflect on your experiences, what you do to cope, and what could be done differently. I will do this through discussion/kōrero and activities designed to help creative thinking. For example, we may use care-full conversations (health cards) to prompt discussion.

The groups are called cooperative inquiry, because through group discussion people identify aspects of their experiences they want to understand better or differently – that they want to "inquire into". During the group meetings we discuss your experiences, and in-between meetings you do a small activity related to your inquiry. For example, this might mean noticing something or perhaps doing something different and seeing how that makes you feel. This means that participating in the project will require a small amount of time, no more than 1 hour, outside of the meetings.

What Happens to the Information?

The meetings will be audio recorded and transcribed (typed up). I will send you these transcripts, and you will have the opportunity to read them and amend them. For example, you may want to add more information for clarification or ask me to delete something you've said. You will have two weeks to do this, after which you will not be able to withdraw or change your data. All information will be kept on a password protected laptop and backed up using password protected secure cloud space. Only myself and my supervisor will have access to the recordings and transcripts. The transcripts will be anonymized which means removing all information that could identify you. At the end of the research, the audio recordings and anonymised transcripts are kept in a secure location for five years before being destroyed, in accordance with Massey University policy.

Participant Rights

You can withdraw from the inquiry group at any time before the group begins or while the group is in progress. You can ask for your talk to be removed from the transcripts, but it will not be possible to withdraw the information you provide after the group finishes, as it will be part of a discussion with other participants. The information you provide will be on the understanding that your name will not be used in research outputs

A summary of findings will be given to all participants, this will also contain links to the published thesis. The findings of this research will also be shared with Arthritis NZ/Mateponapona Aotearoa, a national charity that provides information, advice and support to people living with joint pain and those diagnosed with any of the more than 140 forms of arthritis. The collaboration with Arthritis NZ/Mateponapona Aotearoa ensures that the insights gained from this study will not only enrich academic understanding but also inform resources, practical strategies, and interventions to help women with RA navigate menopause.

Risks and Benefits

It is not expected that this research will cause harm/risk to you, and we hope it will be a fun, enjoyable and interesting process. But talking about menopause may be awkward. We will try to make participating in this study as easy as possible by giving group members permission to feel awkward, working with friendship groups and using activities to get to know each other so that we can work through any awkward feelings quickly, and focusing on the experience rather than explicitly studying menopause.

Each group will also discuss their own ground rules, and revisit these during the project to check they are working or if they need tweaking. These will include what we do if someone in the group becomes upset or has strong feelings as they reflect on their experiences.

If you find any area of the process to be uncomfortable, you can choose not to take part. As the researcher, I will be available to discuss any concerns you have throughout the project and I will have contact numbers available for you if you wish to seek professional support.

The nature of research in small groups involves discussions/ kōrero with other participants. We will ask group members to keep what is said in the group confidential, but we cannot guarantee this. So there is a risk that other group participants might disclose your involvement, identity or what you say to others in the focus group. Taking part in the project means that you are willing to accept this risk. If you change your mind, you can leave the group at any time.

The research is intended to have the following benefits:

1. the cooperative inquiry group method supports participants to define and inquire into what matters to them, and can give them new, more affirmative ways of thinking
2. insights from participants will be written up in academic publications and may impact on future research and support for women with RA going through perimenopause
3. findings will be shared with Arthritis NZ/Mateponapona Aotearoa to develop resources such as fact sheets, articles, webinars, workshops, and information for MyRA, a resource that helps people become active participants in their journey with RA.

A voucher of $20 per meeting will be given to each participant as a token of appreciation.

Project Contacts

Researcher

Jo Miller

School of Psychology

Massey University

Wellington

Email: Jo.Miller.3@uni.massey.ac.nz

Telephone: [redacted]

Supervisor

Professor Sarah Riley

School of Psychology

Massey University

Wellington

Email: S.Riley@massey.ac.nz

What's Next?

If you would like to take part in the study or have a chat with the researcher, please contact Jo by email, text or phone using the above details.

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 24/69. If you have any concerns about the conduct of this research, please contact the Chairperson, Massey University Human Ethics Ohu Matatika 1, email humanethics1@massey.ac.nz

A cooperative inquiry project to understand how women with rheumatoid arthritis navigate perimenopause

PARTICIPANT CONSENT FORM

I have read, and I understand, the Information Sheet attached. I have had the details of the study explained to me, my questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from participating the group discussions at any time without having to give a reason.

1. I understand that I have an obligation to respect the privacy of the other members of the group and **I will not** disclose any personal information that they share during our discussion.
2. I understand that all the information I provide will be kept confidential to the extent permitted by law, and the names of all people in the study will be kept confidential by the researcher.
    a. *Note: There are limits on confidentiality as there are no formal sanctions on other group participants from disclosing your involvement, identity or what you say to others in the focus group. There are risks in taking part in focus group research and taking part assumes that you are willing to assume those risks.*
3. I agree to participate in the group discussions under the conditions set out in the Information Sheet.
4. I understand that I can withdraw from the inquiry group at any time before the group begins or while the group is in progress and ask for my talk to be removed. I will have two weeks to amend the information I provide after the group finishes as long as it does not affect the discussion with other participants.

Declaration by Participant:

I _____ [print full name] hereby consent to take part in this study.

Signature: _____ **Date:** _____

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 22/34. If you have any concerns about the conduct of this research, please contact A/Prof Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800, x 43347, email humanethicsnorth@massey.ac.nz.

Appendix C: Draft hui plan

Session Plan

Who will be at the CI workshops?

The workshops will involve Jo Miller and three other "participants", who can be considered co-researchers.

Per-workshop information

Jo will call and speak to each participant to explain the CI process so that less time will be spent on this in the workshops. Jo will also ensure participants have all the information and have signed their consent forms before the workshops.

Outlines of workshops

The table below is an outline of how the sessions can run. Weekly sessions.

First hui

Actions	Timing
1. Welcome and whakatauki 2. What do we want to achieve together? Kōrero of principles of CI and ground rules which can include: a. Listen to each other. b. Seek to build on other's contributions c. Share the airspace d. Make it safe and welcoming for people who have different experiences to contribute – respectful korero e. Keep what is said - and who said it – confidential (need to think through what this means in a friendship group – talk amongst yourself but not with others?)	10 Minutes
3. Whakawhanaugatanga, getting to know each other activities RECORD a. Jo shares brief intro about herself b. Participants introduce themselves	15 minutes

	c. What drew you to the project, one word to describe how you feel	
4.	Surface challenges – activities designed to facilitate thinking a. Introduce care-full conversation cards, reflect on what is said, similarities and differences in the group b. Prompts for discussion include: themes, and/or similarities and differences in experiences, what do you do to cope, how do you feel about yourself /your body/your relationships, what's been the best experience, what's been the worst experience? c. Possibly introduce the concept of misfitting (disabilities studies – the world is shaped for the able-bodied body, if you're not able bodied you have to negotiate a world not designed for you to use e.g. stairs instead of a slope)	20 minutes
5.	Review the meeting activities, what's sticking out for you that you would like to know more about? And then what would be an action to help you understand that a bit more (it could just be observing it a bit more) a. Identify key insights from the discussion. b. Suggest free writing and observation as a reflective exercise before the next meeting. Can send more details.	15 minutes
6.	Next Steps & Closing a. Plan the next meeting, discuss staying in touch (WhatsApp group and email reflections if they want?) b. Conclude with a quick round of reflections and a closing whakatauki.	

Subsequent hui

Actions		**Timing**
1.	Welcome and whakatauki	10 Minutes
2.	Aims of today and opening Activity a. Three-Word Round: Each participant shares three words to describe how they feel, bringing them into the space.	

3. Reflections on actions a. Each participant shares what they did and learned from their planned action. b. Group collectively reflects on each person's experiences before moving to the next participant. 4. Reflections on free writing a. Take it in turns: outcome of free writing if participants did it (need to keep an eye on the time) 5. Group Reflection a. Discuss any shared learnings or significant developments that emerged from individual reflections. Facilitator Support Offer prompts or activities if discussions slow down or become stuck. Optional Discussion (if time permits) Explore what coping strategies look like. What would you like your coping strategies to be? A two-minute round of free association, considering how experiences have impacted participants' mind, body, relationships/family, and careers.	25-30 minutes
6. Reflections on topics covered last week or issues from today participants want to pick up on – the 2-minute talking challenge a. Read out a summary of topics covered last week and ask participants if they want to speak to any of the topics further.	10 minutes
7. Planning action, quick review and close a. Summarise key points covered. b. What would participants like to learn more about? What actions do they think might help with that? c. Practicalities: next meeting time, last one	10 minutes

d. Conclude with a final one word round where each participant shares how they are feeling, and a closing whakatauki.	

Final Hui

Actions	**Timing**
1. Welcome and whakatauki 2. Aims of today and opening activity a. Three-Word Round: Each participant shares three words to describe how they feel, bringing them into the space.	10 Minutes
3. Reflections on actions a. Each participant shares what they did and learned from their planned action. b. Group collectively reflects on each person's experiences before moving to the next participant.	10-15 minutes
4. Discussion a. Topic challenge - what do participants want to talk about – e.g., any more reflections on the research question? Understanding how women navigate perimenopause with RA b. Mind, body, place, space, relationships, identity game How has it shaped your: i. Mind: e.g. Thoughts; Expectations; Identities ii. Body: e.g. New knowledge; focus on hormones; noticing sensations iii. Relationships: e.g. With partners, work, family, friends iv. Sense of time or place: e.g. when you feel better, how you are in certain place/work c. and/or talk about things that have been covered previously - review these and the other list from the first meeting and ask participants if anything has changed or what might change for them in the future	25 minutes

5. Final Reflection /Adjourning a. If this was a journey, how would you describe it? what are your take-home points of learning? b. Acknowledge contributions with specific appreciation for each group member. 6. Wrap-Up a. Mention next steps, such as working with data and sharing preliminary findings. b. Close with a three-word round on current feelings, and a closing whakatauki.	10 minutes

After each workshop, Jo Miller will generate a summary and preliminary ideas about what has been learnt in the CI session. She will then use these learnings to inform the next workshop, and participants can comment on these ideas if they want to.

Activities that might be used to develop critical thinking include:

1. Use care-full conversation cards, reflect on what was said, similarities and differences in the group;
2. draw and discuss your journey of perimenopause and RA;
3. whiteboard to brainstorm a specific idea with post it notes (in person or online);
4. freeing-up thinking activities designed to bring ideas to the surface, which would be chosen to best meet needs of group preference/cohort and can include:
    a. free writing (individual stream of consciousness writing just for self, share what you want after with the groups),
    b. collage and screenshots (in answer to the question 'what does perimenopause and RA mean for you?')
    c. memory work (describe a memory in detail, reflect on shared and differences in these memories)

Other suggestions are welcome – any member of the group might propose an alternative method for the group to explore.

Appendix D: Hui presentation

WELCOME Whakatauki

Mā whero, mā pango ka oti ai te mahi
/
With red and black the work will be complete.

Inspiring communities. (2019). *Whakatauki information sheet.*
https://inspiringcommunities.org.nz/wp-content/uploads/2019/09/Inspiring-Communities-WHAKAPAPA-Whakatauki-information-sheet.pdf

AGENDA What we'll cover in this session

- Goals, ground rules
- Whakawhanaungatanga, intros
- Surface challenges
- Review and identify key insights
- Next Steps & Closing

GOALS What do we want to achieve?

AIMS

- Get to know each other and a feel for the research method
- Start our inquiry by talking about your experiences
- Enjoy yourselves

PROCESS Ground rules

KORERO AND GROUND RULES

- Listen to each other
- Seek to build on other's contributions
- Share the airspace
- Make it safe and welcoming for people who have different experiences to contribute – respectful korero
- Keep what is said - and who said it – confidential

WARM-UP Whakawhanaungatanga

Introduce yourself

One thing that drew you to the project?

One word on how you're feeling

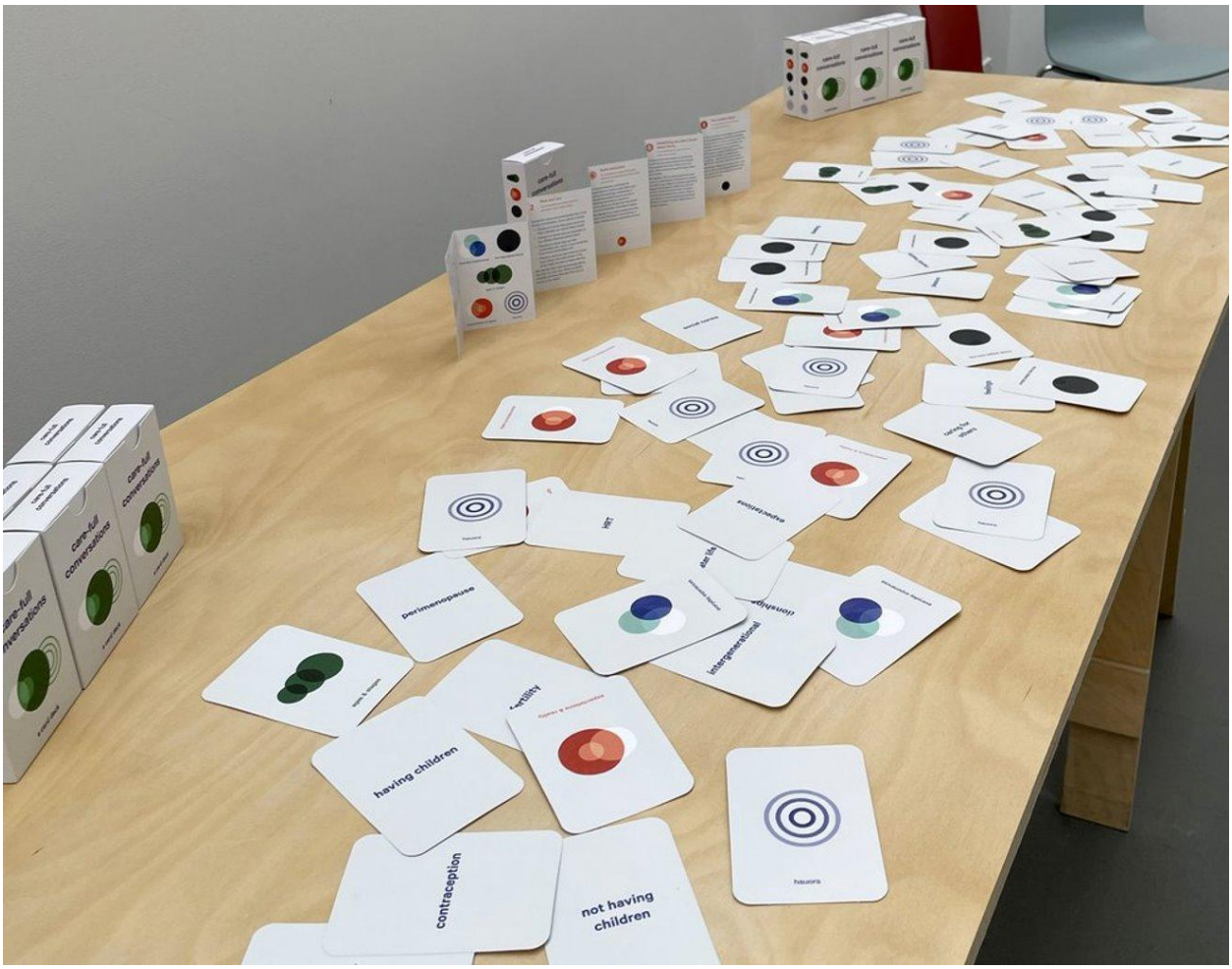
SURFACE CHALLENGES

CARE-FULL CONVERSATIONS CARDS

The cards prompt conversations about women's bodies, health and wellbeing. The cards are grouped into 4 categories: *the less talked about, expectations & reality, ages & stages, everyday experiences and hauora (Māori health).* Select the first 1-3 (from any category) that jump out for you to talk about this evening.

TOP TIP: hold off proposing solutions for now

Appendix E: Care-full conversations cards



https://www.thecoproductionproject.nz/

Appendix F: Miro board of themes (snapshot)

Appendix G: Mindmap of themes (snapshot)

Appendix H: Ethics letter of approval

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

30/04/2025

Dear: Jo Miller

Re: Ethics Application - OM1 24/69 - Using cooperative inquiry to understand how women with rheumatoid arthritis navigate perimenopause

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Ohu Matatika 1 at their meeting held on **Tuesday, 3 December 2024**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Tracy Riley,
Acting Chair, Research Ethics Chair's Committee

Research Ethics Office, Research and Enterprise
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E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz