“It Makes Me Feel Like Less of a Woman”:

A Reflexive Thematic Analysis of Endo Belly

and the Gendered Illness Experience of Endometriosis

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Abstract

Endometriosis is characterised as an incurable gynaecological condition causing inflammatory reactions across multiple bodily systems. Endometriosis affects one in 10 women of reproductive age in Aotearoa New Zealand. Endometriosis has historically been framed through a biomedical lens within Western contexts, with limited attention paid to how wider sociocultural meanings shape sufferers' experiences, especially in relation to gender identity. While there is a developing interest in the broader impact of endometriosis on body image, "endo belly"—the visible abdominal bloating that alters the body's appearance and can prompt significant distress—remains under-researched. This research examines how individuals who experience endo belly construct and negotiate their feminine identity in Western sociocultural discourses that often define womanhood through bodily appearance and normative gender ideals. A feminist, social constructionist approach was adopted to prioritise the embodied lived experience of 59 participants, positioning them as experts in their social realities. The participation criteria included an endometriosis diagnosis by laparoscopy situated within the context of Aotearoa New Zealand. An online qualitative survey, advertised through social media platforms, was utilised as the method of data collection, and the data were analysed using reflexive thematic analysis (Braun & Clarke, 2019). Four key themes were identified: (1) "It Makes Me Feel Like Less of a Woman": Endo Belly as a Disruption of Normative Femininity; (2) Striving to Perform Ideal Womanhood: "We Have to Put On a Brave Face"; (3) The Enemy Within: Battling and Making Peace with the Unruly Body; and (4) Rewriting the Rules: Redefining Femininity and Resistance. The findings suggest that many of the women's experiences of endo belly are associated with psychological and social challenges, as its pervasive appearance-based symptoms disrupt sociocultural expectations of femininity, identity, and illness experiences in Western cultural contexts. Ultimately, this thesis calls for a re-evaluation of healthcare encounters in Aotearoa New Zealand to support empirically guided interventions that better address the appearance-based symptoms of endo belly.

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Chapter 1: Introduction

As a woman in my early 30s, recently diagnosed with stage-three, deep-bowel endometriosis, I experienced the effects of symptoms for many years prior to diagnosis. I have developed a profound interest in how chronic symptoms impact my sense of who I am as a woman, especially with respect to appearance-related issues (and fertility, which is beyond the scope of this thesis). My own experiences led me to investigate gendered identity in the context of endometriosis. Qualitative studies describe how endometriosis symptoms leave women feeling fundamentally defective *as women*: "falling short of sociocultural expectations as a woman" (Mills et al., 2023, p. 292), "shame and embarrassment associated with their symptomatic bodies" (Sayer-Jones & Sherman, 2023, p. 547), and as though these chronic symptoms have "stolen" their identity and joy (Pellizzer et al., 2025, p. 537).

As part of my post-excision care, I was referred to a clinical psychologist, who provided me a professional space that enabled me to voice my concerns related to "endo belly"—the painful, distended abdomen common in endometriosis—and my subjectivity on its intersection with feminine identity. However, many people I have spoken to were not fortunate enough to be provided with access to benefit from that service of care. Therefore, some illness experiences may remain unheard and under-represented, which emphasises the need for research that explores the unmet needs of individuals diagnosed with endometriosis and brings to the forefront the experiences of those without access to psychological healthcare.

For this research, instead of exploring endometriosis symptoms more broadly, as many studies have done, I focus on the symptom of endo belly as a central illness experience of endometriosis. Endo belly is one of my own main symptoms of concern and one that was greatly

neglected in healthcare encounters. This oversight is experienced by many women, although the symptom causes much distress and discomfort. Yet, much like other appearance-related issues in women's reproductive health (Department of Health and Social Care, 2022; Lau et al., 2022; Zhang et al., 2025), the experience of endo belly, and how women make sense of it, remains unexplored in health psychology research.

In sociocultural and medical discourse, endo belly is often constructed as just a cosmetic symptom and a trivial concern compared to other aspects of the illness, such as fertility issues (Ballard et al., 2006; Ellis et al., 2022, 2023; Pettersson & Berterö, 2020; Young et al., 2016). My aim in this thesis, therefore, is to take women's concerns seriously and give directed attention to endo belly. The broad objective of this thesis is understanding how women[1] with endometriosis experiencing endo belly construct and negotiate feminine identity, particularly in a context in which bodily appearance, reproductive capability, and normative gender ideals are often defining features of womanhood. This research aims to provide a more nuanced understanding of how women make sense of their experience of endometriosis, particularly in relation to gender identity.

The data used for this thesis were generated via an anonymous online survey conducted for my Honours project examining experiences of endometriosis symptoms and body image, which included both closed- and open-ended questions (Daniels, 2025). The honours project addressed broad psychological themes and the open-ended responses generated rich, nuanced

[1] Not all people with endometriosis identify as women. However, I focus on cisgender women given that this is the most affected group, there is little research on the topic overall, and inclusion of other genders is beyond the scope of a master's project. Further research with a range of genders would be needed to capture the breadth of experiences of people with endometriosis.

accounts that exceeded the analytic scope of that study that I felt warranted further exploration. Qualitative datasets often contain multiple layers of meaning that cannot be fully explored within the constraints of a single project, and revisiting data through a refined theoretical lens is consistent with the iterative nature of qualitative inquiry (Davidson et al., 2019; Heaton, 2008; Hughes et al., 2020). I therefore conducted an in-depth analysis of the data using a feminist social constructionist lens to deepen engagement with constructions of femininity, embodiment, and illness. This secondary analysis reflects the iterative and evolving nature of qualitative inquiry, where analytic questions develop over time (Riessman, 2004).

An ethics variation for the extended use of the anonymised dataset was documented by the Massey University Human Ethics Committee OM1. A major consideration was that it was impossible to contact participants about additional use and dissemination of findings. In the original study, email addresses were only collected for a prize draw and for those opting in, these were separated from their responses. Furthermore, in line with the ethics protocol, no contact information was retained. However, the Massey University Human Ethics Code section on the "Re use of samples/data" states that where re-consent cannot be obtained, researchers may apply for approval for secondary use of fully deidentified data on a case-by-case basis (MUHEC Code, Section 2) provided that: (1) the new analysis is consistent with the original research scope, (2) risks of harm are minimal, and (3) confidentiality can be adequately protected. Given that the present thesis remains within the same substantive focus (of endometriosis and body image), and no new data were collected, the committee emphasised the need for protection of confidentiality. (See ethics section for more detail.)

In this chapter, I begin by providing the background relevant to the illness experiences of endometriosis and contextualise its symptoms in relation to femininity and identity in

sociocultural discourses shaped by Western gender norms. This process requires me to critically engage with health and feminist psychology literature that investigates gynaecological chronic illness—then specifically, endometriosis— through biomedical, sociocultural, and gendered frameworks, with a focus on the regulation of women's embodied identities.

Background

Endometriosis is a chronic gynaecological condition characterised by abnormal growth of tissue resembling the endometrium (uterine lining) found outside the uterine cavity, causing widespread inflammatory reactions (Giudice et al., 2023). Although this incurable illness is typically found in women during their reproductive years, recent data indicates a growing impact on younger populations. In Aotearoa New Zealand, endometriosis is found to be present in one in 10 women of reproductive age (Culley et al., 2013; Endometriosis New Zealand, 2024; Giudice et al., 2023). However, the actual prevalence of endometriosis remains elusive due to symptom ambiguity and comorbidity, and unreliable methods of diagnosis (Endometriosis New Zealand, 2024; Giudice et al., 2023).

The complex pathogenesis of endometriosis means that its extensive symptom manifestations are not fully understood regarding disease development and progression; however, stem cells are suggested as being instrumental (Velho et al., 2023). Commonly experienced symptom presentations include severe abdominal and pelvic pain, dysmenorrhea (during ovulation), dyspareunia (painful intercourse), and infertility (Kennedy et al., 2005; Van Niekerk et al., 2022; Velho et al., 2023). Due to its systematic nature involving multiple bodily systems, such as hormonal imbalances and lesion overgrowth, endometriosis extends beyond gynaecological health. Symptoms can also include headache, nausea, fatigue, weight gain, and endometrial-like lesion overgrowth (Ellis et al., 2022; Kennedy et al., 2005; Van Niekerk et al.,

2022; Velho et al., 2023). Endometrial-like lesion overgrowth can disrupt the functionality of the organs it affects over time, causing impaired bowel, bladder and digestive processes, and dysphasia, as seen in those with deep endometriosis (Ellis et al., 2022; Habib et al., 2020; Ministry of Health, 2020). Other experienced symptoms include variations to the typical menstrual cycle, such as premenstrual syndrome (PMS), intermenstrual bleeding, and extensive or restrictive bleeding during menstruation, where bleeding during cycles is very irregular or unpredictable (Endometriosis New Zealand, 2024).

This research focuses on a frequently occurring and under-researched symptom of endometriosis commonly referred to as "endo belly". Endo belly is characterised by cyclic bloating of the abdomen that alters the body's physical appearance and can be highly distressing for those who experience it (Luscombe et al., 2009). Its symptoms can occur for a significant period of the menstrual cycle, particularly during the luteal phase leading up to menstruation, where the abdomen becomes severely bloated, causing discomfort and pain due to the heightened sensitivity of the intestinal wall. While many women typically experience bloating during menstruation, the symptoms produced by endo belly are significant in their severity, prolonged, and not restricted to menstrual timing (Velho et al., 2023). The exacerbated abdominal bloating and pain symptoms associated with endometriosis are linked to endometrial-like tissue overgrowth in the pelvic region, as well as hormonal changes typically experienced during menstruation (Mills et al., 2023; Velho et al., 2023).

Among the extensive presentations of symptoms associated with endometriosis, pelvic pain, issues with fertility, and endo belly are prevalent, prominent, and highly distressing for women who live with endometriosis (Cole et al., 2021; Heng & Shorey, 2022; Luscombe et al., 2009; Moradi et al., 2014). A plethora of evidence describes the condition's adverse impacts on

physical and emotional well-being, including body image and identity—that is, how women think about and experience their bodies and their selves (Cole et al., 2021; Ferreira et al., 2016; Melis et al., 2015; Van Niekerk et al., 2022; van Stein et al., 2023). My focus in this study is on how the experience of gynaecological illness, specifically endometriosis and its symptom endo belly, is shaped by the cultural significance placed on women's physical appearance (e.g., thinness, sexual desirability) and gendered expectations. I propose that these taken-for-granted understandings in biomedical and sociocultural contexts inevitably position bodies affected by endometriosis as deviant, shaping how women experience and evaluate their bodies and themselves as women.

In this chapter, I argue that as endometriosis is a gendered illness shaped by ideals of Western femininity, women face the complex challenge of evaluating their body image through the lens of societal expectations that often contradict their embodied symptom experiences. I begin by highlighting prominent social constructionist, feminist, and health psychological literature that explores normative constructions of womanhood and social practices in Western societies that regulate women's bodies to adhere to cultural constructions. Qualitative studies on chronic illness and body image, then endometriosis more specifically, are reviewed to substantiate the argument that the sociocultural pressure to avoid appearing deviant is exacerbated for women living with endometriosis due to their visible, dysfunctional symptoms, which are often trivialised in medical encounters. As a result, these physical symptoms challenge feminine norms, making women's bodies a social marker of failed femininity and shaping their constructions of identity and illness perception. While endo belly is the focus of this thesis, it is important to note that the symptoms discussed above are frequently experienced in conjunction with one another, compounding their impact and contributing to the complex interplay of

biopsychosocial aspects with interconnected gendered meanings (Culley et al., 2013; van Stein et al., 2023). I return to this point later in the chapter.

In the following section, I begin my argument by drawing attention to literature that engages with Western cultural constructions of femininity and how these ideals are complicit in externally regulating the female body in homogenous social contexts. I then demonstrate how these constructions, through processes that "other" non-conforming bodies, move the body away from uniquely instinctual states and towards ones that are manufactured in tandem through the primacy of hegemonic social actions and practices, maintained through external regulation.

Endometriosis and the Cultural Construction and Regulation of Women's Bodies

Endometriosis is more than a physical illness; it is also a cultural construction shaped by dominant Western gender ideologies connecting women's bodies to reproduction and societal expectations, which inform how women should look and behave (e.g., appearance and motherhood) (Jones, 2015; Nezhat et al., 2012; Seear, 2014). Feminist scholars argue that women's bodies are sites of regulation and judgement, shaped by gender norms that equate thinness, beauty, motherhood, and sexual desirability with social value (Chrisler, 2011a; Ussher, 2003). Bordo (2003) echoes this, conceptualising the female body as a domain of social control, where the rigid constructs of femininity are produced, imposed, and externally regulated by social pressures of cultural life. Through continual subjection to discipline, improvement, and bodily maintenance in order to adhere to ever-changing, homogenised ideals of femininity, the female body becomes what Foucault (1995) called a "docile body".

In this context, considerable evidence shows that endometriosis is a distinctly gendered disease embedded with taken-for-granted assumptions of femininity and a deviation from what is understood to be the "nature" of a woman (Jones, 2015; Nezhat et al., 2012; Richmond et al.,

2015; Seear, 2014). From a feminist social constructionist framework, which informs this research, taken-for-granted assumptions of womanhood are not rigid or set in biology, nature or socialisation but are rather continually constructed through shared meaning, knowledge and negotiations that take place in repeated social practices and interactions (Frith, 1997). Women are not perceived as possessing assumed female behaviour because they exist as a female; rather, the repeated performance of sociocultural sanctioned feminine behaviours or traits—such as mothering, submissiveness, and adhering to desired beauty standards (e.g., body shape, size, grooming)—allows a female to be understood as a woman (Mikkola, 2024).

Othering Deviant Bodies

The sociocultural construction of "deviant bodies" serves as a guide to separate what is considered normal from abnormal in society because they challenge gendered expectations, and thus present a threat to society and culture (Chrisler, 2011a; Terry & Urla, 1995). Butler's (1988) notion of performativity of femininity constructs individuals as socially legitimate when they adhere to visually recognisable gender norms, making external recognition of gendered expectations a social requirement. Thus, gender norms and roles are maintained through performance and regulation. Those who fail to correctly enact bodily norms are excluded and positioned as "other" and met with stigma and social sanctions. This social rejection, or "othering", works to maintain the boundaries of gendered normality (Butler, 1988). Below, I discuss two ways that women's bodies are constructed as other relevant to this thesis, namely, the constructions of the troublesome reproductive body and the unattractive fat body.

The Troublesome Reproductive Body

Feminist scholars have critiqued how dominant gender discourses construct women's bodies as inherently troublesome and requiring regulation (Barnack & Chrisler, 2007; Johnston-Robledo &

Chrisler, 2020; Ussher, 2003; Ussher & Perz, 2020). In Western popular culture, representations of the female body often frame menstruation, hormonal changes, ageing, and fatness as undesirable, embarrassing, or in need of concealment and control (Chrisler, 2011b). Both medical knowledge and common understandings of endometriosis have continued to be shaped by gendered discourses of women's troublesome bodies.

Notably, John Sampson—often regarded as the "father of endometriosis"—proposed the widely accepted retrograde menstruation theory in 1925, which linked the disease aetiology to menstrual processes and hence to female biology (Lamceva et al., 2023; Nezhat et al., 2012). Endometriosis has long since been referred to as a menstrual disorder, which has shaped the fundamental way in which the disease is understood as related to the wider pathologisation of menstruation as the body's failure to reproduce (e.g., using terms such as "waste", "debris" and "failed") (Martin, 1988; Seear, 2014). Sampson's retrograde menstruation theory remains dominant in explaining the disease onset and progression, including the consequential adverse symptoms experienced, reinforcing the view of women's bodies as inherently defective (Nezhat et al., 2012).

From a social constructionist perspective, such gendered understandings shape how physiological processes like menstruation and conditions like endometriosis are understood, diagnosed and experienced (Gbogbo et al., 2025; N. Hudson, 2022). Framing ill bodies as deviant enables the representation of the visceral experience of endometriosis symptoms, such as endo belly, infertility, and painful intercourse, as challenging gendered expectations.

The Fat, Unattractive Body

It is widely recognised that the idealisation of thinness as central to the Western image of female beauty in the 20th century is attributed to prominent discourses and institutional

structures (Lelwica, 2006; Volonté, 2019). The intersection of multiple knowledge domains promoted and reinforced thinness as a normative image of beauty during the 20th century (Seid, 1989). The norm of thinness has come to be naturalised through the combined influence of academic, scientific and economic fields, and structures of authority such as the media, healthcare, moral authorities, and political agendas.

From the beginning of the 20th century, Western healthcare agencies started conflating the image of thinness with health. Dietary goals were encouraged in government reports, and Christians increasingly demonised obesity by associating it with the sin of gluttony. Body shape became the focus of fashion, and insurance policies began to include criteria for customers' preferred weight (Lelwica, 2006; Volonté, 2019). Perhaps the most consistent assertions of the idealisation of thinness stem from Western media platforms and the beauty industry, which formulate and emphasise through repeated messaging what is considered hegemonically attractive in society (Black & Sharma, 2001; Gattino et al., 2023).

Consequently, dominant cultural norms in Westernised contexts idealise thinness and sexual desirability, while simultaneously pathologising fatness as a sign of moral failure, self-indulgence, and poor health (Chrisler, 2011b; Fahs, 2017a, 2017b). Such constructions not only equate thinness with health and virtue but also promote fear of deviating from these norms. These discourses position the "natural" female body as problematic, encouraging women to view their bodies as needing constant regulation to meet narrow appearance ideals (Chrisler, 2011b).

Regulating the Deviant Other

Women's bodies appearing as symbolic markers of difference allow for moral judgement and repulsion, as well as experiences of shame for those who are positioned as other (Chrisler, 2011a, 2011b). If a woman is unable to perform or act in line with gendered expectations, she

may be perceived as deviating from normative femininity, even if through no fault of her own. Thus, the performance of gender norms creates an avenue for society to regulate or police a woman's deviation or alignment with socially sanctioned femininity in dominant social systems (Mikkola, 2024).

Dominant gender ideals are reinforced by systems of power (de los Reyes & Mulinari, 2020; Frith, 1997; Hawkey & Ussher, 2022). Gender norms and ideals of femininity are maintained through processes of surveillance of women's bodies, both by themselves (self-surveillance) and others (social surveillance). Femininity is socially and self-surveilled in tandem (Wickens & Haughton, 2023). Social surveillance occurs through the gaze of institutions, especially those related to psychology and medicine. Women's bodily functions such as menstruation, premenstrual changes, and gynaecological illness are constructed as troublesome, as discussed above, and linked to the pathology of madness (Barnack & Chrisler, 2007; Johnston-Robledo & Chrisler, 2020; Ussher, 2003; Ussher & Perz, 2020).

Therefore, surveillance acts as a social and disciplinary mechanism, and the gaze of institutions such as the beauty industry, health campaigns and media reinforce the process of social surveillance (Black & Sharma, 2001; Lippa et al., 1983; Wickens & Haughton, 2023). In addition, the female body has been treated as an entity that requires continual improvement to align with dominant norms of female beauty and sexual attractiveness (Abid, 2021). Subsequently, in individualist culture, people are encouraged to believe that they have a higher means of control over their bodies than what is naturally possible, with self-control reinforced as a marker of femininity (Chrisler, 2011b; Vera, 2021). As a result, women actively regulate their own bodies and behaviours to escape versions of their physical self that may appear as deviant due to the risk of being monitored and judged by others around them (Bartky, 1990; Fahs, 2018).

Some feminist scholars have understood self-surveillance as a form of self-objectification, whereby neoliberal ideology creates an illusion of autonomy in which women feel as if they are freely choosing to adhere to feminine standards as a reflection of moral virtue (Calogero, 2012; Fahs, 2017a, 2017b). This thinking aligns with Crawford's (1980) theory of healthism, which constructs health and well-being as a moral obligation achieved through individual efforts that consist of discipline and self-regulation. In feminist studies, the healthist discourse conflates control over maintaining one's body with feminine worth, a manifestation of the neoliberal agenda. A feminist social constructionist framework, therefore, offers deeper insight into how women regulate their bodies to align with normative feminine ideals such as motherhood, the idealisation of thinness, and sexual desirability of the female body.

Processes of surveillance, in turn, produce emotional and psychological consequences (Bartky, 1990; McKenney & Bigler, 2016; Ussher & Perz, 2020; Wickens & Haughton, 2023). With specific reference to endometriosis, these consequences occur when chronic illness visibly or functionally disrupts normative feminine ideals through the experience of symptoms such as endo belly, infertility, and painful sex (Boding et al., 2023; White, 2000).

In the next section, I explore the diverse literature on Western conceptualisations of female body image and feminine identity. As previously mentioned, endo belly remains an under-researched symptom of endometriosis, as does how endometriosis more broadly connects to the body image and feminine identity of those it affects. Additionally, there is a lack of research conducted in locations where norms may differ from Western conceptualisations; therefore, the data available in these specific areas of psychology is very limited. The following literature review provides some insight into the impacts of common appearance-based symptoms comparable to endo belly regarding how women experience and relate to their bodies. Much of

the existing research is qualitative and produced in mainstream psychology, with a focus on exploring women's emotional responses. These studies provide beneficial insights; however, the approaches taken usually individualise women's distress and lack social context. While some qualitative research takes a more nuanced approach, specifically exploring women's experiences through various intersections of chronic illness, body image issues, and feminine identity, this work often neglects the broader social realities in which these discourses exist. I argue that research on psychosocial and identity disruptions related to visible symptoms of chronic illness provides some basis for understanding endometriosis as an illness in which visible presenting symptoms (i.e., bloating) intrude into body functionality. Again, research in this area is limited, especially studies that specifically focus on endometriosis in locations where norms may differ. Therefore, by exploring these issues discursively through a feminist social constructionist lens, my research aims to address this gap in the knowledge by adding contextual perspectives and understanding to qualitative research, which has previously tended to use individualist approaches.

Body Image, and Ideals of Femininity

In this thesis, I use the term "body image" to refer to how people experience and evaluate their bodies, recognising that this is not a static or internal perception but a socially and culturally constructed process shaped by dominant norms, discourses and interactions. From a social constructionist perspective, body image is not simply a personal perception; it is shaped by these broader social and cultural norms. Women are encouraged to monitor and judge their bodies through these normative lenses, which in turn shape how they experience and evaluate themselves (Fahs, 2018; Terry & Urla, 1995; Wray & Deery, 2008).

An Australian qualitative study validates this conceptual model by demonstrating how discourses of femininity, discipline, and control shape women's responses to their bodies and the way in which they perceive and "manage" their body image (Ryan et al., 2021). The researchers argue that feelings similar to shame, guilt, and the need to manage or conceal the body are shaped by broader sociocultural norms, rather than individual emotions alone. The findings of this study suggest that women's emotional reactions and distress caused by the embodiment of deviance—in this case, premenstrual bodies—are socially constructed through dimensions of "bodily failure" discourse and gendered expectations that associate bodily control with moral value.

For women living with chronic illnesses like endometriosis—where weight fluctuation, bloating, and fatigue are common—normative gender ideals can feel particularly oppressive. Illness-related changes in appearance may be experienced as deviations from femininity, reinforcing body dissatisfaction and shame. Endometriosis challenges dominant cultural ideals of femininity by disrupting the physical appearance, reproductive functioning, and sexual ability of the female body. These traits are central to normative constructions of womanhood in Western societies. When the body deviates from these ideals through illness, weight fluctuation, infertility, or visible symptoms like abdominal bloating, it can be experienced as a site of shame, failure or disgust, creating a sense of psychological conflict and undermining feminine identity in women due to their inability to perform or appear in accordance with the prescribed social role (Eagly, 1987; White, 2000). In the remainder of this section, I explore how cultural constructions of femininity shape women's experiences of their bodies when living with, first, chronic illness and, second, endometriosis in particular.

Chronic Illness and Body Image

A qualitative study conducted in the United Kingdom, with a sample that was largely White British participants, highlighted how chronic conditions can disrupt women's biological functionality and socioculturally constructed gender roles (menstruation, sexual intimacy, fertility, and appearance), causing a deviation from normative identity expectations and heightened body image dissatisfaction (Willmott, 2000). Multiple quantitative studies on women from a range of contexts note that when Western women express concerns about body dissatisfaction and negative perception of self, it is due to the experience of chronic symptoms that cause visible body alterations such as pain, abdominal swelling, and sexual dysfunction (Melis et al., 2015; Sündermann et al., 2020). The intensification of these effects is significantly associated with chronic conditions that predominantly affect women differently, such as gynaecological and breast conditions, as well as body-altering illnesses such as inflammatory bowel disease, irritable bowel syndrome, cystic fibrosis, and diabetes (Cunha et al., 2024; Ojha & Kumar, 2022; Pinquart, 2013; Quick et al., 2013; White, 2000).

For example, common uncontrollable symptoms caused by endometriosis, such as abdominal inflammation and weight fluctuations, can be associated with the previously discussed sociocultural ideas of fatness, heightening the psychological impact of body image concerns (Pehlivan et al., 2022). In addition, pain during sex (dyspareunia) and challenges with fertility can be closely associated with the infertile body, leaving individuals feeling helpless as they stray further away from their preferred body image (Pehlivan et al., 2022; White, 2000). Such experiences are not only shaped by self-perception of internalised norms, but also reinforced by social surveillance. Women experiencing endo belly, for example, report being mistaken as being pregnant in social situations (Sayer-Jones & Sherman, 2023).

Consequently, visible symptoms that affect women's appearance have significant implications for women's feminine identity. According to the "male gaze", these changes disrupt the conventional presentation that encompasses the image of femininity and sexual desirability (Fredrickson & Roberts, 1997). Broader work across body image disturbances in women found social comparison to be a significant contributing factor towards the intensity of the disturbances experienced in youth, leading to maladaptive coping mechanisms, such as eating disorders, as previously explored in self- and social-surveillance studies (Lippa et al., 1983; McKay, 2013; McKenney & Bigler, 2016; Quick, 2014; Quick et al., 2013). As body-altering illness experiences conflict with heteronormative cultural expectations that construct womanhood in Western societies, women may be at risk of evaluating their bodies as inadequate in their social world, affecting their sense of self (Boding et al., 2023).

A plethora of qualitative body image research in Western societies links the experience of chronic illness to a strained relationship with one's body in the form of body image dissatisfaction and social comparison, which can lead to negotiating one's identity. The deviation from a normative-appearing and functioning body caused by chronic illness can produce body image disturbances and exacerbate feelings of isolation, shame and disgust (Boding et al., 2023; White, 2000).

Multiple studies focused on women's experiences of chronic conditions (e.g., gynaecological diseases, gynaecological cancers, and inflammatory bowel disease) yielded similar insights linking body disruptions to body image concerns (Anuk, 2022; Beese et al., 2019; Ojha & Kumar, 2022). Researchers have identified body image dissatisfaction, poor self-image, self-criticism, and psychological distress to have high correlations in ill bodies; however, it was emphasised that greater body image dissatisfaction existed in female adolescents and

women who experienced body-altering symptom severity, such as weight gain and bloating, caused by disease activity and steroid use (Beese et al., 2019; Ojha & Kumar, 2022). Furthermore, body image concerns appeared to be mediators for mood disorders such as anxiety and depression, also increasing in significance with the severity of more visible symptoms such as abdominal bloating (Ojha & Kumar, 2022). Notably, Anuk (2022) found that gynaecological cancer patients acknowledged the illness had psychological consequences due to the deterioration of their perceived feminine identity. Key contributing factors included a negative sense of sexual attractiveness, concerns about reproductive capabilities, negative sexual self-perception, and negative self-image (Anuk, 2022).

In qualitative research, women in Australia reported feeling unattractive and less confident in their bodies due to feeling fundamentally different from female bodies that were not subjected to the physical and functional changes that manifest from endometriosis (Sayer-Jones & Sherman, 2023). These physical manifestations of endometriosis position women to feel less of a woman when evaluating their bodies, which requires public concealment to mask physical deviation from outside judgement and social scrutiny.

Endo Belly and Body Image

The perimenstrual phase has been reported to cause higher body dissatisfaction among women in general due to visible physiological fluctuation, such as bloating of the stomach (endo belly) associated with this phase. This is a naturally occurring physiological process caused by fluid retention and changes to neurotransmitters. In contrast, endo belly is a more extreme variation due to extreme presentations, exacerbated experiences, and longer durations of bloating (Jappe & Gardner, 2009; Luscombe et al., 2009; Velho et al., 2023).

Endo belly is a visual representation of illness in which often uncontrollable inflammation of the abdominal region is triggered by disease flare-ups that alter the body's form to appear larger than its typical state (Ek et al., 2015). This experience is highly distressing and is known to adversely impact individuals' perception of their body image, leading to body image disturbances (Luscombe et al., 2009; Pellizzer et al., 2025). As such, endometriosis is categorised by a high symptom burden and significant psychological distress, where commonly experienced symptoms often force women's bodies to exist outside the boundaries of normative constructions of femininity as determined by Western society (Cole et al., 2021; Kocas et al., 2023; Sayer-Jones & Sherman, 2023).

Qualitative studies from the United States and Australia have highlighted endo belly as significantly impacting women's perception of their appearance due to hyper-awareness of fluctuating abdominal bloating and feelings of looking visibly pregnant (Hunsche et al., 2023; Sayer-Jones & Sherman, 2023). These studies reported that women felt less socially and sexually desirable and unattractive, which was linked to experiencing embarrassment about the appearance of their non-normative bodies. Women also reported that their romantic relationships had been or were negatively affected due to their appearance concerns. Furthermore, many women described the need to cover their bodies to mask the physical presentation of endo belly (Hunsche et al., 2023; Sayer-Jones & Sherman, 2023).

Pehlivan et al. (2022), meanwhile, conducted a quantitative study in Australia whose results supported a body dissatisfaction–driven hypothesis of depression. The researchers reported that the burden of endometriosis disrupts women's feminine identity, owing to the cumulative effect of the disease symptoms alongside gender constructs that are disrupted by symptoms. This leads to negative self-evaluations, which evoke greater symptoms of depression.

They also noted that depressive symptoms are significantly exacerbated in health contexts due to treatment side effects.

The first line of medical treatments offered to women to manage endometriosis commonly cause adverse side effects, which encompass body fluctuations and visual-altering presentation, such as weight gain, bloating, and acne. Due to the primacy of reproductive value in biomedicine, the management of some symptoms is prioritised over others. This reductionist biomedical interpretation of endometriosis obscures the fullness of women's lived realities, which encompass psychological and sociocultural effects extending beyond physical symptoms alone (Jones, 2016).

Healthcare Experiences in the Context of Endometriosis Treatment

The lack of medical consensus around the aetiology of endometriosis contributes to multiple sets of clinical guidelines with inconsistent modes of disease management and interventions[2] (Kalaitzopoulos et al., 2021; Van Niekerk et al., 2022) in which the focus is largely on patients' reproductive organs and function. The condition is frequently depicted as an "enigma", "puzzling" and "mysterious" in literature alongside medical-driven hypotheses, largely due to the unpredictability and variability of disease onset and progression among those affected. Moreover, despite extensive effort, research has failed to rationalise a clear biological cause of endometriosis; therefore, its pathophysiology remains unknown (Bolaji & Shirley, 2018; N. Hudson, 2022).

[2] The range of recommended treatments for various presenting symptoms is reflective of the minimal 7% agreement between these widely used guidelines (Kalaitzopoulos et al., 2021).

Overall, however, the primary focus remains on reproduction (see below). Consequently, experiences of healthcare are shaped by the privileging of reproductive issues. Moreover, these experiences occur in a context of asymmetrical power relationships between women and those treating them. As medical knowledge is often viewed as authoritative, biologically inherent, and empirically grounded, an uneven patient–practitioner power dynamic is reinforced (Alkhamees & Alasqah, 2023; Bientzle et al., 2017; Stevenson et al., 2004). Research on experiences of endometriosis treatment in a range of contexts suggests that patients' experiences are overall negative (Ballard et al., 2006; Ellis et al., 2022, 2023; Pettersson & Berterö, 2020; Samulowitz et al., 2018). Below I focus on the experiences of medical gaslighting (explained below) and the related issue of the trivialisation of women's appearance-based concerns. By way of background, I first explain the privileging of reproduction in endometriosis care and then show how this impacts treatment.

The Privileging of Reproduction in Endometriosis Care

The focus on women's reproductive capacities is part of a long history in which reproduction and motherhood have been foregrounded in biomedicine, linking the (non-)reproductive body with social failure and illness (Jones, 2015; Nezhat et al., 2012). Historically, medical literature positioned the appearance of the female body and its reproductive organs as contributors to women's ill health and perceived emotional instability (N. Hudson, 2022). Adverse physical symptoms experienced by women, suggestive of endometriosis, were often rationalised as a result of women straying from societal gender expectations, such as marriage, motherhood, and sexual morality (Jones, 2015; Nezhat et al., 2012).

During the Middle Ages, theories emerged proposing the experience of endometriosis to be the consequential outcome of women straying from the societal expectations of motherhood

and marriage. One of the earliest recorded such pathologisations is the sociocultural analogy of the “animalistic womb”, whereby the uterus was seen as hungry for motherhood and as inflicting illness and pain when it was deprived of a child (Nezhat et al., 2012). These gendered constructs informed the “wandering womb” theory that explained illness and pain as originating from the uterus migrating around female anatomy on a quest to find children, causing adverse physical symptoms to organs it came into contact with (Jones, 2015; Nezhat et al., 2012). Following this line of thinking, hysteria emerged as another example of gendered pathologisation, theorising the displacement of the womb as causing emotional disturbances in women, leading to conversion symptoms—that is, physical neurological symptoms with no clear organic cause (Dinsdale & Crespi, 2017).

The idea that reproductive deviation and illness were interconnected became embedded in cultural and medical understandings of women’s health (Jones, 2015). These gendered constructions are deeply rooted in historical assumptions and traditional social role expectations that continue to shape contemporary medical discourse and the societal contexts that inform women’s health (Farenga et al., 2024; Jones, 2015; Seear, 2014). This historical legacy is evident in understandings and treatment of endometriosis. For instance, endometriosis was initially depicted as the disease of a career woman, where illness and its symptoms were understood to derive from ambitions that took priority over motherhood and delayed childbirth. This ideology reinforced deviation from societally sanctioned gender roles as unnatural, normalising reproductive disorder and its symptoms as consequential in nature (Nezhat et al., 2012).

Reproduction is still the focus in biomedicine today. Biomedical discourse continues to associate endometriosis primarily with the uterus, menstruation, female hormones, and the womb, linking the disease to women’s reproduction and depicting it as a key contributor to

women's suffering and illness onset (N. Hudson, 2022; Huntington & Gilmour, 2005; Kennedy et al., 2005). Although endometriosis lesions are commonly described as located in the pelvic region on and around the uterus, there is evidence of the growth of the disease in non-reproductive areas, such as the lungs and brain (Kennedy et al., 2005; Seear, 2014). Nevertheless, endometriosis is commonly referred to as an oestrogen-dependent disease, with this hormone being responsible for influencing the progression and endurance of its cells (Dinsdale & Crespi, 2017). Though oestrogen is produced by all bodies, medical discourse established it as a female sex hormone in the 1920s (Casto et al., 2022). This gendered framing continues to shape contemporary understandings of oestrogen as a female sex hormone and, consequently, endometriosis as a gendered disease (Irni, 2016).

Women's Healthcare Experiences

The focus on the reproductive impacts of endometriosis carries over to endometriosis care. For example, Young et al. (2019) found that gynaecologists and medical professionals in Australia predominantly viewed women with endometriosis as reproductive bodies where value was placed on gynaecological functioning and fertility. Moreover, the first line of treatment offered to women to aid symptom management frequently prioritises medically determined "high-risk" symptoms that impact the reproductive body (Jones, 2015). Qualitative data on women's healthcare encounters in a range of Western countries, including New Zealand, reinforce how women's health concerns are pathologised by medical professionals through a lens of the reproductive body (Ballard et al., 2006; Ellis et al., 2023; Pettersson & Berterö, 2020).

This work shows that symptoms related to fertility are prioritised and thoroughly investigated, prompting a quicker endometriosis diagnosis over other symptom presentations. For example, in New Zealand, Ellis et al. (2022) found that 100% of women who underwent a

hysterectomy for symptom relief found it to be an effective treatment. However, in medical encounters, when women tried to prioritise the relief of pain and other debilitating symptoms and requested a hysterectomy, they were met with conflicting concerns from medical practitioners who focused on fertility preservation and their reproductive functioning, arguing that the patient may want children later in life, which at times led to hysterectomy being denied.

In Young et al.'s (2016) study, all the participants described adverse healthcare experiences, which included physicians prioritising women's fertility over other healthcare needs (e.g., relief of symptoms, quality of life) without prior consultation. This included prescribing pregnancy as a treatment to relieve symptoms of endometriosis. This recommendation angered women who did not want to have children. The participants felt that doctors would push pregnancy as a solution no matter their personal situation (e.g., finances, age, health, and relationship status), thus reducing their concerns related to their condition to fertility and future motherhood. Suggesting pregnancy as a valid suppression or treatment of endometriosis symptoms is supported by no empirical evidence. This common recommendation maintains the disproven historical belief that endometriosis is caused by the avoidance of motherhood. Positioning reproductive functionality as central to women's health reinforces gendered expectations and idealised femininity. This medical intervention puts blame on the individual, suggesting her illness is her own doing as a result of not subscribing to gender roles and the social expectation of motherhood (Guidone, 2020; Jones, 2016; Nezhat et al., 2012; Seear, 2014).

These examples show how symptoms primarily related to fertility, menstruation, and the reproductive body are privileged as high-risk/high-priority over other symptoms, no matter their symptom severity (Jones, 2015, 2016). Additionally, many women report that their condition

was only taken seriously once they expressed fertility concerns (Ballard et al., 2006). Pettersson and Berterö (2020) found that the diagnosis process was quickened when women presented with abnormal periods that exceeded pain alone, prioritising disruption to the reproductive process. Otherwise, symptoms are frequently dismissed or minimised by healthcare providers. For example, most women report that their pain was trivialised as "period pain", and that often only over-the-counter pain medication was prescribed, which minimised their suffering (Ellis et al., 2023). Such trivialisation and minimisation of women's experiences and concerns is a common theme in the literature, indicative of medical gaslighting, which I discuss in more detail next.

Medical Gaslighting and Trivialisation of Women's Appearance-based Concerns

Medical gaslighting functions as a mechanism through which gendered constructs are reinforced and pathologised in biomedical contexts, emphasising women's reproductive value while simultaneously silencing the circulation of women's embodied knowledge. Women have reported that medical gaslighting is a significant contributing factor to their healthcare concerns being minimised, dismissed and invalidated by physicians (Khan et al., 2020). This is particularly relevant for the treatment and management of endometriosis symptoms in women, where doctors prioritise fertility preservation and trivialise appearance-based concerns, which can further perpetuate the negative impact such appearance concerns have on the women affected (Luscombe et al., 2009).

Healthcare providers' responses to women's reported symptoms are shaped by the contested status of endometriosis, where medical uncertainty means that surgical confirmation is frequently required for medical professionals to verify an official diagnosis (Allaire et al., 2023; Bülow, 2008; Cuffaro et al., 2024). However, as with the treatment of other contested illnesses, surgical intervention relies on the convincing telling of one's subjective experiences to legitimise

symptoms as valid concerns that require further investigation (Bülow, 2008). When medical professionals do not believe women about the severity of their symptoms, this can lead to women doubting their own perceptions (Guidone, 2020).

A particular area where women's concerns are trivialised or disregarded, relevant to my research, concerns treatments with appearance-related side effects that exacerbate existing appearance-related symptoms. Hormonal treatments are frequently prescribed by physicians. The oral contraceptive pill, multiple progestins, and hormone replacement therapy are widely used first-line treatments; they can also be the only options offered to women to manage endometriosis symptoms (Ellis et al., 2023; Kalaitzopoulos et al., 2021; Luscombe et al., 2009). The side effects of these treatments include weight gain, abdominal bloating, and depression, with many women reporting that the severity of side effects made them regret using these methods (da Costa Pinheiro et al., 2023; Ellis et al., 2022; Luscombe et al., 2009). Qualitative studies have found that women associate their negative body image with weight gain from prescribed hormonal medication (Pellizzer et al., 2025). The experience of worthlessness, emotional distress, and hopelessness due to self-evaluation and physical appearance is considered significant in relation to both endo belly and treatments that cause or neglect the impact of bloating (Culley et al., 2013; Luscombe et al., 2009).

However, doctors rarely consider or take seriously common appearance-related side effects (da Costa Pinheiro et al., 2023; Ellis et al., 2023; Luscombe et al., 2009). Moreover, da Costa Pinheiro et al. (2023) draw attention to medical professionals often dismissing these adverse effects as minor, which significantly impacts women's quality of life and continuation of hormonal treatments. Women do sometimes reject or oppose these treatments for appearance-related reasons, such as fear of weight gain (van Seumeren, 2000). Ellis et al. (2022) found that

hormonal treatments were often considered ineffective by women, who describe the pill as either masking symptoms or never working sustainably. These undesirable side effects result in less incentive to use such treatments. Nevertheless, they continue to be prioritised, disregarding women's experiences.

Additionally, women who resist these treatments may face sanctions from healthcare providers. For example, Young et al. (2019) report that women in their study were perceived as "difficult" for mentioning failed treatments or challenging medical opinions. They were also often subjected to "hysteria discourse" and described as emotional, unstable, or exaggerating their pain. Young et al. (2019) found that medical professionals relied on the authority of the biomedical framework when dismissing women's lived experience of endometriosis. These findings show how, under the guise of scientific neutrality, the gender norms surrounding endometriosis and its symptoms are understood as factual, reinforcing the view of the reproductive body as central to regulating female well-being (N. Hudson, 2022; Seear, 2014). This gendered construction of endometriosis persists despite substantial empirical data and continues to position women's bodies into the gendered narrative that exists in contemporary biomedical discourse (Jones, 2016; Sayer-Jones & Sherman, 2023). Additionally, the existence of these narratives also devalues other symptoms women experience as distressing, such as body image concerns, as secondary, leaving them outside of the scope of medical care. As a result, women are left to manage these struggles individually, reinforcing neoliberal expectations whereby self-regulation and identity negotiation take place (Samulowitz et al., 2018; Seear, 2014).

Moving beyond the Trivialisation of Appearance-Related Symptoms

As I have highlighted in the preceding discussion, when women's bodies are positioned in sociocultural contexts that normalise feminine idealisations, gynaecological chronic illnesses such as endometriosis can actively alter women's self-narratives and identities. These studies suggest that when ideals are physically and functionally disrupted by endometriosis, women often experience emotional and psychological distress, which cannot be explained by physical symptoms alone (Hunsche et al., 2023; Law et al., 2025; Moradi et al., 2014; Sayer-Jones & Sherman, 2023; Vitale et al., 2017). Women with gynaecological chronic illnesses like endometriosis have described their psychological distress as shaped by shame, guilt, inadequacy and failure to embody constructs of normative femininity, resulting in feeling less of a woman (Law et al., 2025; Moradi et al., 2014).

As established earlier, women's experiences of endometriosis in Western society are significantly shaped by dominant gender norms, including those related to women's appearance and reproductive capacity. The intersection of medical trivialisation and sociocultural constructs of femininity reveals how the dismissal of symptoms such as pain and body image disturbances occurs alongside the primacy of female reproductive value. The distress that women report related to these symptoms is thus deemed unimportant and frivolous, but this distress is deeper than simply cosmetic concerns alone. It is also linked to disrupted feminine identity and possible social sanctions (i.e., othering, stigma), which, as I have suggested, are central to experiences of distress and other negative emotions (Calvi et al., 2024; Cole et al., 2021; Mills et al., 2023). Trivialisation by healthcare providers can compound the stigma and marginalisation that women with endometriosis might already experience, as well as exacerbating negative body image and related negative emotions (Calvi et al., 2024; Jones, 2016).

Jones (2016) argues that the restrictive nature of dominant norms of femininity is exposed through women's experiences of endometriosis. A reductionist focus on biological pathology for management and intervention is, therefore, inadequate. Jones suggests that endometriosis requires deeper feminist theorising, as evidenced in the critical feminist literature. Following her suggestion, I now review studies that consider sociocultural constructions of the female body, particularly those addressing endo belly and body image dissatisfaction.

From a feminist social constructionist perspective, I argue that the significance of body-altering symptoms like endo belly can be conceptualised as more than a mere cosmetic concern, as endometriosis is intimately shaped by constructions of gendered identity. This means that women's emotional and psychological relationship with their body, biological functionality, and sociocultural norms of femininity are interconnected and should be further explored. However, research on chronic illnesses like endometriosis has largely failed to apply a broader conceptualisation of body image (e.g., sociocultural expectations, social realities, embodiment and identity) and does not investigate complexities deeper than surface-level dimensions, such as appearance satisfaction (Mills et al., 2023; Sayer-Jones & Sherman, 2023).

Moreover, although endo belly is widely recognised as a highly impactful and commonly experienced symptom of endometriosis regarding body image, biological functionality, and sociocultural meanings of the female body, there remains very limited research on the phenomenon in both the health psychology and biomedical literature. As a result, women's experiences of endo belly in Western societies remain under-recognised by lay people and largely neglected by physicians. Although there is a wide body of feminist literature exploring women's appearance and deviation from feminine ideals, this mostly applies a surface-level lens that focuses on aspects such as weight, premenstrual change, menopause, illness, and

appearance, which mostly pathologises the female body rather than exploring women's embodied experiences in sociocultural discourses of femininity. We therefore need to delve deeper into how women who experience endometriosis make meaning of this issue, including themselves as gendered beings, because of the implications the embodiment of endo belly has for women's sense of self, which is a determinant of quality of life and well-being.

By exploring the connections between endo belly, femininity, and identity construction, my research aims to contribute to a more nuanced understanding of how women make sense of their experiences, particularly in relation to gender identity in the context of chronic gynaecological conditions. This is important for individuals who identify as women and live with endometriosis, as it has the potential to inform more holistic approaches to healthcare and challenge the restrictive gender norms that add difficulty to the lived complexities of endometriosis.

Research Aims and Objectives

In this research, I seek to understand how individuals with endometriosis and experiencing endo belly construct and negotiate their femininity and identity in a context in which Western sociocultural discourses often define womanhood through bodily appearance and normative gender ideals. Given that endometriosis is a chronic condition that disrupts bodily function and can impact gendered identity, examining these experiences can provide deeper insights into living with the condition.

Based on the findings of this review of the literature and the identification of a crucial gap in the existing knowledge of women's experiences with endometriosis, I developed the following three research questions:

1. How do individuals with endometriosis construct and negotiate femininity in relation to their experiences of chronic symptoms, particularly endo belly?
2. What dominant discourses of femininity shape how individuals understand and talk about their bodies and construct their identities?
3. How do individuals resist, challenge or conform to societal expectations of femininity while living with endometriosis?

The next chapter outlines the methodological approach adopted to address these research questions.

Chapter 2: Methodology

In this chapter, I describe the methodological approach adopted for this research, including its intention and rationale in relation to the study's aim and objectives. I begin with the epistemological and ontological assumptions that underpin this study, followed by the research design guiding its application. The participants, recruitment method, data collection procedure, and ethical considerations are explored in detail. Lastly, I situate my reflexivity in connection with the implemented data analysis.

Theoretical Framework

This research was conducted within the feminist social constructionist framework, with an analytical focus on how dominant discourses construct gendered social realities and, in turn, inform how women construct, negotiate and understand their feminine identity in relation to the complexities of their health experiences. This theoretical focus is valuable in feminist and health psychology research because it allows us to explore the intersection of endometriosis, illness experiences, and social realities situated in broader theoretical conversations that encompass gendered identity, cultural narratives, and embodiment. This holistic perspective is largely neglected in the field, as very limited research exists addressing women's body image concerns related to their illness experiences. As presented in Chapter 1, my research aim is to investigate how ideals and dominant constructions of knowledge perpetuated in society shape women's gender identity construction in relation to their experience of endo belly.

From a social constructionist perspective, humans draw on socially and culturally available resources in their various locations to construct systems of meaning-making, allowing for the existence of multiple versions of social reality and "truths". As Burr (2015) explains, existing taken-for-granted knowledge is shaped by the historical, cultural, political and social

context in which it is produced and cannot be treated as objective. However, some forms of knowledge are legitimised over others and assumed simply to be true, natural, or the way things are. This is exemplified through gendered expectations and the sociocultural construction of normative femininity (Abid, 2021; Bordo, 2003; Bugden et al., 2024). Power comes into play as dominant understandings are taken for granted as *the* true source of knowledge.

The social constructionist perspective acknowledges that truths adopted by the dominant Western paradigm are often favoured as taken-for-granted understandings, which can marginalise and invalidate truths produced by other groups, like patients or women, and can result in their silencing and marginalisation (Samulowitz et al., 2018; Seear, 2014). For instance, as I established in Chapter 1, there is compelling evidence showing how medical experts produce and maintain dominant norms pertaining to women's bodies by drawing on prevailing discourses about reproduction, beauty, health, and illness determinants (N. Hudson, 2022; Seear, 2014; Young et al., 2019). This is exemplified in the medical setting, where value is placed on the reproductive body and practitioners prioritise fertility preservation in women with endometriosis over other illness concerns (Ballard et al., 2006; Young et al., 2019).

A feminist lens is often incorporated within critical theoretical perspectives, like social constructionism, to challenge realist views embedded in societal knowledge that treat femininity, gender, biology, medicine and healthcare as interlinked (Ussher et al., 2015). Hence, *feminist* social constructionism acknowledges that femininity, identity, health and illness are all socially constructed through discourses and interactions between people rather than existing as impartial reflections of objective reality (Burr, 2015; Frith, 1997; Hawkey & Ussher, 2022). Feminist scholars largely agree that women's experiences of their health, specifically, gynaecological conditions, are understood in a sociocultural setting that is saturated with gendered constructions

(Frith, 1997; Gbogbo et al., 2025; Guidone, 2020; Sayer-Jones & Sherman, 2021). Generally, feminist research aims to highlight structures that oppress women, with the intention of dismantling said structures (Wilkinson, 2000).

Therefore, feminist social constructionism is most suited as the epistemological assumption to guide this research as it challenges, deconstructs and disrupts the dominant understandings in discourses surrounding the nature of women and feminine identity. As knowledge is assumed to be constructed by social phenomena, feminist social constructionism allows us to question the way in which dominant discourses (medical, sociocultural, societal) relating to gynaecological conditions like endometriosis shape their identities and experiences, which may harm women's self-perception in relation to their experience of endo belly (Frith, 1997). Furthermore, this analytic framework allows women's perspectives to be privileged, situating them as experts of their own realities, while also critically engaging with taken-for-granted understandings produced within dominant sociocultural structures (Burr, 2015). This approach aligns with a 'Big Q' qualitative framework (Braun & Clarke, 2019), which grounds qualitative research within constructionist epistemology through practices of interpretation and meaning making. This theoretical framework, therefore, allows me to explore how women with endometriosis, through the experience of endo belly, negotiate their identities and navigate social expectations of femininity in their everyday lives.

Research Design

The data analysed in this thesis, as mentioned in Chapter 1, were generated as part of my honours project. The project focused on the psychological impact of endo belly on women's body image perception through the perspective of women who experience endometriosis. For that

project, I collected data via an online survey comprising both closed- and open-ended questions to create a qualitative-heavy survey (Wasti et al., 2022).

The survey comprised four sections that collectively addressed the physical, psychological and social aspects of endometriosis. The first section focused on the ways in which the participants managed the broad symptoms of endometriosis and how they affected them in their everyday lives. The second section focused on participants' embodiment of endo belly. The third section emphasised endo belly's effect on participants' well-being, connected to the ways in which they felt about their body image; and the final section focused on how participants presented themselves during times of endo belly and if their presentation influenced their sense of self. The content of the open-ended questions was guided by my lived experience with endometriosis; however, the questions were also cross-checked by my supervisor, who did not have any experience with endometriosis. This process strengthened the design by introducing a degree of critical distance, where my supervisor was able to check for any bias I was unable to identify (Dwyer & Buckle, 2009; Wilson et al., 2022).

Each section began with a closed-ended (yes/no) question that asked respondents if they were affected by various factors. The rationale for starting each section with a closed-ended question was that these items offered an accessible, familiar starting point for participants, helping them recognise and identify which aspects were relevant to them before elaborating in more detail. Presenting participants with a closed-ended question at the beginning of the survey can function as a way to ease participants into questions that disclose specific personal or sensitive experiences, which might feel pressure-inducing if introduced from the onset. This approach can support participants in sharing richer, more focused qualitative responses further on in the survey. Each close-ended question was followed by multiple open-ended questions for

participants to elaborate on their responses (see Appendix A for a copy of the survey). This design allowed for a comprehensive understanding of the layered complexities that compound women's experiences of identity, illness, societal expectations, and psychosocial impacts by integrating numerical breadth and qualitative depth into the analysis. It also allowed for the collection of rich data that capture individual and subjective meaning-making, aligning with a social constructionist perspective. This thesis focuses on the qualitative data that was generated from the survey.

While online surveys do not allow the researcher to verify whether the participant fits the inclusion criteria or to ask follow-up questions and probe participants (Harlow, 2010; Wright, 2005), they do have several advantages, which were important for my study. Firstly, online surveys enhance the privacy, agency and comfort of participants because they are able to complete the survey in an environment and at a time that suits them (Harlow, 2010). This method allowed the participants to complete the survey at a time of their choosing, in a space that they deemed suitable, and on their own digital device, giving participants as much control over the process as possible. Privacy is important to this research topic as specific qualitative questions can involve highly sensitive personal disclosures in relation to participants' medical information, illness experiences, and emotional distress they might have experienced or continue to be affected by. Therefore, establishing a method that best catered to participant privacy was essential to the care and consideration of those taking part in this research.

Secondly, an increase in the quality of data collected can be achieved through self-reported methods, such as an online survey, compared to in-person interviews (Regmi et al., 2016). This is because anonymity can encourage honest responses to sensitive topics. The removal of time pressure allows participants time to reflect and engage with thoughtful responses

and reduce any bias that might arise directly from the interviewer. Therefore, the use of self-reported online surveys in this study could provide deeper analytical insights (Regmi et al., 2016).

Finally, there are also a number of practical advantages of online surveys, including ease of advertising and distribution and automated data collection and processing, all of which lower cost and increase access to people in varying locations (Menon & Muraleedharan, 2020). Accordingly, I was able to gain the participation of diverse individuals from various locations in New Zealand over a short period of time, which is necessary to consider and analyse the various meaning-making processes people may adopt that are specific to their cultural and social realities. These sociocultural specific constructions might be missed if we only gathered data from WEIRD (Western, Educated, Industrialised, Rich, Democratic) societies, which are not representative of the global population (Henrich et al., 2010). Thus, for this study, the benefits of online surveys outweighed the disadvantages.

Recruitment

Given the use of an online survey, I sought to use a purposive approach to reach eligible participants via advertisements on social media. This is a common recruitment strategy for online surveys as it allows researchers to target eligible individuals through social media platforms such as Facebook and Instagram. Facebook and Instagram support groups have been created (e.g., Women with Endometriosis, Endometriosis New Zealand) where those who consider themselves to fit the group's criteria attach their profile to the page to become part of the support community. This approach made it more feasible to access the target population required for this study. Moreover, a free digital space facilitates access by diverse populations from broad geographic locations, potentially allowing greater diversity among participants and encouraging

a greater understanding of what constructs might be universally applicable or representative of a sample set of people (Darko et al., 2022; Gelinas et al., 2017).

However, it is possible that there may be reduced response from those from lower socioeconomic communities, who might not have internet access or a computer/digital device. However, in the Aotearoa New Zealand context, internet access is relatively high through the use of smartphones and Wi-Fi made available in various public spaces (Stats NZ, 2024). An unexpected challenge arose when a new security measure was adopted by the relevant online communities aimed at protecting the privacy of women, which denied researchers access to the community group. I was able to mitigate this development, however, by getting Endometriosis New Zealand, a prominent charity, to agree to post the advertisement on their public Instagram community.

The purposive sampling strategy proved to be highly successful. As Endometriosis New Zealand is a renowned organisation with a large national following and is supported by leading medical professionals in gynaecology, psychology and physiotherapy, its sharing of my advertisement gave credibility to my research and encouraged broad public engagement with my work. Working with Endometriosis New Zealand was also highly beneficial because its community following is highly engaged with its content, increasing the likelihood of eligible people seeing and engaging with the advertisement (and possibly even sharing it). This helped to ensure the advertisement reached the desired demographic, supporting the purposive recruitment strategy. Ultimately, participants were all recruited via social media platforms, first from Facebook, from a number of different endometriosis support pages. When this method of data collection proved to have low success, the strategy pivoted to incorporate Endometriosis New Zealand's platform on Instagram. All of the Facebook groups were closed groups which included

a criterion for individuals to pass to enable them access as members, however, the Instagram page (Endo NZ) was open for public access. All platforms that were engaged with centred around supporting women in New Zealand who have been diagnosed with endometriosis.

Permission was gained to post a digital advertisement recruiting followers of these groups to participate in an online survey, the application form for which was located on Endometriosis New Zealand's website, along with an advertisement that included a link to participate in the study (Appendix C). Individuals invited to participate in the survey were those who had been diagnosed with endometriosis via laparoscopy, lived in New Zealand, were over 16 years old, and were open to sharing their personal experiences and opinions. Eligibility was verified in the actual survey via demographic questions (age and nationality/country of residence). Those who did not meet the specified criteria were thanked for their time and interest and removed from the survey, and their responses to the demographic questions were discarded.

Participants

Sixty participants were initially intended to be recruited for this research; however, due to the overwhelming response rate, a total of 91 participants completed the survey within 20 minutes of the survey being advertised by Endometriosis New Zealand on the 13th October 2024. The response rate was received by the researcher as indicative of a strong desire among women for their voices to be heard and acknowledged, which aligned with the aim of this research. To maintain the integrity of the research, recruitment was not limited to the first 60 responses, and all 91 responses were made eligible for inclusion in the criterion process. Thirty ($N = 32$) survey responses were excluded as they did not complete the full survey, did not consent, or were not in the age range criteria. Table 1 shows both the total responses and those that were eligible after the data-screening process.

Table 1.

Total and Eligible Participant Responses

	Number	Percentage
Total participant responses	91	100%
Exclusions (some responses included more than one exclusion)	Did not complete survey: 28	31%
	Did not consent: 3	3%
	Age ineligible: 5	5%
	Total exclusions: 32	35%
Eligible participant responses	59	65%

The majority were young women of Pākehā (New Zealand European) heritage. The bulk of the group were aged between 26 and 35 years of age, followed by those in the 20-to-25-year age group. The age and ethnicity demographics of the participants are summarised in Table 2.

Table 2.

Demographics of Participants

	Demographic	Percentage
Age	20–25 years	14 (23.7%)
	26–30 years	21 (35.5%)
	31–35 years	8 (13.5%)
	36–40 years	9 (15.2%)
	41–45 years	4 (6.7%)
	46–50 years	2 (3.3%)
	51–55 years	1 (1.6%)
Ethnicity	Asian	2 (3.3%)
	New Zealand European	46 (77.9%)
	New Zealand Māori	5 (8.4%)
	Other	6 (10.1%)

Description of Qualitative Data

The average time participants spent on the survey was 20.2 minutes. After completing the survey, participants were given the option to enter a draw to receive one of four $50 vouchers and/or receive a summary of the research findings. Open-ended responses ranged from brief

comments (1–43 words) to more detailed narratives (up to 476 words). Overall, participants were very generous with the length and richness of their responses. For most open-ended questions, a large majority of responses extended beyond brief answers to more detailed narratives presented in paragraph format, despite the relatively low average time spent on the survey. In these responses, participants did more than describe their symptoms or surface-level interpretations: many responses included subjective reflections of their emotional responses, embodied experiences, and the impact their symptoms had on their sense of identity—both individually and relationally—in various aspects of their everyday lives. Therefore, the level of engagement provided rich, subjective experiences that involved meaning-making and value-based interpretations. Some variability in participation existed, where a few participants' engagement dropped off near the end of the survey, which could have been due to fatigue, as the total number of open-ended questions included in the survey was 15. Additionally, the latter questions required deeper levels of engagement and personal disclosure, which some participants may have found revealing. Nonetheless, the data are well-suited for discursive analysis as they align with the research questions and analytical aims of this study.

Ethics

This study has been conducted and guided by Massey University's (2017) Code of Ethical Conduct and was reviewed and approved by the Massey University Human Ethics Ohu Matatika 1 on the 13th September 2024 (application OM1 24/42).

Ethical considerations are essential when engaging in health research. This is due to the potential existence of vulnerabilities respondents may experience, which can be triggered by certain lines of questioning and the process of reflection. Researchers therefore need to treat sensitive topics with empathy while making sure to balance rigour in the research design. Ethical

considerations included obtaining informed consent, anonymity, confidentiality, cultural considerations, potential psychological distress for participants, data storage, and benefits to participants. These were managed in the following ways.

Firstly, it was essential for anyone who participated in the study to provide voluntary informed consent before proceeding with data collection. This meant that participants were to be provided with a comprehensive overview of all aspects of the study before consenting to participate in the research. This was in the form of a participant information sheet (PIS) that explained the purpose and description of the study, the participant inclusion criteria, the requirements of participating in the survey, how their data will be used and secured, the study involvement risks and benefits, and the participants' rights. The provision of the PIS for participants to read at the beginning of the survey helped participants to make informed decisions about whether they wished to take part in the study (Creswell & Plano Clark, 2018).

Confidentiality and anonymity were the next considerations. As research participants would be disclosing personal information on the basis that it would be kept confidential, this study took the appropriate measures to ensure the highest degree of anonymity and confidentiality of participants (Hammersley & Traianou, 2012). The research survey was online, which aided the anonymity of the participants' identities. As the researcher, I never had any direct contact with participants. As noted above, a link to the survey was posted onto a trusted social media platform run by Endometriosis New Zealand by their administrators. When participants clicked the link, they were directed to the PIS (Appendix B), which then led to the digital survey. There was no direct written or verbally recorded consent transaction between participants and the researcher. Instead, as part of the consent process, prospective participants were asked to click on a self-consent button to take part in the research. To avoid deception,

participants were asked to read the PIS, which outlined the survey details and included the researcher's contact information if anything further needed to be clarified. At the end of the PIS, there was a button that read: "By clicking on the continue arrow below, you are consenting to take part in this research". Participants clicking the button was a clear indication of consent in a digital format. Participants were then directed to screening questions which confirmed their eligibility to take part in the research and were then directed to the survey. The consent process was designed to be informative, explicitly clear, simple, and easy to navigate and understand to ensure that anyone interested in taking part in the research was fully informed before agreeing to proceed as a participant. All survey results were stored according to Massey University's Code of Ethical Conduct guidelines for storing confidential research data. This process required personal information in the form of an email address, but the anonymity of the data was protected because participants were diverted to an additional survey where this information was securely kept. Care was also taken to consider participant expectations and confidentiality in the context of re-analysing the data.

There were no personally identifiable details asked in the survey. All participant details entered in the survey were kept anonymous, and personal details for the prize draw and summary of research findings were collected through a separate link. The personal details required for the prize draw were an email address, and all participants were asked if this was something they wanted to opt into. If the participant answered yes, then they were redirected to a separate survey (Qualtrics) that collected all emails so that no survey answers could be linked to email addresses. Notably, confidentiality cannot be completely guaranteed; however, numerous efforts were made to ensure that only the appropriate amount of information required for this study was obtained.

Based on guidance from the Massey University Human Ethics Committee, additional steps were taken to ensure participant confidentiality in the reporting of findings. As the dataset was fully anonymised and participants could not be re-contacted, particular care was taken in how qualitative data extracts were selected and presented. While the re-analysis remains within the original substantive focus of the study and poses no foreseeable risk or disadvantage to participants, attention was given to managing participant expectations and maintaining confidentiality in dissemination. In qualitative research, there is a small possibility that individuals may recognise their own contributions, or that others familiar with their circumstances could infer identities, particularly where accounts contain distinctive details (Kaiser, 2009). To minimise this risk, data extracts were selected and presented in ways that preserve anonymity while supporting analytic claims. This included removing or generalising specific contextual or demographic details, avoiding the inclusion of rare or potentially identifying descriptors, and not combining characteristics that could increase identifiability. Where necessary, extracts were shortened, paraphrased, or not included if they were judged to carry a higher risk of identification. These practices are consistent with established qualitative research approaches to protecting participant confidentiality in the reporting of findings.

Participant distress and psychological well-being were considered carefully, and measures were taken to reduce the associated risk. First, there was an age requirement in the study where participants had to be 16 years and over in order to take part in the research, in line with New Zealand health and ethical guidelines to promote participant welfare and reduce harm (Health and Disability Ethics Committees, 2019; Hiriscau et al., 2016; Mathews, 2023). It is widely acknowledged that endometriosis and its symptoms can be present in individuals younger than 16; however, including this age criterion protected younger children from potentially

experiencing psychological harm arising from being involved in psychological research, as they might not have the required coping mechanisms needed to mitigate psychological stressors (Dun et al., 2015; Marsh & Laufer, 2005; Nielsen et al., 2023). Furthermore, the age requirement allows adolescents the autonomy to make informed decisions about consenting, which literature, law and ethics recognise them to be capable of doing (Mathews, 2023).

Secondly, there was a likelihood of distress occurring that could arise in response to the survey questions, either during or after the completion of the survey. Given the questions asked participants to reflect on past instances concerning symptom severity, the physical and psychological impacts of symptoms, and internal and external perceptions of body image in relation to identity, there was a likelihood that they could cause participants to relive distressing events and experiences resulting in emotional distress, anxiety, and feelings of confusion. In the PIS, therefore, participants were informed about the nature of the study and questions that would be asked as well as acknowledging this might be distressing. Additionally, they were informed that they were able to skip any questions or withdraw from the study at any time, knowing that only completed survey responses would be used in the research. All participants, including interested parties who did not ultimately continue with the survey, were provided with a list of health services at the end of the PIS. Participants were then provided with the same information at the end of the survey.

Cultural safety is a significant ethical consideration in the research context in Aotearoa New Zealand, as we are a nation that acknowledges and respects the cultural diversity of Māori, who are tangata whenua (the Indigenous peoples of Aotearoa New Zealand) (Bryson & Hosken, 2005; New Zealand Psychologists Board, 2024). A cultural advisor was consulted prior to data collection, and I had discussions with my supervisor on how to uphold whakapapa

(relationships), tika (research design), manaakitanga (cultural and social responsibility), and mana (justice and equity), as guided by *Te Ara Tika: Guidelines for Māori Research Ethics – A Framework for Researchers and Ethics Committee Members* (M. Hudson et al., 2010). Although the research was not centred around Māori participants, I ensured the methods where participant engagement was evident in the research design were conducted in a way that considered and respected the principles of Te Tiriti o Waitangi | Treaty of Waitangi (1840), the founding document of Aotearoa New Zealand.

Cultural considerations considered included constructing the language of the survey with intentional sensitivity towards cultural appropriateness. As social constructionism acknowledges the existence of multiple truths produced through the meaning-making of various sociocultural realities, the construction of language is significant to how culturally specific individuals interpret or engage with the questions being asked. Although the performing of this task was subjective, my supervisor and I made efforts to construct language with this sensitivity in mind, and consulted a cultural advisor before data collection. Additionally, in order to acknowledge participants' time and effort in a culturally appropriate way, we included the cultural practice of koha in the form of gift cards through a prize draw as mentioned above.

Data Analysis

The data analysis was guided by reflexive thematic analysis (RTA; Braun & Clarke, 2019), an expansion of Braun and Clarke's (2006) six phases of thematic analysis: (1) familiarisation with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) writing the analysis report. The expanded version emphasises researcher reflexivity, as the name indicates.

RTA acknowledges the researcher's active role in shaping the research design, the data generated, and the interpretation of the data. This acknowledgement is based on the principle of transparency as a means of evaluating the quality of qualitative research. Researchers must be transparent about their research aims, assumptions and processes, including analysis methods and the purpose behind what they are doing and how they record this in their research methodology (Attride-Stirling, 2001; Braun & Clarke, 2006). In qualitative research, the researcher is classically described as the primary instrument of data collection and analysis (Janesick, 2000; Lincoln & Guba, 1985), meaning that their interpretive lens, positioning, and reflexivity are integral to the production of knowledge. It is therefore essential for the researcher to be transparent regarding their chosen theoretical positioning and the assumptions and values that guide their analytic method, as their presence and subjectivity are inseparable from the research process (Guba & Lincoln, 2009).

RTA can be used to identify, analyse and seek out patterns in qualitative data relevant to the research questions. Codes and themes are organically constructed through the researcher's interpretation. In RTA, themes are defined as having a central organising concept (Braun & Clarke, 2019)—that is, a core concept that connects and organises the material categorised, making each theme significantly more than just a summary of responses. For example, in my analysis, one theme I identified was "Hiding in Plain Sight", where the central organising concept portrayed participants as using modes of concealment, withdrawal, and social isolation during times they experienced endo belly to shield their physical appearance from perceived societal judgement. This concept groups codes such as clothing, self-consciousness, embarrassment, hiding and unattractiveness as functioning as protective mechanisms to avoid social visibility of their "deviant" bodies.

Additionally, to ensure that the richness of the data collected is utilised, an intricate inductive approach was employed, where codes and themes were data-driven, as well as a latent approach to thematic analysis, which overlaps with aspects of discourse analysis, remaining in line with a constructionist paradigm (Braun & Clarke, 2006). Generating themes is an interpretative process that draws on the theoretical frame to make sense of the data (whether realist or other). Hence, generating high-quality themes that are meaningful and have a degree of depth involves more than simply describing what participants have communicated. Rather, the researcher is engaged in *interpreting* meanings—either semantically (analysing the meaning of the research at face value) or, as in the case of my research, latently (analysing the underlying meanings, and assumptions based on what is said, where discursive patterns and sociocultural ideologies are interpreted) (Braun & Clarke, 2006). Following a constructionist perspective involves focusing on the discourses that inform participants' responses, which aligns with the latent analysis procedure of my research. Combining a constructionist perspective with latent analysis enables the researcher to critically explore shared meanings, multiple existing truths, and contrasting interpretations of knowledge produced within participants' accounts. This approach aligns with the research aims and objectives and with the epistemological assumptions of the study (Braun & Clarke, 2019).

In terms of the actual process, RTA follows Braun and Clarke's (2006) six-step process, which I have outlined below in relation to the analysis of my specific data.

Familiarisation with the Data. This phase consisted of me, as the researcher, familiarising myself with the data by reading survey responses multiple times to increase my awareness of the dataset collected. I exported the data responses from Qualtrics into an Excel spreadsheet and printed a hard copy. I read and re-read the participant responses over a period of

a week. This process allowed me to immerse myself in the responses. It was also time-consuming as my survey involved many questions and the number of respondents was significantly greater than anticipated, as I aimed for 60 participants prior to exclusion criteria, and instead received 91 survey responses. However, the positive that came out of this was that I had access to a large dataset with high levels of engagement, with participants providing in-depth responses appropriate for RTA. Given that I had collected these data for my honour's research, they were not new to me. That study explored different concepts, aims, objectives and research questions. However, it was still important to sit with the data again to re-familiarise myself with them, in light of my new research questions and theoretical framing. I therefore allowed time and space for reading the data in a different way, one which aligned with my current epistemological assumptions and initiated the generation of new ideas surrounding the data. This initial phase encouraged the acquisition of new understandings, interpreted directly from the available data, which helped me to avoid generating initial codes that were redundant or insufficient.

Generating Initial Codes. Once I felt a great sense of familiarity with the data in connection to my epistemological assumptions and research aims and objectives, I then moved on to creating initial codes and segmenting the data into latent groups. I generated codes manually by using highlighters to identify different codes and recorded them through the creation of tables in Microsoft Excel. I began with semantic engagement with the data, where I systematically worked through all questions of each section, labelling explicit surface-level content I initially identified (e.g., bloating, body image, clothes, external judgement, embarrassment, self-worth, physical discomfort). This served as a method of entry into analysis, allowing me to identify early patterns from which I could interpret deeper latent meaning.

As the analysis involved exploring a large sample set, developing a coding framework was integral to dissecting specific and manageable groups of meaningful information, which in turn informed the production of potential themes and patterns. The qualitative data responses were very rich and meaningful; therefore, individual extracts of data were coded in multiple ways to avoid a reductionist approach in my analysis. It was common for multiple codes to be applied to individual responses where participants mentioned more than one aspect of concern (e.g., bloating, body image and external judgement). This captured the complex, multilayered aspects of meaning-making that expose the nature of the human experience. Building upon my initial semantic content observations, I constructed codes that were conceptually driven and interpretive of participants' discursive experiences, which were overseen and agreed upon by my supervisor (e.g., appearance/beauty standard, visibility, reproduction, performing expected womanhood, control, partners, looking pregnant, alternative/challenging talk).

Searching for Themes. Once I was satisfied that the codes produced across the dataset would enable the construction of latent theme interpretation, I focused on sorting the codes into interpretive patterns that were intentional reflections of the lived experiences drawn from the participants' responses. At the beginning of this process, the pre-identified headings, which determined the survey structure, helped me to group relevant surface-level codes and identify overarching themes and patterns. However, over the course of the thematic analysis, patterns that I formed through conceptually driven coding enabled the fusion of previously structured survey headings, which led to the generation of latent themes (e.g., the visible overlapping of coding identified in survey responses).

Reviewing Themes. This phase included the refinement of my broad themes and patterns, where I reviewed the integral value of my codes existing in standalone themes or

whether they would better exist in integrated, coherent patterns (e.g., the attractive female body, women as a spectacle, motherhood mandate, reproduction and female value, self-sacrificing woman, discourse of traditional womanhood, unruly body, visibility, reproduction). This included a stage of reworking and re-evaluating themes to determine if they appropriately aligned with the research aim and objective, or whether some codes should be removed from this particular analysis. All themes and codes should work together to tell a relevant story about data responses in association with the research questions.

Defining and Naming Themes. This phase was a continuous process of development where ongoing refinements took place. The first step towards naming and defining themes involved the revision of the individual codes I had identified in the data through a cohesive lens, which allowed me to identify patterns. These patterns were then grouped to form provisional themes based on the researcher's interpretation of constructed shared meaning. Provisional themes were then reviewed to ensure that the elements that made up the themes fit together in a way that was meaningful, whereby some previously identified themes were reframed or removed altogether as they no longer aligned with the research aims. The themes that were retained remained consistent across the participant responses and aligned with the research questions.

The initial naming of the themes reflected the overall discursive functioning and analytic constructions that underlined the themes rather than those that were mere descriptions. The more I immersed myself in the data and report writing, the more I found myself making small but impactful changes as the depth of interpretations developed through the integration and ongoing engagement of the participant accounts.

Writing the Analysis Report. In this phase, I evaluated my findings and worked towards creating a narrative that consisted of interpretive analysis of the categorised themes and patterns

emerging from participants' responses and linking them to the research questions. All themes remained distinctive and included rich interpretation with examples of open-ended responses to support different themes, which are presented in Chapter 3.

Braun and Clarke (2019) highlight that thematic analysis is not objective and recognises the researcher's subjectivity as highly influential regarding how the data are analysed and interpreted. Therefore, the researcher's consistent reflexive process in the RTA is essential to ensure the authenticity of the data analysis. My reflexive positioning in this research stems from my orientation as an insider of the group being studied (Dwyer & Buckle, 2009). As I was part of the group being studied, this method kept me accountable through constantly engaging in reflexivity, enabling a depth of engagement with the qualitative data collected and the social meanings participants' lived experiences communicated.

Reflexivity

The process of reflexivity in analysis is highly influential, as it communicates the structures that inform the knowledge that is produced (Lazard & McAvoy, 2020). In qualitative research, reflexivity is utilised as a method of quality control, in which awareness of the researcher's partiality and positionality, as well as their ability to consistently reflect on this positioning, aims to prevent the researcher's biases from predominantly guiding the study's outcome. Transparency and disclosure of the researcher's personal experiences, ideological understandings, and values provide insight into how the research process might be impacted by the degree to which they can see and understand varying knowledge systems through the interpretive approach that acknowledges sameness and difference (Lazard & McAvoy, 2020).

This is especially relevant when researchers are closely connected to topics they are studying due to personal beliefs or experiences, as they can carry into analysis pre-existing

unconscious understandings and conceptualised truths. If not unpacked, the researcher's unconscious bias runs the risk of compromising the study's quality and integrity. Therefore, my reflexivity in this research process called for a degree of transparency and public openness, as even though I was guided by the epistemological assumption of feminist social constructionism, my positionality may have contributed to underlying beliefs that may have shaped ways in which I constructed meaning and interpreted the participant responses (Lazard & McAvoy, 2020).

There are multiple approaches to reflexivity in data analysis; however, RTA acknowledges the researcher's active role in knowledge production as central in the process of analysis, as this is where the researcher's approach to analysis is fundamentally located. Therefore, the conceptualisation of themes and codes in analysis is understood to represent the researcher's personal interpretations of meaning-making and understandings that transpire from the dataset (Braun & Clarke, 2019). RTA recognises the researcher's knowledge production as specifically emerging from the intersection of the dataset, the theoretical assumptions that guide the analytic process, and the researchers' implemented analytic skills and resources. In this process, the researcher identifies research values and assumptions that may exist in the data, requiring the researcher to make interpretive choices and judgements about them. This framework proposes that due to the researcher's unique subjective experiences, understandings, and social interactions, it is expected that significantly diverse patterns of shared meaning that underpin theme conceptualisations will be produced and vary between researchers (Braun & Clarke, 2019). In this vein, RTA is an appropriate approach for the conceptual and theoretical underpinning of the research questions of this study because it highlights the complex understanding of participants' diverse perspectives of endometriosis and identity, while requiring

the researcher to reflect on their own positioning in the analytical process (Braun & Clarke, 2021).

My reflexive positioning in this research stems from my orientation as an insider of the group being studied (Dwyer & Buckle, 2009). This means that I hold preconceived ideological understandings from my experiences and social interactions regarding endometriosis and identity. I am closely connected to this study because I was diagnosed with stage-three endometriosis at 28 years old via laparoscopy, after years of subjectively experiencing endometriosis and its symptoms both physically and psychologically. I had deep endometriosis prior to my removal surgery, in which scar tissue was found on my bowel, bladder, and abdominal muscles, which subjected me to a consistent experience of endo belly and varying degrees of pain. I had been dismissed by doctors ever since I became symptomatic in my teenage years, and my experience was either minimised or normalised as period pain. I was given hormonal contraceptives and over-the-counter painkillers as mediators. The experience of symptoms caused consistent, unavoidable fluctuations to my body image, and at times I no longer knew what my body looked like. I utilised clothes as a tool to alleviate my pain and conceal my swollen stomach in hopes of avoiding negative external perceptions. As someone who identifies as a woman and has been shaped by Westernised expectations of femininity, my illness experience has included the way in which I evaluate myself and my feelings towards self-identity. This has influenced me to explore other women's experiences of living with endometriosis and how the commonly experienced symptom, endo belly, might shape their sense of self.

My positioning in this research comes with positive and negative influential factors that I am aware of, which require me to engage in an ongoing process of critical self-reflection. The

decision to contact Endometriosis New Zealand to advertise the research survey stemmed from my prior engagement with their social media content as a method of self-help. I was aware of the organisation's large Instagram following and the quality of the content they shared. Additionally, I was familiar with the organisation's encouraging of their followers to participate in psychology-based research, which reflects the strengths of my insider knowledge in shaping data generation and the research design process.

Additionally, reflexivity requires me to reflect on how my theoretical assumptions, background and values shape the data analysis. The process of reflexivity encourages the production of rich, high-quality research that encompasses my transparency, active engagement, interpretation, and theoretical awareness to help construct themes in RTA. My personal experience with endometriosis, endo belly, and identifying as a woman in Western society were of value to the analysis, as they allowed me to identify nuances that existed in the data, and to competently engage with and interpret profoundly personal experiences. My insider orientation encompasses skills such as my ability to empathise with participants' experiences from a place of lived experience, which enhances higher readability, comprehension and understanding of the data.

However, my insider orientation carries with it my pre-existing knowledge systems and take-for-granted understandings deriving from my own experiences, which might interfere with how I interpret the data. This could lead me to unconsciously favouring my established ways of meaning-making and misrepresenting the data by diluting any contrasting or oppositional constructs of knowledge expressed by participants. In order to mitigate the influence of my own lived experiences and truths on my interpretation of the participants' narratives, I actively and ongoingly engaged in reflexivity from the process of data familiarisation and through the

development of codes and themes in the analytic process, with the intention of bringing the participants' experience to the forefront over my own (Dwyer & Buckle, 2009).

Chapter 3: Analysis and Discussion

This chapter presents the key findings of my research, situated within previously explored literature and supported by current psychological research. My research aimed to investigate how individuals with endometriosis—particularly those experiencing "endo belly"—construct and negotiate their femininity and identity in dominant Western sociocultural discourses, specifically in relation to bodily appearance, reproductive capability, and normative gender ideals. As outlined in the previous chapter, reflexive thematic analysis (RTA) was applied in a Big-Q qualitative framework (Kidder & Fine, 1987; Murray & Chamberlain, 1998). The analysis was grounded in a feminist social constructionist epistemology and used a discursive analytic lens. The analytic approach guided the construction of the main themes identified, each of which captured the prevailing illness experiences at the intersection of Western feminine identity as constructed through participants' accounts.

Four key themes emerged from the RTA, with Themes 1–3 each having two subthemes. Together they encapsulate the lived experiences shared by the women who participated in my study:

1. **"It Makes Me Feel Like Less of a Woman": Endo Belly as a Disruption of Normative Femininity**
    a. Endo Belly and the Language of Gross Bodies
    b. Endo Belly as a Threat to "Healthy" Feminine Appearance
2. **Striving to Perform Ideal Womanhood: "We Have to Put On a Brave Face"**
    a. Hiding in Plain Sight: Appearance-based Body Regulation
    b. Holding It Together while Falling Apart: Silence as Concealment and Coping
3. **The Enemy Within: Battling and Making Peace with the Unruly Body**

a. My Body Betrays Me: Battling Gross Bodies
b. Taming the Enemy: Acceptance through Bodily Regulation—"I Know It Will Go Away"

4. **Rewriting the Rules: Redefining Femininity and Resistance**

Collectively, these themes assemble a central analytic story whereby symptoms of a gynaecological chronic illness are constructed as an embodied experience where femininity is threatened, regulated, negotiated, and redefined, consequently shaping how women construct their sense of self and identity.

I quote extracts from the data for illustration. As my participants shared written answers in an online survey format, I have presented participant quotes verbatim, as they were originally obtained, including spelling and grammatical errors. Additionally, given the size of my dataset and the format of responses, I assigned participants a numerical identifier rather than a pseudonym to protect their confidentiality.

Theme 1. "It Makes Me Feel Like Less of a Woman": Endo Belly as a Disruption of Normative Femininity

This theme captures descriptions of my participants' experience of endo belly and its symptoms in relation to gendered body norms. I focus on how participants negotiated their identity in relation to Western standards of femininity, which propose how they *should* look and behave. I show how participants frequently positioned themselves as a failure of womanhood, describing feelings of self-consciousness due to the perception of external judgement and the fear of becoming socially negated (Bordo, 2002; Carson, 2004; Fahs, 2018). As one participant expressed, "I go through depressive episodes when I am having an endo bloat, and I feel like I am not good enough" (R72). This theme consists of two subthemes. The first subtheme focuses

on the appearance of endo belly constructed as "gross" in the participants' responses, while the second subtheme highlights how the participants draw on healthism discourse to construct endo belly as a threat to "healthy" femininity.

Theme 1a. The Language of Gross Bodies

First, I consider how endo belly was rendered a visibly "gross" and a distressing symbol of failed femininity in response to dominant gender discourses that express disgust towards the deviant body (Fahs, 2017a & 2017b). Endo belly was frequently depicted as a highly visible and distressing disruption to cultural ideals of femininity, particularly the thin, composed, and attractive female body (Bordo, 2003). The participants often described endo belly drawing on what Fahs (2017b) refers to as the "language of gross bodies" (p. 93) to mark their bodies out as a visible deviation from dominant ideals of thinness and attractive femininity. Across accounts, participants described feeling "gross" (R33, 60, 70), "fat" (R60) or "ugly" (R70), constructing endo belly as a site of disgust. Using the language of gross bodies, the participants frequently depicted their bodies as outside of what is culturally sanctioned as attractive or acceptable. The following quotes highlight how the language of gross bodies shaped women's relationships with their bodies:

> I feel swollen and unsexy. (R28)
>
> No one likes a fat woman who looks pregnant half the time. (R50)
>
> It makes me feel like I'm not attractive because my tummy sticks out in everything I wear. It makes me have negative thoughts about how I look, and that people don't think I'm attractive because I look pregnant. (R22)

> Sometimes I feel less feminine as flare-ups can be all the time, and then you're always looking like you have just got out of bed, as that's the comfiest thing to wear. (R75)

In these extracts, endo belly is equated with unattractiveness. Rather than neutral observation of bodily appearance, the adjectives "swollen", "unsexy" and "fat" describe endo belly with implicit value judgements. The conflation of "fat" with "looks pregnant", communicates deviation and misalignment with the ideal, with "half the time" emphasising the temporal extent of this deviation. In particular, the adjective "unsexy" explicitly links what is deemed desirable with others' perceptions, especially the male gaze (Bordo, 2002). The gaze of desirability is extended in the subsequent extracts to consist of "no one" (R50) and "people" (R22) more generally. Such universal statements generalise social judgement in line with dominant sociocultural ideals of feminine beauty, highlighting endo belly as a visible disruption to idealised femininity. Even neutral descriptors like "bloating" became loaded, as participants described feeling less feminine, socially unacceptable, or sexually undesirable, because of both the physical manifestation itself and measures taken to mask it (e.g., wearing loose-fitting clothing). These responses highlight how the language of gross bodies shapes women's relationships with their bodies, reinforcing the need for concealment, which I discuss further below.

Theme 1b. A Threat to Neoliberal Femininity

The discourse of healthism is prominent in the responses captured by this subtheme. Healthist discourse privileges the *appearance* of being healthy and, importantly, holds individuals responsible for constantly working towards staying healthy (Crawford, 1980). A consistent pattern across participant responses was the construction of endometriosis as a threat to women's ability to conform to neoliberal femininity. Drawing directly on dominant Western

assumptions about how the female body should look and work, the participants often communicated that endo belly meant their body was "not working how it should", depicting their bodies as failing to conform to contemporary ideals of attractive femininity. For example, "Not good as it's [abdomen] *supposed* to be flat" (R29) indicates taken-for-granted understandings of the female body, where a flat stomach is considered normative and failing to achieve this makes the participant feel "not good". In this vein, the endo belly body was implied to be part of a malfunctioning machine, as in the statement, "Not having control over your body or knowing your body is not working how it should is hard" (R33). The machine metaphor exists in biomedical discourse and supports the idea of individual control over the body, reinforcing the judgement of personal failure when normative expectations of femininity are not met through individualised efforts of control (Sayer-Jones & Sherman, 2023; Segal, 1997).

My participants often emphasised the necessity of striving for the Western ideals of female bodily appearance and positioned themselves as failing or falling short of appearance ideals due to persisting physical manifestations of endo belly. For example, in the following extracts, we see the discourse of healthism, with its stringent gendered body ideals, positioning women as responsible for constant self-management:

> There's so much online that says just do xyz and you will get a flat stomach, just cut out carbs, lower your cortisol, just get 8 hours sleep, just do these 4 exercises and you will get a flat stomach, but it's just not the same for those struggling with endo, which can make it really confusing and leave you feeling like you're in a washing machine going round and round different methods and never progressing/getting anywhere ... It can make you feel like you're not trying hard enough and make you feel as though it's indicative of your character/being stagnant. (R6)

> I feel like my hard work with eating/exercising isn't working. That it's never going to get better. (R49)

Diet, exercise, sleep, and hormonal maintenance appear in these extracts as health directives women are required to maintain. R6 emphasises "just do xyz" and lists health directives (cut carbs, sleep 8 hours, do 4 exercises). The repetition of "just" makes these sound simple and universally applicable, but she immediately contrasts this with the reality of endometriosis. The metaphor of being "in a washing machine" conveys the exhausting, repetitive cycle of trying different methods and "never progressing". Importantly, R6 links lack of progress to *character*, saying stagnancy signals a personal flaw. This shifts the issue from physical health to moral worth. This example shows how participants described maintaining their physical health as more complicated than following do's and avoiding don'ts.

R49 echoed these sentiments. Despite "hard work", she experienced futility ("never going to get better"), highlighting how effort is demanded but not rewarded. The implication is that women have to constantly strive to work on their bodies to maintain hegemonic ideals of femininity. Additionally, this discourse reinforces Western normative construction of the effortless, comfortable, and confident woman as the "properly feminine subject". The neoliberal discourse of healthism constructs women's health, well-being, and appearance-related ideals as moral obligations to be achieved independently, equating women's discipline and continuous effort with virtue. This discourse constructs health and well-being as a personal achievement, attained through consumer choices and behaviours as a part of this active pursuit, as opposed to relying on social supports. Consequently, illness and poor health are often viewed as personal failures, leading individuals to take responsibility for the maintenance of their bodies and minds (Beijbom et al., 2023).

These extracts show how the healthist discourse features in the participants' responses about their non-conforming bodies, especially in how they work (in vain) to try to rectify this, with a lack of results rendered a personal failure rather than due to contextual factors, such as living with endometriosis. Rather than challenging the ideal itself, participants expressed feelings of moral inadequacy, thus restricting subject positions through which women who experience endo belly might find peace and contentment. Instead, participants communicated aversion towards their own body, constructing it as something they were at war with, and inhabiting discourses of struggle and control.

Theme 2: Striving to Perform Ideal Womanhood: "We Have to Put On a Brave Face"

The female body was commonly constructed as a spectacle, with endo belly as a highly visual marker of socially unacceptable deviation from the thin, composed and ideal feminine body (Bordo, 2002; Carson, 2004). The participants commonly depicted the visible disruption to their body caused by endo belly as directly contradicting idealised feminine identities, prompting various strategies to try to conceal the disruption and present the illusion of normative femininity. In this theme, I consider participants' accounts of their efforts to hold together a culturally recognisable performance of femininity and the emotional toll they paid when that performance faltered (Butler, 1988). Participants reported navigating the exhausting physical experience of endometriosis while striving to maintain normative performances of neoliberal femininity. I show how the participants positioned themselves in contrast to imagined "normative" women—those unaffected by the illness—highlighting how dominant discourses frame them as lacking, broken or inadequate. Through these comparisons, they expressed frustration at the unfairness of societal ideals that excluded or invalidated their lived experiences and constructed themselves as falling short of what it means to be a "successful" woman in

neoliberal society. The participants described efforts to conceal both the physical and psychological impacts of chronic symptoms in order to appear composed, controlled and feminine, and I discuss each of these as subthemes below. Their accounts point to the sociocultural pressure to conform to gendered expectations they experienced and their internalised sense of failure when they could not do so.

Theme 2a. "I Have to Hide It": Appearance-based Body Self-regulation

In this subtheme, I focus on descriptions of practices of appearance management and body policing of a body that deviates from the norm (Fahs, 2017b, 2018; Frith & Gleeson, 2008, 2008). Many participants described feeling the need to conceal their bodies in response to a sense of hyper-visibility, and the threat of negative judgement ran through participants' narratives. They disclosed fears of being judged as unattractive or having their symptoms misunderstood, with one stating: "I worry about being perceived as pregnant. I worry about being less attractive to a partner … I developed anorexia because of it" (R30). These fears were associated with heightened social visibility due to endo belly and the construction of the female body as a spectacle (Carson, 2004). Some participants reported needing to legitimise their deviation from ideal femininity in the eyes of onlookers, with one stating: "[S]ome other women don't bloat, and I do. However, I have a reason for the bloating, but I'm not going to go around and tell everyone I have endometriosis, that's why I bloat" (R29). Such comments depict a sense of concern about being judged by uninformed observers, where being read as having an unruly, deviant body is positioned as a negatively perceived identity that requires explanation, which this participant resisted.

The participants often drew on the language of gross bodies discussed under Theme 1, which depicts the aberrant or "grotesque body [that] is open, protruding, irregular, secreting,

multiple, and changing" in contrast with the ideal Western body that is "self-contained, symmetrical, and sleek" (Carson, 2004, p. 99). Women reported self-scrutinising and judging their ill bodies when experiencing endo belly, describing their bloated belly as a sign of shame and failure, as in this example:

> It makes me upset as I feel like I have to hide it, or people will ask questions or judge me. … I think my current partner must think I have a bigger stomach than other women … This impacts our physical relationship because I can be really self-conscious and want to hide my body. (R27)

Here endo belly is compared to other women's bodies and, once again, depicted as a visible deviation from the norm, thereby potentially provoking questioning and judgement from others, including her intimate partner. She constructs her ill body as undesirable not only in the broader social context ("people") but also within intimate parameters, highlighting the male gaze as persistent even in intimate spaces. The phrase "have to hide" accentuates the obligatory nature of concealment, shaped by fear and a sense of social compulsion, showing how dominant norms of femininity regulate women's embodied gender performances in both public and private domains (Ryan et al., 2021).

The participants frequently described extensive self-monitoring to avoid exposure to judgement from external observers through appearance management—concealing or hiding deviant bodies (Rudd & Lennon, 2000)—as shown in the following examples:

> I never used to have negative thoughts about my body, but now it is fairly regular. I want to wear bikinis/crop tops/tighter dresses/skirts, but I am too self-conscious to do this. Lots of my friends are skinny/lean (like I use to be) so now I feel self-conscious hanging out with them. (R72)

> Limits my outfit choices as I can't wear my regular clothes 😂, painful so limits my ability to do general tasks, makes me want to hide away because of how I look. (R74)

These quotes emphasise the connection between the appearance of endo belly and the social practice of concealment. The participants describe feelings of self-consciousness as leading to a desire to hide or to conceal their bodies during flare-ups. The first (R72) emphasises her difference from friends' normative bodies, constructing her body as a site of social exclusion. Likewise, in R74's reference to her inability to wear "regular clothes", "regular" operates as an evaluation of normalcy rather than a neutral descriptive adjective. Using clothing for appearance management was commonly described, resonating with research showing how clothing practices act as self-regulatory, coping strategies in relation to body distress, with women reporting "using clothing strategically to alter and manipulate the appearance of the body and their feelings of bodily anxiety … to present the best possible image of the body" (Frith & Gleeson, 2008, pp. 259–260).

Although concealment was identified as a common social practice during times of endo belly, the participants described a shift towards withdrawal when methods of concealment were no longer a sufficient form of body regulation. Some participants recounted that this appearance work became too onerous or impossible when symptoms became too visible or unmanageable, so that they resorted to completely withdrawing from public and social engagements, as shown in the following quotes:

> For me, in terms of my mental well-being, it's a lot to do with frustration that I have to plan a lot of things in my life around having endo. I don't plan on going away from home during my period (thankfully it's regular so I can do this), I worry about how it will affect

> things like going overseas in the future and things like that which are all invisible to other people so I suffer silently. (R4)
>
> It's hard enough to deal with symptoms of endo, but physical effects like this make you want to isolate more and hide. (R30)
>
> [Y]ou end up planning your life around your cycle and having to cancel plans which then affects the social aspect of my well-being. (R36)

Similar to appearance management, social withdrawal is described as involving self-monitoring ("plan", "worry" [R4) and framed as something the participants feel compelled to do ("have to" [R4]; "make you" [R30]; "having to" [R36]). Self-surveillance and concealment are construed as routine protective strategies. These quotes reflect how the visibility of endo belly intersects with cultural discourses of self-control, appearance, and feminine success, as shown in studies about premenstrual women's appearance management (Ryan et al., 2021).

Participants also described being mistaken for pregnant due to endo belly, which prompted intrusive encounters and reinforced expectations to justify their bodies. These experiences reveal how endometriosis disrupts normative assumptions that position motherhood as the expected outcome of femininity, provoking shame, grief, and feelings of failure (French, 2025). As one participant noted, "I want to be pregnant, but I'm not, yet I look pregnant" (R34). Her situation was experienced as a painful irony, intensifying distress linked to infertility and social judgement. Overall, these accounts show how endometriosis challenges gendered ideals of fertility, bodily control, and femininity, with significant consequences for women's sense of self. It was associated with feelings of failure and deviance, as well as fear of social judgement. Taken together, the participants' accounts of concealment and social withdrawal suggest the

intensification of appearance-based self-regulation to achieve social acceptability and worth (Frith & Gleeson, 2008; Ryan et al., 2021).

These practices are shaped by dominant discourses of heteronormative attractiveness and sexual desirability, reflected in participants' self-comparisons and use of value-laden descriptors (e.g., "gross", "different", "less feminine", "unsexy"). Feelings of shame, disgust, and the urge to hide illustrate how Western ideals of femininity regulate gender performances, encouraging alignment with an idealised feminine appearance to avoid the identity of the other (Butler, 1990; Fahs, 2017a). As feminist researchers argue, practices like concealment are not purely personal or emotional responses but culturally produced strategies for managing bodily deviance within neoliberal gender regimes (Ryan et al., 2021). These findings, therefore, underscore the ongoing negotiation of body image in response to social surveillance (Frith & Gleeson, 2006, 2008; Ryan et al., 2021).

Theme 2b. Holding It Together while Falling Apart: Silence as Concealment and Coping

The participants described having to suffer in silence about the psychological and physical impact of chronic symptoms in order to manage the social and relational aspects of living with an invisible illness. They constructed experiences of minimisation, dismissal and invalidation, especially by medical professionals, as cultural signifiers of gendered expectations, compelling them to mask distress and maintain an illusion of composure. Self-silencing was described as occurring in various internal and external ways, with participants suppressing visible suffering to align with neoliberal feminine ideals of resilience and bodily control (Bartky, 2012; Seear, 2009). The following extracts highlight self-silencing as both a coping strategy and a gendered performance, enacted to meet social expectations of womanhood:

> Other women get to enjoy theirs [lives] without daily pain and discomfort and feel comfortable to wear what they want when they want. No need to try and hide a bloated stomach or hide pain when around others. (R54)

> Having an invisible illness already feels forgotten and like having to constantly prove yourself to others, medical professionals included. Having a bad physical sense of self just contributes to the mental health issues of not being functional enough. (R30)

> We have so much pain, and we have to put on a brave face because 'it's only a period problem'. And when we say we are in pain people tell us to take a Panadol [pain pill] or something. (R69)

Here R54 positions "other women" as the normative ideal against which she contrasts her experience of needing to hide bloating and pain. The necessity of hiding illness is extended in the second extract, in which R30 links maintaining the invisibility of her illness to a constant need to prove herself, suggesting pressure to appear functional. The wider cultural assumptions and expectations that encourage silencing are highlighted in the final quote (R69). Here, emotional masking ("put on a brave face") is depicted as necessitated by wider trivialising of women's pain, especially related to menstruation or reproductive issues (Seear, 2009). This refers to the gendered normalisation of pain in which "women's pain is normalised to the extent that it is sometimes described as part of women's nature or fate" (Kosi, 2025, p, 50).

As well as experiencing pressure to remain composed and silent about their distress, participants also described struggling to maintain what they understood as a "balanced" or "normal" life while managing chronic symptoms. They described being unable to maintain a balanced lifestyle due to the chronic and unpredictable nature of their symptoms, which limited their ability to participate in behaviours associated with health and well-being. Participants

constructed a balanced life through the lens of neoliberal healthism and feminine ideals, involving regular exercise, healthy eating, and productivity (Bartky, 2012; Crawford, 1980). They positioned themselves as falling short when illness disrupted their ability to meet these expectations, as the following quotes illustrate:

> Yes, not good about my body and like I can't exercise because I don't feel well and eat badly over this time. (R67)

> Pain and bloating take up so much of my energy that I don't have time to cover the basics needed for well-being. (R76)

> It's frustrating … I can't live the normal life a mid-20s woman should be living!! (R37)

In the first quote, R67 links feeling "not good" about her body to the inability to meet health directives such as exercise and diet. Her use of the words "not good" and "badly" adds a moral dimension to the description. In the next quote, R76 personifies pain and bloating as consuming energy meant for maintaining well-being, highlighting the forced trade-off between illness and productivity. The final extract sees R37 contrasting what she "can't" do with what women her age "should be" doing, signalling expectations of normalcy and feminine responsibility.

These extracts show how gendered expectations and healthism encourage self-management and the performance of normalcy. When symptoms prevented them from meeting these standards, these participants positioned themselves as failing—producing frustration, emotional exhaustion, and negative self-evaluation. This language reflects the moral pressure and self-surveillance embedded in neoliberal discourses of feminine self-discipline (Crawford, 1980; White, 2000), illustrating how endometriosis disrupts culturally sanctioned ideals of a "balanced" female life.

Participants also recounted how endometriosis symptoms shape how they navigate another key domain of normative femininity: sexual desirability and sexual functioning. They described how symptoms such as pain, hormonal weight gain, and feeling unattractive when experiencing endo belly disrupted their desire and ability to engage in sexual activity. Their accounts presented sexual functionality as a key component of feminine worth, reflecting wider sociocultural narratives that equate desirability, bodily control, and sexual availability with normative femininity (Tappin et al., 2024; Wood, 2017). For example:

> We can't have intercourse and I feel ugly and am in pain so am not interested in anything sexual. (R48)

> I feel less attractive around my partner and my partner feels bad for me and this leads to less intimacy. (R57)

> I am in pain, I can't have a normal sex life. I have gained weight due to hormones. It was hard before I got diagnosed because everyone tells you sex and your period is supposed to hurt. (R50)

In the first quote (R48) links the inability to have sex with feeling "ugly" and experiencing pain, framing sexual participation as contingent on performing attractiveness and physical ease, in alignment with Tappin et al. (2024) who highlight the expectation of women to effortlessly appear as sexual subjects of desire in accordance with mainstream media. Likewise, diminished desirability is connected with relational consequences in R57's quote, suggesting that reduced intimacy confirms the cultural script that women must be sexually appealing to sustain relationships. In the final extract, R50 positions her experience against a taken-for-granted "normal sex life", highlighting how cultural messages ("everyone tells you … supposed to") construct sexual availability as a learned, gendered expectation, whereby neoliberal culture

constructs sexiness as the individual responsibility of women to constantly discipline their bodies, maintain sexually attractiveness, and successfully execute male pleasure to achieve idealised femininity (Wood, 2017). These messages echo the gendered normalisation of pain discussed above (Kosi, 2025; Seear, 2009).

These accounts show how dominant neoliberal discourses of femininity shape women's interpretations of disrupted sexual functioning, framing endometriosis symptoms as a deviation from what women are expected to be and do. In these discourses, sexual desirability, bodily control, and performance operate as moral benchmarks of femininity, and endo belly becomes a visible marker that troubles these ideals.

Theme 3. The Enemy Within: Battling and Making Peace with the Unruly Body

This theme focuses on participants' constructions of endo belly as the "enemy within". For example, the statement "You should feel confident and comfortable with your body, but endo takes that from you very fast" (R54) constructs endometriosis as a usurper that steals ("takes") the ability to align how one "should" feel about one's body and, ultimately, to enact normative femininity. Many of the participants expressed strong negative feelings about endo belly, often using language that reflected disconnection from their bodies. Some described their abdomens as separate from themselves, for example:

> I hate it and wish I could cut it off. (R50)
>
> I don't feel attractive at all with it, and I feel removed from my abdomen. (R66)
>
> I felt horrible in my body daily. I just wanted to disconnect. (R54)

These quotes show how endo belly was experienced as unbearable, with the use of the pronoun "it" distancing the participants from the affected body part. The bloated stomach is constructed

as no longer fully part of the self. This discursive separation highlights how some participants constructed parts of their own body as external or disowned, accompanied by descriptions of pain and loss of control due to repeated failure to manage the symptoms.

In this way, endo belly was commonly constructed as not just a medical condition but as a hostile agent that undermines identity and is held responsible for rendering the female body unruly. These descriptions externalise the illness and the ill body from the self. The participants described how they related to the unruly, traitorous body in two main ways: first, as an entity that they struggled against; and, second, as a thing they were able to tame and come to terms with. I discuss each of these as subthemes below.

Theme 3a. My Body Betrays Me: Battling Gross Bodies

In this subtheme, I focus on participants' numerous descriptions of negative feelings towards their bodies due to abdominal bloating, and their construction of endo belly or their unruly bodies as an external agent obstructing attempts to control bodily appearance. Participants repeatedly constructed the unruly female body as betraying the self by destabilising feminine identity, personifying the non-conforming body, and positioning it as a traitor. Taken together, these constructions shaped a largely negative evaluation of the ill body's appearance, which included disappointment with the body's inability to align with its expected function and physical form despite extensive individual efforts. For instance, R58 stated: "I'm angry towards it. I won't look in the mirror and observe my body**.**" Here she distances and separates herself from her body; she directs her anger at "it" and refuses to "observe" it. This comment, and the following quote, exemplify participants' frequent expressions of anger towards their non-conforming abdomens when experiencing endo belly:

> I like to leave the house feeling great when what I have on. Even just around the house sometimes, too! It makes me feel confident when I'm happy with an outfit. So, when I have endo belly, I can sometimes opt to wear something that I don't feel as good in because it's comfort over anything at that point. It can make me feel angry at my body. (R32)

This participant constructs emotional meaning in relation to her physical presentation. She begins with a sequence of positive feelings ("great", "confident" and "happy"), describing her physical presentation as significant in shaping her emotional well-being. She constructs looking good as a prerequisite for feeling "great". Endo belly obliges her "to wear something that I don't feel as good in", thereby making her "angry at my body". Her language casts her body as a separate entity that limits her expression of ideal feminine appearance.

As part of this pattern, responses frequently contained metaphors of conflict and labour that constructed the relationship between the body and the self as one riddled with opposition and feud. Many participants communicated an ongoing struggle with the appearance of endo belly and with their unruly body, as depicted in the responses below:

> I hate it. Every month you battle with the swelling, and it changes the shape of your body. (R36)

> I really struggle with the changes to my body, I don't like it at all. (R73)

> I've worked really hard to make peace with my body, as it feels as though it has failed me. (R71)

These comments construct the body as an adversary, conveyed by the words "battle", "struggle" and "make peace with". R71 positions herself as at war with her body, which she explicitly

describes as “failing” her. Reconciling with her body requires a great, ongoing effort (“worked really hard”). Together, these accounts construct illness as a monstrous enemy that alters the body’s appearance and functionality so that it deviates from normative constructions of femininity.

This personification of the body also maintains the common Western construction of women’s ill bodies as “unruly” (Bordo, 2003). Endometriosis is depicted as exacerbating the unpredictable and inadequate construction of the unruly female body, which requires increased regulation to keep it under control in line with dominant sociocultural constructions of femininity and the female body (Bartky, 2012). Thus, many participants conveyed the idea that their body had failed them, with endo belly making them “feel like less of a woman. Like, I don’t meet the standard of beauty” (R27). Similarly, another stated:

> It definitely affects how I feel as a woman. I often find myself comparing my body to others … I sometimes feel like I’m not fully expressing my femininity or style because I prioritise comfort over what I might really want to wear. Overall, it can be a challenging emotional struggle that influences how I perceive myself as a woman. (R22)

Such comments exemplify how many of the participants described themselves as less of a woman and inferior to other women. These responses construct femininity as an attribute that can be changed or lost, and implicitly portray femininity as a possession, one that can be forcefully removed from women’s identity by an unruly, ill body.

Theme 3b. Taming the Enemy: Acceptance through Bodily Regulation—"I Know It Will Go Away"

In contrast to participants' descriptions of battling their unruly bodies, this subtheme explores how some participants discursively reframed control as a form of acceptance. Here, femininity is presented as something that can be stabilised and protected alongside illness, rather than threatened by it. The participants quoted below constructed endo belly as manageable when they could regulate or mitigate its effects through temporality, predictability and containment. In doing so, they reconstructed endo belly as a chronic symptom that could be disciplined and kept in check rather than a persistent disruption to neoliberal expectations aligning health management with culturally desirable femininity (White, 2000).

Participants who described less distress than others framed endo belly as temporary, constructing its impact on body image as fleeting rather than identity-disrupting. Knowing that bloating "will pass" enabled them to compartmentalise symptoms and minimise their emotional weight:

> It's mostly frustrating, but I know it will go away, so I don't get too upset about it now – especially dealing with it for 20 years. (R33)

> When I have endo belly, sometimes I don't feel I look good. My endo belly usually gets better, so I just wait it out. (R2)

> Not too much (less attractive) as I know it will pass, but I would get self-conscious depending on what I was wearing. (R31)

Across these extracts, the participants use qualifying adverbs ("mostly", "sometimes", "not too much") and temporal verbs ("will pass", "will go away", "gets better") to soften the

psychological impact of endo belly. Familiarity—"I know", "usually"—functions as a form of experiential authority that enables these women to predict symptom patterns and regulate their responses. Thus, endo belly becomes an episodic inconvenience rather than an ongoing disruption to feminine identity.

Similarly, some participants framed adherence to health practices, such as Pilates, gym routines, and exercise, as ways of containing or mitigating the effects of their illness. These behaviours were described as enabling symptom management while also maintaining bodily discipline and alignment with dominant body ideals (Crawford, 1980; White, 2000). For instance:

> Luckily, I do Pilates, so this form of exercise has been great for my endo and managing the pain as well as keeping me lean. I bloat at times, but it doesn't tend to affect my sense of attractiveness too much as I can rationalise that it is only a temporary flare-up. (R36)

> I gym often to help with pain management, which works for me. (R49)

Discipline is presented in these extracts as both therapeutic and morally valued: practices like Pilates "manage pain" and "keep me lean", linking symptom control with culturally desirable femininity. Temporary bloating is made more tolerable when offset by evidence of bodily effort, health, and thinness. This discourse aligns with broader healthism, where self-regulation and effort protect women's sense of worth and bodily acceptability (Bordo, 2002; Crawford, 1980).

Finally, as alluded to above, participants also described clothing choices as a way to contain and manage endo belly. Although earlier themes framed concealment as protection from social scrutiny, here clothing operates more as a practical tool that enables comfort, reduces distress, and helps women maintain a sense of bodily control, thereby unifying clothing practices

and body evaluation, as suggested by Frith and Gleeson (2008). Participants described choosing "loose", "baggy" or "comfy" clothing during flare-ups and avoiding fitted styles. This was not presented as an attempt to perform femininity for others but as a way to make the body feel more manageable and predictable. Through containment, bloating becomes something that can be lived with and regulated, reinforcing the idea that the illness is controllable rather than identity-threatening. This resonates with appearance management research findings, which indicate that clothing and appearance practices function as methods through which women establish a sense of agency and control over their embodied experiences (Rudd & Lennon, 2000).

Overall, endo belly was rendered by these participants something that can be *tamed*: temporary, containable and responsive to disciplined practices. This framing protects a stable feminine identity by reducing the unpredictability and threat of the "usurper" body. Although not a direct challenge to dominant norms, these regulatory practices function as forms of accommodation that allow women to maintain coherence between femininity, health and illness in a neoliberal context.

Theme 4. Rewriting the Rules: Femininity Redefined

The final theme explores moments where participants resisted or challenged dominant constructions of feminine ideals, body image, and illness. A small number of participants depicted endo belly not as a threat to femininity but as an experience that could coexist with comfort, acceptance, and a reorientation towards alternative values. They drew on alternative discourses that allowed them to resist, reframe, or loosen the grip of normative femininity, constructing forms of acceptance and identity that positioned endo belly as *compatible with*—rather than *threatening to*—their sense of self. Their accounts push back against normative

expectations of appearance, discipline, and moral worth, signalling spaces—however limited—where femininity can be reconstructed outside neoliberal and aestheticised ideals.

Some of the participants drew on discourses of the body-as-functional rather than body-as-spectacle. Instead of foregrounding appearance or shame, these women described their bodies in terms of capability and practicality. In this framing, bloating was presented as physically uncomfortable rather than morally charged, and identity was organised around what the body can do, rather than how it looks:

> I get frustrated but I'm learning to love my body for what it is. (R37)

> [I]t didn't make me feel bad about my body but it did make me feel uncomfortable. (R3)

These extracts construct frustration and discomfort as valid emotional responses while also illustrating a shift away from appearance-based self-evaluation. Through a discourse of the body-as-functional, participants positioned themselves as capable of sustaining a stable feminine identity even when their bodies departed from aesthetic norms.

Others resisted the significance of conventional femininity and described appearance ideals as less meaningful than they once were, attributing this shift to age, maturity, and years of living with endometriosis. The following excerpts show how normative femininity was reconstructed as outdated, peripheral, or simply not worth prioritising:

> To be honest it doesn't affect my perception of appearance. Maybe it would have 10 years ago, but it's definitely not the biggest thing on my mind. (R20)

> I think endo belly affects some other women more significantly. I think it could somewhat be a time thing? I have had it for maybe 6–7 years now and i used to be self-conscious about it as a teen but now its just not a priority for me. (R59)

These constructions rely on temporal distancing and reflexivity to demonstrate shifts in self-understanding. Rather than rejecting femininity altogether, participants recast it as something learned and changeable, allowing for possible alternative identities reflecting poststructural feminist understandings of unfixed femininity, whereby participants actively construct alternative, self-directed definitions (Butler, 1990). This frame of thought resonates with feminist theories that emphasise gender as socially constructed and achieved through repeated ongoing performance, highlighting its malleable nature (Butler, 1988; West & Zimmermann, 1987).

A final discursive pattern in this theme involves negotiated acceptance. Participants did not deny frustration or discomfort; they constructed endo belly as something that could be lived with, deprioritised, or reframed in relation to other symptoms. Acceptance was articulated not as compliance with illness, nor as a complete rejection of normative femininity, but as a pragmatic and emotionally complex stance, aligning with ideas of identity negotiation explored in chronic illness research (Charmaz, 1995):

> Frustrating but I have accepted it. (R33)
>
> I'm not a massive fan, but I have accepted it is something I will experience for a long time yet. On my bad days it really effects me. (R32)
>
> I don't really mind it, I used to feel insecure about it, now it seems insignificant compared to my other symptoms. (R59)
>
> Other than hating my period I don't think it has had much affect on my well being. A lot of people suffer from endo, and I think I've been lucky in getting help and treatment. (R3)

These quotes construct acceptance as a negotiated, ongoing process that can coexist with ambivalence or discomfort. These participants positioned themselves as active meaning-makers rather than passive recipients of sociocultural norms. Thus, while constrained by Western individualism and dominant discourses of femininity and illness, some participants nonetheless articulated small but meaningful resistances that allowed them to reconfigure identity on their own terms, thereby constructing femininity as a site of constant negotiation (Bordo, 2003).The extracts above exemplify how participants equated the embodiment of endo belly with the social perception of feminine unattractiveness. The adjectives “swollen”, “unsexy” and “fat” describe endo belly with implicit moral judgement, rather than simply as observations of the body’s appearance.

Conclusion

The findings in this chapter illustrate how women with endometriosis construct and negotiate their feminine identity at the intersection of their illness experiences, Western sociocultural gender and body image expectations, and biomedical discourses reinforced in their social worlds. My discursive analysis of the four key themes generated using RTA constructs endo belly as an experience that exceeds physical symptoms alone, with participants’ varied experiences being shaped by gendered ideology and socially mediated.

Across the themes presented, women discursively described how culturally desirable discourses of neoliberalism, femininity, healthism, and body image regulation shaped the construction of their identity in the context of illness perception, influencing their behavioural choices in both private and social settings. Participants equated femininity to body image regulation and described the physical inflammation of endo belly as uncontrollable, even by healthism standards, deeming the body unruly. This construction shaped feelings of shame and

feminine failure, which led to concealment practices in an attempt to negate social scrutiny, constructing endometriosis as a threat to the appearance of normative femininity and social and self-surveillance as regulatory mechanisms. Similarly, women's accounts equated performative femininity with moral worth. Their inability to maintain such sociocultural standards—due to illness symptoms, pain, and invalidation—produced significant psychological and emotional distress and feelings of being "less than" women whose feminine functions they perceived as not limited by illness.

In contrast, some participants discursively described an acceptance of endo belly through coexisting with symptom discomfort, and reframed endo belly as manageable, temporary or irrelevant to their identity construction. A select few participants reprioritised feminine norms by challenging normative sociocultural scripts of femininity rather than rejecting them altogether.

The next chapter concludes this thesis by providing a summary of the key findings and their implications, the limitations of the study, and directions for future research.

Chapter 4: Concluding Discussion

In this thesis, I have thematically analysed responses to open-ended questions from an online survey about endometriosis, focusing on accounts of the participants' experiences of chronic endo belly as a common symptom that lacks empirical exploration. Guided by a feminist social constructionist perspective, I explored how participants constructed and negotiated their femininity and identity in the context of their embodied illness and within the constraints of Western sociocultural discourses that shape and regulate normative constructions of the female body. Investigating the connections between endo belly, femininity, and identity construction provides a more nuanced understanding of how women with chronic gynaecological conditions make sense of their illness experience. The findings highlight restrictive gender norms that significantly shape these experiences and have implications for healthcare approaches.

In this final chapter, I provide a summary of the key findings, my interpretations, and their research relevance, as well as a discussion considering the implications of these findings. This research adds to previous studies that have explored women's experiences of endometriosis, highlighting how these experiences are shaped by wider social meanings about gendered norms related to bodily appearance (Mills et al., 2023; Pellizzer et al., 2025; Sayer-Jones & Sherman, 2023). I argue that we need to rethink what is currently prioritised in healthcare encounters with women with endometriosis, and to challenge biomedical reductionism by adopting a holistic and integrative approach to symptom management. I also identify the study's limitations along with future research opportunities, and end with a critical reflection.

Summary of Key Findings and Research Interpretation

My discursive analysis of the participants' survey responses highlights how dominant sociocultural expectations in Westernised realities shape the relationship women develop with

their ill bodies and gender identities, as well as their illness experiences and help-seeking in this area. Rather than focusing on physical symptoms alone, such as pain and inflammation, as distressing, participants depicted endo belly to be a deeply gendered, socially mediated embodied experience that contrasts with normative feminine bodily appearance. In these descriptions, endo belly is not simply discussed as a neutral symptom of illness; rather, descriptions exceed fixed biomedical framings. As I have shown, across the data, participants depicted their ill bodies during times of bloating as non-conforming and socially unacceptable. My participants consistently described chronic, uncontrollable abdominal bloating as producing body shame and a sense of social undesirability because of its deviation from Western understandings of female body image norms. These findings are consistent with recent qualitative studies that highlight body image disturbances and failed femininity rhetoric among women with endometriosis (Calvi et al., 2024; Farenga et al., 2024; Hunsche et al., 2023; Sayer-Jones & Sherman, 2023).

This finding highlights a central discursive pattern in the data: the language of gross bodies (Fahs, 2017b), evident in participants using words such as “gross”, “shame” and “embarrassed” to describe how they felt about the appearance of their bodies during symptomatic episodes. The female body was constructed as a site of moral evaluation, and deviance caused by endo belly becomes an invalidating symbol of feminine failure. Endo belly was therefore constructed not only as a symptom of endometriosis but as a deviant embodiment intertwined with gender norms, feminine identity, social visibility, and societal expectations (Bordo, 2003; Fahs, 2018).

As I have shown, participants frequently portrayed the experience of endo belly as destabilising their sense of feminine identity and described feelings of being “not good enough” or “less feminine” than women whose bodies did not experience appearance alterations due to

chronic illness. This perception included descriptions of feeling ashamed at being misread as "fat" or "pregnant" due to the symptoms of endo belly. This recurring rhetoric of social misrecognition constructs endo belly as a disruption to participants' feminine identity, due to their inability to appear as appropriately feminine in social contexts.

As a consequence, participants described feeling compelled to manage how others perceived them in social contexts, and to monitor how their body was socially "read" due to endo belly disrupting ideals of feminine appearance. This body management or appearance work is reinforced by the neoliberal discourse of healthism that promotes feminine appearance ideals as inherently achievable through discipline, positioning women as personally responsible for managing their chronic symptoms (Crawford, 1980). Within this framework, the participants are morally accountable for self-regulating their bodies and maintaining a normative feminine physique. Many of the participants described implementing various practices and culturally sanctioned forms of bodily discipline (e.g., hormone control, improving sleep, diets, and exercise) to prevent anticipated visible disruption caused by endo belly. Consequently, the physical deviance caused by endo belly was rendered a personal failure, shaping women's illness experiences by framing ongoing management of the female body as a moral obligation.

This obligation connects to the common refrain in the data of needing to constantly monitor and be vigilant about bodily appearance, both in private (intimate relationships) and public spaces. As the analysis shows, many of the participant accounts depicted a sense of hyper-visibility, especially in public and social settings, as leading to self-monitoring and concealment of their stomachs from external onlookers. These descriptions highlight self-surveillance as a mechanism participants utilised to manage feminine appearance during times of appearance-altering flare-ups, including performing body functionality in social contexts through symptom

minimisation, self-silencing, emotional masking, concealment (e.g., clothing choices), or social withdrawal. As described in Theme 2, these very same methods of self-surveillance doubled as a form of gender performance, through which the participants attempted to compensate for their perceived failures regarding bloating, weight gain, lack of energy, and sexual dysfunction in order to present the illusion of control, composure and grace, which are culturally recognisable attributes of normative feminine behaviour (Bartky, 1990; Bordo, 2002; Butler, 1988).

The analysis also shows how the participants' descriptions of self-silencing and self-surveillance were linked to widespread minimisation and trivialisation of endometriosis. Symptoms of endometriosis are frequently minimised by medical and non-medical people alike, as Jones (2015) has argued. Significantly, my findings show how this extends to appearance-based symptoms. Such trivialisation is based on the common gendered construction of symptoms—especially pain and discomfort—as simply intrinsic to female biology and thus simply "part of being a woman" (Kosi, 2025; Seear, 2009). This is evident in many of the participants' accounts of feeling the need to hide, minimise, or "hold it together", "put on a brave face", and refrain from disclosing their distress to avoid stereotypes of deviant or failed femininity, such as the hysterical woman trope (Bordo, 2002). This finding highlights how medical dismissal enforces self-silencing, self-surveillance, and the responsibility of symptom management and bodily discipline.

The participants' accounts are marked by a tension between private and social experiences, where the reality of endo belly was managed privately by participants. However, within public settings, the participants described refraining from making those same acknowledgements or chose to limit any discussion within social interactions relating to their illness experience of endometriosis. This contrast in behaviour appears to function as a strategy

to maintain an acceptable performance of femininity that aligns with normative gender expectations of social presentation and bodily appearance, consistent with theories of gender performance (Bartky, 1990; Butler, 1988). Women's continual minimisation and self-silencing of their illness distress shaped their gender identity construction. The reinforcement of sociocultural and biomedical discourses that encompass gender behavioural expectations, illness, and pain within social interactions is significant, as they regulate modes of behaviour and patterns of thought that are naturalised as requirements in order to socially exist as a valued member of society. In this context, practices of concealment, bodily discipline, self-surveillance, self-silencing, minimisation, and social withdrawal all become taken-for-granted approaches for managing social visibility and societal belonging.

It is important to note that although most of my participants described negative and distressing accounts of endo belly shaped by dominant Western ideals and expectations of feminine identity, there were meaningful instances of resistance towards these. Several of the participants positioned themselves as "accepting" the experience of endo belly for what it is. Some of the participants emphasised appreciating the functionality of their ill bodies, stating that they feel "uncomfortable", not "insecure". They described accepting the dynamic of their existing body while also recognising the ongoing physical and psychological distress caused by symptoms of endo belly. A small number of participants reported that, over time, endo belly had not affected their "perception of appearance" and had impacted them less with age. These responses show how some participants were able to construct alternative frameworks of femininity that involved redefinition from fixed ideals, but these were negotiated rather than dictated, shaped by the inclusion of their illness experiences. This demonstrates that in neoliberal Western society, where sociocultural discourses are saturated with the regulation of women's

bodies, there are existing resources which some women have utilised to help them construct less punitive relationships with their bodies (Bordo, 2003; Butler, 1990; Lupton, 2012).

Implications of the Findings: Rethinking Healthcare Encounters

Endo belly is often constructed as just a cosmetic symptom and a trivial concern compared to other aspects of endometriosis, like fertility issues, as documented in women's health research (Ballard et al., 2006; Ellis et al., 2022, 2023; Pettersson & Berterö, 2020; Young et al., 2016). There is some existing medical research that centres on appearance-based bodily changes experienced by women, highlighting disruptions to their body image and influence on their well-being. However, this body of research remains relatively limited, with many studies emphasising side effects (acne, weight gain) associated with hormonal contraception (Gillen et al., 2024; Karpowicz et al., 2024; Nowosielski, 2022; van Seumeren, 2000) and only a handful directly addressing women's experiences of gynaecological chronic illness. This further reinforces how trivially this issue is treated in the research, and my study is one of the first to treat appearance-based symptoms of chronic illness as clinically meaningful (Anuk, 2022; Beese et al., 2019; Sayer-Jones & Sherman, 2021; White, 2000).

My findings highlight the significance that the appearance-based symptom of bloating holds for women with endometriosis. The participants' accounts describe the many challenges they faced regarding women's gender identity, relationship with their ill bodies, illness experiences, and help-seeking. Due to the lack of attention to this area within biomedical discourse and research, appearance-related illness symptoms are framed as trivial concerns, and women can be positioned as vain for emphasising the distress it causes them. However, these experiences happen within broader sociocultural contexts in which significant social pressure is placed on what are deemed as normative ideals of feminine appearance, making their

unattractive, deviant body appearance influential in shaping the psychological and social aspects of their illness experiences. My findings, therefore, highlight the role of dominant sociocultural discourses related to Western constructions of femininity in how participants negotiate their illness experiences, which are often intertwined with evaluations of self-worth.

Recognising endo belly as a clinically meaningful symptom worthy of medical intervention and further enquiry is essential on the part of healthcare professionals, given many of the participants' descriptions of appearance-based symptoms as carrying significant embodied, psychological, and social weight. The experience of endo belly was described as being inextricably linked with how the participants understood their bodies and identities, which were shaped by the social meanings attached to their visibility, self-worth, relationships, and experience of femininity. Neglecting appearance-based symptoms allows stigma around the visible "ugliness" of bloated stomachs or endo belly to persist, potentially adding to experiences of physical and psychological distress. This can exacerbate harm as reflected in participants' practices of self-silencing, self-blame, and feeling less of a woman due to their uncontrollable body image disruption.

In this context, appearance-based symptoms are clinically meaningful as they affect women's sense of identity, social functioning, interpersonal relationships, intimacy, work life, and mental health, and therefore should be legitimised as a clinical symptom. This particular finding not only reinforces other endometriosis-focused body image research (Hunsche et al., 2023; Pehlivan et al., 2022; Sayer-Jones & Sherman, 2023), but also adds nuance as it demonstrates how the appearance of the female body plays a role in the development and progression of distress among women who are affected by body-altering chronic symptoms.

Importantly, feelings of shame related to bodily deviance can limit opportunities for psychosocial support. My findings suggest that many women feel alone in coping with their symptoms and experience profound social isolation, supporting findings from research in other contexts (Calvi et al., 2024; Cole et al., 2021). This isolation is reinforced by Western gender norms that position women as morally responsible for disciplining their bodies to achieve appearance expectations (Beijbom et al., 2023; Bordo, 2002). Healthcare encounters, therefore, need to include awareness of gendered sociocultural assumptions of bodily appearance. These findings have clear implications for healthcare approaches for women with endometriosis that are rooted in biomedical reductionism in endometriosis care. These findings indicate the need for healthcare professionals to steer towards more holistic and integrative healthcare practices that recognise appearance-based symptoms, such as endo belly, as legitimate medical concerns that require attention in endometriosis care.

Overall, the study's findings identify the need to develop more integrated psychological support as a standardised component of endometriosis healthcare, something which should be acknowledged within healthcare guidelines going forward. This would mean that women diagnosed with endometriosis who identify endo belly as a healthcare concern would be provided access to referral pathways where they could meet with mental health providers who have health psychology expertise. This initiative would require improved communication within client–physician interactions in general healthcare encounters prior to referral, in which clients' appearance-based symptoms are validated as a legitimate medical concern, with the experience of appearance-based symptoms medically recognised as psychologically and physically distressing. Lastly, increased cultural and gender awareness is also essential in order for medical professionals to critically reflect on the patients' social realities and engage in appropriate client-

centred intervention. The integration of these practices within endometriosis health encounters would shift intervention styles from treatment to management, paving a pathway for interdisciplinary care involving the integration of multiple specialists, such as pelvic floor physiotherapists, nutritionists, pain specialists, and mental health professionals (body image and chronic illness), to address the diverse needs of women living with endo belly.

Reflections and Future Research Recommendations

My findings are representative of a small sample set of (cisgender) women who are subject to diverse experiences in their unique social realities located in Aotearoa New Zealand. As a qualitative researcher, I understand that it is implausible to conduct a study that produces objective and generalisable findings; therefore, it is essential to reflect on the researcher's influences and the study's methodological design choices, which shaped the interpretation of deep and nuanced findings. This reflexive consideration provides context for how the findings should be interpreted and informs my recommendations for future research. The depth and nuance identified in the dataset through open-ended responses enabled me to surface a unique and underexplored aspect of the endometriosis experience. The findings highlight endo belly as not merely a cosmetic issue, but an identity-threatening symptom. My research centres the stories of women who struggle with the distress of appearance-based symptoms caused by endo belly, who are left to support themselves and to identify self-management avenues. These avenues are often not empirically informed treatment methods, which result in unsuccessful outcomes that lead to further distress. In particular, the shame and embarrassment associated with endo belly as feminine deviance can lead to isolation, as suggested by participants' accounts of social withdrawal and literally hiding away, not merely concealing bodies. This deserves further investigation, particularly for different groups of women (e.g., women of colour,

teenagers, particular professions) and other genders (e.g., trans men), for whom deviation from gender norms may have different social meanings.

My findings must be read in relation to the recruitment and data collection methods employed. Although I set out to include experiences from a diverse group of participants, most of my participants were white and aged between 20 and 30 years. My data collection method relied on participants having access to the internet during the time I advertised my research survey (13th October 2024), as well as being heavily engaged with Endometriosis New Zealand's social media content. This means that I was more likely to attract women who had internet access, frequently use the internet (possibly younger), and who actively engaged in endometriosis self-help, including online support. Culturally diverse understandings of femininity are more likely to be explored and understood when a diverse sample is analysed. Considering this is a study conducted in Aotearoa New Zealand, this highlights the need for te ao Māori (Māori worldview) perspectives and experiences regarding cultural constructions of femininity in the context of gynaecological illness.

Additionally, my study focused on individuals with endometriosis who identified as women and were predominantly heterosexual. I am aware that there are many existing cultural ideologies, gender identities, and sexual preferences among individuals that may offer diverse avenues/concepts of meaning-making when exploring gender constructions. I suggest that future research in this field considers the prioritisation of diverse demographics of individuals I have mentioned in order to analyse contrasting perspectives, which may offer insight into how to better support individuals who subscribe to diverse sociocultural frameworks of illness embodiment, which would include non-normative experiences of womanhood and femininity.

In addition, age was highlighted by a few participants in my study who referred to alternative constructions of femininity and acceptance of endo belly as related to their maturity. Studies prioritising an older demographic or individuals who have had endometriosis for an extended period of time may offer additional insights that construct different interpretations of identity in the context of illness experiences. Those who participated in my study were likely drawn from a specific socioeconomic background with access to resources others may not have, excluding experiences that might have influenced my findings.

Finally, while the open-ended questions yielded rich responses, it was not possible to probe or follow up on particular aspects, as is the case with synchronous or in-person data collection methods. Other methodological approaches, such as longitudinal studies and in-person interviews, may offer a more in-depth and richer qualitative analysis where participants are able to guide the researcher with their responses and engage more authentically and thoughtfully when approaching this topic. Therefore, it is suggested that future research in this area consider conducting more controlled design methods to increase the validity of the collected data, which would ensure more reliable results.

Concluding Critical Reflections

As I stated at the start of this thesis, I intentionally engaged with this research topic, acknowledging my fundamental closeness to the area as someone whose orientation is that of an insider. I have been diagnosed with stage-three endometriosis and experience chronic endo belly. I have experienced varying standards of healthcare in New Zealand and, as a woman situated within a neoliberal sociocultural context, have experienced the profound impact of endo belly on my body image, sense of femininity, and identity. I have endeavoured to critically reflect on my positioning throughout all process steps of my research, knowing that my personal perspectives

and views would inevitably shape how I, the researcher, interpreted the data and constructed meaning. This reflexivity makes transparent my influence, as the researcher, on the analytic process and resulting interpretations of findings. Despite my subjectivity and orientation, my aim in conducting this research remains to give women who suffer from endometriosis a voice and to position them as experts of their lived experiences. My hope is that these findings will inform more beneficial healthcare practices and understanding by health professionals. Additionally, this research aimed to deepen researchers' understanding of the impact of the intersection of illness perception, social interactions, and gender identity to enrich future research.

I came into this research with experiences similar to those of my research participants, which sensitised me to the fundamental incongruence between the Western idealised femininity and the lived embodiment of endometriosis. My insider orientation led me to take the issues highlighted in my research seriously, shaping my analytic commitment as a researcher in this underexplored area to reveal the significant role it plays in women's lived experiences of endometriosis. Due to my own self-silencing compounded with the lack of support provided in my healthcare encounters concerning undesirable chronic bloating, I had previously thought of my experience as something I was solely responsible for. I found myself incorporating my own healthist practices such as dieting, exercise and supplements and then reverted to concealing my bloating when in public spaces—all of which continue to be unsuccessful.

Engaging with participant responses disrupted my predetermined assumptions that experiences of endo belly were individualised, that only I understood. I did not anticipate the extent to which participants' accounts—often described through raw and emotional language—constructed the experience of an unruly, visibly symptomatic body alongside the feminine expectation to maintain a controlled, normative appearance of the female body. Within Western

society, these two experiences cannot coexist without tension, struggle, or compromise. Interestingly, this pattern of discourse that I identified in the data provided me with a simultaneous sense of despair and relief.

I selected endo belly as central to this study because at the time, there existed little to no research available on this symptom. Endo belly, of course, was also of personal significance to me due to my own distressing experience with the symptom. Reflecting on the rich qualitative participant responses describing significant adverse impacts on their lives, I'm confident that this study will serve as a critical entry point for further research focusing on endo belly in women's lived experiences of endometriosis.

Despite the participants' accounts of endo belly being predominantly negative, I was encouraged to see that a few participants described a more positive outlook on their illness experiences, with endo belly coexisting with their feminine identity. These participants disclosed that with age, maturity, or having lived with the illness over an extended time, they had constructed a sense of identity that allowed multiple experiences to coexist at the same time, exemplifying a social constructionist perspective of multiple existing truths.

The data collected in the online survey have informed both my honours dissertation and this master's thesis. During the last two years, I have been encouraged to see a slow yet steady growth in the development of endometriosis-based research. When I first began this journey, there was a significant lack of research centred on endo belly, and I viewed my research topic as an emerging and relatively niche area of investigation. However, in 2025, I encountered a new study that specifically addresses the psychosocial aspects of endo belly through lived experience, emphasising this symptom as worthy of ongoing investigation (Pellizzer, 2025).

Conclusion

The findings of this research highlight a sample of women's lived experience of endo belly, a common symptom of endometriosis, and how this experience constructs their sense of body image, femininity, and identity in the context of their illness experience in Aotearoa New Zealand. The emphasis on participant voices and discursive analysis has contributed valuable insights into the biological, psychological, and sociocultural complexities that women are positioned to treat as individualised concerns. This thesis highlights the role played by dominant Western discourses—particularly gender and biomedical discourses—with the findings aligning closely with broader feminist and health psychology literature on endometriosis and gender in Western cultural contexts.

In this thesis, I have argued that through the participant accounts, endometriosis is a culturally ingrained gendered disease where symptoms of the illness—specifically endo belly—disrupt the appearance of Western feminine ideology, positioning women as needing to adapt to neoliberal methods of managing their distress, by which we see the cultural regulation of women's bodies. Due to these methods being described as highly unsuccessful and increasing distress within many of the participant responses in this study, I propose a re-evaluation of healthcare encounters in Aotearoa New Zealand to support empirically guided methods of intervention and to ensure successful care of women who struggle with the appearance-based symptom of endo belly. Through continued research and advocacy, health psychologists can further promote women's lived experiences as medically significant and worthy of requiring attention.

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Appendix A: Copy of the Survey

1. Have you been diagnosed by laparoscopy? (Yes/no) – if no, then jump to end of survey thank you message. (quantitative answer)
2. Are you currently living in New Zealand? (Yes/no) – if no, then jump to end of survey thank you message. (quantitative answer)
3. What is your age? (qualitative answer)
4. What is your ethnicity? (qualitative answer)

Can you give me a brief summary of the history of your Endometriosis? (Sectional header)

5. How does Endometriosis affect your everyday life? (qualitative)
6. Do symptoms of your Endometriosis affect your body functionality and appearance? yes/ no (quantitative)
7. What do you do on a daily basis to manage your Endometriosis? (qualitative)
8. What would the best possible outcome of treatment be? (qualitative)

Endometriosis can cause unwarranted changes to the body's appearance due to the conditions body-altering symptoms and interventions such as surgery and medication. This can lead to bloating of the abdomen (endo belly), excess body hair, acne, fluctuation in body weight and problems with fertility that are linked to body image and how society influences what it means to be a woman. We are interested in how you feel about your body and your relationship with your body. (Sectional header)

9. Have you experienced abdominal bloating (endo belly) in the past 12 months? yes/no (quantitative answer)
10. Is there a time when this is more noticeable? (qualitative answer)
11. How does endo belly most affect you? (qualitative answer)
12. How do feel about endo belly? (qualitative answer)
13. How does this differ, do you think, to how other women experience their bodies? (qualitative answer)
14. How does this affect your well-being? (qualitative answer)

How has Endo belly altered your sense of attractiveness? (Sectional header)

15. How does it affect how you feel about your body? (qualitative answer)
16. Does endo belly make you feel more or less attractive? yes/no (quantitative answer)
17. If so, in what way? (qualitative answer)
18. In your view, has it affected your experience of how potential partners/your current partner perceived you? (qualitative answer)

Appendix B: Participant Information Sheet (Honours)

School of Psychology
Massey University
Private Bag 102-904
North Shore
Auckland 0745
Tel +64 9 414 0800 ext 43116
Fax +64 9 441 815

Participant Information sheet

Kia ora, my name is Lindsay Daniels, and I am a psychology student in the honours programme at Massey University. Thank you for your interest in this research, please read the following information to decide if you would like to continue as a research participant.

Project description: The aim of this research is to understand the impact of chronic endometriosis symptoms on how women perceive their body image, from the perspective of individuals with lived experience. The data collected will help to guide the future direction of endometriosis research where mental health is considered in hopes of navigating appropriate and effective health care intervention. Additionally, this research will highlight the daily experiences of endometriosis and its implications directly from the perspective of those subjected to the condition, offering positional insight to professional and non- professional readers of the study.

Who can participate: The study welcomes all individuals 16 years and older currently living in New Zealand who have been diagnosed with endometriosis via laparoscopy who would be happy to share their thoughts and experiences through a short survey. All ethnic backgrounds are welcome to participate. This will be anonymous.

If you choose to participate in this study: If you choose to participate in this study, you will complete a short survey. This survey should take between 10-15 minutes to complete online. This survey will be anonymous. You are welcome to share as much or as little as you want and you are able to skip any questions. You may email me with any additional questions concerning this research which will not be recorded as part of data collection.

What happens after the survey? I will analyse the data collected from the anonymous survey. This data will be used for my honours research report only. Your response will not be used for any other purpose.

The benefits and risks of this research: This study will give you the opportunity to share your personal experience of living with endometriosis and any challenges that are most concerning for you. You will get the opportunity to voice what is most important to you and be part of research that seeks to educate those in and out of the field. As lived experience can be a sensitive topic to discuss, this survey will give you the opportunity to do so in a safe, autonomous environment. There should not be distress involved in the process, however, if you feel you need support at the completion of this survey please contact **lifeline.org.nz**. Upon completion of this survey there will be an additional survey asking for your email address so that you can be put into a draw to win one of for $50 vouchers to thank you for your time and effort. This information will kept separately from your survey response. I will also email through my research findings at the end of my research project.

Data management: Your confidentiality and privacy are a priority. No identifying information will be required in the survey or used in the research. Only the data from the survey will be used in the research. As this is an exploratory honours research project, only descriptive statistics and a thematic analysis of survey data will be included. The survey data will be stored

within a secure file on Massey OneDrive which is password protected. All data will be destroyed upon completion of the research following Massey University's document destruction policies. Your email address will be kept separate from your survey answers to ensure you stay anonymous and will not be used for anything other than the prize draw and sending a summary of my research findings. All data and your email address will be destroyed upon completion of my honours research following Massey University's document destruction policies.

Participant's rights: You are under no obligation to participate in this research. If you decide to take part you have the right to:

- Contact me via email to ask any questions you have about the survey.
- Decline to answer any questions you do not wish to within the survey.
- Exit the survey at any time before completion – in this case your responses will not be saved or used for the research
- be given access to a summary of the project findings when it is concluded.

Contact details:

If you have any questions or concerns about the research you may email me or contact my supervisor.

Lindsay Daniels Lindsay.Daniels.1@uni.massey.ac.nz

Supervisors Name: Kathryn McGuigan

Email: k.mcguigan@massey.ac.nz

Phone: 09 414 0800 ext 43115

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 24/42. 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.

If you feel you need support at the completion of this survey please contact lifeline.org.nz.

By clicking on the continue arrow below you are consenting to take part in this research.

Appendix C: Advertisement

Kia ora everyone, my name is Lindsay, and I am completing my honours degree in psychology at Massey University, New Zealand. As part of my degree, I am taking part in research. This will be conducted through a survey centred around endometriosis and its impact on individuals.

I understand that living with this condition can be difficult and sensitive at times, however, research has shown that lived experience voices are very important to address societal and structural issues. In saying this, the survey is anonymous, and you can choose to exit the survey at any time to put yourself and needs first if you find the questions to be distressing.

We are looking for up to 60 participants, 16 years and older who are currently living in New Zealand and have been diagnosed via laparoscopy. I want to thank you so much for your time in reading this post. Please click the link below to learn more about the survey in more detail before giving consent by proceeding to complete the survey.

https://massey.au1.qualtrics.com/jfe/form/SV_6G6jGnQQdgpZqtg

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 24/42. 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.

Appendix D: Ethics Approved Information Sheet

School of Psychology
Massey University
Private Bag 102-904
North Shore
Auckland 0745
Tel +64 9 414 0800 ext 43116
Fax +64 9 441 815

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
Te Kura Pūkenga Tangata

Participant Information sheet

Kia ora, my name is Lindsay Daniels, and I am a psychology student in the honours programme at Massey University. Thank you for your interest in this research, please read the following information to decide if you would like to continue as a research participant.

Project description: The aim of this research is to understand the impact of chronic endometriosis symptoms on how women perceive their body image, from the perspective of individuals with lived experience.

Who can participate: The study welcomes all individuals 16 years and older currently living in New Zealand who have been diagnosed with endometriosis via laparoscopy who would be happy to share their thoughts and experiences through a short survey. All ethnic backgrounds are welcome to participate. This will be anonymous.

If you choose to participate in this study: If you choose to participate in this study, you will complete a short survey. This survey should take between 10-15 minutes to complete online. This survey will be anonymous. You are welcome to share as much or as little as you want and you are able to skip any questions. You may email me with any additional questions concerning this research which will not be recorded as part of data collection.

What happens after the survey? I will analyse the data collected from the anonymous survey. This data will be used for my honours research report only. Your response will not be used for any other purpose.

The benefits and risks of this research: This study will give you the opportunity to share your personal experience of living with endometriosis and any challenges that are most

concerning for you. You will get the opportunity to voice what is most important to you and be part of research that seeks to educate those in and out of the field. As endometriosis can be a sensitive topic to discuss, this survey will give you the opportunity to do so in a safe, autonomous environment. There should not be distress involved in the process, however, if you feel you need support at the completion of this survey please contact lifeline.org.nz. Upon completion of this survey there will be an additional survey asking for your email address so that you can be put into a draw to win one of for $50 vouchers to thank you for your time and effort. This information will kept separately from your survey response. I will also email through my research findings at the end of my research project if you request this.

Data management: Your confidentiality and privacy are a priority. No identifying information will be required in the survey or used in the research. As this is an exploratory honours research project, only descriptive statistics and a thematic analysis of survey data will be included. The anonymous survey data will be stored within a password protected file on a password protected device and stored for five years following Massey University's document destruction policies.

If you would like to go into the draw for a voucher or would like a summary of the findings, your email address will be kept separate from your survey answers to ensure you stay anonymous. This data (email addresses) will be destroyed upon completion of my honours research.

Participant's rights: You are under no obligation to participate in this research. If you decide to take part you have the right to:

- Contact me via email to ask any questions you have about the survey.
- Decline to answer any questions you do not wish to within the survey.
- Exit the survey at any time before completion – in this case your responses will not be saved or used for the research
- be given access to a summary of the project findings when it is concluded.

Contact details:

If you have any questions or concerns about the research you may email me or contact my supervisor.

Lindsay Daniels Lindsay.Daniels.1@uni.massey.ac.nz

Supervisors Name: Kathryn McGuigan, k.mcguigan@massey.ac.nz

Phone: 09 414 0800 ext 43115

This project has been reviewed and approved by the Massey University Human Ethics Ohu Matatika 1, Application OM1 24/42. 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.

By clicking on the continue arrow below you are consenting to take part in this research.