# “I just felt stuck in a loop of pain and invalidation”: A reflexive thematic analysis of women’s experiences of healthcare for endometriosis in Aotearoa New Zealand

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# Abstract

Endometriosis is a chronic condition affecting 120,000, or approximately 1 in 10, women of reproductive age in Aotearoa New Zealand. Additionally, there is a diagnostic delay, with many women experiencing symptoms for many years before gaining a diagnosis. Interactions with healthcare providers are an essential factor in promoting women's quality of life. Consequently, it is important to investigate the healthcare encounters for endometriosis to improve health outcomes. Previous research has tended to focus on impacts of endometriosis on women's lives, however there is a lack of research examining healthcare systems for endometriosis-related care, especially in Aotearoa New Zealand. Therefore, my research focuses on women's experiences of the healthcare system in Aotearoa New Zealand. I conducted this research from a feminist standpoint theoretical lens to prioritise women's embodied knowledge. I used an online qualitative survey to collect data from 63 women across Aotearoa New Zealand who have been diagnosed with endometriosis. Using reflexive thematic analysis, I formed four main themes: (1) minimisation and dismissal of women's symptoms, (2) mixed experiences of healthcare providers, (3) lack of support from healthcare providers, and (4) what women want from endometriosis healthcare. The findings of my study suggest that women with endometriosis often experience dismissal and lack of support from healthcare providers from when they first present with pelvic pain throughout the whole diagnosis and treatment process. Accordingly, there are current unmet needs in the healthcare system for women with endometriosis and I argue that patient-centred care is required to address those needs.

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# Contents

# Chapter One: Introduction

Endometriosis has been described in other qualitative studies as "a crippling disability" (Huntington & Gilmour, 2005, p. 1128), "a devastation" (Facchin et al., 2018, p.544), and "the most lonely condition I could imagine" (Cole et al., 2021, p.184). Research demonstrates that in addition to the physical symptoms of endometriosis—characterised by chronic pain—the condition has a pervasive impact work, relationships, education, social life, sexual health, and mental wellbeing (Moradi et al., 2014). An integral part of women's endometriosis experiences, and overall quality of life, is their interactions with healthcare providers (Apers et al., 2018), which is the focus of this thesis in which I investigate experiences of endometriosis diagnosis and treatment in Aotearoa New Zealand.

In this introductory chapter, I contextualise the issue, discussing the significance of healthcare relationships for quality endometriosis care and improved quality of life more generally, giving a provide a broad overview of some key aspects of the local health system as they relate to my topic, and introducing my research aims. Before I go on to do this, a note about my use of gendered language in this thesis: although cisgender women make up the largest group of people with endometriosis, I recognise that not all sufferers will identify as women, as indicated in overseas research of the experiences of transmasculine individuals with endometriosis (Ferrando, 2022; Vallée et al., 2023). However, due to the small scale of my research project, I narrow the focus to cisgender women as I would not be able to do justice to the nuanced experiences of gender diverse people. Due to my focus on cisgender women, I use the terms "she, her, woman, and women" when describing my participants and their experiences, as well as the existing literature.

## 1.1. Background

Endometriosis is a poorly understood, under-researched chronic condition (Hudson, 2020). There are several theories as to what causes the condition, but none adequately explain the complexities of who develops endometriosis and why, leaving its cause largely unknown. Hence, attempting to describe and summarise it, is no easy task. Physically, it is a chronic condition where tissue resembling the endometrium (uterine lining) is found outside the uterine cavity (Kennedy et al., 2005).

The most reported symptom is acute chronic pain that varies in severity and frequency (Hållstam et al., 2018; Huntington & Gilmour, 2005). Pain usually occurs during the menstrual period, largely but not exclusively due to tissue inflammation (Cox et al., 2003; Maddern et

al., 2020), though for many women it is present throughout the menstrual cycle. Other than pelvic pain, physical symptoms of endometriosis include heavy, irregular, and painful menstruation, as well as fatigue and infertility (Gupta et al., 2021). The pain experienced can be so severe that it can be accompanied by nausea and vomiting and can interfere with daily functioning (Moradi et al., 2014). Pain and fatigue can also make it difficult for women to regularly attend work or participate in social activities and can impair their quality of life (Nnoaham et al., 2011).

In Aotearoa New Zealand, this chronic condition is estimated to affect 120,000, or approximately 1 in 10, women of reproductive age (Endometriosis New Zealand, 2024). However, this number may be higher due to the number of women who experience endometriosis for many years without a diagnosis (Ballard et al., 2006). Delayed diagnosis is more common than not, with much research showing that difficulty obtaining a diagnosis is strongly linked to gendered healthcare interactions (as discussed further in Chapter Two). Research suggests that healthcare encounters are a major part of the experience of endometriosis and play a significant role in shaping women's illness experiences, health outcomes and wellbeing (Apers et al., 2018).

### 1.1.1. The Importance of Healthcare Relationships and Patient-Centred Care

Studies from multiple countries offer unanimous findings about women's concerns and frustrations regarding endometriosis-related care. Many of the challenges patients face—from delayed diagnosis to feeling dismissed by healthcare providers—arise in, or are greatly impacted by, interactions between healthcare providers and patients (Mikesell & Bontempo, 2022). Therefore, to improve diagnosis and treatment, as well as overall outcomes for women with endometriosis, scholars have pointed to the important role of healthcare relationships. Chapron et al., (2019) argue that "the patient needs to be at the centre of therapeutic decisions" (p. 676) and that the focus of healthcare should be on the patient as a whole, rather than on physical symptoms alone. In this vein, overseas research is emerging on the role of patient-centred care for endometriosis, including in the Netherlands (Apers et al., 2018), Belgium (Geukens et al., 2018; Schreurs et al., 2020), Canada (Nyhof et al., 2020), and Australia (Young et al., 2017).

Patient-centred care, as I explain more fully in the following chapter, foregrounds the relationship between healthcare providers and patients, aiming to provide respectful care that prioritises the needs and values of patients (Ramlakhan et al., 2019). The quality of care

received from healthcare providers can shape how women view doctors and how they feel about themselves. Receiving inadequate care can lead to mistrust, anger and a sense of hopelessness. In contrast, positive experiences with healthcare providers can help women feel guided and supported in the endometriosis journey (Facchin et al., 2018). Positive healthcare experiences also have the benefit of increasing the likelihood that women continue seeing their healthcare provider and comply with medication or treatment (Lamvu et al., 2020).

Turning to the local context, patient-centred care is not just lacking from endometriosis research, but rather from all research conducted in Aotearoa New Zealand. Research has investigated advocating for patient-centred care in dementia (Bone et al., 2010) and mental health care (Mulipola et al., 2022), but there is a lack of local research on patient-centred care for physical health conditions or in general practice. In the next section, I focus on the local health system in relation to patient-centred care more generally.

### 1.1.2. A Brief Overview of the Aotearoa New Zealand Context

Tudor and Rodgers (2021) argue that patient-centred care is necessary in Aotearoa New Zealand for acknowledging diverse healthcare needs, including those of Māori who have historically been underserved and experienced problematic healthcare relationships. In line with the principles of patient-centred care and the Treaty of Waitangi, they argue that healthcare providers need to enact partnership in healthcare. This means considering differing values and practices which will promote wellbeing for both Māori, as the Indigenous people (tangata whenua) of Aotearoa New Zealand, and non-Māori people in a way that is meaningful to them. This view is officially upheld in the national guidelines and standards for health and disability services provided by the Ministry of Health Manatū Hauora (2024). However, the delivery of patient-centred care—and advancing better health outcomes for women—is undermined by (1) system constraints and (2) persistent health disparities, underpinned by social, economic, and political factors (Reid, 2015), as I discuss next.

#### *1.1.2.1. System Constraints and Access to Care*

Access to care is a pressing issue for New Zealanders with endometriosis and is underpinned by both social and economic influences. There are an estimated 120,000 women in Aotearoa New Zealand living with endometriosis, yet a lack of doctors providing specialist care. According to a 2020 study, only 20% of District Health Boards have a specific endometriosis clinic and wait times for public healthcare are long. The study also reported that

there are only 21 public gynaecology surgeons in Aotearoa New Zealand who conduct endometriosis surgery, of which, most are located in Auckland (Endometriosis New Zealand, 2022). For some women, this means that accessing a gynaecologist can be difficult. The geographical location of endometriosis specialists is a barrier that can prevent women from accessing care for endometriosis, particularly women who are from low socioeconomic backgrounds. This furthers health disparities because people who are of higher socioeconomic status are more likely to be able to arrange transportation to an appointment outside of their town/city. Health equity is achieved when access to healthcare is distributed based on people's needs (Reid, 2015). Therefore, if Aotearoa New Zealand is to provide equitable health outcomes for women with endometriosis, the healthcare system must prioritise employing endometriosis specialists throughout the country, rather than just concentrating them in one city.

The lack of specialist care means that often general practitioners (GPs) continue care for women with endometriosis. Therefore, there is a strong case for all doctors in Aotearoa New Zealand to have in depth knowledge of endometriosis, rather than seeing it as a condition that requires purely specialist care. Due to the prevalence of GPs caring for women with endometriosis, this is an area that also needs to be researched to investigate the level of care received by women from their GPs. However, the care from GPs can further health disparities. Seeing a gynaecologist in the public system is a free service, however there is a cost involved to visit a GP. Therefore, women from higher socio-economic status are more likely to be able to afford continued care at a GP than women from lower socio-economic status.

As well as geographical location, access to care in the Aotearoa New Zealand health system is made easier for people with private health insurance (Schoen & Doty, 2004). Even though Aotearoa New Zealand has a publicly funded healthcare system, private health insurance is also available and often means that wait times are reduced for those who are wealthy enough to afford private health insurance (Chin et al., 2018). This means that the social inequities in endometriosis care based upon socioeconomic status are not only present in the access of GPs, but also specialists. Women who are wealthier and can afford private health insurance will get treatment sooner and of higher quality than women who cannot afford the health insurance.

When considering access of care, it is also important to consider the impact that the COVID-19 pandemic has had in Aotearoa New Zealand. A global online survey on the impact of the pandemic on endometriosis care found that almost all the women reported that their care

had been negatively affected in at least one way (Demetriou et al., 2021). As the response to COVID-19 changes healthcare systems and the ways that they operate, it is an opportunity for Aotearoa New Zealand to examine its own healthcare system, identifying areas in need of improvement to facilitate quality care for women with endometriosis.

#### *1.1.2.2. Health Inequity, Ethnicity, and Socio-Economic Status*

To practice patient-centred care in Aotearoa New Zealand, it is necessary to ensure that equity for both Māori and non-Māori is achieved. Even though there are not any known differences in rates of endometriosis by ethnicity, there are different barriers that operate to cause inequities in care (Katon et al., 2023). As a result of colonisation, Māori as a group are socially and economically marginalised and continue to bear the burden of sexual and reproductive health disparities (Smith & Reynolds, 2006; Smith & LeGrice, 2024). This disadvantage extends to healthcare in terms of "(1) differential access to the determinants of health […], (2) differential access to healthcare and (3) differences in the quality of care received" (Selak et al., 2020, p. 7). So, not only are Māori more likely to encounter the barriers to quality care as mentioned above, but they often encounter discrimination in healthcare encounters, in line with international findings on racial discrimination in healthcare (Graham & Masters Atawere, 2020; Moewaka Barnes & McCreanor, 2019).

For example, Harris et al. (2012) conducted a study analysing the data from the 2007 New Zealand Health Survey and found that people who reported that they experienced racial discrimination were less likely to claim that they have been treated with respect, and less likely to feel listened to. These findings are supported by a recent systematic review of qualitative research on Māori experiences of public healthcare published in the last 20 years (Graham & Masters Atawere, 2020). The review showed that "for many Māori, the existing public health system is experienced as hostile and alienating" (p. 193). These challenges can be worsened for Māori women due to the intersection of gendered and racialised discrimination (Smith & LeGrice, 2024; Stevenson et al., 2016). As Markovic et al. (2008) argue, low-income women and those with lower educational attainment are often disempowered in healthcare settings and must accept the biomedical treatments and explanations of endometriosis offered to them, rather than being able to advocate for alternative treatments.

The challenges faced by Māori (women) are related to the fact that the healthcare system operates from a Western biomedical viewpoint. The biomedical model placing little importance on cultural origins, traditions, or experiences, instead emphasising the observable

(physical), measurable, and treatable aspects of health (Graham & Masters Atawere, 2020). Patient-centred care for endometriosis involves the patient and the healthcare provider coming to a shared understanding of how endometriosis is affecting a woman's life and make joint decisions about the best treatments. However, this shared understanding can be difficult when the patient and healthcare provider have different epistemological views (Hintz, 2022). To enact patient-centred care, healthcare providers need to be aware of and respect the different ways of conceptualising health and illness, and women's unique cultural, social, and familial contexts (Romm & Shaffer, 2017). This allows patients tino rangatiratanga (self-determination) which is an important aspect of applying the responsibilities of The Treaty of Waitangi to healthcare. The Treaty of Waitangi should be a guiding document, as it applies to all areas of Aotearoa New Zealand legislation, including healthcare (Berghan et al., 2017).

### 1.2. Research Rationale

The arguments discussed above support the view of patient-centred care as quality care that can improve the diagnosis and treatment of women with endometriosis. However, as I have alluded, much of the research is from overseas. Previous Aotearoa New Zealand studies have investigated the impacts of endometriosis on women's lives (Gilmour et al., 2008; Huntington & Gilmour, 2005; Tewhaiti-Smith et al., 2022) and the impact of endometriosis education in schools (Bush et al., 2017), but healthcare has not been a focus. While international findings are useful, it is also important to consider the distinct experiences of women in Aotearoa New Zealand. There is a need for up-to-date, local research on experiences of care for endometriosis and patient-centred care. Furthermore, Steele et al. (2019) recommend that qualitative research be conducted to investigate the unmet needs of women with endometriosis, to understand the ways in which the healthcare system is inadequate, and to inform relevant, culture-specific, national strategies for comprehensive endometriosis care in Aotearoa New Zealand. This forms the rationale for my qualitative study.

### 1.3. Research Aims

My research aim is to contribute to the literature by investigating women's experiences of endometriosis diagnosis and treatment in Aotearoa New Zealand. I consider the findings in relation to patient-centred care. Taking a feminist standpoint approach (explained in Chapter Three), this research invited women with endometriosis to share their experiences and express their needs and thoughts on the local healthcare system. The study was guided by the following research questions.

1. What are participants' experiences of the healthcare system in Aotearoa New Zealand for the diagnosis and treatment of endometriosis?
2. Are participants' experiences similar across different healthcare providers?
3. Are participants satisfied with the quality of care they receive related to their endometriosis?
4. What recommendations do participants with endometriosis have for improving the level of care in the healthcare system?

### 1.4. Overview of the Thesis

In the following chapter (**Chapter Two**), I provide a review of the current literature regarding women's experiences of healthcare for endometriosis both in Aotearoa New Zealand and worldwide, including the overarching issues medical sexism, which acts as a backdrop to this issue, and patient-centred care.

I then go on to explain the methodology in **Chapter Three**. I explicate my theoretical framework, feminist standpoint theory, and how it centres women's lived experiences. I then discuss the methods I used when conducting my research, describing how I used Braun and Clarke's (2022) approach to reflexive thematic analysis as my analysis tool, and discuss ethical issues.

Next, in **Chapter Four**, I present my analysis and discussion. In this, I follow Braun and Clarke's (2022) advice to combine the analysis and discussion as good practice in qualitative writing, allowing me to contextualise and interpret my themes in relation to existing literature, relevant theory, and wider contexts, thus aiming to deepen my analytic engagement with the data. I present four themes which highlight the participants' experiences of dismissal and lack of support from healthcare providers, their mixed experiences of care, and what they would like to receive from healthcare.

Finally, in **Chapter Five**, in my concluding discussion, I summarise my findings and reflect on these in relation to patient-centred care for women with endometriosis. I conclude this chapter, and my research, by considering implications of my research and future research opportunities and offering suggestions for how to implement practical change.

# Chapter Two: Literature Review

There is, as I have argued, a clear need to research the healthcare interactions between women with endometriosis and healthcare providers locally and internationally. This lack of research, especially studies including women's perspectives, must be situated within the wider, gendered context of medicine, as must any findings that emerge (Hudson, 2021). As Hudson (2022) argues, "endometriosis represents a rich example of the active production of [medical and societal] ignorance due to its longstanding invisibility in biomedical, political and social contexts" (p. 26). A discussion of this invisibility of endometriosis is emerging in the current research, however what is notably missing is an Aotearoa New Zealand specific focus, hence I will also draw from overseas literature in this chapter. I begin by detailing the impact of endometriosis and chronic pain. I then locate the findings of these experiences within the broader literature on medical sexism and gendered responses to pain conditions like endometriosis, considering the wider gendered nature of endometriosis care that shapes (the largely negative) healthcare interactions women report. This sets up the rationale and provides context for my research. Thereafter, I review the literature on patient-centred care, outlining its key principles and scholarship, showing how this approach helps improve healthcare for patients, including those with endometriosis.

## 2.1. Endometriosis and the Impact of Chronic Pain

Due to the subjective nature of the pain and fatigue that come with endometriosis, it can be difficult for women to explain to others how the condition affects their lives. This causes many women with endometriosis to feel as though they are not understood by their friends and family, or that others have no empathy towards them (Facchin et al., 2018), leading women to conceal their difficulties from friends, family, and colleagues for fear of being judged or labelled as 'weak', or a 'hypochondriac' (Grogan et al., 2018; Cole et al., 2021). For example, Gilmour et al. (2008) conducted a qualitative study in Aotearoa New Zealand about the impact of endometriosis on work and found that women preferred not to disclose their condition or their physical problems to their employers or colleagues, especially if they were men. However, this can often be difficult due to the amount of time they had to take off work due to pain, further perpetuating the judgement that they are unable to deal with 'normal' levels of pain. This concealment of symptoms is perpetuated by the way that women who report pain are seen, as explained next.

### 2.1.1. Medical Sexism and the Gendered Experience of Endometriosis

The common mistreatment women experience in medicine such as underestimating and misdiagnosis of pain, especially if it appears as gynaecological, has been linked to pervasive medical sexism (Delston, 2019). The prevalence of medical sexism, both historically and currently, has contributed to inequalities in health for women and has been termed the 'gender health gap' (Boylan et al., 2022). Delston (2017) asserts that "sexism explains a widespread and systemic problem in the medical field and that doctors deny their patients needed medical care for no discernible medical reason" (p. 710). This is especially relevant to endometriosis, a condition with a complex diagnostic process that is poorly understood—largely because its study has not been prioritised in policy and research funding (Hudson, 2022).

Experiences of endometriosis are shaped by views of women's bodies, pain, and illness. Jones (2021) argues that "gendered disability more accurately captures the science and lived experiences of endo[metriosis] than gynecological disease" (p. 196). According to dominant Western biomedical understanding of health, "women's bodies are negatively constructed as sites of failed production, waste, and debris" (Hernandez & Dean, 2020, p. 103). Accordingly, a woman with endometriosis is reduced to having the 'defect' of her body define her health. Alongside this is the common view that women must bear the burden of pain as a normal part of being a woman. Anglesey (2020) argues that if a man were to present to doctors complaining about pelvic pain, he would be tested to see if there was something 'wrong' with his body, for example, appendicitis. However, a woman with the same complaints is dismissed because of the expectation that pelvic pain is 'normal' for a female body rather than a sign of dysfunction. Pelvic pain is conceptualised as a common occurrence during menstruation that women must accept, with no consideration to the intensity of the pain. These gender stereotypes surrounding women's pain and bodies leads to delayed and misdiagnosis for women with endometriosis (Hawkey et al., 2022).

Importantly, diagnoses and treatment recommendations for endometriosis are profoundly shaped by the cultural emphasis on the purpose of women's bodies being for fertility and reproduction (Emad, 2006). Through the biomedical view of women's health, endometriosis is primarily defined and treated with fertility as the focus. This focus has a long history in Western medicine. For example, an ancient Greek belief about how to cure hysteria— which was believed to be caused by the 'wandering womb'—was for women to conceive children as a way of 'anchoring' the womb (Guidone, 2020; Jones, 2015). Similarly, women presenting with endometriosis today are often still pushed by doctors to have children,

either as a treatment (Bullo, 2018; Jones 2015; Wright, 2019) or so that they can then later have a hysterectomy (Young et al., 2016), despite the lack of evidence to suggest that pregnancy could cure endometriosis (Seear, 2014).

In the first instance, being advised to have children as a solution for endometriosis can be upsetting for women who are trying to conceive and struggling with fertility issues, especially as endometriosis is linked with infertility (Guidone, 2020). This advice may also create the impression that they are less valued than women who have children (Facchin et al., 2021). In the second instance (delaying hysterectomy), doctors are often unwilling to explore treatment options that might impact on a woman's fertility if she has not had any children, thereby placing a higher importance on a woman's ability to reproduce than her wellbeing and ability to cope with daily life (Young et al., 2016). Although, it must be noted that having a hysterectomy is debated as a form of treatment for endometriosis (Mikesell & Bontempo, 2020), which may explain the resistance from doctors to consider it as a treatment option.

The explanation of endometriosis as the consequence of delaying or forgoing motherhood has also been linked to failing to comply with dominant gender norms (Jones, 2015). For example, on the assumption that delaying pregnancy triggers disorders of the uterus, the condition has been termed the "career woman's disease" (Nezhat et al., 2012). Endometriosis is also, incorrectly, attributed to sexually transmitted infections caused by 'sexual promiscuity', with pelvic pain seen as a repercussion that a woman must bear as a consequence of deviating from the traditional Western ideal of women as chaste (Guidone, 2020). All these conceptualisations about the cause and treatment of endometriosis are based on the traditional expectations of women as wives and mothers and fail to identify the unique lives and values of each woman with endometriosis.

### 2.1.2. Negative Interactions with Healthcare Providers

Given the preceding discussion it is not surprising that many women struggle to obtain a diagnosis and/or treatment for their condition (Ballard et al., 2006). The average delay between the onset of symptoms and diagnosis of endometriosis is eight years, both globally (Ballard et al., 2006) and in Aotearoa New Zealand (Tewhaiti-Smith et al., 2022). This delay is largely related to the quality of healthcare interactions and relationships (Mikesell & Bontempo, 2022) which coincides with women reporting difficult interactions with healthcare providers (Grace, 1995, Seear, 2009). These difficulties with medical interactions can be due to, for example, healthcare providers normalising women's pain, their lack of knowledge about

endometriosis (Pettersson & Berterö, 2020), or the healthcare provider being unsympathetic and hard to communicate with (Grace, 1995).

#### *2.1.2.1. Normalisation of Pain*

As discussed in the previous section, many women are told that their menstrual pain is a normal part of being a woman. This normalisation of pain for women translates into healthcare interactions. For instance, Denny and Mann (2008) conducted a qualitative study in the United Kingdom investigating women's experiences of endometriosis in the primary care setting. They found that women were often told by their GPs that their symptom of intense pain was normal 'period pain' and their experiences were trivialised. Similarly, Pettersson and Berterö's (2020) qualitative study in Sweden found that women had the experience of being told that their pain was normal and 'just part of being a woman' and that they had a low pain threshold.

As a result of the view of menstrual pain being 'normal', women with endometriosis can also be positioned as overreacting and failing to cope with the pain associated with being a woman (Pettersson & Berterö, 2020). This is especially true for young women as healthcare providers often discredit their experiences and tell them that their pain is due to the onset of menarche and will settle down within a few years (Manderson et al., 2008) and that they are 'too young' to have endometriosis (Wren & Mercer, 2021). Menarche and pelvic pain can be positioned as a positive experience, signifying a girl 'blossoming' into a woman (Krebs & Schoenbauer, 2020), making it difficult for girls or young women to identify what level of pain is 'normal' and what is 'abnormal' because they have limited experience with and knowledge of menstruation. For this reason, it is important that doctors take extra care with younger women in exploring symptoms and considering family histories to identify issues that girls might have thought are a normal part of menstruation (Cox et al., 2003).

The normalisation of women's reproductive pain is supported and reproduced by societal messages, healthcare professionals, and family members, leading women with endometriosis to conceal their struggles rather than advocate for a diagnosis (Matias-Gonzalez et al., 2021). Women from cultures that see pain as a normal part of womanhood are less likely to seek initial treatment, because they may believe that they are overreacting (Facchin et al., 2018; Manderson, 2008).

The normalisation of women's pain delays diagnosis of endometriosis either because women are slow to present to healthcare providers due to failing to recognise their situation as

abnormal, or because when they do seek treatment they are dismissed. This disempowers women and limits their agency (Bullo, 2018). Due to their concerns not being taken seriously, women either have to visit multiple healthcare providers to find one who will take them seriously or give up going to the doctors and put up with the pain (Denny & Mann, 2008).

Along with having their pain normalised, women seeking care for endometriosis are often told that they are exaggerating their pain. When disclosing their painful symptoms, they are framed as attention-seeking or overreacting. This common response is related to the dominant biomedical understanding that frames women as weak, neurotic and attention-seekers who are exaggerating pain (Krebs & Schoenbauer, 2020). Instead of being taken seriously about their pain, women can be told that they should seek a psychiatrist rather than a doctor, because it is psychosomatic (Grundström et al., 2020). This is perpetuated by the fact that endometriosis can only be confirmed by surgery, which is often not conducted (Mikesell & Bontempo, 2022). This means that healthcare providers need to solely rely on women's accounts of their symptoms and their experiences, meaning they are easily dismissed. When healthcare providers do not take women's pain seriously, they are unlikely to refer a woman on to get specialised care (Pettersson & Berterö, 2020), resulting in a longer path to diagnosis.

This is an example of medical gaslighting. Medical gaslighting is a concept that has recently emerged in the literature and is characterised by experiences of inadequate care due to dismissal and invalidation (Merone et al., 2022). Despite the recent discourse around medical gaslighting, it is not a new phenomenon (Sebring, 2021). Medical gaslighting is linked to the power that healthcare providers hold over their patients (Sebring, 2021). There is a power imbalance in healthcare encounters because providers can dismiss women and doubt their experiences. A participant in an Australian qualitative study claimed that healthcare providers have "the power of [your] quality of life" (Young et al., 2020, p. 30). Accordingly, when women experience medical gaslighting and dismissal, it leaves them powerless to change their situation except for seeking a new healthcare provider who might enforce similar power dynamics (Young et al., 2020).

#### *2.1.2.2. Patronised by Healthcare Providers*

Similarly, to having their pain normalised, another result of medical sexism is healthcare providers' attitudes toward women. Women with endometriosis often feel that their concerns have not been heard by medical professionals and that they are being patronised (Zale et al., 2020). Healthcare providers may also make women feel as though they are

inconveniencing them and wasting their time. This can manifest verbally, with healthcare providers talking in a monotone voice and talking over top of women (Hintz, 2022), as well as physically by looking away, sighing, or tapping their fingers (Grundström et al., 2018). These behaviours are the outward manifestation of the belief that women are attention-seeking and neurotic, as mentioned before. In a meta synthesis of qualitative studies about healthcare encounters for chronic conditions, Hintz (2022) found that healthcare providers silenced women both explicitly by preventing them from talking about their pain, as well as implicitly by discouraging them. This is an example of medical sexism due to women's accounts of pain not being believed. Silencing adds to the loneliness that women with endometriosis feel due to lack of understanding from others (Simonsen et al., 2020). Patronisation leaves women reluctant to continue seeking treatment for endometriosis. This is perpetuated if healthcare providers do not have sufficient knowledge and information, as discussed next.

#### *2.1.2.3. Lack of Knowledge and Information*

A lack of knowledge by healthcare providers or the lack of effective communication further contributes to diagnostic delay. Even if a healthcare provider is knowledgeable about endometriosis, unless they can effectively convey that information, it is of little value. Women report that doctors will share misinformation, including myths such as pregnancy curing endometriosis and adolescents being 'too young' to have endometriosis (Denny & Mann, 2008; Evans et al., 2022; Pettersson & Berterö, 2020). This lack of information continues even when a diagnosis of endometriosis is reached. Cox et al.'s (2003) Australian study found that even when receiving a diagnosis, only half of the participants reported receiving information from their healthcare providers on endometriosis. They also found that although many women were referred for a laparoscopy, only half reported being informed about what to expect from and the reason for the procedure.

Healthcare providers' lack of knowledge regarding endometriosis can be attributed to medical sexism and the neglect of research surrounding the condition. Hudson (2022) argues that "endometriosis illustrates how ignorance can shape the trajectory of the condition as well as its contemporary categorization and management" (p. 25). For this reason, women suffer in healthcare encounters due to providers' ignorance about endometriosis.

### 2.1.3. The Aotearoa New Zealand Context

In Aotearoa New Zealand, there is a significant knowledge gap regarding how healthcare relationships impact women's experiences of the condition. One exception is Grace's (1995) now quite dated discursive study of women seeking healthcare for pelvic pain – often caused by endometriosis. The study showed that women had difficulty with healthcare interactions due to unsupportive doctors, lack of communication and information, and a long delay before being referred to a gynaecologist. Grace (1995) concluded the study by arguing that doctor-patient relationships need to be redefined to improve the care that women receive for chronic pelvic pain. However, this study was conducted almost three decades ago and there has been no further research to show how this could be done, or whether it has been done in Aotearoa New Zealand. It is important to have up to date local research to understand whether standard of care has changed in the time between Grace's (1995) study and now, or whether findings are similar, prompting a stronger push for change to healthcare systems.

## 2.2. Healthcare Providers' Perspectives

In light of women's complaints of healthcare providers lacking information about endometriosis, further research has considered the perspectives of healthcare providers and suggests that many feel ill-equipped to help women with endometriosis beyond physical treatments. For example, Young et al. (2017) conducted a study interviewing Australian clinicians about their psychosocial care for women with endometriosis. Many participants reported receiving inadequate training. These clinicians perceived psychosocial care as beyond their scope of practice, and suggested women struggling with the psychosocial effects of endometriosis should be referred to a psychologist.

Other studies reiterate this, with a 2021 study in France indicating that only a quarter of GPs felt they had sufficient knowledge about endometriosis, noting that they were the ones who had additional gynaecology training (Roullier et al., 2021). Likewise, a Swedish study from 2016 conducted interviews with GPs, gynaecologists, and midwives, to investigate their experiences of meeting with women with potential endometriosis symptoms (Grundström et al., 2016). This study highlighted a lack of knowledge from healthcare providers. The healthcare providers from their study described women with endometriosis as a 'challenging group to meet' (pp. 66). This was due to the women needing high responsiveness from their healthcare providers but the healthcare providers not always having enough knowledge and experience to give them the care they needed. Many of the healthcare providers interviewed expressed the desire to support the women and for them to be satisfied with the interactions,

but it was not always possible. They reported the importance of listening to women and taking their pain seriously but noted that appointments were often too short to establish a solid rapport.

Such findings cohere with research conducted from the patient's perspectives to show that healthcare providers tend to focus on physical aspects of the condition in diagnosis and treatment (Geukens et al., 2018) and often neglect to ask for the patient's history and perspective (Chapron et al., 2019). However, due to the impact of the condition on women's lives, treatment for endometriosis needs to go further than addressing physical symptoms, but rather consider social and mental functioning. However, it also shows that healthcare providers want to find solutions for women with endometriosis, but often lack the knowledge or facilities to achieve this. This is part of the rationale for encouraging patient-centred care for endometriosis, as explained below.

### 2.3. Patient-Centred Care

Despite the negative experiences explained above, it is possible for women with endometriosis to have positive healthcare experiences. To improve health outcomes for women with endometriosis, a shift in healthcare encounters is necessary. Researchers are beginning to consider patient-centred care to counter the negative experiences reported by women with endometriosis. Nyhof et al. (2020) argue that healthcare encounters for endometriosis currently leave women's psychosocial needs unmet. Patient-centred care, however, aims to meet both the physical and psychosocial needs of women.

Patient-centred care is based on recognising the needs, values, and preferences of the individual and calls for the healthcare provider to be respectful and responsive to this. It also requires them to view healthcare not just from the scientific, medical knowledge they have, but also from the understanding of the individual's experiences of the illness (Geukens et al., 2018). Although healthcare professionals have medical knowledge, women have experiential knowledge and often this is thought by women to be more significant and trustworthy than medical knowledge because it acknowledges the lived experiences of their condition (Markovic et al., 2008). Patient-centred care does not require healthcare providers to ignore their biomedical knowledge, but instead it emphasises a comprehensive approach with interactions between patients and healthcare providers rooted in collaboration (Cook & Brunton, 2015).

Patient-centred care is one of six dimensions of quality healthcare, according to the World Health Organization (2006), but it is still not widely practiced. There are four key areas

where healthcare providers can show patient-centred care to women with endometriosis, namely: (1) giving support, (2) caring about the patient as an individual, (3) enabling self-management and (4) building trust. I discuss each of these aspects in turn.

### 2.3.1. Support

Women with endometriosis need support to help them navigate their condition, but this is not often offered by healthcare providers. Women will instead turn to friends and families, as well as online platforms for emotional support (Wren & Mercer, 2021). For this reason, including significant others as support people in consultations is an important aspect of patient-centred care (Schreurs et al., 2020). Doing so can enhance women's social support by allowing significant others to understand endometriosis better. Significant others also take on the role of advocate, bringing up any unmentioned concerns and facilitating better outcomes. Involving significant others in consultations, diagnosis, and decision-making can also help give healthcare providers a better understanding of the context of the woman's life.

However, a women might not always have a good support system, meaning that it is important for her healthcare provider to provide emotional support. Apers et al. (2018) conducted a study which found that women with endometriosis were more likely to report having social support if their interactions with healthcare providers were patient-centred. This finding suggests that patient-centred care can be crucial for women to feel supported, especially if they are not receiving social support from their friends and family.

### 2.3.2. Caring About Women as Individuals

As part of providing emotional support, as discussed above, caring about women as individuals is key. Several studies have investigated what women with endometriosis want from their healthcare providers. A common theme was that women with endometriosis want to be cared about as individuals rather than being defined by their condition. Simonsen et al. (2020) found that women with endometriosis want to be seen as a whole person, rather than being limited to a sufferer of a health condition. Nyhof et al. reiterated these findings in their 2020 study where they interviewed Canadian women with endometriosis. They also found that women want their healthcare providers to show genuine interest in them as a person, enquire about their interests and personal circumstances, as well as have a non-judgemental attitude towards them. Women not only want their emotions and feelings to be asked about by their healthcare providers, but they also want them to be validated.

For example, a qualitative study by Denny and Mann (2008) about women's experiences of endometriosis in the primary care consultation in the United Kingdom highlights the value of care. The researchers found that even when GPs did not have an adequate knowledge of endometriosis, if they took the time to listen to their patients and were sympathetic towards them, the patients still considered that they had received adequate care, provided the GP also referred them to a specialist who could provide further information. This finding was reiterated by Pettersson and Berterö (2020), who argue that inadequate knowledge is only a minor concern of women with endometriosis if the healthcare provider is supportive and facilitates a good relationship with the woman.

These studies confirm the need for patient-centred care, highlighting that women can still be satisfied with the care they receive even if their healthcare provider does not have all the answers (Denny & Mann, 2008; Pettersson & Berterö, 2020). Ideally the healthcare provider would have both knowledge and compassion, however this is not always the case as endometriosis a condition that many healthcare providers are not very knowledgeable about. However, if they have inadequate knowledge on the subject, they should endeavour to further inform themselves before the next time they meet with the patient. This is especially important for healthcare providers who regularly see patients with endometriosis. Their care and investment builds rapport with the patient and shows that they are dedicated to improving health outcomes for that woman (Romm & Shaffer, 2017).

### 2.3.3. Prioritising Women's Concerns

Although it might not always be possible to treat endometriosis, healthcare providers should prioritise the symptoms and concerns of the individual woman. By understanding her circumstances, the healthcare provider can seek to improve areas of a woman's life that she is most concerned about. Fernley (2021) conducted a thematic analysis of online autobiographical accounts of women with endometriosis in Australia and found that wanting to being heard was a main wish from women with endometriosis. For example, one woman reported that she wants a doctor who "sees patients as human beings with feelings, goals, and lives, not just a patient" (p. 47). Conversely, Young et al. (2020) interviewed a woman with endometriosis who claimed that her doctor did not believe that she did not want to have children, and therefore tailored solutions around values that are not relevant to her. This highlights the value of prioritising women's needs by listening to their life and reproductive goals.

Prioritising women's needs without making assumptions requires the healthcare provider to understand endometriosis from a critical lens by situating women within their social and cultural contexts (Lyons & Chamberlain, 2006). A critical approach to endometriosis treatment involves acknowledging that the negative aspects of endometriosis are not only physical, but rather are also shaped by social, political, and economic factors (Young et al., 2020). If only one factor is considered, this greatly changes the conceptualisation of endometriosis and how to improve women's lives (McGowan, 2017).

### 2.3.4. Enabling Self-Management

In addition to responding to the individual needs of a woman, healthcare providers should enable self-management for patients with endometriosis. They should explain what the follow-up process is after seeing them, as well as providing resources and recommendations for patients about what they can be doing to help manage their endometriosis (Nyhof et al., 2020). Due to the chronic and often severe nature of endometriosis, even small improvements to a woman's life can help improve her ability to cope with her circumstances. For this reason, providing self-management strategies can give patients autonomy and allow them to focus on little ways they can improve their situation.

### 2.3.5. Trust

Along with support, knowledge, and compassion, trust is an essential component to patient-centred care. Seeking healthcare for endometriosis is a vulnerable process in many ways. Women must trust healthcare providers with private aspects of their life, both physically and mentally, opening their bodies and their personal struggles up to examination (Grundström et al., 2018). The consultations for endometriosis are deeply personal and deserve to be treated with respect.

A vaginal examination is considered standard practice for investigating suspected endometriosis both internationally (Dunselman et al., 2014) and in Aotearoa New Zealand (Ministry of Health, 2020). Cook and Brunton (2015) argue that patient-centred care is even more necessary for healthcare interactions where gynaecological examinations are taking place, due to the vulnerability of having someone else examine a part of the body commonly seen as private. They discuss the issue of a power imbalance within a consultation where women assume they must comply with a physical examination they are not comfortable with. Depersonalisation is a strategy often used by healthcare providers during gynaecological

examinations, however, Cook and Brunton (2015) argue that it is important for the practitioner to instead humanise women. Healthcare providers can humanise women during a gynaecological examination by empathising with women's experiences and acknowledging the value of a woman's body.

To build trust with women with endometriosis, healthcare providers need to be mindful of the power imbalance in consultations and ensure that they are acting in a respectful and trusting manner. One of the ways that trust can be built between a woman and her healthcare provider is for her to have the option to request a female doctor rather than a male doctor, if this were something that would make her feel more comfortable (Nyhof et al., 2020). Often women can feel more understood by women than by men and for some women having a female doctor can ease the power imbalance (Nyhof et al., 2020).

To further build trust, there is also the need for continuity of care (Schreurs et al., 2020). Rather than seeing a new healthcare provider each time they need a consultation, enabling women to build rapport with a singular practitioner can be key to building trust and improving healthcare outcomes for women with endometriosis. It is easier for the woman to feel like she is receiving genuine interest from the healthcare provider if she sees the same person in subsequent appointments (Schreurs et al., 2020).

## 2.4. Conclusion

In this chapter, I have presented the current literature available about healthcare interactions for endometriosis. As argued above, patient-centred care is necessary to improve care for women with endometriosis, however there is a lack of research about this from Aotearoa New Zealand. Due to the diverse and unique needs of women with endometriosis, local research is needed to improve the care in a way that is meaningful to the women of Aotearoa New Zealand. In the following chapter, I will outline the present study, along with my methodological approach to the research.

# Chapter Three: Methodology

In the previous section, I presented a research rationale that argued for the need to conduct Aotearoa New Zealand specific research examining healthcare interactions for women with endometriosis. I also argued the value of a woman's lived experiences as a source of knowledge production. Hesse-Biber (2014) argues that "feminist research projects must begin with women's lives" (p. 6.). Consequently, I am drawing on feminist standpoint theory as a theoretical lens to investigate and prioritise women's lived experiences. In this chapter, I begin by discussing the theoretical underpinnings of my study and present arguments for why feminist standpoint theory is an appropriate theoretical lens when researching women's experiences of healthcare for endometriosis. I will then discuss the design and method by which I constructed this study. This includes a discussion of recruitment, participants, and data collection. Following that, I will detail Braun and Clarke's (2022) reflexive thematic analysis. Finally, I will conclude this chapter by detailing ethical considerations of this research and discussing reflexivity.

## 3.1. Theoretical Framing: Feminist Standpoint Theory

Instead of objectively measuring the success of the healthcare system for women with endometriosis, I take a feminist standpoint approach, which treats "women's experiences as a form of local, situated knowledge" (Morison, 2022, p. 178). Realising that each woman has her own experiences and priorities and will experience endometriosis and the healthcare system through her own perspective, I seek to understand the truth from the perspective of affected women by considering their experiences. I therefore explore how the women in this study make sense of their diagnosis, based on their lived experiences. Furthermore, I approach this research from a feminist standpoint because experiences of endometriosis are gendered.

Feminist standpoint theory is appropriate for experiential studies because it rejects the notion that there is one objective reality, but rather acknowledges that reality is understood according to different standpoints based on people's social locations (e.g., gender, class, race) (Gergen, 2017). Furthermore, Gurung (2020) explains that feminist standpoint theory is a "feminist theoretical perspective that denies the objectivity of scientific research for ignoring and marginalising women and feminist ways of thinking" (p. 107). Because women and their concerns have been long been neglected in research, endometriosis was ignored in research until recently. This oversight entrenches the marginalised status of women, because the

condition remained poorly understood and caused women with endometriosis to have poorer physical and mental health outcomes than those without the condition.

Research informed by feminist standpoint theory puts women's experiences at the forefront of the inquiry (Eagle et al., 1999) and argues that knowledge about the world can be accessed through the unique experiences of women (Gergen, 2017). It gives a voice to women and acknowledges their experiences as a distinct and legitimate source of knowledge that is often excluded from research (Campbell & Wasco, 2000). This allows women's voices to be expressed in a way that is defined by and meaningful for them (Coyle, 2007). Feminist standpoint theory has been frequently used to research topics about women's bodies, including sexual and reproductive issues (Eagle et al., 1999) and how they are experienced within a patriarchal society (Gergen, 2017).

There is a dissonance that occurs for women when they compare their lives and their realities with the dominant way of thinking about their experiences (Hesse-Biber, 2014). As Jones (2016) explains, "those with endo[metriosis] must grapple with both lived experience of endo[metriosis] as a pain disorder in addition to gendered norms that render it invisible in public discourse." (p. 556). Feminist standpoint theory allows these experiences that go against the dominant way of thinking to be highlighted, which is necessary for endometriosis-related research.

Feminist standpoint theory situates the investigation of an issue within the specific time and place of the participant's context (Haraway 1988). Because my focus is specifically on the Aotearoa New Zealand healthcare system within the participants lifetimes, feminist standpoint theory is suitable because it allows participants to express their truth based on their social, geographical, and historical context (Cohen et al., 2021). Although research from other countries is important, it is also necessary to conduct research from a local perspective to gain insight from the women living with endometriosis in Aotearoa New Zealand. Currently, these women's perspectives are missing from the literature, and it is my aim to spotlight their experiences to produce useful knowledge for the Aotearoa New Zealand healthcare system, while also highlighting the situatedness of the knowledge that is produced.

### 3.2. Method

As discussed above, New Zealand women's perspectives are missing from the literature, necessitating this research. Accordingly, I chose to collect data for this study using an online qualitative survey, allowing me to gain responses from women across the country. In the following discussion, I outline my recruitment and selection process and introduce the

online survey as a qualitative data collection method, presenting arguments of the suitability of the method in answering my research questions. I conclude this section by detailing and critically reflecting on my data analysis process.

### 3.2.1. Recruitment

The main recruitment method I used to circulate the link for my online qualitative survey was through social media. I also put physical posters up on the inside of toilet cubicle doors at Massey University Albany campus. I chose these locations as they allow privacy, due to the sensitive nature of the topic. Potential participants could privately read and link to the survey without being seen doing so.

For online recruitment, I made a digital poster that introduced the study, along with the eligibility criteria, and explained the instructions for completing the qualitative survey. I distributed the digital poster online via *Facebook*, *Instagram,* and *Twitter*. I posted on my personal *Facebook* and *Instagram* accounts and the link was shared by friends and family sharing the poster (i.e., snowballing). I also posted the link in several *Facebook* groups. The *Facebook* groups that I posted in included an Aotearoa New Zealand endometriosis support group, Massey University students groups, and a general Aotearoa New Zealand women's group. For the endometriosis support group and women's group, I sent the account administrators my recruitment poster and participant information sheet and requested permission to share my study in the groups via direct message. The administrators approved my requests to post the link to the survey.

To be eligible to take part in my study, participants had to be aged 16 years or older, as per the ethical age of consent for research (Massey University, 2017), and have resided in Aotearoa New Zealand for at least five years so that they are familiar with the healthcare system. Participants also had to be a cisgender woman. As mentioned in Chapter One, I was specifically interested in the experiences of cisgender women because the experiences of transgender and non-binary people are differently nuanced and their unique, perhaps more complex, interactions with the healthcare system fall outside the scope of my small masters-level research project.

The participants also had to have been clinically diagnosed with endometriosis for at least a year. I stipulated having had a formal diagnosis (rather than self-diagnosis) because of my interest in the experience of obtaining a diagnosis as part of the healthcare experience. Additionally, I wanted some time to have elapsed since the diagnosis of endometriosis because

this can be an emotional process for some women. I wanted to ensure that they had sufficient time to process their diagnosis before participating in the study, so as to minimise the chance of negative emotions arising from sharing their experiences. The only way to diagnosis endometriosis with certainty is to have a laparoscopic surgery (Health New Zealand, 2024), however I acknowledge that some women may receive a provisional diagnosis from their healthcare providers without having the surgery. I did not specifically list laparoscopic surgery as an eligibility criterion because I did not want to define what a diagnosis meant to each individual.

Given the personal nature of the study, I chose to give every participant a $10 voucher as a koha (gift) for volunteering their time to take part in the study. If participants opted to receive the koha, they were prompted to provide their email address at the end, however this was not linked to their responses.

### 3.2.2. Participants

The final number of participants in my study was 63. I wanted to have the time and capacity to treat all the responses from my participants with care and do their stories justice, so I followed the recommendations of Terry and Braun (2017) who advise that a sample size of up to 100 participants is suitable for a qualitative survey for smaller studies such as theses. I let the survey remain active for one month, with the intention to extend it until I was satisfied that I had rich data. As a ballpark figure, I was expecting that at least 30 participants would elicit enough rich data to form a satisfactory analysis. After a month, I had received 63 responses which all elicited rich data and I was satisfied to close off the survey from further responses. My survey was active for all of October 2023.

The age of the participants ranged from 18 to 53 years, with most falling into the 21 to 40 age range. Although all ethnicities were encouraged to participate in my study, most participants (51) were New Zealand European. See table 1 for an overview of the participants' ethnicities and age ranges, and table 2 for a summary of the participant's demographics along with their aliases.

**Table 1**

*Overview of Ethnicities and Age Ranges (n=63)*

| Ethnicity | no. | Age Group | no. |
|---|---|---|---|
| Asian | 3 | 16-20 | 3 |

| | | | |
|---|---|---|---|
| British | 1 | 21-25 | 11 |
| Canadian Métis | 1 | 26-30 | 15 |
| Cook Island Māori | 2 | 31-35 | 9 |
| Dutch | 1 | 36-40 | 10 |
| Māori | 4 | 41-45 | 5 |
| New Zealand European | 51 | 46-50 | 7 |
| | | 51+ | 3 |

**Table 2**

*Participant Demographics (n=63)*

| Alias | Age | Ethnicity | Years Since Diagnosis |
|---|---|---|---|
| Emily | 35 | New Zealand European | 1-5 |
| Maria | 21 | New Zealand European | 1-5 |
| Lizzy | 31 | New Zealand European | 1-5 |
| Hannah | 26 | Dutch | 1-5 |
| Pauline | 51 | New Zealand European | 1-5 |
| Keri | 25 | New Zealand European | 1-5 |
| Elaine | 53 | New Zealand European | 10+ |
| Amber | 37 | Māori | 5-10 |
| Caitlin | 20 | New Zealand European | 1-5 |
| Violet | 28 | New Zealand European | 5-10 |
| Chloe | 26 | New Zealand European | 1-5 |
| Meryl | 43 | New Zealand European | 1-5 |
| Charlotte | 37 | New Zealand European | 1-5 |
| Amy | 28 | New Zealand European | 5-10 |
| Aroha | 28 | Māori | 5-10 |
| Holly | 31 | New Zealand European | 1-5 |
| Lana | 26 | New Zealand European | 5-10 |
| Georgia | 28 | New Zealand European | 5-10 |
| Alisha | 26 | New Zealand European | 1-5 |
| Debbie | 40 | New Zealand European | 5-10 |
| Lisa | 42 | New Zealand European | 1-5 |
| Selina | 47 | New Zealand European | 10+ |

| | | | |
|---|---|---|---|
| Paige | 30 | New Zealand European | 10+ |
| Kelly | 36 | New Zealand European | 10+ |
| Kirstin | 50 | New Zealand European | 1-5 |
| Ziran | 41 | Asian | 1-5 |
| Melissa | 35 | New Zealand European | 10+ |
| Grace | 23 | New Zealand European | 5-10 |
| Kaia | 21 | Cook Island Māori | 5-10 |
| Jess | 36 | New Zealand European | 10+ |
| Genevieve | 18 | New Zealand European | 1-5 |
| Tanya | 37 | Māori | 10+ |
| Jasmine | 29 | New Zealand European | 1-5 |
| Lauren | 34 | New Zealand European | 1-5 |
| Cassandra | 31 | Canadian Métis | 1-5 |
| Michelle | 53 | New Zealand European | 10+ |
| Savannah | 31 | New Zealand European | 5-10 |
| Chelsea | 29 | New Zealand European | 10+ |
| Rochelle | 46 | New Zealand European | 1-5 |
| Arushi | 43 | Asian (Indian) | 1-5 |
| Serene | 28 | Asian | 5-10 |
| Olivia | 32 | New Zealand European | 10+ |
| Nicola | 48 | New Zealand European | 5-10 |
| Haley | 26 | New Zealand European | 5-10 |
| Steph | 25 | New Zealand European | 1-5 |
| Sara | 24 | New Zealand European | 5-10 |
| Rachel | 47 | New Zealand European | 10+ |
| Erin | 39 | New Zealand European | 10+ |
| Shannon | 37 | New Zealand European | 1-5 |
| Sally | 37 | New Zealand European | 1-5 |
| Kathleen | 47 | New Zealand European | 10+ |
| Lily | 24 | New Zealand European | 10+ |
| Milena | 20 | New Zealand European | 1-5 |
| Zoe | 29 | British | 10+ |
| Faith | 25 | New Zealand European | 10+ |

| | | | |
|---|---|---|---|
| Freya | 38 | New Zealand European | 1-5 |
| Talia | 25 | New Zealand European | 1-5 |
| Isla | 21 | Cook Island Māori | 5-10 |
| Danielle | 43 | New Zealand European | 10+ |
| Fiona | 47 | New Zealand European | 5-10 |
| Rose | 33 | Māori | 1-5 |
| Madi | 25 | New Zealand European | 5-10 |
| Eloise | 26 | New Zealand European | 10+ |

### 3.2.3. Data Collection Method: Qualitative Online Survey

I used an online qualitative survey as the data collection method for my study. Surveys have long been a popular data collection method for mixed-method studies; however, a fully qualitative survey is a relatively new approach to research (Braun et al., 2020). The survey I developed asked open-ended questions, which participants responded to in their own words and in as much detail as they wanted. Terry and Braun (2017) note that qualitative surveys are suitable for gaining the experiences and understandings of participants because they allow participants to express their experiences in their own words and define for themselves what is important information on the given topic. This is particularly important when discussing a sensitive topic such as endometriosis. I considered the stigma surrounding endometriosis, and women's experiences of not being believed, as discussed in the previous chapter, when choosing the data collection method.

When sharing about their experiences of endometriosis, a woman is detailing some of the most intimate details of her life and therefore it was my intention for my participants to feel as comfortable as they could throughout the whole process. Consequently, the women who participated in my study could remain anonymous and share only what they were comfortable with. For this reason, an online qualitative survey was advantageous over the more popular qualitative interview.

Attending in-person interviews can be complicated by multiple reasons, including having a chronic condition. Therefore, I judged it to be most appropriate for the cohort of my study to provide an option where they could complete the study in their own time and take as long, or as little, time as they needed. This also speeds up the data collection process because multiple participants can submit responses at the same time and I had instant access to the data,

rather than arranging an interview time and having to transcribe afterwards, as would be the case for face-to-face interviews.

Another advantage of using a qualitative survey was that it could reach more people in less time in a more geographically widespread area than a face-to-face interview (Braun et al., 2020). Geographical diversity is important because the findings are more likely to reflect the experiences of women in different healthcare contexts across Aotearoa New Zealand. Having a larger participant group also means there is the opportunity for more women to share their experiences strengthening the reoccurring themes I was able to discern.

A potential limitation of collecting data online is that people who do not have access to the Internet would not be able to participate in this study (Braun et al., 2020). However, Internet access is relatively high in the country, including through cellphones and mobile devices with an internet penetration rate of 95.7% (Kemp, 2024). Women might also be less likely to complete the survey if they do not have a high literacy level (Braun et al., 2020). To mitigate this, I clarified that correct spelling and grammar is unnecessary and that I am interested in participants' responses in their own words. Participants were asked about their demographic characteristics to be able to contextualise the findings, although to keep a high level of anonymity, I chose to keep demographic questions at a minimum, asking only their age, ethnicity and how many years it has been since their diagnosis.

#### *3.2.3.1. Procedure*

The qualitative survey was completed online and accessed through a link. Before commencing the survey questions, a page of information was displayed about me as the researcher, the research, eligibility criteria, and what participating in the study would involve. Participants were informed of how many questions they would be answering and that there is no right or wrong answer to any of the questions because the research aim is to discover their experiences. They were asked to answer in their own words and reassured that any spelling or grammatical errors are not an issue. Participants were encouraged to take as much time as needed and provide as much detail and explanation as possible. Information about support services was provided to participants on the following page including websites and helplines for endometriosis and mental health-related support. The information page stated the purpose of the research and detailed how the data from the survey would be used, as well as detailing procedures around confidentiality and anonymity. Finally, another information page explained

informed consent. Participants had to check a box confirming that they had read the information and were giving informed consent to participate.

Taking the recommendation of Braun et al. (2020), demographic questions were asked before the other questions, as they are often the least threatening questions for participants to answer. After the demographic questions, the questions that followed progressed from broad to specific. The questions prompted participants to explain their answers or to think about why they had answered that way.

After completing all the questions, participants submitted their responses and had the choice to opt in to receive the koha and/or the results of the study. If they wished to receive a koha or results of the survey, they were taken to a separate survey which recorded their email addresses so that their details were not linked to their answers. Many participants did not share their email address for the koha or results. Of those who did, all requested to be sent a copy of the results, but, surprisingly, not all of them accepted the koha, demonstrating a desire of participants to share their experiences without expectation of receiving anything in return. My intention behind offering a koha to every woman who participated in my study was to honour them for the time they took to share their experiences. However, now that I know many women chose not to request the koha, it would have been a better design choice to invite participants to enter a draw to win a koha of a larger value.

### 3.2.4. Data Analysis: Reflexive Thematic Analysis

To analyse the data, I used reflexive thematic analysis as developed by Braun and Clarke (2022). What distinguishes reflexive thematic analysis from other forms of thematic analysis is "the researcher's reflective and thoughtful engagement with their data and their reflexive and thoughtful engagement with the analytic process" (p. 594). Accordingly, during every step of the analytic process, I considered my own subjectivity. Reflexive thematic analysis is recommended when the data source is a method other than interviews, the sample size is large, and one wants to identify patterned themes across the dataset (Braun & Clarke, 2022). For this reason, I chose reflexive thematic analysis as the most suitable form of data analysis for this research.

Braun and Clarke (2006, 2022) detail six phases used in the process of analysing data by thematic analysis. Although the phases are intended to be completed in order, they note that this process should also be recursive, moving between the phases at any given time. I discuss

both Braun and Clarke's (2022) recommendations, as well as my engagement with the analytic process below.

#### *3.2.4.1. Phase 1: Familiarisation with the Data*

In the first phase, I actively read through the data set, looking for meaning and links. Rather than the more formal coding in the following phase, in familiarising myself with the data, I was actively engaged, and made notes in my journal on what interested me from the data without labelling it. Despite my large sample size, I read and reread the entire dataset until I was confident that I was fully immersed in the depth of the data. In reflexive thematic analysis, researcher subjectivity should not be viewed as a problem but as a resource to aid in the analysis process (Braun & Clarke, 2022). Based on this, I engaged reflexively with the data, considering any existing assumptions I had and any data extracts that surprised me. This active engagement allowed me to fully immerse myself in the data.

#### *3.2.4.2. Phase 2: Generating Initial Codes*

After familiarising myself with the data, I began coding by identifying and interpreting patterns of meaning and why they were interesting, organising the data in meaningful ways. Quality coding requires allowing time for both deep immersion and distant reflection (Braun & Clarke, 2022). For this reason, I repeated this phase on multiple occasions to allow me to form a more complex engagement with the material. The coding was partly led by my research questions and what I was expecting to find from the data, but I also looked to code for patterns that I did not expect. Bearing in mind that there will be inconsistencies in all data sets (Braun & Clarke, 2006), for authenticity I utilised all available data while coding, including those extracts that did not align with the dominant patterns. I recorded the codes both manually, making notes and highlighting on a physical printed copy of the survey transcripts, as well as digitally in a spreadsheet.

When forming codes, and later themes, I used a largely inductive approach. My analysis was data-led and worked from the 'bottom-up' using my data as a starting point. While coding, my aim was to code semantically, with the focus being on representing the data with its explicit meaning. This is based on the recommendations of Terry et al. (2017) who suggest that inductive and semantic coding is best suited to work using theoretical frameworks that align with a (critical) realist ontology, such as my experiential study drawing on feminist standpoint theory. Inductive coding was suitable for my research because I wanted to represent my

participant's experiences as they were, without a preconceived idea of what I might expect to find from my participant's accounts. I chose to focus on more semantic coding because although I interpreted the data to form themes, I wanted the analysis to stay true to what my participants said and be grounded in their experiences.

#### *3.2.4.3. Phase 3: Generating Themes*

After the data had been coded, I used the codes to form themes. As opposed to codes which are specific features of interest, themes are broader and identify an overarching pattern. Braun and Clarke (2019) describe themes as "creative and interpretive *stories* about the data, produced at the intersection of the researcher's theoretical assumptions, their analytic resources and skill, and the data themselves". Importantly, themes are not seen as being 'in' the data, or emerging from the data, rather they are constructed by the researcher (Braun & Clarke, 2019). I used a thematic map as a visual tool to connect codes and form themes. It is important to consider all themes at this stage as they will be refined in the next stage. At this stage the themes that I developed all had many sub-themes as I found many patterns of interesting data but had not yet refined them to be nuanced and compelling.

#### *3.2.4.4. Phase 4: Reviewing Themes*

After developing themes, in the fourth phase, I refined them and established which themes I wanted to include in my analysis and which ones I needed to discount. According to Braun et al. (2019, p.854), themes should "tell a coherent, insightful story about the data in relation to the research question". The themes that I generated from the data told a story about women's experiences of healthcare for endometriosis, finding patterns across the dataset while also honouring the original text of each participant. During this phase, I compared my thematic map to the dataset to ensure that it was accurate to the meanings present in the data. My focus was on looking at which themes specifically related to answering my research questions. There were many interesting themes that I developed that I had to discard because, although interesting, they did not aid in answering my research questions.

#### *3.2.4.5. Phase 5: Defining and Naming Themes*

After finalising my themes, I defined exactly what they encompassed and gave them a concise, descriptive name. This included both themes and sub-themes. Braun and Clarke (2006) recommend ensuring that each theme fits with the narrative being told and that one is

not paraphrasing the data but rather identifying what is of interest about the data extracts. I found that even after beginning phase six of producing the report, I was coming back to this phase and refining the themes as my narrative developed to tighten them and make them more compelling.

#### *3.2.4.6. Phase 6: Producing the Report*

After the themes were finalised, the final phase of my analysis was to produce the write-up. While writing up my analysis, I was mindful to form an argument rather than merely describing the data. In forming the argument, I considered the story that I was telling through the data, as well as providing evidence from the data that was vivid and compelling. In this step, I found that I had so much rich data with compelling quotes that I tried to include too many quotes. As a result, I had to read my analysis as a whole and limit quotes to only those which aided my argument.

## 3.3. Ethics

I applied for a low-risk notification, meaning that it was peer reviewed and deemed to be a low-risk study. Consequently, as it has not been reviewed by one of Massey University's Human Ethics Committee it is my responsibility to ensure ethical conduct throughout my research. I used the Massey University Code of Ethical Conduct (2017) to inform my ethical decisions for this study. It outlines four guiding principles: autonomy, avoidance of harm, benefit, and justice. Accordingly, I ensured that my participants freely chose to participate, minimised the risk of harm, and provided benefit to participants and to society, as well as fairly distribute the benefits and harms of the study.

### 3.3.1. Informed Consent

People should only participate in a study when they have been given adequate information about what participating would entail and they have given consent based on this information (King, 2019). To meet this requirement, I complied a comprehensive information sheet before the beginning of the survey and participants had to check a box to acknowledge they have read the information and agree to participate. This information sheet gave details about the purpose of the study, the research aims and how the data will be used. It also included contact email addresses of both me and my supervisor to allow participants to get in contact to seek more information, ask questions or express concerns before they choose to complete the

survey. The contact email addresses were also presented on the digital poster that advertises the survey so that people did not have to click into the survey to access this information. The information sheet informed participants that they do not have to answer any questions if they do not feel comfortable to do so, and do not have to complete the survey if they do not want to. However, I concluded that by using an online method, it is unlikely that women will feel under pressure to submit the survey.

### 3.3.2. Anonymity and Confidentiality

Although a qualitative survey cannot be completely anonymous, there is a high level of anonymity by using this method. Except for the option of providing a contact email address for the koha, no personal details were requested. Participants were given pseudonyms, and any identifying factors were changed as soon as the data had been collected. The transcripts of the survey responses were stored securely on an online hard drive and are only accessible by myself and my supervisor.

### 3.3.3. Right to Withdraw

Participants were informed that at any stage during the survey, they can choose not to continue. By using an online survey, it would be easy for participants to withdraw during the survey, however, due to the high anonymity of the qualitative survey, it was not possible for a participant to withdraw their responses after their final submission of the survey. This was communicated to participants on the consent form.

### 3.3.4. Benefits and Risk of Harm

Participants could benefit as individuals from this study by having their experiences validated and experiencing a sense of relief through having the opportunity to express their feelings and experiences for someone who is genuinely interested and non-judgmental. It is empowering for women who might have experienced disbelief of the genuineness and severity of their symptoms to be asked about their unique experiences. It gives a voice to these women who have often been silenced and allows them to represent themselves in research in this field and identify their own unique needs. They may also have derived a sense of satisfaction from helping the researcher and potentially others with endometriosis.

There are also potential advantages beyond individual benefits. One of the aims of this study is to identify the ways in which the Aotearoa New Zealand healthcare system could

improve for the care of women with endometriosis. This would be a benefit not only to the participants of the study, but also to other women in Aotearoa New Zealand who are seeking diagnosis and treatment for endometriosis either currently or in the future.

Although participants could have felt a sense of relief or gladness for being able to talk about their experiences, there was also the possibility that because this is a sensitive subject, it might bring up negative or distressing emotions. This possibility was stated in the initial participant information sheet. There was also information provided at the beginning of the survey of where to get help if it is required for any distressing emotions participants might experience.

### 3.3.5. Cultural Considerations

Due to the culturally diverse population of Aotearoa New Zealand, there are a diverse range of women who live with endometriosis whose responses I welcomed in my study. To honour the obligations of research to uphere Te Tiriti O Waitangi, I was guided by *Te Ara Tika Guidelines for Māori Research Ethics* (Hudson et al., 2010). Based on this document, I ensured to respect the dignity of all women who responded to my survey by practicing māhaki (respectful conduct). Applying māhaki to the analysis of my study includes respecting Māori philosophies and spirituality. Although I did not seek to recruit Māori women specifically, I ensured that my survey would be culturally appropriate for women of all ethnicities, including Māori.

## 3.4. Reflexivity

Due to the qualitative nature of this research, the findings of this study relied on my analysis of the data and therefore was influenced by my own identity and situation. Wilkinson (1988) argues that all feminist research should reflexively analyse the research process and to ensure that feminist objectives are achieved through the research, such as highlighting women's experiences and social conditions. Therefore, it is important for me to be reflexive during the research and reflect my thinking back to myself to acknowledge the viewpoints and understandings that I bring into this study (Shaw, 2010), as well as ensuring that my research is beneficial to women. Reflecting on these factors are necessary to situate the knowledge that is gained through this study because the research cannot be separated from the researcher (Lafrance & Wigginton, 2019).

Braun and Clarke (2022) write of reflexive thematic analysis: "We stress the importance of a deep, engaged, and critically open reflexivity throughout the research process"

(p. 18). They recommend a reflexive journal as a useful way to achieve this. Based on their recommendations, I kept a reflexive journal as a means of capturing my thoughts and insights as well as a way of using writing to engage reflexively with my study.

I do not personally have endometriosis, so I am conducting this research as an outsider. Outsider research is important because it means that it is not the sole responsibility of people experiencing stigma and mistreatment to advocate for themselves. It also recognises the responsibility to reduce stigma for other people (Wigginton & Setchell, 2016). However, researching as an outsider can have its challenges as well. It is possible that I might misinterpret or oversimplify results. To mitigate this, I have considered my position as an outsider throughout the whole research process.

Due to my data collection method being a qualitative survey, I do not think my role as an outsider negatively affected the responses that participants gave to the survey, unlike a face-to-face interview where it would have been more relevant to specify that I do not have endometriosis. Despite not having endometriosis, I acknowledge that my position as a woman and my own experiences with gender and reproductive health will likely affect how I perceived the results of this study. This means that the results of this study will be seen through the lens of my own experiences and will show women's experiences of the healthcare system in Aotearoa New Zealand for the diagnosis and treatment of endometriosis as I understand them.

## 3.5. Conclusion

In this chapter, I have discussed feminist standpoint theory as a theoretical framework which allows me to highlight women's voices as key to research. In the second half of the chapter, I detailed the method I used when undertaking my research, including a rationale for the use of an online qualitative survey as my data collection method. I detailed the process of reflexive thematic analysis and concluded by considering ethics and my own reflexivity as a researcher. In the next chapter, I will present the findings of my study and provide interpretation.

# Chapter Four: Analysis and Discussion

In this chapter, I present the main findings of my study as outlined in the previous chapter and locate them within the context of the current literature. The aim of my research was to investigate how women experience the diagnosis and treatment of endometriosis in the Aotearoa New Zealand healthcare system. As detailed in my literature review, the current literature from other countries paints a picture of healthcare encounters for endometriosis comprised of invalidation and lack of information. However, it also presents a form of hope in the research about patient-centred care for endometriosis and placing the needs and experiences of women at the forefront of the healthcare encounter. Likewise, the participants in my study reported negative, invalidating experiences of healthcare. However, similar to the current literature, they also wrote of positive healthcare encounters they had experienced, or wished they had experienced, sparking hope for future women seeking healthcare for endometriosis in Aotearoa New Zealand.

I developed four themes that capture the shared experiences of the women in my study, as presented below in Table 3.

1. The first theme '**dismissal as a barrier to healthcare**' explores participants' accounts of healthcare encounters before they received a diagnosis and the dismissal that they experienced that caused a delayed diagnosis. This was experienced primarily by pain being normalised by healthcare providers.

2. The second theme '**mixed experiences of healthcare providers**' explores participants' differing experiences with healthcare providers, with a focus on the provider's gender and competency. It also discusses the insufficiency of the public health system when compared with private care.

3. The third theme '**lack of support from healthcare providers**' investigates the participants' accounts of support they received, or did not receive, both emotional and practical. It also discusses the need for women to advocate for themselves in healthcare encounters.

4. Finally, the fourth theme details **what the women want** from their healthcare providers. This theme explores the role of validation, compassion, and endometriosis education in shaping positive healthcare encounters.

**Table 3**

*Summary of Themes and Sub-themes*

| Theme | Sub-themes |
|---|---|
| **1.** Minimisation and Dismissal of women's symptoms as a barrier to healthcare | |
| **2.** Mixed experiences of healthcare providers | 2.1. The role of healthcare providers' gender and medical sexism |
| | 2.2. Healthcare providers' competency |
| **3.** Lack of support from healthcare providers | 3.1. Emotional and practical support for women with endometriosis |
| | 3.2. Women advocating for themselves |
| **4.** What the women want from endometriosis healthcare | 4.1. Women want to be believed and validated |
| | 4.2. Women want compassion |
| | 4.3. Women want more endometriosis education |

When asking participants to share written answers as I did, there will inevitably be spelling and grammatical errors in the text that they have submitted. To stay true to the words of my participants, all data extracts are verbatim, retaining the original grammar and spelling they used in their answers. To maintain anonymity, I have used pseudonyms and have removed any potential identifying details.

### 4.1. Theme One: "I Just Felt Stuck in a Loop of Pain and Invalidation": Minimisation and Dismissal of Women's Symptoms

In this theme, I explore the ways that medical sexism (Delston, 2019) featured in women's experiences and how that prevents them from seeking or receiving treatment. This theme focuses on accounts of their symptoms of endometriosis being dismissed as a gendered

form of “medical gaslighting” (explained below). This theme adds to the endometriosis literature, which documents consistent reports of women feeling disbelieved or ignored when they present with symptoms of endometriosis in primary care (Hudson, 2022).

Firstly, menstrual pain was commonly described as being normalised by friends and family, as well as healthcare providers, which delayed the participants’ recognition of their pain as abnormal. After seeking treatment for their pain, they reported being disbelieved by healthcare providers and turned away. Finally, even when they were able to see a doctor who believed their symptoms and offered treatment, it was frequently limited to contraception and over-the-counter painkillers, with no underlying causes investigated. The participants reported that healthcare providers did not believe the extent of the symptoms that they were describing. Overall, healthcare providers minimised and frequently disregarded reports of pain by telling participants that it was related to “normal” menstrual pain. This is captured by Cassandra’s experience in the following extract.

> Although I had painful periods for as long as I could remember, I had always been told that it was normal, even though I was curled in a ball for two days of my period [...] Pre diagnosis, the pain was always brushed off as being normal. I was given birth control to attempt to control the pain, but it was not enough. Even my parents, including my mother who is a nurse, viewed the pain as normal. They did not seem bothered that my pain was affecting me every month. Having this pain normalised, and ignoring the pain made it so much worse.

For Cassandra, having her mother, a healthcare provider, normalise and ignore her painful periods was a cause of distress and disappointment. However, what was perhaps most disappointing was the dismissal by healthcare providers having her pain ‘brushed off’ as normal.

Similarly, Savannah and Kelly recounted how when seeking healthcare for their painful periods they were told by multiple providers that period pain was normal. This is vividly captured in Savannah’s response. She shared that she “complained to several doctors, just got put on the pill and told that periods are supposed to hurt.” Savannah’s experience highlights the expectation that menstruation and pain will go hand in hand, which coincides with other research. Windrim et al. (2024) found that women in Ireland reported healtcare providers telling them that menstrual pain was “part of being a woman” (p. 5). The following extracts vividly capture healthcare providers’ normalisation of the participants’ pain.

> I always had excruciating period pain to the point where I couldnt stand and my vision was impaired. I visited doctors often about this problem and was told I didnt have a problem, that my problem wasnt real and was given 10 codiene to deal with the pain. That made me feel like a drug seeker and like it was all in my head. (Debbie)
>
> I saw several doctors before I was finally diagnosed. Some of them told me that my pain was normal, while others told me that i was just being dramatic. I was so frustrated and angry. I felt like i was going crazy. (Sally)
>
> I have been told that the cause was being too thin, being too fat, it was all in my head. Everyone gets periods, you get used to it [...] getting constantly told it looks like nothing is wrong was embarrassing and upsetting. I spent years trying to tell myself it was in my head and I was just sensitive. (Keri)

The normalisation of pain is especially striking in Debbie's account as she reports severe symptoms (inability to stand, impaired vision) being dismissed. Debbie implies that her motives for seeking help could be seen as dubious (drug seeking), and Sally and Keri explain that they were made out to be 'dramatic', 'crazy', and 'sensitive'. Their experiences are an example of the biomedical model of healthcare which positions women as 'weak' or as exaggerating their pain and the tendency for women's pain to be considered psychological or hysterical (rather than real) (Krebs & Schoenbauer, 2020; Windrim et al., 2024). This is evident in accounts like those of Debbie, Sally, and Keri who report being told by healthcare providers that there is nothing wrong with them—that their pain is "all in their heads", making them feel like they are "going crazy". These responses, ironically, lead to their psychological distress (Khan & Majeed, 2024).

Such experiences can be understood as medical gaslighting—when healthcare providers downplay or dismiss reported symptoms causing patients to question the truth and legitimacy of their own perspectives and feelings, and even their own sanity (Fielding-Signh & Dmowska, 2022; Sebring, 2021). Medical gaslighting is common in women's healthcare experiences (Sebring, 2021). In the case of endometriosis, it is made possible by the common tendency for women's menstrual pain to be disregarded as 'normal' and therefore an experience that any woman should expect without question or complaint (Matías-González et al., 2021). This is evident in Freya's experience of being dismissed by healthcare providers. She shared that, "When I told my doctor about the pain during intercourse, he said it was 'just

part of being a woman.' I believed them. I thought that my pain was normal, and I just had to learn to deal with it."

Freya's account highlights the gendered dimension of the medical gaslighting commonly described by the participants and can be traced to "normative views of women's pain as less worthy of care" (Windrim et al., 2024, p. 166), especially if it is related to gynaecological factors. Indeed, healthcare providers were often reported to use the common view of menstruation as naturally painful as a reason for minimising or dismissing the women's reports of pain. This view is part of a broader systemic gender bias that makes healthcare professionals more likely to minimise or dismiss women's pain than men's (Hoffmann & Tarzian, 2001; Windrim et al., 2024). As Jones (2016) argues, "by constructing endometriosis as a menstrual disorder, medical practitioners normalize severe pain as an expected part of female reproductivity" (p.7).

The tendency to disregard menstrual pain as 'normal' can make it hard for those suffering complications to distinguish 'normal' from 'abnormal' or excessive pain (Ballard et al., 2006). The participants' highlighted this as a key issue. For example, Emily shared: "It was a painful journey. Before the diagnosis, I spent many years downplaying my pain, thinking it was a 'normal' part of menstrual cycles." Due to their pain being dismissed, participants talked about having to "just put up with it" when they were in pain. For example, Maria remarked that, "the healthcare system has caused me to second guess myself so much and has taught me that I shouldn't worry when I'm in pain, and I should just put up with it." In a similar vein, Holly said: "I was left to deal with this pain by myself and the only reasoning I was given [by healthcare providers] was that it was normal." Holly's statement highlights how women commonly must deal with endometriosis symptoms on their own, and their confusion differentiating between normal(ised) and excessive pain in help-seeking. Distinguishing 'normal' from 'abnormal' menstrual pain is a key factor in seeking healthcare and receiving a diagnosis for endometriosis (Ballard et al., 2006). Medical gaslighting, through the normalisation of pain, discouraged participants from seeking treatment. For instance, Emily's belief that her pain was 'normal', meant she was slow to seek medical advice about her menstrual pain, leading to a delay in diagnosis. Emily's experience of delayed diagnosis due to normalisation of pain is not unique, but rather is consistent across endometriosis literature (Cole et al., 2020, Hawkey et al., 2022; Young et al., 2015).

When participants eventually did seek medical care, they commonly encountered dismissive treatment as a result of the minimisation of their symptoms, including inadequate

advice and a lack of meaningful information. They reported that they were given misguided, incorrect, generic, or partial information about treatment for endometriosis leaving them feeling as though they were being humoured, placated, or "fobbed off". Erin, for example, described such advice as patronising.

> Specialists tend to give you a formulaic brochure and standard pain medication. I was directed to some resources and a previous specialist provided information about supplements that would be beneficial. There is a lot of emphasis on the classics of 'eat well, exercise and meditate' which can be condescending and patronising when you can't even stand up, nor leave the house.

Here Erin recounts that she received inadequate, generic care, suggesting that her reports of severe pain were not taken seriously and that she was not being treated according to her own unique experience and needs. Her story suggests this inadequate care is related to a lack of recognition of the severity of her symptoms, leading her to describe it as "condescending" and "patronising", aligning with other descriptions of healthcare interactions.

Similarly, participants recounted receiving inaccurate advice, such as the recommendation to have a baby, despite the lack of evidence that pregnancy causes a reduction in endometriosis symptoms (Young et al., 2016). Such inaccurate advice could lead to disappointment and anger, as in Keri's case: "I got told that getting pregnant would fix the problem, and that if it didn't they would do surgery. So I had a baby, and now 2 years later am waiting on surgery but being told my only option is to try a *Mirena* [intrauterine system] first". Notably, even after Keri followed the advice of her healthcare providers and it was unsuccessful at decreasing her endometriosis-related pain, the promise of surgery was not followed through.

In the case of healthcare providers sharing misinformation, sometimes this can be attributed to a lack of sufficient training or information but a desire to find a solution. However, this lack of knowledge and valid information must be understood in relation to the broader, pervasive gender bias that creates gender inequities. As Hudson (2022, p. 21) argues, the "absence of knowledge on a particular subject (endometriosis) is a result of structural, cultural and political processes and forces which privilege certain voices and communities." Consequently, even though endometriosis is a subject that has been identified by researchers and women as a necessary research subject, it remains under-funded and under-researched (Hudson, 2022).

## 4.2. Theme Two: "Some Helpful, Some Not": Mixed Experiences of Healthcare Providers

When discussing their experiences of healthcare providers, the participants wrote about mixed experiences, describing how the quality of the care differed between the different types of healthcare providers they saw. In this regard, Grundström et al. (2018) speak of the 'double-edged experience' when it comes to women seeking healthcare for endometriosis, with women having both positive and negative experiences. Similarly, the women in this study also reported of mixed experiences, some good and some bad. In this theme I explore the different factors that they highlighted as influencing the quality of care. The first sub-theme focuses on the participants criticisms of male healthcare providers, and preference for female caregivers, which implicitly points to gender dynamics and the operation of medical sexism, albeit not overtly named or criticised, including the gender. The second sub-theme discusses quality of care in relation to specialisation of the healthcare provider, and whether the woman was seen in the public system or by a private gynaecologist.

### 4.2.1. "He Was Arrogant and Rude": The Role of Healthcare Providers' Gender and Medical Sexism

Since endometriosis is a condition mainly affecting women, unsurprisingly some of the participants reported the gender of their healthcare provider as influencing their care. When participants discussed negative healthcare interactions, they often emphasised that the healthcare provider was male. The implication was that a female healthcare provider would not have behaved in the same way, thereby hinting at sexism but not overtly naming it. For example, when discussing her negative experiencing of a rude gynaecologist, Kirstin also mentioned that he was male: "A visiting [city] hospital gynecologist (male) scoffed and said 'you don't just develop endometriosis in your 40s! If you had endometriosis YOU WOULD KNOW!' He was a rude and condescending prick." Here, Kirstin attributes the gynaecologist's "condescending" and "rude" responses to his gender, assuming that if she had seen a female gynaecologist she might have been treated with more respect. Similarly, below Elaine describes her desire to have had a female healthcare provider.

> The hysterectomy actually made the pain worse, but the GP (male, of course) was pretty dismissive of that too and basically said that eventually everyone either dies or gets better [...] The only time I felt heard by healthcare providers in New Zealand was when

> I talked about how it affected my sex life - that seemed much more important than my general wellbeing. I'm sure if I had had a female healthcare provider somewhere along the way things would have been different.

Elaine's account suggests that her main goal from healthcare was relief from pain and overall wellbeing, but she recounts that her healthcare provider instead prioritised her sex life. Her remarks imply that her male healthcare provider views her through the lens of being purposed for sex and is prioritising a man's pleasure over her own wellbeing, leading her to conclude that her experience "would have been different" if she had seen a "female healthcare provider somewhere along the way". Elaine's experience echoes the findings of an Australian study in which gynaecologists were interviewed about their perceptions of women with endometriosis (Young et al., 2019). The researchers found that women's bodies were viewed by gynaecologists as purposed for 'heteronormative sex and reproduction'. Young et al. (2019) conclude that although most women with endometriosis value symptom relief and quality of life as treatment goals, healthcare providers perceive a woman's physical ability to have sex with men as a primary treatment goal.

In a similar vein, Shannon explained how she was stereotyped based on her gender and societal expectations of women: "first Gyno GP I got to see was [an] older male and [he] basically told me I was imaging the pain and it was my job as a mother/wife to deal with it. He was arrogant and rude." Shannon's experience highlights how gender features in healthcare interactions. Here, Shannon describes the disregarding of her symptoms through medical gaslighting ("imagining the pain") and references to stereotypical gender roles of wife and mother. The implication is that her own welfare should be secondary to her family's, in line with the traditional gender ideal of the self-sacrificing woman (Lowe, 2016). Her story illustrates how women's experiences of endometriosis care are shaped by gendered expectations of fulfilling and improving their ability to fulfil the roles of good mother and wife, rather than improving their quality of life (Young et al., 2019).

Several participants expressed the expectation that female healthcare providers would provide better care by talking about the compassion they received from female healthcare providers. For example, Selina contrasts the experiences she had with her GP and specialist by comparing their gender: "I did not feel believed or listened to by my (male) GP for 10 years until I finally got my referral and diagnosis. I felt immediately validated and listened to by my (female) gynaecologist." Similarly, Erin thought positively about her experience of female GPs: "[they] have been mostly great – I now go to a practice with only female GPs."

The gender of health providers has also been found by other studies to play a role in quality of care for women. For example, Sandhu et al. (2009) conducted a systematic review of ten quantitative studies from the UK, USA and Netherlands and found that out of all the dyads of patient-doctor relationships in general practice, having a female doctor and a female patient fostered the most patient-centred care, with more conversations about psychosocial aspects of care. Conversely, they found that having a female patient and a male doctor was the dyad that reflected the least patient-centred care. These results tie into the experiences of my participants receiving better care from a female healthcare provider. Generally, as alluded above, female healthcare providers were described by the women as "compassionate", "brilliant", and "wonderful". Male healthcare providers were described by participants as "arrogant", "rude", and "patronising".

It is important to note, however, that enacting medical sexism is not necessarily restricted to male healthcare providers but is systemic and occurs whenever medical means are asserted to instil the patriarchal gender hierarchy (Delston, 2019). However, in my data, the underlying assumption appears to be that medical sexism is limited to male doctors, rather than being seen as a systemic issue. The participants' expectations that female healthcare providers will inevitably provide better care is related to the expectation that they will not behave in similarly sexist ways to male doctors. This assumption can facilitate feelings of betrayal if female healthcare providers do enact medical sexism and women have a negative experience with a female healthcare provider. For example, Michelle described feeling let down when her female doctor dismissed her: "I also had a female doctor at the time so that's a little disappointing". Michelle's disappointment suggests that she expects a female healthcare provider to be more compassionate and offer better care based on her gender, which may not always be the case.

### 4.2.2. "I Have Been Pushed Aside for Years": Quality of Care Compromised by Health System Issues

The participants commonly reported mixed experiences related to the different kinds of healthcare providers they saw, either generalist or specialist. There was an overall divergence between views of whether a specialist or a GP was more helpful. For example, Rachel claimed that GPs are "about as much use as boobies on a bull". In contrast, Danielle says that specialists are a mixed bag but "GPs have often been the ones who take endo[metriosis] seriously". Similarly, Hannah describes specialists as "dismissive and short", however Debbie describes

specialists as “amazing”. As the quotes indicate, most participants had both bad and good experiences with the different types of healthcare providers they saw for endometriosis care regardless of whether they were a generalist or specialist. This finding is consistent with those of Grundström et al. (2018), who reported that women have both positive and negative experiences within healthcare, with positive experiences characterised by healthcare providers making patients feel acknowledged and seen. Indeed, if quality of care were purely based on knowledge about endometriosis, then it would follow that women would have more positive experiences with gynaecologists who specialise in women’s reproductive health, rather than GPs who are knowledgeable about a range of medical issues. Based on the accounts of my participants, this did not appear to be the case. Rather, it seemed to depend more on the individual healthcare provider and their approach to care than their specialisation as to whether women had a good experience with them or not.

However, when it came to experiences in either to the public system or private healthcare, public care was consistently described as inferior to private care suggesting that health system issues in the over-stretched public sector undermine the quality of care. Women unanimously shared that their experiences with private healthcare were better than in the public system. An example of this is Erin who compared the difference between public and private by describing the public healthcare system as “not great” but the private healthcare system as “fantastic”. Savannah reiterates this point and explains that due to long wait times and dismissive specialists, it was not until she paid to see a private gynaecologist that she received “exceptional” care, as illustrated below.

> I had to pay out of pocket for private gynae coz [the] public waiting list was long and insurance refused cover. She worked me up and then referred me [to] surgery publicly. Public surgeon said nope, no endo[metriosis]. My private gynae reviewed the images and pointed out all the endo[metriosis] the public surgeon missed. Care received from my private gynae has been exceptional. She knew I was paying out of pocket and never charged me full price. She listened and cared, didn’t discount or invalidate me. The care I received from the public system was shameful. Rushed into surgery on the day, not given enough time to ask questions.

Savannah’s story suggests that she had to be able to pay for better care—either by buying health insurance or paying out-of-pocket, which she was willing to do. This highlights inequity in the health system. The implication of Savannah’s experience is that those who cannot afford private care have to settle for care in the public sector that she describes as inferior (poorly

performed surgery) and "shameful"—implying that this should not be the case. Essentially, Aotearoa New Zealand has a two-tiered health system meaning that although much of its healthcare is funded through governmental public funding, there is also a private sector where the wealthy, or those with private health insurance, can 'queue-jump' and access quicker diagnosis and treatment (Chin et al., 2018), as in Savannah's case.

Due to the unanimous description of private healthcare for endometriosis as superior to the public system, it would follow that every woman deserves to be seen by a private gynaecologist. However, a private gynaecologist is only accessible for many women if they have health insurance. Moreover, as Savannah explains above, even for people who do have medical insurance, the insurance may refuse to cover any expenses related to endometriosis due to it being a 'pre-existing condition', meaning that even for those who can afford medical insurance, not all of them can be seen privately due to when they were diagnosed. These are clearly systemic issues that affect who can receive quality care, usually disadvantaging those from marginalised groups, like low-income, Māori and Pasifika women (Moewaka Barnes & McCreanor, 2019; Reid, 2015).

Participants described paying to see a specialist, as Savannah did, that they "couldn't afford" just to try to access quality care. Sara states: "The whole public system experience made me go and get private health insurance that I can't really afford but I need help and the public system isnt going to help me." Alisha also recognised that she could not rely on the public system. She writes about having to pay the private fee to see a specialist herself to finally receive a diagnosis of endometriosis as illustrated below.

> My gp refused to agree that there was something wrong. It wasn't until after at least 4 years of going to my gp I decided to make an appointment with a specialist and pay the $400 fee where the specialist confirmed endo[metriosis] that my gp finally agreed. But it is still a slow journey getting anywhere in the public health system, your going in circles.

Evidenced by Alisha's experiences, women who are unable to access quality care become desperate and do whatever they can to receive help for their endometriosis. For example, Kaia mentioned accepting a job position just to get health insurance:

> The only time I noticed any momentum was when I received private health insurance that provided immediate coverage for pre-existing conditions. It's shameful to admit but the role was one I did not care for, in a field I had no interest in. I applied for the

> role for the simple benefit it offered of insurance and I resigned as soon as I was eligible to do so. You see, at that time it had been about a year and a half that I had left the workforce due to uncontrolled and unmanageable pain and symptoms […] I knew that I needed to do anything I could to get access to insurance because if I didn't, I didn't know what I would do.

In her response, Kaia highlights her desperation to receive quality care, necessitating behaviour that she describes as "shameful" to allow her to access quality care in order to return to paid employment in the long-term. Kaia's experience and those of the other women with similar reports of seeking to access better care in the private sector illustrate the systemic factors that affect access to healthcare in Aotearoa New Zealand.

The necessity of being able to afford private healthcare to access quality care reinforces the socio-economic divide between those who can afford to pay for it and those who cannot. This divide was evident to participants with many of them with health insurance describing themselves as "lucky". For example, Paige says: "I think I have been extremely lucky to have gone private and I believe my experience would have been extremely different if I didn't have insurance." Like Paige, Holly also described herself as lucky to afford private care, as quoted below.

> What makes me sad is that I was fortunate enough to get a diagnosis and treatment because I could afford to. Not many people can and they are left to live like this. So a diagnosis is most likely related to a person's financial position, which in NZ is cruel.

Similar to Holly's assertion that it is 'cruel' that quality endometriosis care is linked to financial position in Aotearoa New Zealand, Isla expressed anger at an unjust system:

> I oftentimes felt that those of us with endometriosis should fight for a rebate in the taxes we pay because the "universal healthcare" that we are sold does not cover women's health. Endometriosis has a prevalence equivalent to both asthma and diabetes and yet receives not even a fraction of the funding (let alone recognition) that both of those conditions get.

Isla argues that Aotearoa New Zealand's free or subsidised healthcare that is promised to all residents does not provide adequate care for women's health conditions like endometriosis. Indicating how endometriosis is marginalised compared to other prevalent conditions, which are experienced by both men and women, highlights the unfairness that is rooted in gender inequity that cuts along ethnic and classed-based lines as well (Hudson, 2022).

In contrast to the quality care accessed in the private sector, several participants shared their experiences of being deprioritised in the public system in which they were "queued" for years. For example, Shannon says, "the public system is a joke [...] I have been pushed aside for years as I was not a top priority". Similarly, Holly noted that when she was seen in the public system, they told her that she would not be put on the waitlist for surgery for endometriosis because she was not trying to conceive at that time. Like Holly, other participants told how their requests on the waitlist were declined, as in the examples below.

> Our system is incredibly underfunded. Right now in [my city] our doors are closed in public gynae to everyone except those with gynae cancer. So many people missing out on care because our health system lacks funding. We lack funding for endo[metriosis] and recognition on a national scale. (Haley)

> My doctor had tried to refer me to the DHB (District Health Board) gynaecologist a number of times and they wouldn't accept my referral because I wasn't 'severe enough'. This was at the [city] DHB – back in the day of DHBs – and my doctor told me they only had resources to accept a third of all the referrals they got for gynae. The DHB just didn't have enough resources and so they prioritized other people over me. I think that was justified – I know people worse off than I was and they did manage to get surgery – but I just wish that everyone had been able to get care instead. (Eloise)

These accounts highlight that not only is public care inferior, but it is literally not accessible in some cases, most impacting those without the means to get private care. Haley describes widespread lack of access as she describes "doors being closed" except to those with the most dire disease. The funding pressures referred to in these excerpts result because "the national healthcare budget in Aotearoa/NZ determined through political process imposes a stricter cap on spending, which limits access through rationing and queueing" (Chin et al., 2018, p.840). This rationing and queuing are clear in both accounts and means that not everyone is able to get care, of whatever standard, in the oversaturated public system.

### 4.3. Theme Three: "It Was Like Being Thrown to the Wolves": Lack of Support from Healthcare Providers

This theme explores women's experiences of support for endometriosis from healthcare providers. In the first sub-theme, women discuss the lack of emotional and practical support given by healthcare providers. The second sub-theme focuses on women's accounts of needing

to seek their own information about endometriosis and advocate for themselves in healthcare interactions. The experiences they describe are shaped by the biomedical model, which dominates Western medical settings. This model prioritises the biological aspects of illness and tends to neglect the social and psychological aspects of the individual (Lyons & Chamberlain, 2006). Hence, women observed a dissonance between the support they wished to receive and the support that was offered.

### 4.3.1. "I Just Wish There Had Been More Support Offered": Emotional and Practical Support for Women with Endometriosis

Participants' common experience of being left to fend for themselves by healthcare providers is vividly captured by Rachel who wrote that, for her, there was "really not much [support] to be honest. It was like being thrown to the wolves." Rachel's experience of being "thrown to the wolves" summarises the feeling of helplessness that women feel after receiving an endometriosis diagnosis with little further support. Facchin et al. (2018) argue that being diagnosed with endometriosis is an "irremediably disruptive event" (p. 547). Accordingly, after being diagnosed, women report a range of emotional responses to diagnosis and therefore need support to help make sense of and manage their condition (Evans et al., 2022).

In my study, responses varied. Some participants expressed feelings of relief and validation after receiving their diagnosis of endometriosis. For example, Georgia explained, "I felt a lot of relief after being diagnosed – that my pain was not made up. It also gave me some validation and language to put to my period pain to almost justify it to other people." This supports other literature that claim diagnoses are important to socially locate the experiences of the individual (Brown et al., 2011) and to provide social and biographical legitimation (Hudson, 2022). However, knowing they have a chronic condition was hard for some of the women to process and brought up negative emotions like "grief" (Tanya) "melancholy" (Jasmine), and "fury" (Emily). These experiences are indicative of the disruption endometriosis causes in women's lives.

According to Facchin et al. (2018), one of the hardest aspects of having endometriosis for women is accepting they have a condition that there is no cure for. Therefore, for some participants, diagnosis came with mixed feelings of both relief and grief simultaneously, as illustrated by Lizzy: "After diagnosis I felt validated, relieved that this wasn't all in my head, though also upset, angry, frustrated that diagnosis took so long and that there is no cure." Lizzy's experience shows the complex emotions that may follow an endometriosis diagnosis.

Because of the range of emotional responses after diagnosis, women need psychosocial support (Evans et al., 2022), which was reiterated by my participants.

My participants commonly wrote about wanting both emotional and practical support. However, emotional support was often lacking, as Tanya recounted, "the provision of emotional support was notably absent and something that I had to actively seek myself." Similarly, Lauren described how she was offered practical support by healthcare providers following her diagnosis, but not emotional support which, like several others, came from her family.

> If anything, I was offered mostly practical support from healthcare professionals. Emotional support came from my husband and family. Infertility and endometriosis [are] very socially isolating and more emotional support from healthcare spaces would've been helpful but I understand they are under pressure.

As Lauren explained above, even though she had emotional support from her family, it was something that she would have also liked to have received from healthcare providers. As well as emotional support to cope with the mental challenges that come with living with endometriosis, women also need support to help navigate the practical and physical aspects of endometriosis and implications of treatment (Nyhof et al., 2020). For most participants, this was limited to the provision of information. For some this was positive and useful. For example, commenting on the support she received, Sally said: "they provided me with a lot of information about endometriosis, including the causes, symptoms, and treatment options. Also answered all of my questions patiently and thoroughly". However, in contrast, most participants, like Chelsea, shared the opposite: "medical support was sparse. No explanation of what to do next etc or even what endo[metriosis] really was. I had to research a lot myself."

Many participants experienced a lack of sufficient information after diagnosis and treatment. For instance, Steph said that "after diagnosis through [to] surgery I still felt there wasn't enough information or ways to help with pain." Similarly, Cassandra said: "post diagnosis, i feel like i was given half the information I needed from doctors. I left the hospital not knowing what was normal and what wasn't." In addition, several participants were disappointed at the lack of follow-up and support after surgery. Madi explains her experience: "I was surprised that my post op[eration] checkup was 5 months after my surgery (and was a 10 minute phone call at best) and that was pretty much all the support you get from the gynae team." This experience was echoed by Lizzy who stated that she is still having pain even after

the surgery and wishes that the follow up appointment had been longer, so she had time to discuss her pain.

### 4.3.2. "I Had to Shout Pretty Loud": Women Advocating for Themselves

As a result of being left to fend for themselves, a common experience that participants shared was the need to advocate for themselves or find information by themselves. The need for self-advocacy is related to healthcare providers' dismissive responses (discussed in theme one) and their failure to offer substantive support (theme two). In relation to being "fobbed off" by healthcare providers, some participants described self-advocacy as having to "fight to be believed" (Chelsea). This idea is well illustrated in the following extract from Eloise's account below.

> I should say, I'm pakeha, middle class, and I understand the medical system well. I advocated for myself a lot during my journey to diagnosis and I knew how to do that effectively. There are a lot of people who don't have all my privilege and who feel intimidated by their interactions in the medical system. I worry a lot about what kind of care those people get. It's not fair that you have to fight for yourself to get the care you need but it's the reality of the health system in New Zealand.

Eloise's remarks highlight not only the need to "fight" for care, but also the difficulties involved particularly for those who are not socially privileged in terms of ethnicity/race and class. This highlights the power relations related to interpersonal and systemic racism and classism, which researchers have highlighted in the country's health system (e.g., Graham & Masters Atawere, 2020; Moewaka Barnes & McCreanor, 2019; Selak et al., 2020). Eloise attributes her confidence in navigating healthcare encounters to her social privilege of being white middle class and believes that was a key factor in her accessing quality care. Participants' accounts of having to advocate, and even battle, to receive needed care, align with much of the international scholarship, such as the findings of Young et al. (2019) and Windrim et al. (2024). Windrim et al. (2024), for example, also found that the women in their study spoke of having to advocate for themselves to ensure their needs were met.

Many participants advocated for themselves through information-seeking as they could not rely on healthcare providers to provide information. In Kirstin's case gaining information about endometriosis helped her to secure an endometriosis diagnosis. Kirstin shared: "I had started doing my own research on endometriosis and had thought there were similarities [in] symptoms." This reiterates the findings of Windrim et al. (2024) who reported information

seeking as a way to ‘back yourself up’ when support was lacking from healthcare providers. Likewise, Hannah said she was motivated to decipher misinformation about endometriosis and find answers for herself, as stated below.

> I found most GP’s have been dismissive over the years and a lot of misinformation has been provided to me. Luckily I have the means and drive to find out information for myself. I feel let down by the health care system.

As discussed in theme one, Hannah mentions the dismissal that she received from healthcare providers, and the misinformation as discussed in theme two which placed the onus on her to find out information for herself.

Many women discussed support groups online facilitating access to more information about endometriosis and causing them to feel less alone. For example, Ziran described joining online forums to learn as much as she could about endometriosis and Emily turned to online platforms for support. Emily explains, “support groups became an integral part of my coping mechanism, offering a platform to share and learn from collective experiences.” When women were not given sufficient support from their healthcare providers, they had to turn to other avenues to find the support that they desired. Lana discusses her experience of online support system below.

> I was madly depressed before getting my diagnosis as i thought my body was broken, im still struggling with depression from the illness but knowing what i have and having access to support groups for my illness has helped massively. facebook endo[metriosis] pages and endonz has an amazing help line that gives you a free consultation to talk about your symptoms of endo[metriosis] and answer any questions you might have before seeing a gp.

Lana’s access to online resources helped to inform her before seeing a healthcare provider so that she had the knowledge to advocate for herself in future healthcare encounters. The experiences of my participants are similar to women from a British study on the therapeutic affordances of endometriosis online support groups (Shoebotham & Coulson, 2016). The researchers found that two of the most valued aspects of online support groups was connection to others and exploration of information, as expressed by my participants. These online support groups are necessitated by the insufficiency of the current healthcare encounters. Women with endometriosis are not able to access the connection or information that they desire surrounding

their endometriosis diagnosis, meaning they must turn to strangers on the Internet to fulfil their needs, rather than having their pain legitimised by their healthcare providers.

## 4.4. Theme Four: "I Wish the Path Had Not Been Littered with So Many Invalidating Encounters": What the Women Want from Endometriosis Healthcare

Despite all the invalidating experiences detailed in the previous themes, women in the study also described the good encounters. This theme explores the positive healthcare encounters that women had or wished they had. Many participants discussed the experience of finding one healthcare provider who finally took their pain seriously and helped them throughout their journey of diagnosis and treatment and navigating their daily lives in between. This is similar to an Australian study which found that a patient's experience of healthcare for endometriosis was positively impacted by finding 'that one doctor' who took them seriously (Fernley, 2021). In light of the need to find a doctor who provides quality care, I have formed three sub-themes of what women want from their healthcare encounters based on their responses. The women who participated in this study want (1) to be believed and validated, (2) to receive compassion, and (3) healthcare providers to be more informed about endometriosis.

### 4.4.1. "I Was Relieved to Have an Official Reason for the Pain": Women Want to Be Believed and Validated

Many of my participants wrote of their desire to be believed and have their accounts of their struggles validated. As Young et al. (2019) assert, "to exclude women's experiential knowledge is to ignore a large piece of the healthcare puzzle that addresses the complexities of endometriosis" (p. 351). There were several participants who wished they had had their embodied and experiential knowledge taken seriously by their GPs earlier, so that they could have received help earlier. For instance, Lauren felt that GPs did not trust her to know her body and that something was not right with it. She says, "earlier investigations are needed at the point of GP contact. Patients know when something is not right with their body, there needs to be more trust in that." Like Lauren, Lizzy also wished that she had been trusted earlier. She claims, "what would have been useful is GPs listening to me when I was younger. I believe earlier diagnosis would have helped me manage the condition better and seek earlier treatment."

Some of my participants wrote about feeling validated after positive healthcare encounters. For example, Jasmine said, "finding a good specialist who not only understood but

also validated my experiences with endometriosis was very important." Jasmine only received quality care once she found this specialist who validated her experiences. Healthcare providers believing the experiential knowledge of the participants was key in facilitating better healthcare outcomes for them.

Most participants experienced a long struggle to have their experiences recognised and taken seriously described by Emily in the following quote.

> Overall, my healthcare experience felt like a never-ending battle to be heard. There [was] some comfort provided by support groups and a few empathetic healthcare professionals. Yet, the initial lack of belief and validation from various healthcare providers stings till today.

This account underlines that empathic, validating care was not a common experience for Emily as an endometriosis sufferer, which is echoed by other participants and studies (eg. Windrim et al., 2024; Wren & Mercer, 2021). The participants commonly reported that one of the hardest aspects of seeking healthcare for endometriosis was encounters of medical gaslighting (Merone et al., 2022): healthcare providers who disbelieved them or who made them feel as though they were exaggerating, as discussed in theme one. For instance, in the quotes below, Madi reflects on her encounters with healthcare providers who did not believe her and dismissed her.

> My surgery was jan[uary] 4 and they found endometriosis in my pelvis, uterus and pouch of Douglas. I cried when I was told, it was a massive relief to know I was right, there was something wrong with me. I also then felt angry, that I'd been telling these medical professionals for years that something was wrong only to be brushed off.

Madi's experiences highlight that the relief and validation of diagnosis can also be clouded by the realisation that previous healthcare providers had failed to take her seriously. Grundström et al. (2018) found a similar result, with participants of their study talking about their anger or sadness after receiving an endometriosis diagnosis because of the amount of time they were not taken seriously.

Like Madi, several participants only received validation after their endometriosis diagnosis and wrote about the relief that came with this. Haley explained: "I felt suddenly like all the pain and suffering before was in fact valid, rather than me being weak or just being unlucky with painful periods". Similarly, Maria described the solace of receiving a diagnosis, by writing: "I felt a warm sense of relief in knowing that I wasn't crazy." Through diagnosis,

Maria's pain was legitimised, and her narrative shifted from the 'weak', 'hypochondriac' woman (Krebs & Schoenbauer, 2020) to a woman experiencing endometriosis-related pain.

### 4.4.2. "My Current GP is Compassionate and Listens and is Wonderful": Women Want Compassion

Participants frequently mentioned positive encounters with healthcare providers who were compassionate and genuinely trying to improve their quality of life. Faith illustrates her gratitude for a compassionate GP in the quote below.

> My current gp is the best gp I think I'll ever find. She wants to get to the bottom of what I have and will send me to specialist if she doesn't have the expertise or will get tests done to make sure I'm okay [...] She was compassionate and is definitely wanting me to get better and better quality of life.

Women described wanting compassion from their healthcare providers and for those women, like Faith, who experienced compassion, they all argued it made a positive difference in their journey. Unfortunately, not all participants received compassion from every healthcare provider. Instead, many had contrasting encounters with different doctors, as Aroha describes in the following extract.

> I was diagnosed with endometriosis but, as the surgeon said coldly afterwards, 'its only a tiny bit so it doesnt explain why your pain is so bad' - she only took two samples. I was so angry and ashamed - I felt belittled, like it was a diagnosis but one I didn't deserve because the pain wasn't really endo[metriosis] [...] Compassion from the surgeon/gynae in believing my pain and promising to help healed so much of the trauma I had received as a patient.

Aroha's experience demonstrates that receiving an endometriosis diagnosis is not enough to constitute a positive healthcare encounter, but rather it is also how women are treated by their healthcare providers that makes the difference. Her experiences align with Pettersson and Berterö's (2020) finding that if the healthcare provider was compassionate, their limited knowledge of endometriosis was only a minor concern for patients. This is reiterated in Kelly's account, below, in which she interprets compassionate listening as part of professional competence.

> The second doctor that I saw in February 2020 immediately explained the limitations of the public health system; validated that my experience of symptoms might not be

> "normal" and made me feel listened to. I appreciated her professionalism so much that I bought her flowers. […] After surgery, I wrote to that [first] doctor to hopefully inform her future patient care. She replied that her notes record the diagnosis and could not appreciate that the other comments might've caused me to hesitate seeking future treatment.

Kelly's act of buying flowers for her doctor shows not only her gratitude but also how rare the experience of being heard and taken seriously had been until then. This is an example of women's desire for mutual respect in healthcare encounters. By validating her experiences and explaining everything clearly, Kelly's doctor was placing her at a similar respect level to herself, rather than the first doctor that looked down on her. In contrast, the original doctor's response to Kelly's feedback demonstrates the doctor's assumption that she had achieved a good outcome for Kelly because she had diagnosed her. This response failed to recognise compassion as essential to good care, in alignment with patient-centred care which prioritises empathy and validation (Nyhof et al., 2020).

### 4.4.3. "There is a Lot of Misinformation Out There": Women Want More Endometriosis Education

When asked what changes, if any, they would like to see in endometriosis-related healthcare, many participants discussed the need for greater awareness and knowledge of endometriosis in general. Lizzy said, "I feel that wider society do[es] not understand enough about the systemic impacts of endometriosis. Colleagues and family members still see it as 'just bad period pain', and so the stigma I face continues." However, the main concern was education for healthcare providers as those responsible for ensuring quality care for endometriosis. As Hannah put it: "I wish health professionals had more training in endometriosis care. There is a lot of misinformation out there and this contributes to poor patient outcomes." Like Hannah, several participants stressed the importance of professional training for healthcare providers to improve health outcomes for women. This education needs to be implemented at a larger scale than the individual healthcare provider. The participants realised that it was not solely the responsibility of the healthcare provider to seek out information, but rather it needed to be compulsory training for all healthcare providers so that they know to identify potential endometriosis in women.

## 4.5. Conclusion

The findings in this chapter outline the experiences of participants with endometriosis-related healthcare in Aotearoa New Zealand. Present across the first three themes was a narrative of the struggle that participants went through in trying to access healthcare. Participants experienced dismissal and medical gaslighting which caused them to have delays in diagnosis, as demonstrated in theme one. Once they had obtained a diagnosis, there was also a struggle to access quality care, as shown in theme two. Finally, there was a lack of practical and emotional support offered to participants in theme three. As a response to these struggles and inadequacies detailed in the first three themes, the fourth theme demonstrates examples of quality care that participants wanted to receive, such as validation, compassion, and more education for healthcare providers. In response to the findings in this chapter, I will now provide the concluding discussion, including a summary of the findings, recommendations for implementing change, and future research in the following chapter.

# Chapter Five: Concluding Discussion

Research both internationally and locally has investigated women's experiences of endometriosis, documenting their struggles to be taken seriously and receive a diagnosis. As I highlighted in the literature review, Aotearoa New Zealand has far less scholarship in this area, although encouragingly, there have been recent publications such as Tewhaiti-Smith et al. (2022) that focus on women's experiences of endometriosis in Aotearoa New Zealand. However, there are relatively few international and no local studies that focus on women's experiences of their healthcare encounters. This information is crucial to improving the care that those with endometriosis receive in alignment with the ideals of patient-centred care. Hence, my study speaks to the need for more qualitative research in this area (Steele et al., 2019), including local studies of the unique experiences of women in Aotearoa New Zealand.

My research was inspired by the need for knowledge that can contribute to better care for endometriosis. I sought to investigate women's experiences of seeking care for endometriosis in the local healthcare system and address the gap in patient-centred care endometriosis research in Aotearoa New Zealand. In this chapter, I discuss a summary of the findings and consider the implications of these findings. I argue the need to rethink the medical encounter for women with endometriosis and that patient-centred care can be a solution. I recommend future research opportunities, and finally I close with a personal critical reflection of the research.

## 5.1. Summary of Findings

The women who participated in my study shared their experiences of healthcare for endometriosis – both positive and negative – and described their endometriosis journeys, from initially presenting with pelvic pain or other endometriosis-related symptoms, to diagnosis and treatment, and to the recovery after. Notably, participants reported long waits for diagnosis due to medical sexism and healthcare providers normalising their menstrual and pelvic pain, making it hard for them to receive a diagnosis. Particularly evident was the lack of trust of the participants' embodied knowledge, with healthcare providers positioning them as dramatic, drug-seeking, hypochondriacs with symptoms that were 'all in their heads'. This dismissal and medical gaslighting was a cause of distress for participants. Moreover, the dismissal that participants reported did not end after their diagnosis, but rather continued throughout many subsequent healthcare encounters. Participants noted the lack of information and support they received. Participants had to seek information online and receive emotional support from

family and friends, but they noted that these are examples of support that they would have liked to receive from their healthcare providers as well.

Many participants noted variations in the quality of care received across different providers, with some reporting that GPs provided better care and others that gynaecologists were preferred. However, they were unanimous regarding the insufficiency of the public specialist care compared to private practice. Some participants described feeling 'lucky' if they had health insurance to obtain private care. Others shared how private healthcare was gained by means such as saving up to pay out of pocket, waiting in pain for three years during a health insurance stand-down period, and applying for a job solely for the benefit of health insurance. Those unable to access health insurance or pay for private care described long wait times and poor-quality care.

Although many of the participants' stories were characterised by negative experiences, there were also positive experiences. Participants thought highly of healthcare providers who believed them, validated them and were compassionate. Participants described the times when they did experience this or expressed a wish that they wished they had. Nevertheless, overall, participants painted a picture of a healthcare system that is insufficient for their needs. Participants argued for healthcare providers to be better educated on endometriosis and to quash any spread of misinformation. Many participants were not satisfied with the care they received and were unable to access quality healthcare and support. This lack of quality care necessitates healthcare for endometriosis to be re-examined to ensure better outcomes for women, as I will discuss below.

### 5.2. Rethinking the Medical Encounter

My findings present an argument to rethink the medical interactions for women with endometriosis. As I demonstrated in the previous chapter, current healthcare interactions for women with endometriosis in Aotearoa New Zealand left participants distressed, frustrated, and hopeless. In Western societies, including Aotearoa New Zealand, health and healthcare is primarily conceptualised through a biomedical model which values the physical aspects of health but largely ignores psychosocial factors. This model is individualistic holding people responsible for maintaining their own health through healthy lifestyle choices (Lyons & Chamberlain, 2006). This reductionist and individualistic perspective underpin our country's care for women with endometriosis.

Consequently, healthcare providers are trained to provide biologically-based, pharmaceuticals to patients and to seek the simplest explanation first. Often, healthcare

providers view patients presenting with complex symptoms and needs, such as women with endometriosis, as a 'challenge' (Frayne et al., 2023). This is also perpetuated by issues such time constraints in appointments, and an underfunded, oversaturated public health system. Nonetheless, despite the difficulties in providing care for endometriosis, dismissing women is not the solution, and points to underlying issues that impede patient-centred care.

As my participants' accounts demonstrate, dismissal and medical gaslighting are prevalent in healthcare encounters. Fielding-Singh and Dmowska (2023) argue that gender discrimination is "fueled by longstanding stereotypes that associate femininity with irrationality, ignorance, and deviance on the one hand, and maleness with rationality and normality on the other" (p. 4). Accordingly, the participants' experiences of dismissal can be understood in relation to these longstanding gender biases that inevitably shape healthcare practices and relationships. These experiences are compelling and provide the need to address wider systematic attitudes about women to improve care. Women's healthcare experiences will not improve until their embodied knowledge is trusted and valued.

In addition, my findings indicate unique needs and a desire for change in healthcare encounters for endometriosis, that align with findings related to experiences of sexual and reproductive healthcare more broadly (e.g., Morison et al., 2022; Stevenson et al., 2016). The care that women require from their healthcare providers may vary from what men need (Nyhof et al., 2020), however, the current healthcare system operates in a male-as-default mode, resulting in healthcare encounters that fail to meet the needs of women. My research adds to the existing literature that emphasises the key role of emotional support and empathy for women with endometriosis (eg. Nyhof et al., 2020; Pettersson & Berterö, 2020; Windrim et al., 2024).

### 5.3. Implications for Patient-Centred Care

My findings add to the case for implementing patient-centred care to improve healthcare for women with endometriosis. The descriptions of care that the participants found helpful or wished to receive align with a patient-centred approach to care. In contrast to participants' experiences of healthcare providers not listening to, and dismissing them, they valued healthcare providers who made them feel heard, enquired about their situations, and showed initiative in providing care. Instead of conceptualising healthcare from a biomedical model, patient-centred care values the role of reciprocal relationships in healthcare encounters, seeing both the patient and the practitioner as partners. Nyhof et al. (2020) provide six elements of importance to women when practicing patient-centred care (1) fostering a healing

relationship, (2) exchanging information, (3) addressing emotions/concerns, (4) managing uncertainties, (5) making decisions, and (6) enabling self-management. This model of care coheres with the needs of my participants and can be used as a guide to improve care. As mentioned in the previous chapter, participants were disappointed and upset by the lack of emotional support, information provided, and lack of agency. They were also hurt by the patronising relationship from their healthcare provider. My study shows that patient-centred care would be beneficial and is indeed necessary for Aotearoa New Zealand to implement to address these hurts.

### 5.3.1. Recommendations for Practice

Based on my findings, I provide recommendations to improve healthcare for women with endometriosis below. First, an area in clear need for change is publicly funded care for endometriosis. Many participants reported long wait times in the public system, or even the inability to be seen at all. All women, regardless of the severity of their pain should have the oppourtunity to be referred to a gynaecologist through the public system if they believe that they are experiencing abnormal menstruation or pelvic pain. To facilitate this, more public gynaecologists are required, therefore, Aotearoa New Zealand should make this a priority when training and hiring new doctors.

Second, the experiences of the participants in this study demonstrate that many healthcare providers lack knowledge of endometriosis and how to assist women who suffer from it. Therefore, more information needs to be provided, especially to GPs. A practical example of educating GPs on endometriosis is demonstrated by a recent initiative in France. In 2020, France introduced a new module on endometriosis as part of the national qualifying exam for GPs. This was necessitated by the lack of confidence of GPs in diagnosing and treating endometriosis, with only 25% of GPs considering they knew enough about endometriosis to satisfy the needs of their clinical practice (Roullier et al., 2021). Aotearoa New Zealand should follow France's lead and implement an endometriosis-specific module as part of the mandatory training for GPs. On top of this, there should be standardised guidelines for quality of care when treating women presenting with pelvic pain and other endometriosis-related symptoms.

Third, as part of their training, healthcare providers must be trained about medical sexism and how to be open to prioritising women's experiences as a valuable source of knowledge. Young et al. (2020) describe women's navigation of knowledge and power within the medical encounter as a "complicated dance between their own embodied knowledge and

the clinical expertise of their doctors" (p. 37). To acknowledge the complexity of the power dynamics in a healthcare encounter, medical training needs to include the social and structural factors (or social determinants) that support good sexual and reproductive health outcomes and health equity.

Finally, healthcare providers need sufficient time and expertise to listen sensitively to women and provide emotional support which was notably lacking from my participants' responses. Participants wrote of wanting healthcare professionals who took the time to listen to them and validate their experiences, genuinely wanting to improve their quality of life. This finding is consistent with the current literature (eg. Berterö et al., 2019; Nyhof et al., 2020) which reports women's desires to receive validating care from their healthcare providers. Berterö et al. (2019) found that even for healthcare providers who wanted to give that level of care to their patients, many reported that they were constrained by appointment times and heavy workloads. Consequently, it is essential for appointment times to be allocated to reflect the more time-consuming consultations that might be required for women with endometriosis.

### 5.4. Aotearoa New Zealand as Endometriosis Advocates

To implement change in Aotearoa New Zealand, it is important for new health policy to be brought into effect. The Ministry of Health released a Women's Health Strategy in 2023 which aims to "achieve pae ora | healthy futures for all women" (p. 1). This strategy acknowledges that there is a lack of understanding and support for women with endometriosis and claims that facilitating a healthcare system that works for women is a priority (Ministry of Health, 2023). The findings of my study confirm this and provide a compelling case for action. Although Aotearoa New Zealand is not the first country to release a strategy to improve endometriosis care, with both the United Kingdom and Australia preceding them, there is still the opportunity to be a trailblazer in implementing changes to improve health outcomes for women with endometriosis. Despite several of my participants reporting their experiences of patient-centred care, those were rare compared to the invalidating encounters. This demonstrates that there is a need for change. My research locates the argument within an Aotearoa New Zealand context and highlights areas for improvement for the Ministry of Health to consider when making changes to align the healthcare system with their new strategy.

### 5.5. Future Research Recommendations

My study contributes to the research in Aotearoa New Zealand around endometriosis healthcare, however due to the relatively small sample size, it has left a lot of unknowns. As I

discussed in Chapter Four, normalisation of pain leads to delayed healthcare seeking. Although I have made recommendations for ways to improve the healthcare system for diagnosing women with endometriosis, more research needs to be conducted on the stigma and barriers that prevent women from seeking healthcare due to abnormal menstruation.

Another area for future research would be how gender diverse people experience endometriosis care. Endometriosis is often associated with women and the care for endometriosis might assume that the patient is a woman. People who do not identify as women with endometriosis will experiences difficulties of care different to women, and this is an important area needing research. To the best of my knowledge, there is currently no Aotearoa New Zealand located research focusing on gender diverse people with endometriosis.

Finally, in contrast to my study which took a broad lens when examining women's experiences, future studies could adopt a more specific lens. Two focus areas I would suggest to further clarify healthcare experiences are location and culture. I conducted my research with a national focus and chose not to ask participants to specify which region of Aotearoa New Zealand they reside in. However, one of my participants mentioned her experience of living in a small town where she was seen by a gynaecologist visiting from another, bigger city. Her experience highlights the geographical nuance of experiences for women living rurally, or in smaller towns, presenting an area for future research.

Similarly, I welcomed women of all ethnicities to participate in my study. However, most respondents were from the majority ethnic group of New Zealand European, therefore it did not specifically address cultural needs of women. Future research could focus on a more specific demographic and examine the gender health gap in endometriosis in relation to the intersection of culture and endometriosis care, especially for Māori wahine. As discussed in Chapter One, Māori experience sexual and reproductive health disparities, therefore it is necessary for their unique experiences to be highlighted in the literature. August (2005) argues that "Māori knowledge about the female body is essential for the protection of our identities as Māori women" (p. 122). Accordingly, it is important for research to identify specific experiences, drawing on mataranga Māori and/or from a Kaupapa Māori perspective to fully honour the knowledge production of endometriosis from a Māori world view.

### 5.6. Concluding Critical Reflections

As mentioned in Chapter Three, I actively and reflexively engaged with my research all throughout the research process. As part of this, I have critically reflected on the whole journey of my research. Not having endometriosis myself, I had no personal experiences of

healthcare encounters for endometriosis. However, I came into the research with a somewhat negative view of healthcare encounters from my own experiences with healthcare providers for non-endometriosis-related healthcare. I was expecting to find similar experiences from my participants about their endometriosis-related care. Although many of my participants described their negative experiences with healthcare encounters, I was encouraged by those who discussed their positive experiences.

I am also encouraged by the progress endometriosis research is making even in the time it has taken me to complete this research. I started planning this research in 2021 and commenced the research process in 2022. At that time, there was a lack of public information about endometriosis and many people I talked to had never heard of it. Now two years later in 2024, I can see many new advances in endometriosis research and advocacy, and many people I speak to about my research will now comment that they know someone with endometriosis.

One exciting innovation in endometriosis advocacy is the *Endo45* application (app) developed by New Zealander Julie Oliver. The *Endo45* app aims to help people with endometriosis by tracking symptoms and habits, providing information and helping to improve quality of life (Reitsma, 2024). This is a practical example of technology facilitating better health outcomes for women with endometriosis. It is also encouraging that the Ministry of Health released a women's health strategy last year, as mentioned before. Although they fail to clarify the implications of this strategy, these developments leave me hopeful nonetheless that the changes I have argued for might go beyond recommendations and become reality.

## 5.7. Conclusion

The findings of my study demonstrate a sample of women's dissatisfaction with their healthcare for endometriosis, resonating with the international literature on endometriosis and local reproductive health research. I have argued that a cohesive strategy is needed to improve healthcare for women with endometriosis to facilitate better quality of life advocating for patient-centred care. To achieve better outcomes, I propose that the Aotearoa New Zealand healthcare system needs to firstly employ change at the systemic level, by eradicating medical sexism and addressing the issues of the contrasting standard of care in public and private practice. There is also a need to ensure quality of care from all healthcare providers assisting women with endometriosis. More training and information for healthcare providers is required, regarding both endometriosis and patient-centred care. This is necessitated by the importance of the encounters between women and their healthcare providers. The current Aotearoa New

Zealand healthcare system is failing women, which is an issue of social justice that requires urgent attention.

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# Appendices

## Appendix A: Survey Questions

### Section 1: Demographic Information

1. How old are you?
2. What is your gender?
    - Female
    - Male
    - Other (please specify)
3. Have you had an official diagnosis of endometriosis?
    - Yes
    - No
4. How long ago did you first identify as having endometriosis?
    - Less than one year
    - Between one and five years
    - Between five and ten years
    - Ten or more years
5. Were you born in New Zealand?
    - Yes
    - No
6. Which ethnic group do you belong to? *(If your answer includes more than one ethnic group, please indicate which one you consider to be your primary ethnicity).*
    - New Zealand European
    - Māori
    - Samoan
    - Tongan
    - Indian
    - Asian
    - Other (please specify)

**Section 2: Open-ended Qualitative Questions**

7. Please tell me about your experience of the process of getting an official diagnosis for endometriosis.

   This could include:

   - The lead up to your diagnosis
   - Your thoughts and feelings before receiving a diagnosis
   - Your thoughts and feelings after receiving a diagnosis

8. Overall, how would you describe your experience of the healthcare you've received for endometriosis?

   *In your answer, please include anything you feel has been especially useful and/or anything you would have liked to be done differently.*

9. Thinking about the specific healthcare providers you have seen (GP/general practitioners, gynaecologists or others), what are your experiences with them?

   *Please also comment on the extent to which you felt that your concerns and ideas* were heard or prioritised.

10. Can you share a bit about support, if any, that you received following your diagnosis?

    *This could include practical support (e.g., information, treatment options, pain relief etc.) or emotional support (e.g., compassion from the doctor, strategies to improve your quality of life, etc.). The focus here is on healthcare spaces or providers, but you can also comment on other sources of support.*

11. Please feel free to share anything else you would like about your experience with endometriosis.

    Anything you feel is important or that I did not ask but should have.

**Appendix B: Participant Information Sheet**


## *Women's experiences of the diagnosis and treatment of endometriosis in New Zealand*

## INFORMATION SHEET

Thank you for your interest in this research. You are invited to take part in this study. Whether you decide to take part or not is your choice. If you do not want to take part, you do not have to give a reason.

**About the researcher:**
My name is Bethany Oram, and I am completing a thesis for my Master of Science with an endorsement in Health Psychology through Massey University. For my thesis, I am doing research on women's experiences of healthcare for endometriosis in Aotearoa New Zealand.

**Eligibility criteria:**
You are eligible to complete this survey if you:

- are 16 or older
- are a cisgender woman (assigned female at birth and identify as a woman)
- have been clinically diagnosed with endometriosis
- have been diagnosed with or self-identified as having endometriosis for over one year
- have lived in Aotearoa New Zealand for 5+ years

**What is the research about?**
I am interested in how women with endometriosis have experienced the local healthcare system in relation to diagnoses and treatment of their condition. I am interested in hearing your experiences and opinions through your own words and stories.

**What will I be asked to do?**
You will complete an anonymous survey online with open-ended questions about your experiences discovering you had endometriosis, seeking medical help, and receiving support.

- The survey can be completed in your own time, so you can take as long as you need. The average completion time is estimated to be around 30 minutes depending on the detail of your answers
- The questions are open-ended, meaning you will write a response in your own words and asked to explain answers to yes/no questions

- You will be required to answer in your own words, based on your own perspectives and feelings. There are no wrong answers

For participating in this study, you will be given the option to receive a **$10 Giftpay voucher** as a koha. If you wish to receive the Giftpay voucher, then you will need to provide an email address at the end of the survey. Your email address will be able to be seen by the researcher but will not be linked to your responses.

**Privacy**
All information you provide will be kept anonymous; there will be nothing linking you to your responses. If you provide an email address for the draw, this will not be linked to your specific responses.

**Participant rights**
You are under no obligation to participate in this study. If you decide to participate, you have the right to:

- Ask any questions about the study at any time during participation
- Decline to answer any question or stop completing the survey (i.e., withdraw participation)
- Provide information on the understanding that no identifying details will be used
- Receive a summary of the project findings when it is concluded

**Benefits and risks of participation**
This study is for research purposes. There are no immediate benefits to taking part beyond a chance to share your story. The findings will contribute toward ensuring better care for endometriosis in future.

There are no major risks anticipated in taking part, but if you do feel you would like support or to discuss your experience further, you can contact the following services.

* Although women are the largest group who experience endometriosis, not all sufferers identify as women. However, given the limited scope of my relatively small project, I am only able to focus on this group. I do so acknowledging the importance of gender-diverse people's unique and complex experiences as an important avenue for future research in Aotearoa NZ. For international research on this topic see here and here.

**Project Contacts**
You are invited to contact either the researcher or the supervisor if you have any questions about the study.

**Researcher:**
Bethany Oram
Massey University
Email: bethany.oram.2@uni.massey.ac.nz

**Supervisor:**

Dr Tracy Morison
School of Psychology
Massey University, Palmerston North
Email: t.morison@massey.ac.nz

Te Kunenga ki Pūrehuroa

Massey University School of Psychology – Te Kura Hinengaro Tangata
Palmerston North, New Zealand
T +64 6 3569-099 ext 85071 : W psychology.massey.ac.nz

*This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research.*

*If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact the Research Ethics Office, email humanethics@massey.ac.nz*

**Appendix C: Support**


**Support**

There are no major risks anticipated in taking part, but if you do feel you would like support or to discuss your experience further, you can contact the following services.

- *Endometriosis New Zealand* – https://nzendo.org.nz/ Ph: 0800 733 277
- *Insight Endometriosis* - https://www.insightendometriosis.org.nz/ Ph: 07 8555 123
- *Healthline* - 0800 611 116
- *Lifeline* – 0800 543 354
- *Anxiety Helpline* - 0800 269 4389 (0800 ANXIETY)
- *Depression Helpline* - www.depression.org.nz Ph: 0800 111 757
- *Sexual Harm Helpline* - 0800 044 334
- *Women's Refuge Crisis Line* - 0800 733 843 (0800 REFUGE)

For psychological support, the following websites will assist you in finding a registered psychologist in your area:

- *New Zealand Psychological Society* – www.psychology.org.nz/public/find-psychologist
- *New Zealand College of Clinical Psychologists* – www.nzccp.co.nz/for-the-public/find-a-clinical-psychologist

## Appendix D: Respondent Consent


### Respondent Consent

I confirm that I have read and understand the information sheet for this study.

- I know who to contact if I have any questions. I understand that I may ask further questions at any time, including when I have already started the survey.
- I understand that my participation is voluntary and that I am free to withdraw at any time while completing the survey, but will be unable to withdraw once I have submitted my response.
- I have received enough information about the study.
- I agree to having my answers recorded anonymously.
- I agree that any extracts from my answers may be used in reports and publications arising from the research.
- I agree to take part in this study under the conditions set out in the information sheet.

I have read and understood the information sheet for this study and consent to collection of my responses.

*(Please click on the 'Yes' choice if you wish to proceed.)*

Yes

No

## Appendix E: End of Survey


The survey is now complete.

Thank you for participating in this research. Your time, knowledge, creativity, and ideas are appreciated. If you have any questions or queries regarding this project, please don't hesitate to contact the following:

**Researcher:**
Bethany Oram
School of Psychology (Manawatū campus)
bethany.oram.2@uni.massey.ac.nz

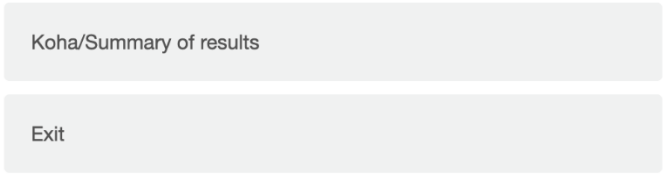
**Supervisor:**
Dr Tracy Morison
School of Psychology (Manawatū campus)
Tel +64 6 951-9216
T.Morison@massey.ac.nz

**Request a summary of results**

If you wish to claim the koha for participating or receive a summary of the results, please select the 'Koha/Summary of results' option below, before clicking on the '**Submit**' button to complete this survey and be transferred to a separate webpage to enter your contact details. Please be aware that you will need to meet the eligibility criteria of having completed or reasonably attempted to complete the stories and answered the associated questions, in order to receive the koha.

If you select this option, your survey data will still remain anonymous, while the koha and sharing of results will only access this separate contact detail.

In either case, please click on the **Submit** button below to lodge your responses and close the survey.



# Appendix F: Low-Risk Ethics Notification

27/05/2023

Dear: Bethany Oram

**Re: Low Risk Notification - 4000026978 - A case for patient-centred care: A qualitative study of women's experiences of the diagnosis and treatment of endometriosis in New Zealand**

Thank you for your notification which you have assessed as Low Risk.

Your project has been recorded in our database for inclusion in the Annual Report of the Massey University Human Ethics Committee.

The low risk notification for this project is valid for a maximum of three years.

If situations subsequently occur which cause you to reconsider your ethical analysis, please contact a Research Ethics Administrator.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

**A reminder to include the following statement on all public documents:**

*"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research.*

*If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Professor Craig Johnson, Director - Ethics, telephone 06 3569099 ext 85271, email humanethics@massey.ac.nz."*

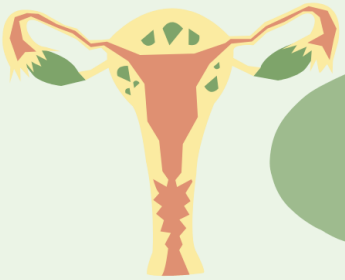
Please note, if a sponsoring organisation, funding authority or a journal in which you wish to publish requires evidence of committee approval (with an approval number), you will have to complete the application form again, answering "yes" to the publication question to provide more information for one of the University's Human Ethics Committees. You should also note that such an approval can only be provided prior to the commencement of the research.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840 E
humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

## Appendix G: Advertisement



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

**Healthcare for Endometriosis in Aotearoa New Zealand**

**Do you or someone you know have an endometriosis diagnosis and want to be part of an online research study?**

My name is Bethany Oram and I am doing my Master's thesis looking at women's experiences of the New Zealand healthcare system for the diagnosis and treatment of endometriosis.

You can participate if you:

- Are age 16+
- Are a cis-gender woman (assigned female at birth and identify as a woman)*
- Have been clinically diagnosed with endometriosis
- Have lived in Aotearoa New Zealand for over 5 years

Participants would complete an anonymous survey online with open ended questions about your experience discovering you had endometriosis, seeking medical help and receiving support.

For participating in this study, you will receive a $10 Giftpay voucher

**If you are interested in participating in the study and would like to know more information please contact Bethany Oram by email bethany.oram.2@uni.massey.ac.nz or Tracy Morison t.morison@massey.ac.nz**

**Use the link below or scan the QR code to start the survey:**
**https://massey.au1.qualtrics.com/jfe/form/SV_5dIYcHlDsVG6st0**

*Although women are the largest group who experience endometriosis, not all sufferers identify as women. However, given the limited scope of my relatively small project, I am only able to focus on this group. I do so acknowledging the importance of gender-diverse people's unique and complex experiences as an important avenue for future research in Aotearoa NZ. For international research on this topic see: https://doi.org/10.1530/RAF-21-0096 and https://doi.org/10.3389/fmed.2023.1266131