“People think you're crazy or hysterical, or anxious, or you just get labelled a drama queen”: Exploring the Stigmatisation experiences of women with Endometriosis.

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Abstract

An estimated 200 million reproductive-age women worldwide and approximately 1 in 10 New Zealand women suffer from endometriosis. Endometriosis is associated with chronic pelvic pain, heavy bleeding ,infertility, exhaustion, and irregular menstruation. Endometriosis can pervade all aspects of a person's life with negative impacts on physical health and emotional well-being. This reduced quality of life is further compounded by a significant diagnostic delay, with a reported average of 8.4 years in Aotearoa, New Zealand (Tewhaiti-Smith et al., 2022). It is well-documented across many health conditions that stigma is a barrier to health-seeking behaviour, engagement in care, and treatment adherence. No research has been conducted in Aotearoa, New Zealand to explore the role stigma plays for women with endometriosis, and very few have been conducted globally. This study aimed to address this gap and explore the experiences of women living with endometriosis focusing on the role of stigma psychosocial well-being and as well as diagnostic delay. Six women with endometriosis took part in a semi-structured interview process. Interpretative phenomenological analysis (IPA) was utilised to allow the participants to fully and deeply describe their stigmatisation experiences associated with endometriosis The analysis revealed that the women experienced significant emotional distress due to the stigmatisation at all stages of their endometriosis journey including early menstruation experiences, during their quest to get a diagnosis, and even after a diagnosis had been achieved. The findings suggested that structural stigma was the driving force behind the public stigma and self-stigma that was experienced. This was largely connected to society's norms and

expectations involving menstrual etiquette and gender stereotypes, a lack of awareness and education about endometriosis, and a structural ignorance at a political level with a lack of funding for research and resources. These findings gather a glimpse into what it is like for these women to battle endometriosis and highlight the stigma that accompanies the disease. Much more research is needed into understanding the complex construct of stigma, and how this influences women who have endometriosis. It is essential that further research into this topic is conducted so that women living with endometriosis feel heard and are supported, and the mystery surrounding this enigmatic disease has one day disappeared.

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Firstly, I would like to thank my supervisor, Dr Kathryn McGuigan, for sharing your time and great wealth of knowledge with me. Your guidance and support was greatly appreciated. You challenged me, had faith in me, and understood me. I will be eternally grateful that you were on this journey with me, particularly with the kindness, empathy and understanding you showed to myself and all other sufferers of this terrible disease.

This thesis is for my daughter Amber. Life has not been easy watching and living with a Mum who has endometriosis. This is for you, your future daughters, nieces, and granddaughters. May we break this cycle of ignorance and dismissal and find a cure for all women and future women who may be the unlucky 1 in 10. To my friends, family, and colleagues, thank you for your ongoing support, your faith, words of encouragement, and most importantly for understanding my desire to complete this story.

Lastly, I would like to thank the women who participated in my research. You shared your hard and raw experiences with honesty and trust, of which I am thankful for. I wish you all the best to achieving peace in your endometriosis journey in the future. Kia Kaha.

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CHAPTER ONE: Endometriosis, the Mysterious Disease

Endometriosis: "A riddle wrapped in a mystery inside an enigma" (Ballweg, 1995, p. 275)

1.1 Introduction

Too often I have had to explain what "endometriosis" is. Whether it be my hairdresser, or physio, workmate or friends, many people I have spoken to about my disease have limited knowledge about what endometriosis is. This baffles me. We all know about other conditions just as common such as diabetes and asthma. We see the adverts on the television, the pamphlets in the doctors' clinics and hear about it on the radio, yet despite endometriosis affecting similar numbers of people in New Zealand, we do not see the same attention for this debilitating disease.

Endometriosis has been described as a "enigmatic disease" due to its difficulty to diagnose given its variable morphology, symptomatology, and widely debated etiopathogenesis (Acién & Velasco, 2013). For women with endometriosis, every story is different. The range and severity of the symptoms can vary so much for each individual; this combined with a disease having no exclusive pathognomonic symptoms, makes it difficult to identify. Diagnosing endometriosis can only be done via invasive laparoscopic methods, and then once diagnosed, current treatment options are deemed unsatisfactory. Without a definitive theory about the origin of endometriosis, advances in treatment options are restricted and require invasive interventions (Acién & Velasco, 2013).

I look back on my endometriosis journey and consider my own thoughts and actions. Diagnosed at 23, I remember being told I had endometriosis, but I never did anything with that word. I did not tell many people; I did not do any research; I simply shut it away from a world that did not understand. Today, I still feel the 'guilt' and

'judgement' when a pain killer is taken and people are looking, I 'hide' my illness when I 'ring in sick' after a long night of pain, and I 'shy' away when people ask where I was and why I missed another social occasion. It is only just recently that I have begun to wonder why I behave this way? Why do I feel feelings of guilt, judgement, dismissal and shame when I talk of my disease? Where does this stigma come from?

Stigma, in any form, has the potential to worsen the negative impacts of endometriosis including psychosocial well-being. According to Sims et al. (2021), endometriosis-related stigma is thought to act as a deterrent to receiving a timely diagnosis. Symptom concealment and adhering to "menstrual etiquette" (p. 5) to avoid stigmatization from friends, family, workmates, and other social, and health care settings are common for women with endometriosis. Repeated encounters with dismissiveness, invalidation, normalisation and inadequate understanding by others when presenting or describing symptoms such as chronic pelvic pain, heavy bleeding and painful menstruation, make it difficult for sufferers to pursue a diagnosis. Consequently, women may experience increased symptom severity, disease progression, increased psychological problems, and delayed access to treatment and care.

It is my own personal journey and reflection about my own behaviours associated with endometriosis that have led to the desire to do this research. I have questions regarding the shame and stigma I felt, and still feel, and it is this that has inspired me to delve deeper into this forbidden topic; to attempt to make sense of the experiences and behaviours associated with this.

It is recognised that at times research and work in endometriosis ignores the complexities of gender. Cisgender women assigned female at birth are not the only

people who menstruate (some cis-gender women do not menstruate), trans and other gender diverse people also have periods (Frank, 2020; Rydström, 2020). There will be different realities and experiences of menstrual experiences regardless of gender identify and as such menstrual taboos, shame, and stigma will impact everyone differently (Corrigan & Watson, 2002; Koninckx et al., 2019; Major & O'Brien, 2005). However, for the purposes of this research, my focus is on my experiences and those of women, therefore, I will use the words female and women when referring to people with endometriosis.

This first chapter will firstly define endometriosis, before delving into the theories that have been proposed to explain the etiology of this enigmatic disease. A discussion about what it is like to live with endometriosis follows, covering not only the physical ailments, but also the deeply women psychological effects as well. Intertwined with these challenges are the stigmatisation experiences that women with endometriosis encounter which can contribute deeply to their physical and emotional pain. These are discussed along with the research objectives of this study.

The Best Definition of Endometriosis

Endometriosis is a chronic gynaecological condition that has been dubbed the "missed disease" (Hudson, 2022, p. 20) due to its enigmatic aetiology and inconsistent diagnosis and management. Endometriosis was considered rare in the 1980s, but it is now recognised as a common disease, affecting an estimated 200 million reproductive-age women worldwide (As-Sanie et al., 2019; Hudson, 2022). Equating to approximately one in every ten women worldwide, the Endometriosis UK website reports similar numbers of women affected by endometriosis, as there are affected by diabetes or asthma. In New Zealand, it is estimated that a quarter of

females have experienced some sort of pelvic pain, and 120,000 women in New Zealand are impacted with endometriosis (*Endo Information*, 2022; Tewhaiti-Smith et al., 2022). Despite its occurrence, endometriosis is of the most underdiagnosed diseases (Pooja Sikka, 2020). The only way to reach a definitive diagnosis of endometriosis is through laparoscopic techniques, which is deemed invasive and undesirable, which means many women may have the disease, but not be diagnosed. The variation of presenting symptoms and the fluctuating nature of the disease also means that some women are simply not diagnosed or have a delay in diagnosis. It can be that some women are asymptomatic, yet have severe disease, whilst others present with intolerable symptoms, and only a small number of lesions (Zondervan et al., 2018). According to Agarwal et al. (2019), approximately 60% of the endometriosis cases that exist, are in fact undiagnosed, partly due to this difficulty with diagnosing. Taking these women into account would mean the estimated prevalence rate is probably higher than current statistics suggest (As-Sanie et al., 2019).

Despite the prevalence rates of endometriosis rising, and it being described as a "modern pandemic" by the American Endometriosis Association (Seear, 2014, p. 6), classification and identification of the disease remain complicated (Hudson, 2022). Whilst endometriosis can present very differently among women, a common consensus has evolved that endometriosis can be described as an oestrogen-dependent, inflammatory, gynaecological disorder (Greene et al., 2016; Hudson, 2022; Seear, 2014; Zondervan et al., 2018). It is defined by the presence of endometrial like tissue growing outside of the uterus, in the pelvis. This tissue responds to hormonal changes in the body during the monthly cycle, causing the cells

to grow, then break down and bleed. Unlike menstrual blood, which exits the body after menstruation, this blood is trapped, causing inflammation and scar tissue (Alimi et al., 2018; Greene et al., 2016; Hudson, 2022; Zondervan et al., 2018). The most common place for the tissue to deposit and implant in, on and around other areas of the body is the pelvic region, including the ovaries, however it can also be found on the fallopian tubes, uterine ligaments, bladder, bowel and pouch of Douglas (Alimi et al., 2018; Young et al., 2015; Zondervan et al., 2018). More uncommonly, areas of deposits have been seen in the brain, knees (Seear, 2014), diaphragm, gastrointestinal track, abdomen and pericardium (Ceccaroni et al., 2012), and lungs (Ceccaroni et al., 2012; Seear, 2014). Further to the mystery of these endometrial tissue findings in remote locations, more confusion about the disease's etiology is fuelled by the rare findings of endometrial tissue also found within men's bodies (Jabr & Mani, 2014; Rei et al., 2018; Seear, 2014). Discussed in the next section are the theories of endometriosis, which similar to the presentation and classification of endometriosis, vary and show uncertainty about the exact detail of this enigmatic disease.

Theories of 'The Modern Disease'

Debate also exists about the history of when endometriosis was in fact first discovered (Seear, 2014). Whilst some believe Carl von Rokitansky was the first to discover endometriosis by microscope in 1860, (Acién & Velasco, 2013; Smolarz et al., 2021), it can be argued that Daniel Schroen, first documented the disease in 1690, when endometrial tissue was found on skin lesions (Canny & Lessey, 2013). It wasn't until the 1920's that a full morphological and clinical picture of endometriosis and adenomyosis was given by the surgeon Thomas Cullen. Following on from this in 1927, John. A. Sampson was the first to demonstrate that endometrial tissue

detected outside the uterus was, in fact, of endometrial origin. When he performed surgery on menstruating women, he discovered that the peritoneal lesions bled similarly to the eutopic endometrium. It was through this finding that he proposed the Retrograde Menstruation Theory, and the term "endometriosis" was coined (Acién & Velasco, 2013).

Known as the most widely accepted biomedical theory for the development of endometriosis, the Retrograde Menstruation Theory postulates the existence of endometrial cells outside the uterus being due to a retrograde flow through the fallopian tubes during menstruation (Pooja Sikka, 2020; Vercellini et al., 2014). It is believed the endometrial cells are driven into the fallopian tubes by a pressure gradient resulting from uterine contractions. Once they reach the peritoneal cavity, the cells implant and grow, causing the development of endometriosis. Cysts and lesions are formed, inciting an inflammatory reaction from hormonal changes, as a result scar tissue and adhesions grow (Greene et al., 2016; Gupta et al., 2015; Luigi Della et al., 2020; Pooja Sikka, 2020; Vercellini et al., 2014).

Despite the Retrograde Menstruation Theory being the 'main' theory of endometriosis, there are some flaws with the proposal. Greene et al. (2016) argues that more than 90% of women who menstruate, undergo retrograde menstruation, yet only a small proportion of these (6-10%) experience endometriosis. Because of this discrepancy, other factors such as genetic, biochemical or immune factors are thought to contribute to the implantation of the retrograde tissue for women with endometriosis. Women with endometriosis commonly experience other disorders related to immune dysfunction such as rheumatoid arthritis, chronic fatigue disorder and fibromyalgia. Features of women with endometriosis that are consistent with

an autoimmune aetiology include active macrophages, impaired cellular immunity, high T- and B-lymphocyte counts, and decreased NK cell activity (Sinaii et al., 2002). These features limit the elimination of menstrual waste, which promotes endometrial cell implantation and growth in ectopic regions (Pooja Sikka, 2020; Sourial et al., 2014).

Another common theory is the Coelomic Metaplasia Theory, which proposes that metaplasia is the cause of endometriosis, with the transformation of normal extrauterine cells into endometrial cells. This changing of cell from one form to another is thought to be stimulated by hormonal or immunological factors (Koninckx et al., 2019; Sourial et al., 2014; Zondervan et al., 2018). Whilst this theory can explain the occurrence of endometriosis in prepubertal girls, males, and as well as endometriosis in other regions of the body, it is imperfect, as it does not explain the endometrial growth in prepubertal girls who lack the necessary, driving hormone, oestrogen (Sourial et al., 2014). Thomas and Rock (1991) argue the endometriosis found in men is associated with high dose oestrogen as a treatment for metastatic prostate cancer, not metaplasia, and so dismiss this theory. Noted also is the idea that if coelomic metaplasia is a form of metaplasia, then it should occur more frequently than it appears to , and it should present in higher amounts as women age. Statistics do not back this up, and so this theory is debated.

Research also suggests that endometriosis has a strong hereditary component. According to Koninckx et al. (2019), hereditary factors are estimated to account for 50% of endometriosis. Women have a 6-9% chance of developing endometriosis if their sister or mother has it, and 15% higher chance if they had endometriosis classed as ‘severe’. Bias has been proposed to explain this link, at least in part, since women with a family history of the condition may be more likely to

receive medical testing. However twin studies have also been done which show a connection between genetics and endometriosis (Parazzini et al., 2017).

1.4 Living with Endometriosis is Hard

This next section discusses the experiences of women living with endometriosis, in relation to the physical and emotional pain that they can feel. Unfortunately, the theme of disinterest and unimportance is carried through with research, as very few rigorous, qualitative studies have investigated what it is like for these women to live with the disease (Moradi et al., 2014). The studies conducted by Grogan et al. (2018), Denny (2004), Moradi et al. (2014), Bullo and Hearn (2021) and Huntington and Gilmour (2005) are used to highlight the impact of living with this disease and show how these experiences are intrinsically related to stigmatisation.

1.4.1 Physical Symptoms

A theme throughout the literature for women with endometriosis is one of pain, particularly chronic pelvic pain (Hudson, 2022). The pain is not resigned to the abdominal areas during menstruation; women detailed experiences of chronic pelvic pain, pain during menstruation (dysmenorrhoea), pain during sexual intercourse (dyspareunia), back pain, pain during ovulation, pain having a bowel motion or pain when urinating (Sims et al., 2021). Pain that had moved into the back and down the back of the legs was also mentioned by women in the study conducted by Grogan et al. (2018). Examples of the descriptors of pain that women gave in the four qualitative studies are synthesised in Table 1.

Table 1: Descriptions of pain associated with endometriosis.

Researcher	Descriptor of pain
Grogan et al., (2018), 34 women from the UK	"excruciating", "non-stop" as well as "a twisting, throbbing, stabbing, suffocating, nauseating, shocking and numbing", "debilitating" (pp. 1369).
Denny (2004), 15 women from the UK	"intense" and "overwhelming", "it was like someone knifing you" "imagine someone with nails clawing inside your stomach" (pp. 644).
Moradi et al. (2014), 35 women from Australia	"Sharp", "stabbing", "horrendous", '"tearing", "debilitating" and "breath-catching", "like someone had heated a knife and was ripping it up through my stomach" (pp. 4)
Bullo and Hearn (2021).	"Like my womb is going to explode", "like someone cutting you", "someone putting barbed wire in your belly button in a figure of eight", "a hot poker or a knife being shoved inside me" "Feels like 'stabbing', 'twisting' like my womb is going to explode", "Like someone is cutting you, beyond human Consciousness", "like someone possesses you" , "my womb is angry", "agony", (pp. 277-280).
(Huntington & Gilmour, 2005). 18 women from New Zealand	'a gnawing pain that would keep me awake', 'it's a constant ache', 'on the rack', 'crippling disability', 'it feels to me like I'm sitting on a knitting needle', 'The pain was a crippling disabling pain. It felt like my insides were coming out of my body at times. My legs used to feel like they were lumps of iron' (pp. 1128).

The descriptions illustrate the intensity and embodied nature of endometriosis related pain. Bullo et al. (2021) looked at the metaphors that women with endometriosis pain used and found that pain is conceptualised with physical and psychological elements where pain is located in their bodies and outside their bodies, all contributing to a lack of feeling of control and agency. The other important element of pain is the ongoing fear of pain, how to cope with pain, and the concealment of pain. Concealment of pain was described in the studies by Moradi et al. (2014) and Grogan et al. (2018) as a direct result of stigmatisation experiences

associated with the pain including negative judgements, trivialisation, embarrassment, shame, and normalisation.

Endometriosis also has a correlation with infertility. Recent data suggests that somewhere between 30-50% of women diagnosed with endometriosis may be affected by infertility and up to half of women who are struggling to get pregnant may suffer from endometriosis (La Rosa et al., 2020; Smolarz et al., 2021). The diagnosis of endometriosis is frequently discovered after infertility examinations begin. Infertility is seen to be compromised with just mild endometriosis; this causal link is poorly understood by health professionals. Severe cases of endometriosis are seen to effect infertility with poorer quality of the eggs and embryos, embryo implantation, and ovarian reserve. Adhesions are thought to prevent fallopian tube function and thus embryo transport as well (Hickey et al., 2014).

Literature frequently reports the negative psychological affects infertility can have on women with endometriosis. Women described how they struggled with the identity of being a woman who cannot have a child (Moradi et al., 2014). They reported feeling worried, depressed, anxious, inadequate, which often led to lowered self-esteem (Cox et al., 2003; Moradi et al., 2014). Cox et al. (2003) noted the stigmatisation felt by these women contributed to feeling judged as “not real women”, because they could not have children (p. 5).

As well as pain and infertility, other physical symptoms often reported for women with endometriosis include heavy bleeding, fatigue, lack of energy, gastrointestinal and circulatory problems, migraines, nausea and dizziness (Moradi et al., 2014; Olliges et al., 2021; Smolarz et al., 2021). The study conducted by Moradi et al. (2014) also found the knock-on effect of these symptoms was that women struggled with their appearance; some were often pale due to the heavy bleeding,

while others gained weight due to their inability to exercise, and a selection of women reported scars from surgery which they found difficult to cope with.

1.4.2 Psychological Symptoms

Endometriosis has not only physical, but also psychological effects, which can be attributed to not only the severity of the chronic pain, but also to the stigmatisation reactions which are noted to accompany this disease (Ballard et al., 2006). Stigmatisation experiences such as dismissal and trivialisation were reported by Moradi et al. (2014), and for these women many feelings of frustration, anger and distress resulted. The women experienced "feeling upset, angry, depressed, uncertain, weak, powerless, helpless, hopeless, defeated, disappointed, frustrated, exhausted, and felt like a burden to others" (p. 6). They also reported having feelings of low self-esteem, confidence and control. Contributing to these factors were concerns about fertility; the uncertainty on whether they would be able to have children, whether they actually wanted children, and feelings of guilt about passing the disease onto their daughters.

The women were made to think that they had made up their symptoms, and reported not being listened to, or understood by friends, family, colleagues and health professionals (Moradi et al., 2014). In the analysis conducted by Young et al. (2015), five studies reported that emotional well-being was reduced due to the ways others responded to them in regard to their condition. Emotional struggles of depression were compounded by family members labelling them as 'hypochondriac's' (Cox et al., 2003) and health professionals being dismissive of their symptoms (Cox et al., 2003; Whelan, 2007). This was noted to significantly damage their self-esteem (Cox et al., 2003).

Links between endometriosis and depression and/or anxiety are well known in the literature (As-Sanie et al., 2019; Luigi Della et al., 2020; Moradi et al., 2014; Smolarz et al., 2021). A meta-analysis conducted by van Barneveld et al. (2022) found patients with endometriosis suffered significantly higher rates of depression (10-86%) and anxiety (10-79%) compared to healthy controls. There were no differences between these rates and those of other people who suffer from chronic pelvic pain, leading researchers to infer that these are not due to the endometriosis itself, but to the discomfort that emerges from it instead.

1.4.3 Stigmatisation and Quality of Life

Many studies have reported a reduced quality of life for women who experience endometriosis (Bień et al., 2020; Gao et al., 2006; Olliges et al., 2021; Simoens et al., 2012). For these women personal lives, work lives and social lives can be impacted (Denny, 2004; Moradi et al., 2014). In the workplace women noted how persistent symptoms meant they had to take sick days, and it restricted their ability to conduct their work activities to the best of their ability. Some women were forced to change or give up their jobs as they were unable to conduct their work whilst using strong analgesia (Denny, 2004). Relationships with partners and friends were also affected, with some women breaking up with their partners due to their inability to understand their illness. The women found the unpredictive nature of the disease hard and were often forced to cancel social events and activities, or even juggle social events around their menstrual cycle (Denny, 2004).

Wrapped very tightly and intrinsically around these physical symptoms are the accompanying psychological symptoms of guilt, anger, hopelessness, depression, anxiety and lack of control (Cox et al., 2003; Denny, 2004). Women with endometriosis often feel helpless and out of control because of the unpredictability

of endometriosis, lack of a cure, and varied effectiveness of treatment options, as well as the consequences of untreated symptoms (Markovic et al., 2008). At a vulnerable time, where self-esteem, confidence and control are already low, women can feel a lack of support from family, friends, colleagues and medical professionals. Denny (2004) noted women having negative experiences with medical professionals who dismissed their complaints about pain, as well as friends and family who disbelieved them, accused them of being neurotic or exaggerating their symptoms. Other stigmatisation experiences have been described by women which included spoken and unspoken judgements, expectations, trivialisation and dismissal (Cox et al., 2003; Grogan et al., 2018; Moradi et al., 2014). In turn, this makes women feel even more helpless, confused, and powerless over their own bodies and lives. Medical professionals often attribute women's pain and symptoms to psychological factors, which can further delay the diagnosis for women with endometriosis who are already at risk for developing depression and anxiety (Cox et al., 2003).

Receiving a diagnosis of endometriosis can be a huge turning point for women (Huntington & Gilmour, 2005). Not only can it result in access to management and treatment possibilities, but it can also bring social support from groups or organisations by connecting with others who may be experiencing the same symptoms. Women felt relief that a medical label was attached to them, bringing a degree of legitimisation and genuineness to the symptoms they were feeling. It enabled them to disclose and talk about their symptoms, and openly give justifiable reasons if they could not meet social, work or personal expectations (Ballard et al., 2006). Gaining a diagnosis can also bring negative emotions to women when they discover the ambiguous nature of the disease which has no cure and limited successful treatments. This, as well as the limited knowledge about the disease can

cause furthers frustrations, hopelessness, and anxiety among the women (Facchin et al., 2017).

1.5 The New Zealand Picture

Very little quantitative and qualitative studies have been done in New Zealand to investigate symptom presentation, prevalence and diagnostic delays for women with endometriosis. A recent study conducted by Tewhaiti-Smith et al. (2022) surveyed women in Aotearoa with endometriosis and found concerning statistics associated with delay in diagnosis. Despite the mean age of women being low (16.9 years) when symptoms first started, it still took on average an alarming 2.9 years for these women to first seek medical help. From there, a further average time of 5.8 years was reported before a formal diagnosis was made. Putting this together, the mean diagnostic delay for those with endometriosis was 8.7 years. Just as alarming is the number of doctors seen on average, which was 4.8, before this diagnosis was made.

In the past few years New Zealand has been following Australia's lead with the promotion of endometriosis through increased media coverage and the introduction of national guidelines adopted to improve practitioner awareness. A dominant advocacy group, Endometriosis New Zealand has played a key role in recent media coverage as well as organising events, such as Endometriosis Awareness Month. The media has increasingly been on board with the recognition and promotion of Endometriosis with a selection of articles being produced in the last year which challenges stigmatisation towards women in health, as well as women with endometriosis. Examples of these are shown in Table 2.

Table 2: Small selection of articles on STUFF and NZ Herald from 2021-2022

Article Source	Date	Article title
https://www.stuff.co.nz/pou-tiaki/128063887/calls-for-public-health-apology-to-endometriosis-sufferers	26 March 2022	Calls for public health apology to endometriosis sufferers
https://www.stuff.co.nz/national/health/300501295/women-with-endometriosis-forced-to-seek-unaffordable-private-care	30 Jan 2022	Women with endometriosis forced to seek 'unaffordable' private care
https://www.nzherald.co.nz/nz/endometriosis-people-suffering-stigma-debilitating-pain-and-insufficient-public-healthcare/D3AYNAJES5FBXXFTJBFP53M74Q/	18 March 2022	Endometriosis: People suffering stigma, debilitating pain and insufficient public healthcare
https://www.nzherald.co.nz/nz/in-her-head-womans-life-threatening-endometriosis-delays/I67L7BGIIMUJP4LVF27BWUL7BQ/	13 May 2022	In Her Head: Woman's life-threatening endometriosis delays
https://www.nzherald.co.nz/nz/in-her-head-womens-health-paris-endometriosis-diagnosis-and-surgery-agonising-wait/AVM5EROH54MIQ7DSWFCBSO2WR4/	5 May 2022	In Her Head: Women's health - Paris' endometriosis diagnosis and surgery agonising wait
https://www.nzherald.co.nz/nz/in-her-head-womens-health-mum-dallas-endometriosis-story-20-years-of-pain/ZY4TRQLWV7FRBYYYIJIZNQCZVU/	5 May 2022	In Her Head: Women's health - Mum Dallas' endometriosis story, 20 years of pain
https://www.nzherald.co.nz/lifestyle/fitness-star-kayla-itsines-reveals-worrying-signs-of-endometriosis/UADZDZAVEWWEDW3HOMTZCAQR4Y/	3o March 2022	Fitness star Kayla Itsines reveals worrying signs of endometriosis
https://www.nzherald.co.nz/lifestyle/new-study-discovers-one-in-seven-women-fired-for-managing-endometriosis/FR5X7N7IORI5KJANIJB3HVTFBE/	27 Nov 2021	New study discovers one in seven women fired for managing endometriosis
https://www.stuff.co.nz/pou-tiaki/128330750/life-with-endometriosis-is-a-painful-waiting-game	12 April 2022	Life with endometriosis is a painful waiting game

In 2005 the first guidelines in respect to endometriosis were published by The Society of Human Reproduction and Embryology (ESHRE). Further guidelines were published by the World Endometriosis Society (WES) in 2013, and the best practice guidelines, the Diagnosis and Management of Endometriosis in New Zealand, was

published by the Ministry of Health in 2020. It is thought that these implementations at a national medical level have positively influenced the diagnostic delay time for women in New Zealand. The mean delay before 2005 was reported to be 8.4 years, compared to after 2012, where the mean delay was 2 years. This reduction is optimistic; however, this delay time is still lengthy given the negative impact living without a diagnosis, and thus treatment options, have on individuals, families and society (Tewhaiti-Smith et al., 2022).

Given the mean age of when symptoms first started for the women in the study conducted by Tewhaiti-Smith et al. (2022) was 16.9, many adolescents are affected with their education, relationships, and socially. 23.9% of endometriosis respondents reported giving up their studies completely, whilst an average of 5.8 study days was lost per month. For women in the workplace, an average of 3.1 days was taken as sick days every month due to symptoms, and more than half the respondents were forced to reduce their hours and work part-time. 7.8% of the women with endometriosis had given up their jobs entirely due to the symptoms they endure.

Additionally, many women are affected financially, emotionally, physically and socially by these lengthy delays in diagnosis. Armour et al. (2020) reported the negative impacts endometriosis had on relationships, whether it be with work colleagues, friends, or partners. Pain, fatigue, nausea, depression, and anxiety associated with other co-morbidities such as bleeding, bladder and bowel issues contributed to breakdowns in relationships. Sims et al. (2021) describe the diagnostic delay as having serious repercussions on physical and psychosocial consequence, but also worsening of symptoms and disease severity and delayed access to appropriate therapy. Seear (2009) also noted the reduced quality of life women suffer as they

wait for a diagnosis with experience fear, worry, anxiety, self-blame, financial, and relationship difficulties. Mentioned also was the consequence lengthy delays can also have ramifications of fertility, which can contribute to anxiety issues and diminished emotional well-being.

1.6 Rationale for this Study

Given the prevalence and health impact endometriosis has on women, their families and society, it is surprising that very few qualitative studies have been conducted globally to explore the role stigma plays for women with endometriosis. Research has neglected to look at the possible impact stigmatisation particularly the impact this may have on their emotional and physical wellbeing, as well as their ability to come forward, seek help, and obtain a much-needed diagnosis. This is particularly true in Aotearoa New Zealand where societies menstrual taboos and shame are strong, where policies and funding at a government level neglects the health needs of those with this disease, and where societal awareness and education of endometriosis is minimal. With one-in-ten women effected by this disease in Aotearoa, research in this area is vital. This research will help to fill this much needed gap, giving a voice for women suffering from this disease in Aotearoa and much needed insight into the complexities of stigma and its association with endometriosis.

1.7 Research Aim

This study will seek to explore stigmatisation experiences women with endometriosis in Aotearoa New Zealand encounter, and in particular investigate the relationship between stigma and psychosocial well-being, as well as diagnostic delay, for women living with endometriosis.

In doing so the proposed study will seek to answer the following questions:

1. How do women with endometriosis in Aotearoa New Zealand describe their experience of stigmatization?
2. How does experienced stigma influence help seeking behaviours for women with endometriosis in Aotearoa New Zealand?
3. How does experienced stigmatization impact the emotional well-being of women with endometriosis in Aotearoa New Zealand?

CHAPTER TWO: Stigma, the Complex Construct

2.1 Stigma

Illnesses bring a double whammy: they not only inflict pain, suffering, and loss, but they also elicit a social response called stigma which involves stereotyping, prejudice and discrimination (Corrigan, 2014). This social response can make one feel ashamed, embarrassed, fearful, isolated and rejected. This response can be so harmful, it is thought that the prejudice and discrimination that frequently accompany disease or disability may be as crippling as the ailment itself (Corrigan, 2014). This chapter explores the current literature surrounding stigma that will serve as the theoretical framework for my research. I will first introduce stigma by exploring its history and origin, and then attempt to define this complex social construct in relation to endometriosis. A synthesis of the philosophies surrounding the theory of stigma will also be performed which will examine the purpose or consequences of stigma, giving deeper clarity to why stigma exists on societal, intrapersonal and structural levels. Finally, the chapter will conclude with a detailed examination of stigma, purely associated with endometriosis. Previous literature which has observed stigma experiences of women with endometriosis will be discussed, with an aim to understand the possible causes and consequences of stigma for women with endometriosis.

2.1.1 Defining Stigma

The term 'stigma' originated in the early Greek and Roman communities, where signs on the body in the form of a burn or cut were used as a mark to signify something bad about the person. This visual brand helped people in society to identify others who were slaves, traitors or criminals; identifying them as immoral,

with a lower status, and therefore one to avoid (Goffman, 1990; Johnston-Robledo & Chrisler, 2013; Jones & Corrigan, 2014). Progressing into the 18th century, the term stigma had extended to include evidence of physical illness or disease, and in early twentieth-century sociological theory, it had also come to refer to physical and symbolic indicators of social deviance or disapproval (Jones & Corrigan, 2014).

Today, stigma is known to be the process through which an attribute or characteristic that distinguishes an individual or a group from others, is seen negatively, and consequently holds them in a lower regard (Crocker et al., 1998; Goffman, 1963; Gray, 2002). A wide variety of attributes are deemed as flaws by society and thus can be classified as stigmas. These include physical illnesses such as HIV/AIDS, obesity, and epilepsy, as well as physical disabilities such as amputation (Herek, 2014; Livneh et al., 2014). Mental illnesses including bi-polar and schizophrenia are often 'whispered' about and, in Western, industrialised countries, considered a weakness. Similarly, until the last decade, depression was also covered up and hidden due to harsh societal judgements (Corrigan & Kosyluk, 2014). Actions that violate social norms such as prostitution, drug use, and homosexuality, as well as demographic characteristics including gender, ethnicity, socioeconomic status and religion, can also be deemed as stigmas. Socially constructed, the degree of the 'flaw' each attribute brings, varies hugely across cultures and time (Phelan et al., 2008).

The Difficulties with Defining Stigma

Attention to stigma has grown exponentially of late, with a vast number of studies conducted on the definition and theories of stigma, conceptualisation of stigma, the impact stigma has had, as well as the management of stigma (Bos et al., 2013; Link & Phelan, 2001; Sims et al., 2021). Goffman's work in 1963 enabled stigma to be explicitly defined; instead of merely being a physical mark utilised by the Greeks

and Romans. The construction of stigma was developed with reference to the sociocultural process by which individuals or groups are labelled as abnormal, shameful, or otherwise unwanted by others. Using Goffman's terms, stigma is defined as an "attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one" (Goffman 1963, p. 3). Goffman (1963) originally described stigma as being associated with an "undesired differentness," of which there are three types: "abominations of the body" (such as physical deformities including amputations or burns), "blemishes of individual character" (such as addictions or criminal behaviour), and "tribal" identities or social labels associated with excluded groups (for example, ethnicity, gender, sexual orientation) (Goffman, 1963, p. 4).

Since Goffman's (1963) original definition, difficulties in defining stigma and applying it to a wide range of unique conditions, has been acknowledged. Stigma exists across a wide range of physical and mental illnesses and disabilities, as well as a variety of social situations deemed as 'unacceptable' or 'outside the norm'. People with deformities such as an amputation may experience stigma in a different form or way compared to someone who is bisexual, or divorced, or to someone who is ill with lung cancer or sick with HIV/aids. No one size fits all with stigma, and thus this earlier definition of stigma, proposed by Goffman (1963), has been developed and expanded considerably over the past 60 years. Different representations or conceptualisations of stigma have been framed according to the different references or orientations each discipline brings (Corrigan, 2014).

Stafford and Scott (1986) gave the definition of stigma as being a "characteristic of persons that is contrary to a norm of a social unit" (p. 80). A characteristic was defined as something someone may have done, or do, what they

may believe in, or who they are, such as a physical or social trait. A "norm" was defined as a "shared belief that a person ought to behave in a certain way at a certain time" (p. 81). Crocker et al (1998), was also influential with the development of these ideas with a further suggestion that stigma involves negative stereotypes that devalue the stigmatised person. A definition given was "stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context" (p. 505). Jones et al. (1984) also contributed with the observation that a relationship exists between an attribute and a stereotype. The attribute is seen as a "mark" which is negatively linked to a set of negative evaluations, known as "stereotypes" (Link & Phelan, 2001).

Link and Phelan (2001) further developed the definition of stigma, particularly with a sociological perspective viewpoint, by adding a component of discrimination to that of Jones et al. (1984). Resulting was a conceptualisation of stigma, which is composed of four elements, all of which coincide in a situation where political, economic or social power exists. The elements include the identification and labelling of differences, the linking of these labels to undesirable characteristics or stereotypes (determined by dominant cultural beliefs), a separation of "us" and "them" for the individuals with the labelled differences, and then finally a status loss or separation, which results in rejection, exclusion and discrimination for these people.

Whilst differing conceptualisations of stigma exist in the realm of sociology, a common theme inherent in these descriptions are the three aspects of stigma that exist: Stereotyping, prejudice, and discrimination (Jones & Corrigan, 2014; Link & Phelan, 2001; Major & O'Brien, 2005). Stereotypes are inferences drawn about persons based on their classification into a certain group or category, based on their qualities, attributes, or behaviours. Prejudice refers to the unfavourable attitude

associated with the stereotype, while discrimination refers to the actions taken as a result of the prejudice, such as rejection or discouragement (Jones & Corrigan, 2014).

Defining Stigma Associated with Endometriosis

Because stigma is such a complicated phenomenon which is applied to such a wide range of fields, it is impossible to have an exact definition for this construct that fully satisfies every occasion. It makes sense to allow for definitional flexibility as long as researchers know exactly what is meant by the word when it is employed. For the purpose of this thesis, Goffman's definition will be honoured, with the definition including two vital components: the recognition of difference an individual or group has from mainstream society, and the act or behaviour of devaluing those with the difference, from society. Stigma will be defined as 'the awareness of a particular trait that an individual's or group possesses (stereotyping), is marked as being different, and has been evaluated, and deemed to be considered discreditable by the mainstream society (prejudice and discrimination).'

Breaking this definition down, 'traits' that women with endometriosis may have include symptoms such as pain, infertility, heavy bleeding and painful sex, as well as comorbidities such as depression, anxiety and fatigue. These traits may be stereotyped into negative assumptions about these women such as that they are 'lazy' because they stay in bed, or 'weak' because they cannot handle their pain, or that they are 'whingers' because they verbalise their abnormal symptoms. Consequently, these women may be ignored, belittled, or rejected and their 'traits' that are deemed discreditable by the stigmatisers, may be normalised or dismissed.

2.1.2 The Theory of Stigma

"No theory seems by itself to provide a full answer to our fundamental question of why some groups are stigmatized and not others." (Stangor & Crandall, 2000, p. 66)

Goffman (1963, p. 4) originally described three types of stigmas: "abominations of the body" (such as physical deformities including amputations or burns), "blemishes of individual character" (such as addictions or criminal behaviour), and "tribal" identities or social labels associated with excluded groups (for example, ethnicity, gender, sexual orientation). The work of Phelan et al. (2008) also found three objectives of stigma, all of which mapped very closely with these ideas of Goffman. Additionally, the purpose of each type of stigma was explained, which gave insight as to why stigma exists in many social settings. These included, keeping "people down", "keeping people in" and "keeping people away" (p. 365).

The first function of stigma that Phelan et al. (2008) discovered is exploitation and domination, which is described as "keeping people down" (p. 365). Goffman (1963) also acknowledged this time of stigma, but instead described this type of stigma as "tribal stigma". For this type of stigma to happen, it was suggested that a degree of power is exerted over the individual or group being dominated, which in turn causes an inequality. Examples of this occurring is when we see stigma against women, minority ethnic groups, or people with a lower socioeconomic status. It is thought that this type of stigma is conducted so that people can gain power, wealth and a higher social status over others (Bos et al., 2013; Goffman, 1963; Phelan et al., 2008).

The second function of stigma described by Phelan et al. (2008) is to enforce social norms with written or unwritten rules, otherwise known as "keeping people in" (p. 365). A failure to comply with these social norms usually results in shame, and

a negative judgement on one's character. This provokes a fear of being ostracised and thus deviants are encouraged to conform to the social norms. Similar to when exploitation and domination occur, a dominant group is influential in setting what is determined acceptable or unacceptable behaviour. In this case however, the dominant group do not gain anything in a significant way; only conformity of the non-dominant group is obtained. Again, this matches Goffman's categorisation described as "blemishes of individual character" (Goffman, 1963, p. 4-5). Examples of people who may stigmatised include homosexual or transexual people, those who have substance abuse, obesity or have conducted crimes (Bos et al., 2013; Goffman, 1963; Phelan et al., 2008).

The last function obtained through stigma is disease avoidance, commonly known as "keeping people away" (Phelan et al., 2008, p. 365). Goffman (1963) described where people with physical impairments such as an amputated foot were stigmatised. The evolutionary perspective explained by Phelan et al. (2008) notes that this social exclusion of deviants is due to the need to protect oneself against infectious diseases; it could be seen as a form of natural selection and thus contribute to survival. Whilst this theory explains reactions to physical deformities or visible illnesses, noted is the inability of this theory to explain the stigma associated with non-visible illnesses such as depression, fibromyalgia and cancer (Bos et al., 2013; Goffman, 1963; Phelan et al., 2008). Other explanations to the 'disease avoidance' type of stigma have been proposed by both Stangor and Crandall (2000) and Kurzban and Leary (2001). Both of these theories correspond very closely to the work of Phelan et al. (2008), with ideas surrounding domination/exploitation, social norms and disease avoidance.

According to Stangor and Crandall (2000), it is the perceived threat or danger to the person or culture which results in stigmatisation. Domination and exploitation are the result of a threat of losing power or wealth, whereas the enforcement of social norms stems from a threat of social disorder and disharmony. Disease avoidance also occurs from a threat to wellbeing and survival when one is faced with diseases or infections from others (Phelan et al., 2008; Stangor & Crandall, 2000).

Kurzban and Leary (2001) believe the stigmatising group's feelings of threat contributes to the five reasons why people may negatively evaluate and then socially reject others. The first reason is the threat of an insufficient exchange with people they are interacting with. Examples of inadequate resources could be a lack of wealth, social status, or intelligence. The second reason we get stigma is the threat people feel with others who non-comply or who behave in an unpredictable manner. This is similar to the idea proposed by Stangor and Crandall (2000), they suggest individuals or groups that deviate and do not conform to social norms threaten disharmony, which increases hostility and the threat of conflict. The third reason we get stigma, proposed by Kurzban and Leary (2001), which also reinforces the work by Stangor and Crandall (2000) and Goffman (1963) , is the concept of disease avoidance or "abominations of the body" (Goffman, 1963, p. 4), where any physical deviations from what is proposed as being 'normal' by society, is met (De Ruddere & Craig, 2016). People with mental or physical disabilities are also seen to take up an unfair portion of societies resources, without contributing to the survival of the group. This behaviour is seen to be a hindrance to the survival and reproductive means of the group as it may take away valuable resources needed for others. Lastly, stigma can also occur when all people do not belong to one group. Those who deviate from the norms and show a lack of loyalty to the group are seen as a direct competition and

threat to survival. It is thought that the ability for human beings to reject others based on a feeling of threat is due to an evolved psychological mechanism human beings possess. It is thought that these triggers still occur, even without an objective basis for feeling threatened, due to an ingrained conditioned response people have (Newman, 2022).

2.1.3 Types of Stigma

In 2011, Pryor & Reeder established a conceptual model for HIV-related stigma that sought to provide further clarity to the current but diverse literature on stigma. The model described four dynamically interrelated manifestations of stigma; public, self-stigma, stigma by association and structural stigma.

Public Stigma

Public stigma is considered to influence the other types of stigmas and is described as the negative reactions from society towards the person with what is deemed as a stigmatised condition (Bos et al., 2013; Jones & Corrigan, 2014; Pryor & Reeder, 2011). Previous theorists such as Goffman (1963) and Crocker et al. (1998) refer to this type of stigma in their definitions and descriptions of stigma, similarly to Scambler (1998) who defines this as being enacted stigma.

For women with endometriosis, negative reactions from friends, family, health professionals and work colleagues are reported to be common (Hudson, 2021; Seear, 2009; Sims et al., 2021). This form of stigma called public stigma, takes on many forms which can include discrimination, shame, embarrassment, fear, rejection, and stereotyping. Stigmatising actions towards women with endometriosis also occurs. These include criticising, ignoring, trivialising, dismissal and normalisation (Hudson, 2021; Seear, 2009; Sims et al., 2021). Tewhaiti-Smith et al. (2022) notes that globally the normalisation of chronic pelvic pain when patients are

seen by a doctor, happens formally and informally. The literature shows this culture of normalisation contributes to a diagnostic delay for women with endometriosis.

Self-Stigma

Self-stigma is the second type of stigma in Pryor and Reeder's concept. It is very strongly connected to public stigma; due to the awareness one may have of potential social devaluation associated with their stigmatising condition. This type of stigma, partially described by Scambler (1998) as felt stigma, is also known as an internalising stigma. The internalisation of public stigma is felt, and consequently negative emotions such as fear, shame, and poor self-esteem develop (Pryor & Reeder, 2011). The progressive model of self-stigma developed by Corrigan et al. (2011) explains four stages of self-stigma; being aware of associated public stigma, agreeing with these negative attitudes, applying these stereotypes to oneself and then resulting is a diminished self-esteem. Pryor and Reeder (2011) also mention the social withdrawal which can develop from social stigma. Due to the anticipated public stigma, people isolate themselves as a way of preventing the shame from happening, which in turn shields social support and access to treatment options. For women with endometriosis, this is a common behavioural pattern that has been observed in many studies (Ballard et al., 2006; Moradi et al., 2014; Rea et al., 2020; Seear, 2009).

Stigma By Association

The third type of stigma described by Pryor and Reeder (2011) as being closely connected to public stigma is described as stigma by association. Goffman (1963) described this as courtesy stigma which happens when people close to the person with the stigmatising condition feel the need to hide their connection to them or encourage the person to conceal their condition. This is thought to be due to the devaluation the close friends or family feel from the public, because of their

association to the stigmatised person. A common theme amongst research associated with endometriosis is the encouragement women feel from their family members such as Mother's and Auntie's, as well as their friends to conceal their abnormal menstruation symptoms (Culley et al., 2013; Matías-González et al., 2021; Seear, 2009).

Structural Stigma

Structural or institutional stigma is the fourth type of stigma Pryor and Reeder (2011) establish in their model. This type of stigma involves institutional policies or legislation, as well as the perpetuation of cultural norms at a societal level which result in stigmatisation. An example of this regarding endometriosis may be the lack of funding, acknowledgment or policies at a government level which addresses the health needs of those with this disease. The recent study conducted by Tewhaiti-Smith et al. (2022) mentions the need for an increase in global awareness and knowledge, as well as the creation of better policies and health strategies to obtain gender and health equality for women with endometriosis (Tewhaiti-Smith et al., 2022).

2.2 The Stigma of Menstruation

According to Goffman (1963), a stigma is any stain or mark that distinguishes one person from another; it sends the information that those persons have a flaw of body or character that tarnishes their appearance or identity. Menstrual blood is a stigmatising mark that fits all three of Goffman's (1963) categories of stigma. Firstly, the act of bleeding can be seen as an "abomination of the body" (p. 4). The definition of abomination from the *Oxford Advanced Learner's Dictionary* 2022) is "a thing that causes disgust and hatred or is considered extremely offensive". The notion that menstrual blood is an abomination is illustrated by Laws (1990), when she

interviewed men about how they saw menstrual blood. They described the blood as dirty, unclean, and seen as necessary as it was a form of cleansing or excretion process; all of these descriptions fit the definition of an abomination. Given the aversion to menstrual blood and the secrecy, concealment and avoidance associated with it, the act of menstruation also fits into the second category of Goffman's (1963, p. 4) "blemishes of individual character". The last category of Goffman's "tribal identities or social markers associated with marginalized groups" (p. 4), can also be applied to menstruation, given only girls and women menstruate, a tribal identity of 'femaleness' is made (Johnston-Robledo & Chrisler, 2013).

Menstruation is especially significant to endometriosis since heavy and painful periods are frequent symptoms experienced by people with endometriosis. Any discussion about endometriosis requires a discussion about menstruation. Therefore, menstruation is especially pertinent to endometriosis, since it is thought that menstrual taboos are playing a key part in the significant delays we are witnessing in women seeking medical care for abnormal menstrual symptoms and receiving an endometriosis diagnosis. Consequently, this stigma is also thought to inertly contribute to the negative psychological well-being of women with endometriosis (As-Sanie et al., 2019; Sims et al., 2021).

2.2.1 The Taboo of Menstruation

Despite the year 2022, menstruation is still rendered unfavourably, resulting in social interactions in which menstruation is portrayed as a crisis that must be concealed due to its social stigma. Menstruation is still considered a taboo that must be physically and verbally suppressed. Menstrual etiquette refers to the unspoken rules' women should follow which involve the concealment, or inattention of anything related to menstruation such as menstrual products, menstruation

or menstrual abnormalities (Mondragon & Txertudi, 2019). This behaviour surrounding menstrual etiquette that women adopt, and encourage younger women to adopt, is thought to be driven by fear of criticism, ridicule, and ostracism by society (Seear, 2009).

Menstrual products are a fundamental part of a woman's life, yet menstrual etiquette requires that they be purchased, stored, used, and disposed of without men noticing (Laws, 1990; Seear, 2009). Costos et al. (2002) confirmed this belief when participants spoke about how their mothers kept everything hidden, as they never once saw any evidence of menstrual products being used. Sanitary wear such as pads and tampons are designed and advertised as being undetectable, or barely visible, and menstrual products on television make no direct reference to menstruation or blood. Instead, they utilise blue instead of red liquid to demonstrate the effectiveness of the goods. These actions, subtle, yet purposeful, exemplify the notion that menstruation is a discreditable condition, which should be hidden to avoid embarrassment and shame (Johnston-Robledo & Chrisler, 2013).

The menstrual etiquette imposed by society restricts the communication process surrounding menstruation. Because menstruation is considered to be something private that is not spoken about, any communication regarding menstruation, whether formal or informal, has been generally suppressed (Mondragon & Txertudi, 2019). From their very first period, women are encouraged by other women, usually mothers and aunties to conceal any sign of menstruation (Laws, 1990). A study conducted by Costos et al. (2002) interviewed 138 women residing in the United States, to obtain information about the nature of the mother-daughter communication regarding menses. It was found that a discussion between the mother and daughter regarding menstruation did not happen in the majority of

the participants. Of the mother's that did talk, many only gave instructions about the technical aspects of menstruation, particularly how to use menstrual products. The importance of concealing menstruation was reported to the girls, by their mothers, in a nonverbal way. Daughters reported never ever knowing when their mothers had their own periods, as everything was hidden, including any signs such as menstrual products. The mother's also never spoke about menstruation using the correct terminology, instead euphemisms were used such as "the curse" (p. 54).

Seears (2009), had similar findings with her narratives exemplifying the unspoken expectation to keep any sign of menstruation hidden, including sanitary wear and pain relief. This is illustrated in the narratives given by participants: "It's like a dirty word, no-one talks about it" (p. 1225), "Yes, it was a bit hush hush" (p. 1223). Criticism and disapproval that occurred when women spoke of menstruation to their friends, mothers, partners and colleagues was also reported. One woman was told by her mother to "'take a Panadol and go to bed. Just put up with it" by her mother when she reported significant pain (p. 1223).

Another example of the taboo of menstruation still occurring is the period education in schools. Girls and boys are often separated during puberty talks at school, conveying the message that menstruation is a topic which should be kept secret with only girls present (Johnston-Robledo & Chrisler, 2013). For boys, even less information is given to them about menstruation, than girls, by family members and in schools. Allen et al. (2011) conducted a study to explore how men learn about and perceive menstruation. Recollections were made by the boys about how they mainly found out about menstruation through their sisters or friends who were girls. One boy saw an advertisement on television about period products and remembers asking his dad who was nearby about what a period was. He was simply

told “Ask your mother” (p. 139). Another participant had memories of the boys being separated from the girls at school. Whilst the boys played board games, the girls were secretly taken away and informed about menstruation.

All of these examples emphasise the notion that menstruation is taboo; it should not be talked about, it should be hidden, and any information regarding it should be particularly concealed from males. This stigma surrounding menstruation could be reduced if males were educated and the topic of menstruation became open and free to discuss. If males were more comfortable and supportive of female menstrual cycles, then this cloud of secrecy and concealment would not be necessary.

2.2.2 Concealment of Menstrual Abnormalities

The communication taboo surrounding menstruation is seen as a barrier for women to understand the difference between normal and abnormal menstruation symptoms. Ballard et al. (2006) notes how women are reluctant to disclose early pain experiences with friends or family members, partly because of embarrassment, but also because women did not want to look weak and incapable of coping with what they perceived to be regular, yet painful, periods. Griffith (2017) used multiple qualitative methods to investigate how social stigma related to menstruation, infertility and sexual intercourse exacerbates symptoms of endometriosis. Sixty-five participants, made up of women with endometriosis, gynaecologists and chronic pain medical professionals were used in the study. Griffith reported numerous stories of how menstruation was not talked about, and thus women could not gauge if symptoms of endometriosis such as heavy bleeding or pain were normal. One participant had abnormal bleeding from the age of 13, however she had no reference

to what a normal period was, and thus was not diagnosed with endometriosis until she was 32. She stated:

> *"In my family, it wasn't ever to be talked about, it wasn't something we really ever discussed. I always had heavy periods and just thought it was normal." (p. 46)*

When women do eventually seek the courage to break the 'menstrual etiquette' and disclose abnormal concerns to close family or friends, they are often met with stigmatisation comments which downplay or normalise their symptoms. Common reactions such as being told to deal with it by taking a pain killer, or to just go to bed, resulted in their subjective experiences of pain or heavy bleeding, which is abnormal, to be redefined as normal (Ballard et al., 2006; Seear, 2009). For some women, whilst they did recognise that their symptoms were disruptive and concerning, they adopted self-stigma which resulted in the reinforcement to themselves that it was normal, due to seeing their mothers deal with similar issues, silently (Ballard et al., 2006; Seear, 2009).

Several women reported a common dismissal of abnormal symptoms in their teens, by their doctors, with their mothers being told "Oh it's her age; it'll settle down." (Griffith, 2017, p. 51). It is believed that the commonly heard notion that 'women should put up with it, as it is part of their role in life', has become so engrained in society, that even the medical professionals blur the lines between what is abnormal and normal menstruation (Griffith, 2017).

2.2.3 A Feminist View of Menstrual Etiquette

According to Laws (1990), feminists believe social rules or etiquette around menstruation are very much about gender. The purpose of this etiquette is to emphasise and maintain the status differences between men and women. This

hierarchy is communicated and maintained by menstrual etiquette, which dictates how menstruation should be handled and discussed. Laws (1990) remarks that any behaviour that calls attention to menstruation discredits women, and so it is common for men to allude to it more freely, always in a derogatory nature. Men are known to use insulting phrases such as "jam rags" and "too wet to plough" (p. 73) to describe menstruating women and use a variety of sexual and derogatory connotations associated with sex and menstruation.

Male attitudes to menstrual pain are also damaging as they are frequently met with a denial and failure to be empathetic. Laws (1990) describes this as a form of social behaviour which aims to dictate the menstrual etiquette of silence to the women. This behaviour is not only seen by husbands and partners, but from male medical professionals as well. Stigmatisation reactions of dismissal and trivialisation are also thought to be mediated by power imbalances. Matías-González et al. (2021) gave very specific examples of this very notion when one participant was dismissed by their male gynaecologist when she had pain after a procedure. The doctor dismissed her symptoms, prevented her from receiving adequate treatment and redefined her symptoms as something else in a condescending way:

> *“The gynaecologist tells me that these are gases, that I have nothing… and I’m like "doctor, they are not gases, the pain I have is too strong, I have something". "No, you have gas, I’ll explain", and then he draws something and then dispatches me.” (p. 70)*

Moradi et al. (2014) also gives narratives of participants being dismissed by male doctors when pain was described:

> *“I know I suffered with the pain and it was bad. But my GP [family doctor] I’d been telling him since I was 13 years old something was wrong, and he was*

male and he just didn't want to follow it up…he sort of just brushed it off– you're OK." (p. 5)

Women are also frequently told their symptoms are psychosomatic by male doctors; again, this can be explained as a consequence in a sexual-political context (Laws, 1990). This is illustrated by a narrative from the work of Denny (2004):

"I was experiencing a lot of pain on penetration…I went to the doctors and they did an internal and said 'Look, everything is perfectly normal' and suggested that it might be a psychological problem, and I might just be anxious." (p. 645)

Laws (1990) and Seear (2009) both describe men accusing women of trying to get out of things, such as household duties, tasks at work, and sex, when they disclose their pain. According to Seear (2009), men react with frustration and are displeased as they believe the duties are obligations, and thus the women are withdrawing from a duty that they owe, to them. Again, this another reaction to women, associated menstruation, that seeks to create a gender power balance, with women at the bottom.

2.2.4 How Gender Stereotypes Contribute to Stigma

It is well documented that women report more pain than men to medical professionals yet receive poorer care in regard to obtaining correct diagnosis and adequate treatment (Lloyd et al., 2020). It is also noted women are more likely to be administered antidepressant medication and be referred to mental health agencies, compared to men. These gender disparities are explained to be resulting from stereotype endorsement that renders women as emotionally more expressive and hence irrational (Lloyd et al., 2020). Anke et al. (2018) conducted a literature review investigating gendered norms associated treatment of pain. Findings agreed with Lloyd et al. (2020), showing women were perceived to be more emotional, as well as

hysterical, complaining, untruthful and wasting health professional's time. Women were also alleged to exaggerate their pain levels and were more likely to be assigned psychological, instead of somatic causes for their pain. Lloyd et al. (2020) registered that woman, due to this unfair stereotypical belief, are met with more scepticism and doubt when presenting with pain. Consequently, they are often dismissed, and their pain is normalised.

Menstruating, or premenstrual women are often portrayed in negative ways in society, which in turn reinforces harmful gender stereotypes. These women are often portrayed as being tearful, irritable, weak, miserable, physically ill, mentally unstable, easily enraged, out of control, and potentially violent (Chrisler, 2013). All of these attributes can be noted to be of a 'discrediting nature'. The last thing women want, is to be seen as the weaker sex, and thus it is no surprise that women simply put up with abnormal period pain or bleeding, instead of seeking help (Chen et al., 2018; Cox et al., 2003). Griffith (2017) found that endometriosis, the 'woman's disease' is linked to women's silence as well as to gendered taboos. They noted feeling an oppression of their gender and loss of equal status due the linking of endometriosis to menstrual bleeding and pain, sexual dysfunction and infertility. Noted was the discrimination they felt because they did not fit neatly into the assigned female gender role.

Women felt part of the role of being a woman, was the pain they should experience during menstruation, and they should just endure it (Cox et al., 2003; Denny, 2004; Moradi et al., 2014). Cox et al. (2003) described women who felt like they failed their duty as a female since they could not have children, and resented judgements from society that they were not real women. One woman in the review conducted by Young et al. (2015) described feeling incomplete as a woman for not

being able to conceive naturally. Other women reported feeling "guilty", "inadequate", and " a bad person" because they struggled with sexual intercourse. In particular they spoke about not meeting society's 'expectations, as well as their partners (p. 227). These findings give evidence of how stereotypes, contribute to the social stigmas menstruating women, particularly women with endometriosis, face.

2.3 Stigma and Endometriosis

"Endometriosis is stigmatized and stigmatizing." (Griffith, 2017, p. 43)

In 2019 an American organisation called the Society for Women's Health Research (SWHR), conducted a discussion forum to evaluate diagnosis and treatment for women with endometriosis. An expert group consisting of researchers, clinicians, patients, industry and government officials discussed barriers to diagnosis and treatment and priorities for the future. Emerged was the concern that endometriosis symptoms associated with menstruation, infertility and/or bowel issues were often met with societal stigma, and thus contributed to diagnostic delay (As-Sanie et al., 2019). The plausibility of stigma as being a driver of suboptimal psychosocial wellbeing and diagnostic delay among individuals living with endometriosis was investigated by Sims et al. (2021). The literature found only five publications relevant to stigma associated endometriosis; the review by the SWHR group (As-Sanie et al., 2019), a brief editorial (Quinlivan & Lambregtse-van den Berg, 2021) two qualitative studies that explored stigma associated with endometriosis (Matías-González et al., 2021; Seear, 2009) and one on the perceptions of adolescent girls and boys about the symptoms of endometriosis as sources of stigma and shaming (Gupta et al., 2018). The lack of studies done that investigate stigma associated with endometriosis is disconcerting, given the prevalence of endometriosis and the impact it has on individuals, families and society.

The study conducted by Matías-González et al. (2021) investigated experiences of stigma among Latina women living with endometriosis. Focus group discussions were used to illicit participants' experiences, opinions, perceptions and beliefs on living with endometriosis and endometriosis related stigma. Whilst limitations were that the recruitment was done via an educational endometriosis programme, and only Latin women were used, findings showed frequent stigmatizing experiences in daily lives for the Puerto Rico women. Seear (2009) used individual semi structured interviews with 20 Australian women diagnosed with endometriosis and chose to focus on the reluctance women have to disclose issues associated with their menstrual cycle. Found where themes of concealment due to societies hidden, but well-known rules of 'menstrual etiquette'. Any attempt to acknowledge menstrual abnormalities such as pain or heavy bleeding was thought to evoke and reinforce stereotypes of women as essentially weak and expose them to potential stigmatisation. Descriptions of being ostracised and criticized by family members, friends, sexual partners and employers were told. The study conducted by Gupta et al. (2018) focussed on adolescents, however these were just their perceptions of what it would be like for girls with symptoms similar to endometriosis. Focus groups were used to investigate their thoughts surrounding what it would be like as a teenager with endometriosis like symptoms; particularly interactions with friends, family, people form school and healthcare workers.

Upon analysing these studies on stigma related endometriosis, as well as studies that concentrate on overall experiences women have with endometriosis (Ballard et al., 2006; Cox et al., 2003; Denny, 2004; Fernley, 2021; Grogan et al., 2018; Markovic et al., 2008; Moradi et al., 2014; Young et al., 2015), themes related to all

four types of stigma in the model proposed by Pryor and Reeder (2011), stigma have emerged. These, along with the consequences, will be described individually.

2.3.1 Public Stigma involving Endometriosis

Women with endometriosis have reported negative attitudes from a range of people including their friends, partners, mother's, aunts, work mates, employers, doctors, specialists, the media, as well as silently through organisations and legislations. This type of stigma, described as public stigma, involves stereotyping, prejudice and discrimination. It is suggested that the formal and informal stigmatisation experiences women receive from society, including the normalisation of period pain, and the 'taboo' surrounding women's issues and menstruation, all contribute to delay time for women to seek professional advice (As-Sanie et al., 2019; Moradi et al., 2014; Van Der Zanden et al., 2020). According to Moradi et al. (2014), women normalised their significant period pain or other symptoms due to fear, embarrassment and the reaction they received from their family, friends and doctors. These reactions from friends, family, medical professionals and society are discussed next.

Reactions from friends, family and society

A main theme that emerged when exploring the reactions from friends and family was the label women feel that gets attached to them as being 'whiners' or 'complainers' when they disclose their abnormal symptoms such as pain, heavy bleeding and painful sex. Their pain was often dismissed and trivialised by friends and family who would show a lack of empathy and understanding (Jones et al., 2004; Matías-González et al., 2021; Seear, 2009).

Examples of where public stigma is experienced by women with endometriosis are reported in studies by Matías-González et al. (2021); Fernley (2021) and Seear

(2009). Matías-González et al. (2021) described women being labelled as “changas”; a cultural term in Puerto Rican given to someone deemed to have excessive whinging or complaining without a good reason. The qualitative study conducted by Seear (2009) mentioned women feeling ‘judged’ and ‘criticised’ when they spoke about their painful periods to friends or family. Fernley (2021) reported women wanting to feel no “shame, judgement or stigma with periods, women’s health or symptoms” and to be able to “share their symptoms with no fear” (p. 48). Women with endometriosis experienced being called ‘complainers’ or ‘hysterical women’ when they spoke about their abnormal symptoms. They felt others thought they were exaggerating and were weak, looking like they could not cope. Young et al. (2015), proposed these reactions were due to the ‘hidden’ nature of the disease, and it wasn’t until there was proof such as a diagnosis and photos of the endometriosis after surgery that the women felt vindicated.

Some women found their partners unsympathetic and frustrated when they experienced pain with sex. They were criticized and accused of using it as an excuse to avoid sex. Others felt ‘shame’ and ‘embarrassment’, and thus did not disclose their pain to anyone (Cox et al., 2003). ‘Rejected’, ‘guilty’, ‘inadequate’ and ‘bad person’ were words that woman used to discuss how they felt about not meeting their partner’s needs, or even societal’ s expectation regarding sex (Hudson, 2022; Jones et al., 2004).

Another theme arising from the data was the notion that painful menstruation was a normal thing that should be endured as part of a women’s everyday life. This normalisation was commonly made by other women, such as friends, mothers and aunties. They were often encouraged just to take pain relief, or spend the day in bed, with little concern about the impact their period pain was

having on their day-to-day activities. They were also encouraged from older women to keep their pain hidden from others (Cox et al., 2003; Jones et al., 2004; Matías-González et al., 2021; Moradi et al., 2014; Seear, 2009; Young et al., 2015).

Markovic et al. (2008) notes that women who saw aunties or mother's endure similar symptoms with their periods, also normalised their own symptoms as their exposure to only someone with 'abnormal' symptoms, meant they took this as the norm. According to (Seear, 2009) women also concealed their menstrual problems, such as pain or heavy bleeding as it was thought to evoke and reinforce stereotypes of women as essentially weak. Noted was the seeking of help, which was discouraged by other women, due to the reinforcement of these negative stereotypes.

Teachers were also seen to normalise period pain (Markovic et al., 2008). Adolescent girls presenting with severe pain at the sickbay were simply given a hot water bottle, pain relief or sent home. The normalisation of period pain was emphasised when the teachers readily excused the girls from activities, did not acknowledge the severity of their symptoms or encourage the girls to seek professional medical advice. While their support was noted, these actions reinforced the notion that period pain should be not a concern (Markovic et al., 2008).

Stigmatisation experiences were also witnessed in the workplace. For many women employers and colleagues showed a lack of sympathy and they felt their illness was disbelieved and trivialised (Ballard et al., 2006; Denny, 2004). Seear (2009) described how women felt judged by their colleagues, accused of malingering and reprimanded by their employers when they disclosed difficulty due to symptoms of endometriosis. Employers were also documented to question one's suitability to their jobs (Seear, 2009) and give warnings regarding the use of sick days (Denny, 2004). Women studied by Jones et al. (2004) described feeling guilty at having to

have time off and embarrassed when an attack of pain happened at work; particularly when having to explain this to a male employer.

Reactions from Health Professionals

Positive and negative interactions with health professionals were reported by women, although, although the negative interactions were emphasised more often (Moradi et al., 2014). The majority of unfavourable experiences were associated with health providers who did not want to hear their worries, did not have time to answer their queries, and normalised the abnormal pain or bleeding that they were having. Women were very slow to seek medical help, often taking years to see a doctor (Moradi et al., 2014). According to Culley et al. (2013) this was due to women feeling embarrassment, shame, and for fear of looking weak. When women did overcome various stigmatising experiences from friends, family and society, and decided to seek help, some are met with further dismissal and disbelief by medical professionals, particularly GP's who play a pivotal role in the identification of this disease (Cox et al., 2003; Markovic et al., 2008; Matías-González et al., 2021; Moradi et al., 2014). The women's concerns were dismissed as the doctors felt they were exaggerating the severity of their symptoms, and that period pain or painful sex was normal (Ballard et al., 2006; Grogan et al., 2018; Markovic et al., 2008; Matías-González et al., 2021; Moradi et al., 2014; Seear, 2009). Teenagers, in particular felt their experiences of pain were not taken seriously and that they were disbelieved (Moradi et al., 2014). Matías-González et al. (2021) described how participants were labelled as "changa" by their doctors when they reported endometriosis related pain, as well as by specialists when after surgery women had discomfort.

Cox et al. (2003) and Markovic et al. (2008) describe the majority of women shopping around for a doctor who would listen, take her seriously and believe her.

Doctors showed reluctance to refer women onto specialists, instead they often encouraged women to get pregnant. It was noted by Cox et al. (2003) that participants sensed a degree of stigmatisation experiences from their doctors due to the gender specific nature of their problems. Seear (2009) and Markovic et al. (2008) observed that health professionals were only more likely to take complaints by women more seriously when it was related to infertility. Proposed was that infertility was seen as a more legitimate concern than period pain, which is historically and societally constructed as normal.

Documented by Denny (2004) was the reluctance women felt to disclose their dyspareunia(painful sex) with their GP's or specialists. According to Witzeman et al. (2020) previous studies show approximately 2/3 of women experiencing sexual problems, do not seek medical help. Despite dyspareunia being one of the most commonly experienced symptoms of endometriosis for sexually active women, health professionals rarely probed information concerning this from their patients (Young et al., 2015). This observed disconnect between patients and their practitioners in discussing dyspareunia is thought to be from the embarrassment and shame women feel at disclosing such sensitive information (Hudson, 2022; Seear, 2009), especially if a male physician is involved (Witzeman et al., 2020). The reluctance for physicians to engage in topics of sexual intercourse is proposed to be as a result of cultural differences and the societal stigma associated with discussing topics associated with menstruation and sexual intercourse (Witzeman et al., 2020).

2.3.2 Self-Stigma involving Endometriosis

When the criticising, ignoring, trivialising, dismissal and normalisation from friends, family, health care professionals and colleagues is experienced, women with endometriosis can experience self-stigma. These actions can be internalised, agreed with and then applied to oneself. An example of where self-stigmatisation occurs for women with endometriosis is the understanding they take on that their abnormal symptoms are normal. This is shaped by the beliefs of others, whether it be their friends, mothers or doctors which dismiss and trivialise their symptoms. This refinement of one's subjective experience is discussed in the study by Seear (2009) with participants dismissing their own pain as being normal after friends and family did the same. Jones et al. (2004) also reported participants who after having their symptoms normalised, began to doubt themselves, including the severity of their own symptoms.

Laws' notion of menstrual etiquette is another example where self-stigmatisation occurs. Seears (2009), describes how younger women are encouraged by older women and mothers to conceal any aspect of menstruation. For women with endometriosis, they are commonly given pain relief, sent to bed and told to be quiet by their mothers as a means to hide their menstruation, and thus avoid being ostracised by society. For the younger women, they internalise this concealment associated with shame, agree with it, apply to themselves by adopting this practice of concealment and then in turn experience feelings of isolation and rejection.

For women who experience infertility or sexual discomfort due to their endometriosis, they can also internalise the public stereotypes associated with these problems. Jones et al. (2004) reported that women with dyspareunia felt inferior and inadequate since their sex lives were drastically different from those shown on

television. The stereotypical ideation that portrays a female role to be one that has to have children, is also adopted by the women with endometriosis. Women narrated that they felt “inadequate”, and “did not feel like a complete woman” due to the adoption of this self-imposed stereotype. Resulting was feeling of depression, exclusion and inadequacy (p. 128).

2.3.3 Stigma by Association involving Endometriosis

As Goffman (1963) firstly recognised, persons who do not possess a stigmatizing attribute, may still feel a sense of shame and embarrassment, due to their association or relationship with a stigmatised person. These people, too, feel the stigma, and so act in ways to conceal this relationship for fear of also being labelled as being different (Pryor & Reeder, 2011). For family and friends of women with endometriosis, a common theme is the normalisation and concealment they encourage those with the disease to adopt. Whilst Seear (2009) notes that many studies have failed to explain this phenomenon, she proposes that it is linked with the ‘taboo’ of menstruation. I propose to go one step further and link this to a type of stigma called stigma by association. Not only do other women hide their own menstrual habits from others, but they also deliberately hide those of other women including abnormal menstrual symptoms they may have. An example of this is the narrative of Rosa in the study conducted by Markovic et al. (2008). Rosa explained how she was expected to continue working despite the pain she felt, due to the family’s reputation she had to uphold. Her family were perceived as being hard working, and so were positioned by society as being strong, not weak, and wealthy. Rosa needs were subordinated and silenced by her family when she was encouraged to hide her pain from society, this being an example of stigma by association.

Markovic et al. (2008) also reported further examples of stigma by association when schoolgirls presented at school with bad period pain. They were they were very quickly whisked off to the sick bay, were excused from school duties and sent home with no discussion or concern about their level of pain from the teachers. This act of secrecy and hurriedness could be attributed to the stigma attached to menstruation that teachers subconsciously felt.

2.3.4 Structural Stigma involving Endometriosis

I like to think of structural stigma being the 'big rocks of stigma' in a jar, where all the other sorts of stigma such as public, self, and stigma by association are the smaller rocks that infiltrate through. Institutions have the power to constrain opportunities and resources, such as access to care, education, and funding, all of which can result in stigmatisation, particularly for minority groups (Hatzenbuehler, 2016b; Link & Phelan, 2001). Hudson (2022) claims the significant ongoing gaps in our understanding of the endometriosis with its aetiology, symptoms, diagnosis and treatment is due to structural stigma, or structural ignorance at a government level which places endometriosis as a low public health priority. It is proposed that the lack of funding and research given to the disease, resulting in the non-production of knowledge, is attributed to the fact that it is a women's disease, involving a women's body. Negative historical constructs surrounding menstruation and menstruating women, are also noted as contributing factors behind the ignorance that seeks to silence and marginalise women with endometriosis. Sims et al. (2021) also notes that when an illness has low diagnostic uptake and engagement in the health care system, such as endometriosis, it can be prone to an element of stigmatisation from the public. The uncertainty and ambiguity associated with endometriosis, as well as the

wilful ignorance to investigate and understand this disease, does in fact bring about experiences of stigmatisation for women with this disease.

For women with endometriosis, in New Zealand, these stigmatisation experiences are very real. Legislations, national policies, practices and media that collectively make up the big rocks set the foundations of society; they influence and give definition to what individuals in society should value and deem important.

Legislation and Policies

In 2020, best practice guidelines were developed by the Ministry of Health as a way to improve diagnosis and management of those with suspected endometriosis at a primary and secondary health care level in New Zealand (Ministry of Health, 2020). This was thought to be driven by other policies developed worldwide such as the World Endometriosis Society (WES) guidelines and the updated Society of Human Reproduction and Embryology (ESHRE) diagnostic guidelines published in 2013 (Tewhaiti-Smith et al., 2022). According to Deborah Bush (a director of Endometriosis Society), this document produced by the Ministry of Health, is just a piece of paper, with no real action behind it. It merely provides guidelines to practitioners; no funding, resources, or even an action plan, have been implemented by the government since. In contrast, the Australian government, has started the process of removing this stigma. In 2017, the Australian Minister of Health gave a national apology for the delay with diagnosis and treatment of endometriosis sufferers in Australia. Since then, $58 million has been injected into an action plan that includes specialist care, funded MRI scans, and education and research.

This lack of interest, funding, and action by the New Zealand government to provide structures, legislation and pathways to help sufferers of endometriosis

within the New Zealand health system can be seen as not only a form of neglect, but specifically, an act of stigmatisation for these women.

Practitioner Knowledge and Misdiagnosis

A common theme mentioned in many studies is the misdiagnosis occurring at this GP level, with many women noting the lack of adequate knowledge that doctors seem to have on endometriosis (As-Sanie et al., 2019; Tewhaiti-Smith et al., 2022; Van Der Zanden et al., 2020; Young et al., 2015). Van Der Zanden et al. (2020) conducted a study in the Netherlands, where the diagnostic delay from a GP point of view was researched. Many GP's reported a lack of awareness of prevalence rate of endometriosis, with almost all thinking it was a rare condition. A lack of adequate training and knowledge about endometriosis was acknowledged, as well as the difficulty in distinguishing between physiological discomfort some women naturally have with their periods and pathological conditions like endometriosis.

In the study conducted by Hudelist et al. (2012) it was found that 74.3% of patients eventually diagnosed with endometriosis had at least one diagnosis prior to this. This could be due to the lack of knowledge health professionals have about this disease, but it could also be due to the enigmatic nature the disease possesses. It has long been recognised that the existence and severity of a patient's symptoms are disproportionate to the extent of the endometriosis observed. Some women may have few symptoms and be riddled with the disease, and others suffer immensely with pain and only be diagnosed as having mild endometriosis. There is no explanation why some women may have symptomatic or asymptomatic endometriosis, but we do know that this quality can make the disease difficult to treat and somewhat of a mystery (Greene et al., 2016; La Rosa et al., 2020; Smolarz et al., 2021; Young et al., 2015; Zondervan et al., 2018).

Endometriosis does not have a set of defined symptoms. Often women who present for medical help appear with symptoms which could belong to other medical conditions as well, such as migraine, gastrointestinal problems, backache and abdominal pain; this makes diagnosing difficult. Many women present with infertility and pain, which makes it hard for a health professional to justify intrusive means such as surgery, when a number of conditions could be causing this (Acién & Velasco, 2013; Agarwal et al., 2019). The absence of non-intrusive and inexpensive diagnostic tools such as biomarkers to diagnose endometriosis are greatly needed. It is thought the extra lengthy delays young women experience in their diagnosis, compared to other women, is due to the hesitation of young women, parents, and primary care providers because of the intrusive nature of pelvic examinations or laparoscopies (As-Sanie et al., 2019; Hudelist et al., 2012). The study conducted by Hudelist et al. (2012) reported women experiencing abnormal menstrual symptoms under the age of 19 years waited on average 12 years for a diagnosis. Arruda et al. (2003) also found younger women waited significantly longer to be diagnosed with an average of 12.1 years for women under 20, compared to women over 20-29 having an average of 4.5 years, and women over 30, 3.3 years. The last few years have seen the development of transvaginal ultrasounds or magnetic resonance imaging to detect endometriosis on the ovaries, or deep endometriosis found on particular areas such as the bladder, rectovaginal septum, and sigmoid colon. (As-Sanie et al., 2019) However, these techniques do not detect superficial endometriosis, which is the most common type, particularly in adolescents (Dun et al., 2015).

Access to Adequate Care and Treatment

After an initial GP referral to a specialist, access to gynaecologists, and long waiting times for surgery were also noted as structural barriers for women to receive

a diagnosis of endometriosis (Moradi et al., 2014). As-Sanie et al. (2019) reported an average of seven visits were made by women to their health care providers before being referred to a specialist gynaecologist. In New Zealand, this average was slightly less alarming, with a reported average of approximately five doctors' visits before being diagnosed with endometriosis (Tewhaiti-Smith et al., 2022). It was reported that the average diagnostic time from seeing the first doctor, to gaining a diagnosis, was six years. Whilst this was high, it was noted that trends show this to be decreasing since 2005. It was proposed that this was due to the increased awareness of the disease within society and at a medical level (Tewhaiti-Smith et al., 2022), which proves that structural stigmas such as a lack of knowledge or awareness play a pivotal role in a diagnosis. A huge divide is seen in New Zealand between the public and private health care sectors. People that do not have private health insurance are faced with lengthy waits, and for people living rurally, these wait times are exacerbated and access to specialist medical care is difficult due to achieve. Ethnic minority groups, such as Māori, that live remotely, who already experience poorer health outcomes, are further disadvantaged with access to care (Tewhaiti-Smith et al., 2022).

The final step for women who have been diagnosed with endometriosis, is a treatment plan to help manage symptoms. No cure has been found for this disease, and with its debatable etiology, inconsistent symptomology, and questionable classification system, current treatment options are currently limited. Hormonal, surgical or a combination of both, are frequently used, however many women gain little or inadequate relief from the major symptom of pain with these treatments (As-Sanie et al., 2019; Young et al., 2015). On average, 11-19% of women report no relief in pain after treatment, and 5-59% reported to still have some degree of residual

discomfort at the completion of treatment. Between 5-16% of women discontinued treatments due to the adverse side effects such as hot flushes, weight gain or insufficient effectiveness, limiting its utility or lifespan. Recurrent pain is prevalent following treatment discontinuation, with 17-34% of women reporting pain recurrence after discontinuing therapy. Laparoscopy proved to be inadequate as a treatment option for many with 20% of women showing no improvement after surgery and 55% of women needing additional surgery within seven years. Disease reoccurrence after surgery was reported to be 30-50% (As-Sanie et al., 2019). The lack of adequate treatment options for endometriosis is directly related to a lack of funding and interest received at a structural level, all dictated by institutions, policies and legislations.

Lack of General Awareness and Education

Media are beginning to play a part in reducing structural stigma for women with endometriosis. A Herald campaign, "In Her Head' has featured over the past few months, with an emphasis on investigating gender specific health experiences wāhine have had in New Zealand. A number of articles detail the bureaucratic structures that are letting women down, regarding access to care, being heard, and achieving accurate and timely diagnoses.

Advocacy groups such as Endometriosis New Zealand have also strived to get recognition and significance for endometriosis as a common disease. This group, now registered as a charitable trust provides support, education and a forum for women to get together and help each other. Other online groups such as Instagram and Facebook groups are also now a common tool for women to gain information and support. According to Tewhaiti-Smith et al. (2022), it is the combination of these advocacy groups and the high-profile coverage in the national media that is

increasing the consumer and practitioner awareness of endometriosis in New Zealand. Bringing awareness to this disease, is key to reducing stigma. Awareness can normalise what was once a 'taboo' subject of society and give it an allowance to be disclosed. The more we can talk about it, the more it feels ok to talk about it, and the more women feel empowered and comfortable to seek help.

A common theme when reviewing literature was that of the lack of education about this disease, whether it be the patient herself, the general practitioner, or even the gynaecologist (As-Sanie et al., 2019; Cox et al., 2003; Fernley, 2021; Moradi et al., 2014). Many women report being diagnosed with endometriosis, having had no idea about the disease beforehand (Moradi et al., 2014) , while others were shocked that they have been treated by gynaecologists who lacked knowledge and expertise when treating women with the disease (Cox et al., 2003).

Within New Zealand, no formal compulsory education exists regarding endometriosis for our young people. Whilst the topic of menstruation is covered in the health curriculum, abnormal symptoms, including endometriosis, is not (Ministry of Education, 2014). In 1996, Endometriosis New Zealand developed a programme in schools to improve adolescent knowledge regarding endometriosis. The programme called the *me* program (Menstrual Health and Endometriosis) is delivered in some schools in the Canterbury and Marlborough regions of New Zealand. Because this programme is not funded by the government, the delivery of the programme to certain schools was only made possible via funding from private organisations (Bush et al., 2017). A review of this programme in 2017 has shown significant improvement in the education for these young people. While just 10% of Canterbury and Marlborough students had heard of endometriosis in 1998, that number jumped to 32% and 41%, respectively, by 2015. Improved awareness for the adolescents

resulted in earlier presentations to health professionals for abnormal symptoms that were occurring. It is thought that educational programmes similar to *me* is crucial to encouraging conversations and reducing stigma so that an assessment, diagnosis and treatment can occur in a timely fashion (Bush et al., 2017; Tewhaiti-Smith et al., 2022). The lack of funding given to this programme from the New Zealand government, so that all adolescents in New Zealand can benefit, is another example of the structural stigma, that exists today in Aotearoa New Zealand.

Inequality of Minority Groups

In 2018, the Global Equity Hub, established by the World Health Organisation conducted a literature review of over 170 studies of gender and equity in the global health workforce. One of the key messages emerging from the review was "In general, women deliver global health and men lead it" (Manzoor & Thompson, 2019, p. 3). It was reported that women only make up 25% of leadership roles, yet 70% of the global health workforces. Concerning was this lack of gender balance in these community-global leadership roles, resulting in a loss of female perspectives and knowledge in the designs and delivery of female health. Evidence was given that women in these leadership roles give greater priority to sexual and reproductive health, which in turn has an effect on the design of national health plans, systems and policies. For women with endometriosis, this lack of female voice in the leadership roles, is another act of structural stigmatisation.

According to Tewhaiti-Smith et al. (2022), gender inequalities associated within the health sector have been recognised amongst professionals. On the basis of human rights, gender equality and health equity, there is a need for a specific women's health strategy that caters for the gender specific needs of our female population, including resources and funding, in New Zealand, as well as globally.

Within New Zealand, a movement has been seen to bring health gender equalities into action. A non-government organisation called the Women's Health Action group has been established to work with health professionals, policy makers and other non-profit organisations to help action health policies and deliveries for the good of women (Action, 2014).

The study conducted by Tewhaiti-Smith et al. (2022), mentions other barriers such as financial, logistical and socio-economic, as well as ethnic and gender inequalities which also prevent equitable healthcare for women with endometriosis. As a woman growing up in a very small rural Māori community in Northland, these barriers are very real. It is not uncommon to travel long distances to receive any sort of healthcare, and then, any specialist healthcare is restricted due to a shortage of professionals working in these remote areas of New Zealand. It is not uncommon to hear of women waiting over a year to see a public gynaecologist who travels just once a month to the Far North. From there, waiting times for surgery, or further specialist care are also excessive. Unless you are financially able with private health insurance, you are waiting potentially months, or even years to be seen and diagnosed.

This is just one example of many where systemic changes are needed to promote equity and efficacy within our public health system in Aotearoa New Zealand. For women with endometriosis, the big rocks seem to be all in the hands of our government. Unless legislations and policies are produced, and structures are put in place to cater for these women, such as education, and access to specialised, timely care, this structural stigma will continue to exist. Resulting will be a society which will continue to deem these women not worthy of the healthcare they deserve.

2.4 The Theory behind Stigma Associated with Endometriosis

Women with endometriosis have symptoms of heavy bleeding and/or chronic pain; both of which can produce stigmatisation attitudes in two different ways. Heavy bleeding is associated with the stigmatising mark of menstrual blood, which explained earlier, fits all three of Goffman's (1963) categories of stigma. The chronic pain women feel with endometriosis can also lead to stigmatisation due to the deviation it brings from societal norms (Kurzban & Leary, 2001; Phelan et al., 2008; Stangor & Crandall, 2000). Consequently, observers devalue and discredit those with chronic pain due to this failure to conform to a societal norm (De Ruddere & Craig, 2016).

Consistent with evolutionary biological theories of stigmatising behaviour outlined by Kurzban and Leary (2001), prejudice towards those who experience chronic pain is common. People's perceptions of others' contributions to their own and the community's well-being determine the degree to which they are valued, much as they did in the hierarchical social systems of our ancestors and early hominins (De Ruddere & Craig, 2016). For women with endometriosis, or unexplained chronic pain, they could be seen as a threat to survival or reproduction due to the perceived inability to fairly contribute to the survival of the group. In the case of unexplained chronic pain, scepticism about the veracity of the pain complaints and possible devaluation of the other person may result from a lack of a clear medical explanation for the pain or from a failure to fit with a restricted biological viewpoint centred on acute pain (De Ruddere & Craig, 2016).

Literature shows that people stigmatise "outgroup" members. "In group" persons are those similar to the observer which could include relatives, friends, and

age mates, whereas "out group" people have distinct skin tones, ideologies, etc (O'Brien & Major, 2005). Women with endometriosis or unexplained chronic pain could be considered to be outsiders or the "out group". In the context of pain or suffering, observers have less empathy and altruistic desire for members of social out-groups than for members of in-groups, and "out group" members' pain complaints tend to be ignored or dismissed (De Ruddere & Craig, 2016).

Ruddere and Craig (2016) propose that observers which include the general public and all medical professionals attribute lower levels of pain to patients when a clear basis for their pain is not found. It is believed that they are less sympathetic and inclined to help, dislike the patients more, and suspect deception when no clear medical reason is found. Thus, observers dismiss or trivialise pain complaints and express doubt about credibility. For women without a diagnosis of endometriosis, this could account for the stigmatisation reactions they experience from family, friends and medical professionals.

2.5 Consequences of Stigma

Literature specific to stigma related to endometriosis has frequently reported two main behaviours women adopt as a result of stigma: concealment and isolation. These behaviours are thought to contribute significantly to a women's reluctance to seek medical help and thus impact diagnosis, management and treatments of endometriosis.

When women experience negative reactions from others which involve being labelled, criticised, dismissed or trivialised, a common reaction is to conceal their symptoms (As-Sanie et al., 2019; Griffith, 2017; Grogan et al., 2018; Hawkey et al., 2022; Moradi et al., 2014; Seear, 2009; Young et al., 2015). Hiding their illness from

family, friends, health practitioners and colleagues, means the women's experiences of endometriosis symptoms are not told, and they feel like their voices are not heard. This is commonly described as "suffering in silence" (Griffith, 2017, p. 52).

Studies reviewed give a glimpse into the specific stigma experiences which lead to concealment and isolation. Women in the study conducted by Matías-González et al. (2021), spoke about how they preferred to stay in bed, to not go to school, not attend social occasions and refuse to see a doctor for nine months, due to the stigma they had experienced. They felt they were labelled as moaners or disbelieved when their pain was described. Grogan et al. (2018) also reported women concealed their symptoms and chose to lie about their absence at social events, due to others thinking their illness was not legitimate, and out of fear of being negatively judged. Jones et al. (2004) found women were labelled as 'moaners', and because of the link to menstrual taboos, decided to conceal their symptoms. Cole et al. (2021) described women covering up their pain symptoms with painkillers or choosing to continue having painful sex as they did not want others to know there was a problem. This was due to stigma reactions of others, but also the guilt women carried that they were affecting others, and the desire to be normal.

Griffith (2017) noted that when women 'suffer in silence' as a result of stigma, feelings of isolation can be exacerbated, which in turn increases stress levels, disease progression and symptoms. Studies by Jones et al. (2004) and Cole et al. (2021) specifically link the acts of isolation and concealment to feelings of loneliness for these women. The tendency for women to conceal symptoms was seen by Ballard et al. (2006), Jones et al. (2004) and Seear (2009), as particularly troublesome as it meant they were unable to gain comparative evidence from other women, as to what was normal, or not. This meant women isolated themselves, sometimes took harmful

levels of painkillers, questioned their own symptoms and did not seek medical attention.

The connection between concealment and isolation with the diagnostic delay and treatment of endometriosis is explicitly mentioned as concerning by many studies. Whether it be because of the normalisation women adopt from their stigma experiences, or the reactions from people which put them off, it is noted that these stigma experiences limit women's willingness to seek care, which delays diagnosis, treatment and management, and potentially causes exacerbations of symptoms (As-Sanie et al., 2019; Markovic et al., 2008; Matías-González et al., 2021; Sims et al., 2021).

2.6 Summary

Despite its high prevalence and well-documented adverse effects on individuals, families and society, endometriosis, and the stigma associated with endometriosis, is vastly understudied (Sims et al., 2021). Discussed in this chapter was the origin of stigma, the complexity of its nature and why this makes it difficult to have one universal definition of stigma. For the purpose of this thesis, Goffman's definition involving two components, the recognition of difference, and the devaluing of those with the difference, is honoured. Women with endometriosis may experience pain, infertility heavy bleeding, dyspareunia, depression, anxiety or fatigue, and for them it is these traits that may be evaluated and deemed discreditable by society. Negative judgements and stereotypes may be applied by family, friends, medical professionals and society in general, and reactions of normalisation, dismissal, and trivialisation are common.

For women with endometriosis, an extra complex dimension exists, whereby the disease is gendered specific, and closely associated to menstruation, and all of its

taboo's. The unspoken menstrual etiquette that society, even today, possess, plays a huge role in the lack of education and thus ability to render symptoms as normal or not, as well as come forward and seek help when things are not right. Consequently, endometriosis-related stigma projects multidimensional negative effects on timely care, treatment, and quality of life for those with this disease. According to Sims et al. (2021), stigma also "mediates, undermines, and corrodes psychosocial well-being" (p. 4). Additional research to fully elucidate, comprehend, and estimate the quantitative scope and qualitative complexity of endometriosis-related stigma is needed (As-Sanie et al., 2019; Sims et al., 2021). The following chapter will outline and discuss the methodology used in this thesis to explore the stigmatisation experiences of women in Aotearoa New Zealand.

CHAPTER THREE: Methodology

3.1 Research Design

The purpose of this study is to explore the stigmatisation experiences of women with endometriosis in Aotearoa New Zealand. This chapter will begin by describing the research paradigm adopted in this study including the philosophical framework, interpretivism, which consists of a set of assumptions and beliefs, of which my research has been based on. This qualitative research investigation utilized an interpretative phenomenological analysis (IPA) as its primary approach to allow the participants to fully and deeply describe their stigmatisation experiences associated with endometriosis. It was used with a purpose to understand and interpret these experiences, with the aim to further our knowledge of the impact it has on these women. The IPA approach is detailed and its theoretical underpinning is explained and justification is given as to why it was an ideal approach to be used in this study. Next, the recruitment process, data collection methods, and data analysis used in this study are described. A discussion surrounding limitations of this approach is given, as well as the ethical and cultural considerations that are a necessary thought in any research project are also given.

This study takes on an Interpretivist Paradigm which has key characteristics of interpretation, subjectivity and understanding. This paradigm is opposite to the positivist one, where the sole aim is to discover a single reality via using objective means. Instead, interpretivism acknowledges a single reality does not exist and cannot be found, instead it seeks to understand the reality, and interpret it. The ontological position of interpretivism is known as relativism and the epistemological stance used in this study is subjective (Sharan & Elizabeth, 2016). Research using the

interpretivist paradigm is not trying to discover a single, universal, observable reality, but instead believes realities are relative; multiple individual realities exist, which differ from person to person. This is because realities are socially constructed and each individual has different experiences, beliefs and attitudes that influence their own perceptions and meaning (Scotland, 2012; Sharan & Elizabeth, 2016). As explained by Sharan and Elizabeth (2016), a result of this co-construction is that knowledge is constructed, not found.

To understand women's experiences of stigma associated with endometriosis, it is important to adopt this interpretative paradigm. Stigma is socially constructed; societies norms and expectations determine whether an individual is deemed discreditable or not (Goffman, 1963). Stigma also varies amongst different cultures and communities; it is not a fixed, unique, agreed upon, or quantifiable thing that positivist and quantitative research presupposes it to be. Instead, there are many different constructions and interpretations of reality, in this case stigma, all of which are changeable and dynamic over the course of time (Sharan & Elizabeth, 2016). When looking at stigma, there is no single reality that exists, it is difficult to define, it is not universal, and it is not measurable. This research aims to explore this reality, to interpret the experiences women are having in regard to stigma, and to gain an understanding of what this means in relation to them.

As the Interpretivist Paradigm involves interpretation, subjectivity and understanding; all of these three defining attributes fit the purpose of this research. Given the limited knowledge about the experiences of stigma for women with endometriosis, it is entirely appropriate to adopt an exploratory qualitative approach in this research. This method of investigation fits with the aims of this research as it

is particularly useful both for exploring what it is like to experience particular things and the meanings this has for the individuals (Chamberlain & Murray, 2008; Liamputtong, 2019; Merriam, 2002; Willig, 2013).

This social constructivist/interpretivist stance enables real world issues to be investigated, particularly around social processes involving prejudice and power (Chamberlain & Murray, 2008; Liamputtong, 2019). For women with endometriosis, gendered power imbalances associated with gender inequalities and stereotypes, result in many health inequalities. This, intertwined with the complex construct of stigma, results in women with endometriosis being marginalised and vulnerable. Liamputtong (2019) and Willig (2013) note that qualitative research is essentially crucial for individuals or groups who fit this category. Researchers utilising qualitative methodology are the instrument for data collection; they must work closely with the individual, ask questions, probe and listen carefully to make sense of what the participants are conveying. The text in the form of words and stories that the participants tell the researcher enables a deep, rich description of the phenomenon to be exposed (Liamputtong, 2019; Merriam, 2002; Sharan & Elizabeth, 2016). For this study, I used semi structured interview questions to evoke feelings and thoughts regarding stigmatisation experiences of the participants. The questions were only a guide, as probing was used to delve into topics of emotional depth and sensitivity in order to really capture the lived experiences for these women.

3.2 The Interpretative Phenomenological Approach

IPA is a qualitative research technique developed specifically for use in psychology (Reid et al., 2005; Smith et al., 2022; Smith & Nizza, 2022). The aim of IPA is to study experience, getting as close to the lived experience of the participant as

possible. IPA is also concerned with exploring and understanding how a participant is making sense of a lived experience in their own personal and social world. It also seeks to examine how people makes sense of these experiences, and the meanings these experiences give (Reid et al., 2005; Smith et al., 2022; Smith & Nizza, 2022; Stainton Rogers & Willig, 2008; Willig, 2013). Smith et al. (2022) describe IPA to have three key theoretical underpinnings: phenomenology, hermeneutics and idiography. Phenomenology is concerned with examining experience, hermeneutics with interpretation, and idiography with the nature of specific accounts (Smith et al., 2009). I will briefly discuss these in turn.

3.2.1 Phenomenology

Phenomenology can be described as a reflective study of an individual's lived experience (Given, 2008; Willig, 2013; Yüksel & Yıldırım, 2015). The aim of phenomenology is to fully understand and describe a specific phenomenon and to give meaning to the participants' lived experiences regarding this phenomenon (Willig, 2013). Phenomenological was an appropriate methodology to gain insight into stigmatisation experiences women with endometriosis have.

There are two main approaches to phenomenological research in psychology- the descriptive and the interpretative. Descriptive phenomenology involves exploring, investigating and describing the phenomenon, whilst interpretative goes further and seeks to understand the experience associated with phenomenon (Matua & Van Der Wal, 2015; Smith et al., 2022). Given this study seeks to understand the influence stigmatisation experiences may have on the diagnostic delay and psychological health of women, the interpretative phenomenological (IPA) will be used.

Phenomenology was founded by Edmund Husserl who established the importance of examining an experience in its own terms, or as he famously stated "go back to the things themselves" (Smith et al., 2022, p. 8). To do this, an IPA researcher must put aside their own assumptions or preconceptions about the world, which are understood to serve to obscure the true nature of any experience. Importance was attached to using one's conscious awareness and using reflection to examine the lived experience in a phenomenological inquiry (Smith & Nizza, 2022).

Heidegger contributed further to Husserl's ideas with his view that each person brings a subjective experience due to their position and relationship with the world, and because of this the variety of each individual experience is recognised in IPA (Smith & Nizza, 2022). The participants are viewed as experts, and the subjective knowledge that each individual can give is highly valued. Because of this, IPA participants may communicate their lived experiences by telling their own stories, in their own words. According to Eatough and Smith (2017), the experience and the sense of meaning that people create from the experiences, are more essential in IPA than the structure of the actual phenomena itself. In order for these meanings to be produced, Husserl observes that the person must be systematically and carefully reflective of their lived experiences. It is the role of the researcher to help draw out and interpret these reflections (Smith et al., 2022).

3.2.2 Hermeneutics

The second major theoretical framework of IPA, also introduced by Heidegger is hermeneutics. Hermeneutics is often referred to as the theory of interpretation (Eatough & Smith, 2017; Smith et al., 2022; Smith & Osborn, 2015). Combining phenomenology with hermeneutics, IPA requires an interpretative approach to

discover the true meaning of the participants' experience. The necessity of this combination is described by Smith et al. (2009) as "Without the phenomenology there would be nothing to interpret, without the hermeneutics, the phenomenon would not be seen" (p. 37). In IPA it is important the researcher adopts a detective stance of scratching the surface and digging deep to uncover individual subjective experience. This involves closely engaging in participant's recounts, by questioning, and searching for clues about what it actually means. This process of interpretation involves the linkage of both the researcher and the participant and is referred to as "double hermeneutic" (Smith & Nizza, 2022, p. 8). The researcher is trying to make sense of the participants who are also trying to make sense of their own experience (Smith et al., 2022; Smith & Nizza, 2022).

3.2.3 Idiography

Finally, IPA is idiographic in that it focuses on the analysis and understanding of particular, or individual cases in detail, instead of at a population or group level, such as in nomothetic enquiry (Smith & Nizza, 2022). As a consequence, attention is given to detail, with a need for a rich, descriptive analysis to be done of each case or individual, before comparisons and generalisations are made across cases (Smith et al., 2022). In order for this thorough detailed analysis, small sample sizes are adopted in IPA. A homogenous sample is also desired so that differences between the individuals are due to individual differences, instead of demographic. Samples should also be selected purposely so that the experience of interest is represented with participants offering rich descriptions to a research question that is significant to them (Smith et al., 2022; Smith & Nizza, 2022). A variety of sample sizes have been used in IPA studies with some using one, four, nine or even 15 or more. In order to

give a comprehensive detailed account of the cases many researchers are recognising the need to keep the sample size small so that this can be done (Smith & Osborn, 2008). Master's studies using IPA have a recommended sample size of five (Smith et al., 2022; Smith & Nizza, 2022). However, it does depend on the quality of the individual cases, and what the researcher is prepared to give in terms of commitment and time (Smith et al., 2022).

3.3 Research Questions and Procedure

The following section details the recruitment process, sample selection, data collection, interview process, transcription and finally the process of analysis that an IPA study adopts. The research questions were:

1. How do women with endometriosis in Aotearoa New Zealand describe their experience of stigmatisation?
2. How does experienced stigma influence help seeking behaviours for women with endometriosis in Aotearoa New Zealand?
3. How does experienced stigmatisation impact the psychosocial well-being of women with endometriosis in Aotearoa New Zealand?

3.3.1 Recruitment and Participants

The sampling process used in this research had IPA's orientation throughout. IPA is deeply committed to idiography and in line with this the sample size was kept small and selected purposively (Smith & Osborn, 2008). The goal initially was to interview eight to ten participants, however after six interviews were conducted and themes were found, it became clear I had more than enough quality data.

The participants were recruited using snowball sampling focusing on a homogenous sample. By making the sample as uniform as possible, in regard to social or cultural factors, any variations within the group may then be acknowledged and examined (Smith et al., 2022; Smith & Nizza, 2022; Smith & Osborn, 2008). A homogenous sample was achieved with all participants being 18 years or older, having a confirmed laparoscopic diagnosis of endometriosis; this can be any stage (1-4), and all participants were residing in Aotearoa New Zealand. The details of the participants are covered in Chapter Four, findings (see Table 4).

3.3.2 Reflexivity

Due to the subjective nature of qualitative research, it can be highly influenced and shaped by the researcher (Dodgson, 2019; Shaw, 2010; Willig, 2013). A qualitative researcher is very much a part of the research process, from the beginning where by an epistemological stance is developed, to the middle where one is listening and engaging with stories and narratives, to the end, when the analysing of data, and then the reporting of findings is required (Willig, 2013). Throughout this, the researchers' prior experiences, assumptions or beliefs can all influence the research process whether it be intentionally or unintentionally, and so it is necessary as a researcher to reflect on this (Shaw, 2010). In IPA, where the researcher is heavily involved in a hermeneutic and interpretative process and utilises subjectivity to make sense of and understand lived experiences, this reflection is even more important. It is vital that the researcher recognises how their own subjectivity could influence the data collection, analysis and interpretation, and thus shapes the research and its findings (Shaw, 2010).

Reflexivity refers to the ongoing process of self-reflection that researchers participate in to increase their knowledge of their behaviours, thoughts, assumptions and expectations (Darawsheh, 2014). I was careful to recognise and evaluate my own participation in the study in regular meetings with my supervisor and a diary. This process allowed me to be critical and mindful of how my own self such as my beliefs, personality, history and interests may influence the outcomes of this research. Such self-awareness will enhance the rigour of this research, with goals of transparency, honesty and accountability being met (Darawsheh, 2014; Dodgson, 2019).

Dodgson (2019) illustrate the importance of describing the intersection of the contextual relationships between the researcher and the researched. Positionally, I am an insider in this study. I was diagnosed with endometriosis in my early 20's and understand the impact this disease has on my personal, social and work life, how it can impact one financially, and the emotional toll that living with this disease can take. I have suffered from pain since my late teenage years and accompanying this was then years of heartache and despair associated with infertility. I bring empathy and compassion into this research with a shared understanding of what it is like as a woman, a mother, a partner, and a female seeking a career, to live with this disease. I am passionate about addressing the stigma I see that accompanies this disease. I have been met with and understand the daily criticism, judgement, dismissal, and trivialisation from friends, family, and work colleagues that can occur when you cannot attend a social function at the last minute or have to leave work early and resort to the couch, or when you feel have to take another painkiller. I also understand the pain that can surface emotionally when some medical professionals ignore and dismiss the agony felt.

It is important to recognise that my insider status may contribute both positively and negatively to this research (Finefter-Rosenbluh, 2017). Right from first contact, the woman in this study were made aware of this insider status. I was transparent about this, and so when the information was shared with them about the research, I also shared a small piece of my journey. One of the advantages of being an insider is the acceptance given by the participants towards the researcher. This is particularly important as it gives the possibility of strong relationship between the participant and the researcher made up of trust, openness and good rapport. For the participants this could mean more willingness is given to disclose their attitudes and tell their own personal stories surrounding such a sensitive issue. It is believed that participants are more open with someone who they see as 'one of them' and thus the data collected is of a greater depth (Dwyer & Buckle, 2009; Hockey, 1993). Being an insider also brings prior knowledge, which can be helpful for when researching such a complex phenomenon such as stigma and endometriosis (Finefter-Rosenbluh, 2017; Hellawell, 2006). An outsider may not understand the context of endometriosis, such as certain language and terminology used, or have the background required to fully understand and make meaning of the disease and thus the experiences that the participants may describe (Hockey, 1993).

Being an insider can also have its disadvantages. Hockey (1993) describes how insiders can be "too familiar" (p. 202) and this has possibility to bring bias into the research. Berger (2015) and Dwyer and Buckle (2009) both explain how it is particularly important to not let the interview and questions used not be shaped by one's own familiarity with the phenomenon studied. Whilst I am familiar with endometriosis, the same cannot be said for my knowledge of stigma. When doing the literature review I realised how little I knew of the processes of stigma that

actually exist. Dwyer and Buckle (2009) describe how participants may hold back from giving true descriptions of their own experiences due to the preconception that the researcher already knows what these experiences are. Being aware of this is important, and throughout the interviews I used probing questions to really get the participants view, to make sure that the experiences described were unique to them.

During the interview and analysing process, a self-reflective journal was used to facilitate reflexivity (Smith et al., 2009). My own assumptions, emotions and reflections were noted and subjectivity examined. The journal gave me a chance to be critical of my own stance, as I noted all sorts of thoughts from agreements and disagreements I may have had with participants, to ideas I had for improvements, and any frustrations I may have had due to my own experiences. This journal helped me to distinguish and separate my own perceptions from those of the women that were interviewed. It was important that their own experiences were not clouded by my own judgements and that these women had a chance to tell their own story (Dwyer & Buckle, 2009). Whilst I am classed as an insider, my own experiences may be very different to others, so acknowledging this was important throughout. I am passionate about this topic, and in particular for being an advocate for others, and so to be this advocate, I sought to be honest, neutral and fair in my position as the researcher.

3.3.3 Interview Process

The semi structured interviews conducted in this study were all less than 60 minutes in duration. Initially it was thought that two interviews would be conducted, the first to explore the women's endometriosis journey and the second to investigate any stigma experiences, however it was decided to conduct just one interview, with a follow-up if needed. I felt it was important to keep to one, to allow the flow of the

conversation to continue, avoiding fragmentation, and also logistically conducting two interviews was difficult. No follow up interviews were needed with the participants used. One participant did email me further information that she wanted added to her narrative after the interview.

A pilot interview was used to test the appropriateness of the questions, gauging whether they were suitable and obtained the required information. This interview also gave me the opportunity to practice my interview skills, as it was my first-time conducting IPA. The interview guide (Appendix E) consisted of nine main questions, with four based around the women's own endometriosis journey, and five about their stigma experiences. Smith and Osborn (2008) note the importance of starting with more general questions to get the participants talking and feeling comfortable. In keeping with the flexible nature of IPA, not every question was asked to every participant, and the questions were not necessarily asked in a specific order (Smith et al., 2022). The interviews were really a conversation, where the women had an opportunity to tell their stories of stigmatisation in their way. The initial 'practice' interview was valuable as the question regarding structural stigma did not suit and was reworded. Additionally, feedback suggested I did not lead her into the interview gently and slowly. Therefore, the interview was changed so that the questions about menstruation were first, which then lead the participant to talk about their endo experiences from there.

The location of the interview was left to the participants to decide so that it was convenient for the participant and that they felt comfortable. Having a quiet, safe and uninterrupted place was also important (Alase, 2017; Smith et al., 2022; Smith & Osborn, 2008). Two of the participants came to my home for the interview,

while the other four participants conducted the interview over zoom with initially felt awkward however I did get used to this. I always started the interview with a little chat about myself and asked general questions about themselves. This was a nice way to begin the interview, settle any nerves, and make connections so that the participants felt more relaxed.

Finally, the interview was recorded and transcribed using two devices: using a tape recorder supplied by the school of psychology (Massey University) , and also using an app called Otter ai. on my phone. Before the interview, permission was granted from the participants, to allow for the recording and transcription of their interview. As the interviews were conducted, traditional 'note and pen' was used to write down any important non-verbal observations that were noticed.

3.3.4 Ethical Considerations

Due to the sensitive nature of this topic, and the potential for distress, a full ethics application was made through Massey University Northern committee. Approval was granted by the Ethics Committee at the Massey University. Ref number NOR 22/15.

Protecting Rights, Dignity, Confidentiality and Privacy

Human participant protection has always been a sacrosanct commitment of the researcher, but much more so for an IPA researcher (Alase, 2017). I made every effort to safeguard the study participants' rights, dignity, and privacy. The confidentiality of participants was never jeopardised (Alase, 2017; Smith et al., 2022). Participants who wished to be in the study were emailed a copy of the information sheet (Appendix A), the flyer which advertised the project (Appendix B), and the consent form (Appendix C). This was to ensure they knew what the project was about

and what was involved. They were encouraged to ask questions if needed. Once participants were confirmed a rough interview guide (Appendix D) was emailed out so that participants had an idea of the questions which would be asked. This was to reduce any shock or potential alarm. The participants were required to sign a written consent to be part of the study and for the interview to be recorded, before the interviewing process began. This was checked again verbally at the beginning of the interview. Participants were informed at all stages of the research, verbally and written, that they may withdraw their participation without penalty, up to two weeks after the transcripts were made. Whilst the study was voluntary, a $40 Hardy's health shop voucher was offered as a token of appreciation.

All information provided by the participants, as well as their written consent forms, were kept confidential and accessible only to me. The audiotapes and transcripts were stored in password protected encrypted devices. Electronic and written data will be stored for five years and the interview recordings disposed of once they are not needed. The participants were made aware of these processes. The anonymity and confidentiality of the participants was preserved by not revealing their names and identity in the data collection, analysis and reporting of the study findings. A pseudonym was used and I was the only person able to match the identity of the participants with the voice recordings. Privacy and confidentiality of the interview environment was managed with the participants choosing their desired place for the interview without access by outsiders. When the interview was conducted via zoom, security was ensured with only the participant having access to the zoom meeting. Once the interview was transcribed, I emailed the transcript, with the Transcript Release Form (Appendix F) to the participants where they were offered an opportunity to check over their transcripts. They then signed the

Transcript Release Form and emailed it back when they were happy with the transcript. A summary of findings was offered to all of the participants when the research was completed.

Minimising Harm to Participants

Unintended harm may be caused when talking about such sensitive issues regarding a person's experience of stigma related endometriosis (Smith et al., 2022). To alleviate any discomfort or embarrassment I began the interview with a non-formal chat acknowledging the personal and sensitive aspect of endometriosis. I shared some of my own personal journey briefly to build a rapport and addressed what we could do if the interview became upsetting in any way. The participants were advised that they could take breaks at any time, could skip questions or even stop the interview if it was causing them distress. Questions were asked in a calm, empathetic and caring way, and no judgement was given at the participants responses. Many of the participants showed visible signs of being upset during the interview. Some did comment on how the interview brought up traumatic memories and it made them realise just how much trauma they had been through. I always made sure the interview concluded with them in a calm state, and for three of the participants who displayed distress, I did follow up the interview with a text to check in and see how they were several hours later. Many of the participants thanked me for listening to their stories and they were excited to be part of the study and to potentially help others in the future. After the interview an information sheet (Appendix A) detailing support services was offered.

The emotion and distress displayed by the women did upset me. I checked in with my supervisor about this and debriefed without disclosing information with a friend. Hearing back from the participants about the control and power they had felt

doing the interview also helped process the emotional side. Emotions and thoughts were written in my reflective journal, and when needed I checked in with my supervisor to discuss any concerns.

Cultural Considerations

The research was conducted in a way so that it upheld the principles of Te Tiriti o Waitangi. Protection, participation and partnership were recognised and upheld to the best of my ability throughout the research. It is important Māori have an equitable opportunity for engagement in the research project, thus Māori women had the right to participate in this research. All participants were asked if they had any cultural traditions that they would like to have happen at the interview. Growing up in a small rural Māori community, and teaching in a rural school in Northland, as well as having many friends who are Māori and adhere to their customs, I was very familiar with any Māori protocols. I was aware of showing respect to Māori participants by using culturally responsive practices such as taking my shoes off, starting the interview with whakawhanaungatanga, offering kai, inviting support people to attend and closing with a karakia. It was not taken-for-granted that all Māori participants may want to follow this cultural protocol, so this was checked prior to the interview. I did interview two Māori participants, however prior to the interview they declined the request for any special cultural practices.

3.4 Data Analysis

The framework for IPA analysis described by Smith et al. (2022) was adopted in this study. I outline what I did at each stage of the framework.

Step 1: Reading and Reading Again

The first step of the IPA analysis described was the immersing of the researcher in the transcript of just one individual case. To get close to the participants' voice and engage in their world, the transcript was read and re-read many times whilst simultaneously listening to the audio-recordings and reading any observational notes taken during the interview (Smith et al., 2022).

Step 2: Exploratory Notes

The transcript was printed out and stuck onto very big card (Appendix G). Exploratory notes were things that stood out and were handwritten in the right-hand column of the transcript. These were separated into three categories: descriptive, linguistic and conceptual which reflected the different levels of interpretation associated with IPA (Smith & Nizza, 2022). To distinguish between the notes, a colour coding system was used; descriptive = black, linguistic = purple, conceptual= red. The descriptive notes were face value descriptions of things that mattered to the participant such as events, experiences, objects, locations etc. Linguistic notes were identified as anything that explored language, such as the use of language features (pronouns, verbs etc), phrases, terms, pauses, laughter, tone and repetitions. Any emotive words were also highlighted to help identify trends (Smith et al., 2022; Smith & Nizza, 2022).

Step 3: Developing Experiential Statements

Smith et al. (2022, p. 76) note the new terminology used for analysis in IPA. "Experiential statements" is the updated term used instead of "emergent themes" in the upcoming literature, as well as "Personal Experiential Themes (PET)" which is used to describe the clustering of experiential statements. The next part of the

analysis consisted of transforming the experiential statements into themes, which served to capture the nature of the experience, and the psychological processes associated (Smith & Nizza, 2022; Smith & Osborn, 2008). These experiential statements were handwritten in the left-hand column of the transcript.

Step 4: Searching for Connections across Experiential Statements

The experiential statements with accompanying quotes were printed, cut up and spread out on a big table, in a random order. From there, the statements were moved around to form clusters of statements that seemed to fit together or were similar in some way.

Step 5: Naming and Consolidating of Personal Experiential Themes (PET's)

Each of the clusters was assigned a title which summed up and described characteristics of the statements placed below. The clusters were lined up with the experiential statements and accompanying quotes and page numbers were underneath. This formed the participant's Personal Experiential Themes (PET) shown in Appendix H. It was important to have all of this information so that an evidence trail was formed and one could track back to the original data if need (Smith et al., 2022).

Step 6: Moving to the next Individual Case

The next step was to move on to the next individual case and repeat the process. It was important to remember the idiographic nature of this enquiry, which meant it was important to treat each case as its own entity. The first case and its findings were put aside and the new case was investigated with a clear and non-prejudice stance (Smith et al., 2022).

Step 7: Analysis across cases

Once all the individual cases had been analysed an iterative process was carried out. This process involved checking quotes and experiential statements were good representations of the individual cases and the checking that these could be linked back to the transcript. Sometimes the re-naming of themes occurred, or quotes were replaced in order to get a good representation. Once this check was completed patterns of similarities and differences were looked at across the PET's and the experiential statements. Again, the PET's and accompanying experiential statements were cut up and spread across the table, they were re-organised and moved, and sometimes re-named, as connections were found. This final analysis produced Group Experiential Themes (GET), (Appendix I), which were named to reflect the PET's and statements.

3.5 Approach to Validity and Quality

Qualitative research calls for its own evaluation, far different to quantitative research. Smith et al. (2022) describe a number of frameworks developed to identify quality and validity of qualitative studies, however given IPA has very specific defining features of phenomenology, hermeneutics and idiography, using a benchmark specific for IPA is important. In 2011, Smith developed a set of guidelines to evaluate the quality of IPA research developed and reviewed using studies associated with illness, and thus I deemed this the best one to use.

In practice I focused on endometriosis and stigma rather than dealing with journey to diagnosis and pain for example. I conducted a practice interview to help me refine my interviewing skills and techniques to gain rich descriptions. I was rigorous in my analysis with extracts within and across participants. I allowed myself

sufficient space to explore the emergent themes, and the aim of the analysis was to move beyond descriptions to interpretations. This required me to engage in the double hermeneutic process. Also, when analysing I paid attention to both similarities and uniqueness. And finally, the aim of the write up was a coherent narrative.

CHAPTER FOUR: Findings

4.1 Chapter Overview

The objective of this research project was to explore the stigmatisation experiences for women with endometriosis. This chapter outlines the findings of this study in three subsections (see Table 3).

Table 3: Summary of Group Experiential Themes and Sub-themes

	Theme	**Subthemes**
What's wrong with me?	Initial Symptoms	Early menstruation experiences
		The traumatic nature of abnormal symptoms
		Normalisation of abnormal symptoms
	Trying to get answers	Lack of knowledge
		Medical professional's reactions
		The public health system
		Reactions from others
		Internalising the pain and stigma
Finally, a diagnosis	The reluctance to diagnose	
	The value of a diagnosis	
What now: living with endometriosis?	Living with endo is hard	Endo rules your life
	The perpetuation of stigma	

Six women from all over New Zealand participated in the study. They ranged between 28 and 50 years old, and all of them had had a diagnosis of endometriosis for over a year. The age of symptom onset was when the women first experienced severe abnormal pain. Notably while Tee always had extremely heavy periods, the pain only began when she was 28 years so she was the oldest to get diagnosed. Vanessa and Gloria had the shortest diagnostic delays with Vanessa being the only

participant in her twenties. A summary of the participants demographics are presented in Table 4.

Table 4: Demographics of Participants

Participant	Ethnicity	Age	Currently Residing	Age of Symptom onset	Age of Diagnosis	Diagnostic Delay (years)
Rachel	European	50	Kerikeri	14	32	18
Magda	European	38	Takaka	10	33	23
Sarah	European	41	New Plymouth	13	40	27
Vanessa	European	28	Christchurch	24	27	3
Gloria	European	41	Kerikeri	15	18	3
Tee	Māori	48	Snells Beach	28	36	8
Average		41		17.3	31	13.6

4.2 What's wrong with me?

This section of findings details the women reflections on their diagnostic journey, particularly the difficulties they faced to get their diagnoses. Their narratives are used throughout this section to capture emotions and experiences Interlaced with both these themes is stigma; intrinsically these stigmatisation experiences go hand in hand with emotional distress.

4.3 Initial Symptoms

This theme captures their experiences with early menstruation, the traumatic nature of unexpected menstrual pain and bleeding, the women's own normalisation associated with menstrual etiquette and the lack of knowledge or awareness that they and others had about their own disease.

4.3.1 Menstruation experiences

"You grow up thinking it's a dirty thing that you can't talk about." (Rachel)

Most of the women experienced their first period at a young age of 10-12 years old. There were individual differences between the time of their first period and the time at which symptoms became unbearable; for some heavy bleeding and/or pain started very quickly after their first menses, while others it came on later after their first child was born, or when they ceased taking the contraceptive pill. There was an element of surprise and alarm for most women when they received their first period. They attributed this to a lack of knowledge and stigma around menstruation.

The reality of periods for the participants was shocking and traumatic. In addition, the women did not expect their periods to be accompanied by extreme pain, heavy bleeding, or even vomiting and fever, and these symptoms came as surprise. As well as being shocked, these unexpected symptoms led to distress and stress.

"I got my first period really young I think I was 12. It was my first year of intermediate and pretty rapidly started having, really heavy. periods. And like to the point where I had to get picked up from school and nothing was, yeah, you know, pads and tampons weren't working and lots of pain quite early on. " (Gloria)

"I remember one particular episode when I was at work because I worked at Macca's and I was in agony and had to go to the bathroom and I was vomiting, you know, feverish and you know, really stressed." (Rachel)

Most of the women interviewed spoke about the lack of knowledge and conversations they had had about periods during their adolescence. Most got their knowledge of menstruation either through health classes school, older friends, or were self-taught. The limited conversations that had existed between the women and their mothers and these often consisted only of mechanical explanations, such as how to use pads or tampons. Conversations between the women and their friends was surprisingly scarce or non-existent. Two of the participants had older sisters and mothers but, they had never seen any evidence that they lived with other women who menstruated. Menstruation was something that was not spoken about at all at home, and any evidence of it, including sanitary items, were hidden.

> *"I didn't even know much about periods to be honest"… "It was just it was a hidden thing in those days. Because I had no concept of mum maybe having a period or when my stepsister who was older did. My stepsister was older, no, she'd never talked about it. So, I guess I just thought that that was the thing to do. Yeah. "…. "No, I can't remember talking about it with friends." (Rachel)*

It could be that sex education and discourses around menstruation were not as openly discussed due to the age of the participants (for example, the oldest participant is now 50 years and got her period at age 14). The women with teenage daughters mentioned they made a real effort to break this taboo, creating an environment of open communication about menstruation. Despite this, the women still felt currently that menstruation should be kept from men. Magda (38 years) refrained from discussing menstruation in front of men, including her own father, or male friends.

"Even my dad, I still just don't feel that comfortable talking about, I guess it's probably from me, or maybe my like, kind of over mindfulness that they're uncomfortable." (Magda)

The menstrual etiquette practised in Rachel's home and with her friends was one of concealment where periods, period symptoms, and products were not discussed which had a lasting effect on her own perception of menstruation. Rachel said *"You felt like it was a dirty thing. And that's something that you had to hide and keep to yourself."* When she had her period she said, *"I felt dirty and more insular."* It is unclear whether she thought menstruation was something dirty, or unclean, and thus must be hidden, or perhaps because it was hidden, it must be classed as dirty, and seen as an 'abomination of the body'. Goffman's (1963) notion of stigma is that "abominations of the body" (p. 4), can tarnish one's identity or appearance marking them as having undesirable differentness. This leads them to hide these abominations in fear of being stigmatised. Rachel retreated into herself and hid her period, and instead of seeking help when her period was extremely painful, the stigma surrounding menstruation contributed to a poorer sense of self and may have led to delays in seeking help. My findings regarding menstruation reflect those of other research (e.g. Hudelist et al. 2012), where families who did not speak about menstruation during adolescence, and/or thought it to be a negative event, contributed to attitudes of shame around menstruation. This stigma and shame also meant that women regarded dysmenorrhea to be something a women should put up with, and so took much longer to communicate that they had issues and seek advice.

4.3.2 The traumatic nature of abnormal menstruation symptoms

"I'm crawling out of my skin, laying in the fetal position, wanting to die, wanting to vomit." (Sarah)

All of the women recalled very clear and significant episodes of severe pain prior to being diagnosed with endometriosis. One thing that stood out clearly was the fear that accompanied this physical pain. The following excerpts show examples of the severity of pain felt by the women and why the experiences are framed as traumatic and shocking:

"It was like the rug got pulled out from underneath me, it was like what the heck is going on?" (Magda)

"I actually thought I was having a miscarriage because I was in so much like pain…. I was in a state." (Sarah)

"It just felt like someone drove a knife through my like pelvic area. I just like bent over and cried out in pain." (Vanessa)

Participants also had a fear of the unknown, and lack of control in regard to how bad the pain could get, as well as a fear of not knowing what to do, and how to cope with the level of pain they were experiencing. Both Magda and Gloria experienced pain so bad, they were fearful of dying during these episodes.

"I would have such bad pain that I literally thought like, well, if I'm going to the toilet, I'd bring my phone because I thought I'll just probably die and I should tell somebody I'm dying so they know, because I just thought nobody can help me in this much pain and not die." (Magda)

For Tee her pain meant she was unable to show affection to her children, and this added to her fear. She had concerns about her ability to care for them and how this would affect her relationship with them later in life.

"I was scared that I couldn't even hug them because I was in such pain and that went on for about six years."(Tee)

For Rachel, a significant amount of her fear stemmed from feeling like she could not share her pain with others, leaving her alone and isolated. She realised that her concealment of pain was directly related to the etiquette of menstruation that she had adopted.

"Part of that was not just the pain, but the fact that you had to suck it in and keep it to yourself." ..."It's to do with it being about your reproductive system, periods. You know, you grow up thinking it's a dirty thing that you can't talk about and so then if there's something wrong in the area, then yeah, you definitely don't want to go in there talking about that. And no one wants to hear that." (Rachel)

Heavy bleeding was also a common symptom which brought about huge amounts of distress for the women. There was constant fear that they would leak blood during their period, as for some, sanitary items were insufficient to control the flow of blood. Several of the women bleed throughout their cycle, which also added stress as they feared that they would be unprepared and leak. Seear (2009) found similar behaviours where distress was associated with fear of leaking blood. Menstrual blood can be considered an "abomination" (Johnston-Robledo & Chrisler, 2013, p. 182) and so women in this study and that of Seear's, feared enormously that they would be classed as discreditable and stigmatised if any signs of menstrual blood were exposed.

These episodes of pain and bleeding had been so severe for the participants, that they were clearly engrained in their memories, and framed as traumatic and shocking. All six women shared very distinct traumatic episodes from the past that

left a lasting emotional effect on them and the process of retelling their experiences was traumatic and distressing and difficult to hear at times. Some of the women were very tearful during the interview, often having to stop and recollect themselves. The others had a change in volume or tempo of their voices when recalling very vivid traumatic events. One woman spent the majority of the interview sobbing as she relived her story. For example, Gloria reflected on her journey during the interview and said "*It makes me feel anxious just talking about it. I feel quite anxious. Yeah, like just going through it, it's like it's quite traumatic*." Rachel felt her trauma was not just associated with pain, but the situation of not knowing what was happening, and feeling like she had to hide her pain. She said, "*I think the trauma was to do with a combination of the pain and been uninformed and having to carry on as normal*." Rachel's trauma was also very clearly linked to anticipated stigma, with the need she felt to conceal her symptoms.

The level of trauma and distress was somewhat unexpected but highlights how trauma can live in the body, be felt and relived (Straussner & Calnan, 2014). It should also be noted that for some, the enormity of their symptoms and the trauma they had been through only become apparent to them as their story was told. Whilst this aligned with the purpose of IPA which is to explore and understand how a participant is making sense of a lived experience (Smith et al., 2022), it is important to note that telling a story can bring up things that were not considered prior to consenting. I feel that even though it was distressing, I did get the impression the participants felt a sense of justice and power to tell their stories. They wanted to be able to make change for those just beginning in their endometriosis journey.

Stigma contributed to both the hidden nature of menstruation and the lack of education about abnormal menstruation symptoms which contributed to poor

psychological health and trauma. The stigma meant they had no gauge for what was abnormal, meaning the women lived with their own pain and bleeding for many unnecessary years before seeking help and diagnosis. The inability to not being able to discuss menstruation (Griffith, 2017) plus the secrecy associated with menstruation all lead to a lack of conversation about periods, even with friends. This all lead to concealing their own menstruation from others, even in their family home. Concern over heavy bleeding illustrated menstrual blood is regarded as a stigmatising mark which fits Goffman's three categories of stigma: the "abominations of the body," the "blemishes of individual character," and social labels associated with social groups that are marginalised (Goffman, 1963, p . 4). Menstruation has an additional factor with it being a symbol of femaleness. According to Laws (1990), the concealment women adopt regarding menstruation is connected to the status difference between males and females with avoidance of anything associated with menstruation by women, as a way to avoid the possible discreditation and further marginalisation. Matías-González et al. (2021), Seear (2009) and Johnston-Robledo and Chrisler (2013) all noted the connection between menstruation and endometriosis and believe the stigmatised status of menstruation and the communication taboo around the issue is what contributes to the lack of awareness of this disease.

4.3.3 Normalisation of abnormal menstruation symptoms

"I would have had it in my head that this is normal."(Rachel)

A lack of conversations about periods meant a lack of conversation about pain, and thus awareness about abnormal period pain. Because of this the participants, as well as their friends and families, normalised the pain and bleeding that they

experienced. Magda thought everyone else had the same severe pain as her and could not comprehend why they were silent about it. These ideas resulted in her concealing her pain. She did not want to appear weak and since others did not share their pain they must have been stronger.

> *"So the fact that I'm having a response that other people can cope with. I just remember thinking I can't understand how all of these women are having periods like this. And like, are we really not talking about how awful this is?"... "Everybody else is having this and who wants to be a whinge?" (Magda)*

Magda's own perception was also clouded by her mother's reaction to her pain. The combination of seeing her own Mother suffer during her period, and her mother's flippancy about her own pain, also normalised her pain. She remembers her mother saying *"Some people are like that. It's okay. You'll be okay"*. *My mom would throw up a, you know, she would be really unwell. And so, I knew that, but I never knew that that wasn't normal."*

For Rachel, her mother's reaction when she had a severe attack of pain at work one day, also shaped her own normalisation. She felt the lack of urgency her mother showed downplayed her pain. For Magda and Gloria, it was not until their friends witnessed them in severe distress and pain, and verbalised that it was not normal to them, that they realised themselves it was not the norm. Magda presented at the emergency department with her friend who argued with the doctor that having to have morphine for period pain was not normal. For Gloria, her turning moment was when she had passed out in pain at her flat and her flatmates expressed that this was not normal.

Stigma contributed all aspects of this theme of initial symptoms. The hidden nature of menstruation and the lack of education about abnormal menstruation symptoms contributed to poor psychological health and a delay in diagnosis. Normalisation of period pain by the participants own mothers also influenced their help seeking behaviours. This was seen also in the study by Hawkey et al. (2022) and Hudelist et al. (2012) where normalisation of period pain by participants, as well as negative attitudes surrounding menstruation and menstrual concealment by mothers, contributed to delays in a diagnosis of endometriosis. Griffith (2017) found similar results with participants also adopting secrecy and concealment with menstruation. These findings suggest the stigmatised status of menstruation whereby menstrual blood is regarded as a stigmatising mark (Goffman, 1963) is still influencing women in Aotearoa. There is a clear connection between menstruation and endometriosis this study supports that the stigmatised status of menstruation and the communication taboo around the issue is contributing to a lack of awareness of endometriosis, delays in help seeking, and consequently diagnosis, for women in Aotearoa.

4.4 Trying to Get Answers

This theme captures the stigmatisation within the experiences the participants faced on their quest to get answers. A lack of knowledge about endometriosis from the medical professionals was apparent, which lead to poor interactions and negative experiences in the public health system. The women were faced with reactions from friends and family which contributed to their internalisation of shame and embarrassment, leading to isolation and concealment. The structural and public stigma impacted the women's psychological health leading to internalised stigma, delaying help seeking to find the much-needed answers.

4.4.1. Lack of knowledge of Endometriosis

"It was just such medical jargon to me, it meant nothing. And just this random long word I'll never be able to pronounce again."(Magda)

All of the women noted a lack of awareness and general knowledge surrounding endometriosis. They had no knowledge of it as an adolescent and believed their own mothers had never heard of it either. There was disbelief that when they did finally talk to doctors about their symptoms that there was often no mention of endometriosis. All women believed this was an enormous barrier to them receiving their diagnosis in a timely manner. They felt the doctors had minimal knowledge about the condition and thus it was something not even thought about during their consultations. Vanessa, Sarah, Tee and Rachel all had to present to multiple doctors before the possibility of endometriosis was even mentioned to them. Vanessa saw six different doctors who did not even mention the possibility of endometriosis to her yet it only took a very quick consult with the gynaecologist who believed straight away that she had endometriosis.

"Never something I was mentioned to you by any of my doctors…..So that's also surprising because it seems it's so common that you know a female doctor maybe hasn't come across this knowing someone who has that it was even kind of put forward as maybe a possibility but yes, I saw my specialist. He was great. It was such a quick appointment because he just sort of knew straight away and then he actually booked me in for surgery."(Vanessa)

Tee, Magda and Vanessa all heard about endometriosis for the first time from a gynaecologist. They had not seen any advertising about the condition or knew anyone with it prior to this. For Magda, the concept was so foreign she was quite bewildered at the suggestion of a medical term she had no idea about. These women

believed that if they had known about endo they certainly would have presented to the doctor much earlier. Sarah and Rachel learned about endometriosis from friends who had it. They said it seemed to be something that none of their numerous doctors mentioned or considered and they were the ones to suggest that they had symptoms which matched endometriosis.

The findings from this study corresponded with the ideas of As-Sanie et al. (2019) who proposed that it was a lack of disease awareness and education involving health care providers which contributed to a diagnostic delay for women with endometriosis. On average women with abnormal symptoms took seven visits to their doctors, before a referral was made to specialist care (As-Sanie et al. (2019). In this study all of the women reported seeing many different doctors over numerous years until their concerns were formalised. The irony of this was it was such a difficult journey to be referred to a gynaecologist, yet once there, endometriosis was suspected very quickly within their consultation. This statistic follows similar patterns to the research conducted by Tewhaiti-Smith et al. (2022), on New Zealand women, where there was an average of 4.8 doctors seen before a diagnosis was made.

4.4.2. Medical Professional Reactions

" For years and years and years, doctors would just say to me all this is normal."

(Sarah)

Stigma of menstrual and pelvic pain by medical professionals is contributing to women feeling silenced and dismissed (Hudson, 2022; Matías-González et al., 2021; Seear, 2009). These same reactions of dismissal, trivialisation, normalisation and silencing of pain by medical professionals were experienced by the participants in

this study. Presenting to a medical professional for help regarding possibly 'normal' pain and bleeding associated with the sensitive and personal topic of menstruation, took a lot of courage for the women. When this was commonly met with negative reactions this left the women feeling upset, alone, angry and powerless. The following excerpts highlight the emotional impact of the reactions of the medical professionals.

"My feeling was that there was no concern. And it was just a bugger and something I had to put up with for the rest of my life that I happen to have painful periods. And almost like there was something wrong with me for that. So, I mean, it doesn't go away." (Rachel)

"I specifically remember her laughing at me and saying I would know if I had endometriosis. So, yeah, literally laughed in my face… I remember how impacted I was by that conversation, that's always stayed with me. And you know, it affected my trust of the medical system. Absolutely. You never heal from something like that." (Rachel)

"The first gynaecologist basically just said to me, oh just go on the pill and it's not a big deal and just like totally dismissive."(Sarah)

The women all presented to multiple doctors on numerous occasions, over a long period of time, before they felt like they were listened to. For Rachel the reactions she received meant she refrained from seeking further help for another ten years, and only because she could not get pregnant. For Sarah, she went to six different doctors and three gynaecologists before she was taken seriously and received a diagnosis 27 years after her first symptoms began. She spoke about many occasions where she was dismissed by the doctors, and her symptoms were trivialised and all she was offered was Brufen, Panadol, or to go on the pill. A very

common reaction from GP's was to prescribe birth control. Sarah felt this was a way to silence her concerns instead of directly addressing them. Sarah reflected this 'band-aid' solution actually prevented them from addressing the disease in its early stages of progression. Sarah also spoke about how she turned up in the emergency department one night and felt like her pain was trivialised. She felt the staff were "nonchalant" and did not seem to take her concerns seriously. She compared how she would have been treated if she had of presented in pain for a broken leg which illustrates how stigmatised pelvic pain is treated.

> *"Just like not taking it seriously not being like, you know, if you went in there and you had broken your leg or something like you would be given the good drugs, you'd be attended to straightaway." (Sarah)*

For Magda, it took many doctors, many emergency departments visits and many horrific incidences of pain over a span of 20 years, until she was listened to. She recalled a few particularly traumatic instances. At 13 her pain was dismissed by her doctor and she was put on the pill; she felt more to control her acne, instead of the pain she presented with. At 15 she experienced a ruptured cyst, again her pain was normalised by the doctor as the doctor just said *"that just happens sometimes. And your kind of yeah, you're fine enough, you know." (Magda).* All these types of instances meant that Magda did not seek further help for another 10 years.

> *"A couple of times I ended up in emergency here. I had a friend that was with me during this saying 'this is definitely not right', and even the doctor, I had morphine put up my bum because I couldn't hold anything down. And he was like, 'Well, this is relatively normal."* (Magda)

For some participants even the gynaecologists contributed to dismissal and distress. Gloria recalls, "*I got sent to a gynaecologist - he told me my pain was just*

normal and I just needed to find a way to deal with having a period." No further solution was offered and it was only as Gloria's mother persisted that Gloria eventually obtained a diagnosis of endometriosis at 18, six years after her symptoms began.

The lack of voice and input the women had with their own treatment plans was another way they were silenced. Both Gloria and Tee spoke about their desires to get hysterectomy's years earlier, however these ideas were quickly dismissed by the health professionals at the time. Looking back, they both displayed guilt and sadness that they had not advocated more for what they wanted. Tee can no longer have any more operations due to her risk of bleeding out, and with her form of aggressive endometriosis which grows throughout her whole body, she is left with no real treatment options. For Gloria if she had of had her hysterectomy when requested her further issues (including her misplaced IUD, ectopic pregnancy and uterine tumour) which all caused her years of excruciating pain and psychological distress would have been avoided.

Many of the women felt frustration, anger, and helplessness when they reflected on the dismissal they felt by medical professionals which was associated with their age, gender or socio-economic status. For the women who experienced their first symptoms in their teens or early 20's, they felt they were not taken seriously due to their age, and because of this were not in a position to question the doctors due to power imbalances.

"You know, how often you know, how many times do you go and pursue especially as a teen, you know, female, saying, hey, something doesn't seem right. And them saying, well, it is. So, you just believe them." (Magda)

The women also felt they could not question the medical decisions due to being less educated than the doctors as it was disrespectful, and that they were not in a position to do so. When Magda did try and voice her opinion, she was met with a threatening undertone by her doctor when she said she did not want to go on birth control.

"Oh, well, you can go on birth control. And I said, well, I'm not thinking about birth control and she said, okay, well if you want to live a life of pain, then do that." (Magda)

For Gloria she felt her gynaecologist dismissed her for a number of reasons. Firstly, she felt he disliked women. This was also agreed upon by her own GP who knew the specialist. She also believed the gynaecologist felt threatened when a student doctor questioned him about his dismissal of her symptoms and she also felt he disliked the fact that she was a nurse.

"Honestly, he should not be practicing. He hates women. I just felt like he hated me. From the moment I walked down, he decided he'd already decided what was there was nothing wrong with me….I don't know why I just feel like he doesn't like women and I went and cried in the bathroom for like an hour." ..."He just didn't like that I was a nurse and then I was like health educated or something. He was so rude to me. I left and I cried."..."He didn't like that the student questioned him either. And so, then he put his foot down and he said to me, I'm taking you off the gyno list and I pretty much don't want to see you again." (Gloria)

Magda and Gloria felt they were unfairly labelled as having anxiety or depression issues when they went to the doctor concerned about their endometriosis symptoms. For Gloria, this concerned her deeply as a generalised

anxiety label was put on her medical record and she felt that every time she went to the doctor she was judged and brushed off as being anxious.

"I've had doctors tell me I have generalized anxiety, and I should go and see somebody for that and go on medication. And that's because I went with pain and symptoms, and worried. And then as soon as somebody says you're anxious, it's on your record, and then every time you go in there, ahhh….I think that was the worst for me .There was a real long time there where it really affected me and affected my work." (Gloria)

Magda was also deeply affected by the doctor suggesting she was depressed because she could not go out and do day-to-day activities due to her pain. She felt judged by the doctor and labelled as being "defiant" or "difficult" because she was not willing to take the anti-depressants that she was offered.

The women were left very despondent, unsure and even questioned themselves because of these reactions from their doctors. Both Gloria and Magda no longer felt comfortable seeking help from them. Gloria found it ironic that she felt she probably does have anxiety now as a result of not being listened to.

"I probably do have anxiety now. Because, you know I think people with endo do have anxiety because it creates this whole thing where you're not listened to. And you question yourself and you're told it's all in your head. And then you start to think, oh, am I crazy? And I think that's probably been one of the hardest things for me is like, Am I making it up? Am I attention seeking?" (Gloria)

These narratives of the women show specific examples of conversations with medical professionals which had deeply entrenched undertones of dismissal in them. The women's abnormal symptoms were normalised, dismissed and trivialised due to stigma around menstrual pain and power imbalances between doctors and patients.

Women were silenced, given very little agency in decision making or framed as anxious, depressed or deviant patients. These experiences had a significant impact on the women's ability to reach a diagnosis in a timely manner, impacted trust of the medical profession, and perpetuated the cycle of silence. The women were left rejected, confused, despondent and in despair after being told by numerous doctors that what they were experiencing was normal. This is traumatic and leads to distress – all of which is avoidable if menstrual stigma was challenged and medical professionals were properly educated.

4.4.3. The Public Health System

"I feel like all my public health experiences have been really negative. And all my private health experiences have been really positive." (Gloria)

In the context of healthcare, structural stigmatisation refers to institutional policies, cultural norms, and organisational practises that restrict consumers' access to health services, quality of care and treatment, and ability to attain optimum health and well-being (Klein et al., 2021). A major finding in this study was the emotional distress the women experienced that stemmed from structural stigmatisation experiences in the public health system. Of the six women, Tee was the only participant who thought her journey in the public health system was adequate. For the other five women, resentment, disappointment and anger were emotions that surfaced when they told their stories.

The study showed that access to care was a huge problem for the women. Three of the women lived rurally, or in smaller towns where they did not have many options in the way of gynaecologists to choose from. The limited options meant if they had exhausted the opinions of the specialists in their area, they had no other

options. Sarah lives in New Plymouth and she felt the quality of her care was compromised as the better specialists were located in the main cities such as Auckland or Hamilton. She had known of friends who had to 'cheat the system' and use other people's addresses to receive the care they needed.

As mentioned previously, Gloria hit rock bottom when the one gynaecologist in her area refused to believe anything was wrong. After pleading with him to investigate her pain, he told her he was taking her off the list and that he did not want to see her again. Left in daily debilitating pain, she had no option but to go private, which she could not afford. Financial concern played a huge part in the women's journey. For some they could not access private insurance due to their endometriosis being a pre-existing medical condition, and so they had no option but to pay for necessary care themselves.

> *"I was really suffering for a while there and trying to go through the public system because I couldn't afford to go privately, you know, had kids and family and all that, and I knew if I went private, it's going to cost me a shit load of money. And like no one is going to insure me. I've already had the diagnosis young and then all the other issues." (Gloria)*

Legislations also prevented women from receiving adequate care and treatments. Due to a change in legislation, the painkillers Rachel had been using to manage her endometriosis symptom became restricted which meant she now had to talk with the pharmacist every time she needed it. This caused a huge amount of anxiety for her as she felt she could not disclose it was for endometriosis as she felt she would be judged. Instead, she claimed they were for other injuries to obtain them. The fear and anxiety associated with obtaining the pain relief Rachel needed

was felt so intensely that she started to send her husband in with a fake illness, or she drove an hour and a half to a different town to get them.

"I don't know why I just didn't say I've have got endometriosis but I didn't want them to think that I was a wus, because I needed hitting painkillers for period pain. Or that it wasn't justified, that I get them and then you know, have to go through a process of talking to someone, so it's just avoiding that. Yeah. So, I didn't even have decent painkillers that I knew that I needed…. It made me feel a bit like a criminal." (Rachel)

The long waiting lists that the women experienced to see specialists or to have surgery were also met with frustration and prevented them from receiving a diagnosis sooner. Four of the women shifted between both the public and private systems to gain a quicker diagnosis. For Magda who could not afford private care, she saw her specialist in a private consultation, knowing she also worked in the public, and then went onto the public surgical wait list. Gloria's story was the most shocking one involving waiting times in the public sector. After two and a half years of excruciating pain and being dismissed by the one gynaecologist in the area, Gloria paid to get an ultrasound privately. It was lucky she did as it was then then they found a massive tumour which had a chance of being cancerous. To her dismay, they refused to put her on the urgent list, and she was told it would be a 6-12 month wait and was encouraged to go privately to receive the care she needed. In despair, Gloria was forced to borrow $35,000 off family and pay for a private operation.

"Had I waited six months. I reckon I wouldn't have been able to walk. I could hardly walk. I was waddling. I had so much pressure. It was so awful. By the time I had even had my private surgery. It was awful. Yeah. Like so awful. And I had to stop working. It ruined my career." ..."And the tumour, by the time they

got that out I was 7 and half months pregnant, it was massive. Yeah, like he said he was surprised at how massive it was when he opened me up. And they thought it was cancerous because it was so aggressive." ..."And then oh yeah the funny thing is an April this year, so my surgery was almost two years ago. Now. So, in April this year, I got a message saying they'd like to see me at the preassessment clinic." (Gloria)

The women were also concerned about the skill level of the medical professionals they had in the public system. There was concern that the gynaecologists they were referred to in the public sector were not specialised in the field of endometriosis. Magda worried *"The fact that they have regular gynaecologist doing surgeries on people with endometriosis is just like saying you're gonna have your Dentists deal with breast cancer."* Magda specifically sought an experienced gynaecologist who specialised in endometriosis in the private sector, with the aim to have her do her surgery in the public sector. She experienced huge fear, concern and anxiety on the day of her surgery when she found her surgeon was replaced with a younger, less experienced one. She went into the operation extremely stressed as she knew the importance of having a specialist in the field of endometriosis and feared the new surgeon had not read her notes and did not know her symptom history well enough. Unfortunately, the operation was complex, and even though another surgeon was called in to help, Magda was left with nerve damage which forced her to quit her job. Despite the two years stand down period for private health insurance she quickly joined up and lived in unbearable pain for that time.

"And I remember like, my mom was like, Magda, why are you going to sit around waiting for two years, you know, and I was like, I have no other choice, what else can I do? Like I don't know what else to do. I have to find a way to live

a normal life again. Not that it was normal. But now I was just incapacitated all the time, it was just to a degree where I couldn't function anymore." (Magda)

Three of the women reflected on their stays in a public hospital as being a very negative experience and highly traumatic. Magda found the nursing staff to be rude and lack understanding and care. The pain that she experienced was excruciating and so she was given morphine by the nurse. When it continued she was offered more, however at this stage Magda had such a fear that she was going to die if she fell asleep, that she declined it. The reactions of the nurse then were entirely inappropriate as she was completely dismissed and not given any dinner. At this stage it had been 24 hours since she had had her surgery, with nothing to eat.

"*I had really awful stomach cramps and I kept buzzing and they said, "We'll give you more morphine." They just kept wanting to give morphine and I was like, I don't feel like I should have any morphine. I'm feeling like I have to remind myself to breathe. And I was scared to fall asleep because I felt like I would die*."

..."*She got pissed off that I said I didn't want that and stormed out and knocked the wheelchair that was out from underneath me. I didn't see anybody for probably hours after that." (Magda)*

Rachel's negative experience in hospital and in the public health system was so heavily imprinted on her, that although it was recommended she further surgery, she refused, simply because it would have been in the public system. For Gloria, working in the public system as a nurse was particularly difficult for her emotionally as she struggled with working in a system she felt had let her down all of these years. It disappointed her and as she saw others also being not listened to, and it concerned her that if she had this treatment as an educated person, how was it for others?

Eventually she had lost so much faith in the public health system she worked for, that she left it and gave up her career as a nurse.

"That's the thing that annoys me too, with my nursing education and stuff. It's not from lack of access, people are accessing but not getting referred, they're not getting treatment." ... You see it in Māori health all the time and they say, oh, you know, Māori people aren't accessing it. But yeah they do. They just don't get listened to." (Gloria)

Tee was the only participant to speak favourably of the gynaecologist team and doctors she had in the public system. She did, however, receive a real fright when one night a nurse was asking her to leave as they needed her bed. Tee put her foot down and told the nurse she was not going home as she felt unwell. That night she woke to her bed saturated with blood as a haematoma had formed. If she had been discharged she would have died.

This structural stigma experienced not only contributed to a delay in diagnosis for these women, but it also contributed to a huge amount of trauma, and poor emotional health.

"So, I feel really let down by the system. Like, right through my life." ..."I didn't trust them at all. I just couldn't, lost all faith. I'd rather spend all my money (on private health care)." (Gloria)

"I am not a fan of the public system, bloody terrible." (Sarah)

"It's like just kind of really sucks knowing you're just beating your head against the wall to get support especially in the public system." (Magda)

The following words sum up the women's thoughts on their journey though the public health system: "let down", "really negative", "lost all faith", "not a fan", "bad". These findings suggest that the structural stigma that is embedded in our public

health system worsens health outcomes for women with endometriosis. The narratives show that the stigma experienced deterred these women from accessing and using healthcare services that they required and from receiving a high quality of care. The structural stigma experienced fostered unmet needs, treatment withdrawal and delayed help seeking for these women; impinging on their rights to receive quality health care. It was clear that access to good quality care and treatment was compromised due to the structural stigmas that are embedded in our healthcare systems in Aotearoa, New Zealand. Livingston (2020) describes how it is both access and quality of care that are focal points of the literature on structural stigma in health-care systems. Access to and use of health care services are impacted by a multitude of variables, which are often classified into person, practitioner, and system domains. The person and practitioner domains are associated with their respective attitudes, skills, behaviours, and resources. The system domain includes structural components including institutional rules, processes, and resource allocation (Livingston, 2020). The findings in this study indicated that these women had limited access to care owing to practitioner and system factors. Access to care and treatment was hindered by insufficient practitioner expertise, inadequate resources, and system policies. The women experienced frustrations about the lack of GP and nursing knowledge, lack of available specialists who provide specialised care, and long wating lists.

This research also identified inadequate care for women with endometriosis in the public health system. When practitioners participate in stigmatising activities, they are not just actors of the health-care system and major structural components of organisations and systems, but also agents of structural stigma (Livingston, 2020). Substandard clinical practises among health care professionals include diagnostic and

treatment overshadowing, uncaring and unhelpful behaviours, authoritarian and non-collaborative approaches, the withholding of information and services, employing task-oriented and depersonalised methods, and excluding or rejecting individuals from receiving services (Livingston, 2020). On their path to receiving a diagnosis, each of the women in this research encountered some, if not all, of these factors. They were dismissed, judged, labelled, refused care, shown a lack of care, and their own opinions regarding their treatment plans were dismissed by medical professionals.

4.4.4. Reactions from others

"People think you're crazy or hysterical, or anxious, or you just get labelled as a drama queen."(Gloria)

Throughout their journey to gaining a diagnosis, the women were very sensitive to the reactions they received from others, whether it be family, friends or colleagues. Already experiencing a raft of emotional distress ranging from fear and despondency to anger and bewilderment, mainly due to reactions from medical professionals and the public health system, further stigmatisation from those closest to them took a huge emotional toll. Stigmatisation in a subtle non-verbal way was experienced much more than in an outspoken verbal way. The women seemed to have a real fear of being labelled or judged as being 'lazy', or 'weak' or as 'complainers', yet none of them gave specific details of being told verbally that they were these things. From this I inferred that subtle undertones of disapproval from others must have occurred in the form of body language, gestures or facial expressions. The following narratives highlight the women's experiences of stigmatisation:

"I didn't want them to feel like I was less of a person I think, or and I didn't want them to yeah, I think it's possibly more than I didn't want him to think that I was a whiner. Like a complainer, or weak. ... I didn't want people judging me by the fact that I had this illness that they didn't understand, and quite possibly thought that I was overreacting about because they don't understand unless you experience it yourself. Or judging me for the fact that I used it as an excuse for things or that I had no tolerance of pain or that I any of that or that I was a negative person." (Rachel)

"Everybody judges. Like family and friends. Just everybody." ... "I didn't like the judgment of the fact that you know, I appear lazy because of fatigue" ... " So, for my birthday all I wanted was for them (parents) to join me and read the articles I was like, just understand me and the severity because it's kind of hard sometimes." (Magda)

"I just really early on learned to just ignore it. You know, like, because I didn't like the judgment of the fact that you know, I appear lazy because of fatigue. I just was hard on myself like, yeah, I must just be lazy or weak of something. And I hated the idea of being weak…. I liked being tough. So, this didn't fall in line with my identity."(Magda)

The lack of understanding from family and friends was felt to be linked more to the lack of awareness and knowledge of the 'mysterious' disease, instead of a lack of care. Because the disease had rarely been heard of, and little information was known, the women felt the disease, and the symptoms they were experiencing were both dismissed. Unfortunately, the women feared the negative judgements from their friends and family to such a degree, that they stopped talking about their illness. Instead, they hid it from others, often avoiding people by refraining from attending

social functions and for Gloria and Magda, they even quit their jobs. This led to the women feeling more alone, isolated and powerless. The women felt lost in feelings of despondency and powerlessness and thinking there was nothing they could do, they stopped seeking help. This contributed to a delay in diagnosis for four of the women.

The invisible nature of the disease was most challenging for the women as it meant physically the women often looked like there was nothing wrong so people took their illness on face value. The women felt they could not disclose their pain symptoms to others because it was not visible to others, so there was a fear that they were malingering or 'faking' their pain. Gibbons (2000) found similar results for women with chronic pelvic pain where the invisibility meant participants were not believed or understood. For a person to be considered legitimately ill in the eyes of others, he or she must typically have a credible explanation for his or her illness. In addition, there is a belief that real and valid diseases have organic causes (Newton et al., 2013). For endometriosis, it is not always possible to provide a credible explanation or cause, particularly when doctors are hesitant to refer women to a specialist for a diagnosis. It is also complicated as after surgery nearly all participants in this study continued to experience symptoms.

Several of the women spoke about the stigmatisation they experienced regarding not fulfilling specific gender roles that society expected of them. Sarah felt a real disapproval from others that she had not followed societal' s norm and had children. This was particularly difficult as she had made a personal choice not to have kids as she feared she would not be able to manage them with her endometriosis.

"And like my whole thirties it was like "when are you having kids, when are you having kids?'" Being this age is a weird age to be and to not have children and

have people judge you and I guess not understand the reasoning a lot of behind of why I don't have children." (Sarah)

For several of the participants, looking after kids, running the household and working was difficult when they were in pain. Typically they would not ask for help or disclose to others that they were struggling, they instead laboured on and suffered. Relating this to Goffman's (1963) theory, the secrecy and concealment adopted from the women was a way to hide one being classed as 'discreditable' and subjected to stigmatisation. The women felt they would be devalued if they talked about their pain too much or showed to others that they were in pain. This also relates to the theory of Kurzban and Leary (2001) where one may feel stigmatised due to the feeling of inadequacy as a potential social exchange partner. One with an illness may be deemed as a burden to society's resources and a threat to the survival and reproduction of the group. Public stigma and reactions contributed to the stigma surrounding endometriosis, but also stigma of pain and gender roles.

4.4.5. Internalising the Pain and Stigma

"And then you start to think, oh, am I crazy?...Am I making it up? Am I attention seeking?" (Gloria)

Not only did the stigmatisation reactions that the women experienced from medical professionals, friends and family impact the women emotionally, but it also left a huge mark or influence on the way the women reacted. In some case their identities were challenged, they judged themselves, they were hard on themselves, and they experienced a variety of emotional feelings such as guilt, loneliness, despondency, and despair. The findings suggested that the normalisation of their abnormal menstrual symptoms deeply imprinted on their own self. Five of the

women reflected on their lived experiences during the interview, and realised they too had normalised their own pain throughout their lives.

"You know, you kind of like just I guess there's a part of you that just starts living with it and thinks that it's normal." (Sarah)

"I stopped realizing I was even in pain. And he'd be like, are you okay? And I would be ahh, yeah I'm shit, I should probably take something. I haven't even been registering it. And I think that's kind of sad."(Gloria)

"I put up with it so long that I didn't recognize that it wasn't normal". (Rachel)

It was a combination of normalisation, and being dismissed by multiple people, that lead the women to giving up on their journey to finding out what was wrong. Magda spoke about how she as a coping mechanism chose to ignore it and block it out. She said, *"I just really early on learned to just ignore it.", "You just kind of block it out and get on with it,".* Others mentioned that they also kept it to themselves and tried to get on with daily life. They felt defeated, despondent and did not know what else to do. They just gave up.

"So, I was really gutted at that point because I was feeling really terrible. So, then I just gave up for a while, I just gave up on all of it really. And just thought oh well I'll just get on with my life, take drugs. Just be medicated."(Gloria)

"No, I never bothered (to seek further help) because when you have every doctor replying with this as normal, you don't really feel like there's a point in being the naggy patient…so I didn't bother pursuing anything." (Magda)

For Magda and Gloria, the trauma they have experienced has been so significant and intense they cannot speak of their experiences. As Magda spoke about this, she was extremely upset and emotional.

"Yeah, so I haven't really acknowledged it because it's too painful to like any friends or yeah, I've kind of hid it. I've just started actually the past few months saying, you know, I'm having a lot of pain today or a lot of fatigue or something." (Magda)

The study also found that women began to question or doubt themselves about the symptoms they were feeling. This was a direct response to the judgements they had witnessed or thought they would receive from others. For Gloria she experienced this emotional distress quite severely.

"And you question yourself and you're told it's all in your head. And then you start to think, oh, am I crazy? Am I just Yeah, I think that's probably been one of the hardest things for me is like, Am I making it up? Am I attention seeking? Is it like, you know, and so you start to question yourself. Even to the point where it's like, do I have like mother issues or something, it all in my womb, like, do I have issues with my own mother, like, do I have to get sick so that people pay attention to me, is it psychological? Yeah, you know, in those moments when people were telling me there's nothing wrong." (Gloria)

As well as doubting themselves, the women became highly critical of themselves. The judgements they had received from medical professionals and family and friends had been adopted onto themselves. This internalisation of the public stigma as explained by Pryor & Reeder (2011), was consequently met with negative emotions such as fear, shame, guilt, and poor self-esteem.

"I just was hard on myself like, yeah, I must just be lazy or weak of something."

..."But I wonder like, were they getting worse? Or was I just maybe not as resilient." (Magda)

"I feel sad for them because the kids sort of didn't have their full mum." (Tee)?"

In summary, concerns about what and who to tell and the fear of being discovered, were significant sources of psychological distress among the women with endometriosis. To protect themselves from stigmatisation, the women employed a variety of coping mechanisms which included avoiding situations where the stigma was likely, selective disclosure, or by associating themselves with others who had the same condition. They also employed denial as a way to minimise judgements from others, and themselves. Internalised stigma thus was contributing to delays in diagnosis and psychological distress for the women in this study.

4.5 Finally, a Diagnosis

Reaching a diagnosis was a pivotal point for the participants, particularly, for their diminished self-esteem and self-worth they were feeling from years and years of normalisation and dismissal from others. This following section focuses on the emotions felt when the women found an answer to their pain and gained a diagnosis. The section concludes with a discussion about the value of a diagnosis, in regard to their psychosocial well-being, as well as the drawbacks a diagnosis can bring.

4.5.1 The Reluctance to Diagnose

"There was no talk about the importance of a proper diagnosis or anything."

(Magda)

It was felt that medical professional lacked a desire to find a reason or gain a diagnosis for the participants abnormal pain or bleeding. Instead they were quick to treat their pain with painkillers or offer hormone treatment such as birth control. For Magda, it was highly important for her own piece of mind to find out the cause of her symptoms; a diagnosis was just so valuable for her.

"Oh, you done having kids. You could just have a hysterectomy. But it wasn't like there was no talk about the importance of a proper diagnosis or anything. It was just straight into 'Do you want to just take birth control or do you want a hysterectomy?'" (Magda)

These observations concurred with the ideas from Sanie et al. (2019) where it was found that 50% of specialists surveyed believed their reluctance to refer patients was due to the absence of effective treatments. Both As Sanie et al. (2019) & Young et al. (2015) mention the enigmatic etiology of endometriosis and the overlap of symptoms that it shares with other common ailments such as irritable bowel syndrome that contribute to the delay in diagnosis. Similar to the findings by Young et al. (2015), women in this study described how doctors were quick to suppress their symptoms with oral contraceptives instead of investigating causes. In addition this contributed to misdiagnosis and framing the issue as psychological, instead of gynaecological.

Three of the women in this study felt the doctors became more interested in helping them reach a diagnosis when their endometriosis symptoms became related to fertility. For Rachel, she had been experiencing pain for years. It was not until she presented to the GP with concerns about not being able to conceive, that she was referred to a gynaecologist. For Magda, she felt her first gynaecologist was only focused on fertility and getting pregnant. She felt she was quickly dismissed by her due to her not being interested in having children.

"I did find that if you do want kids and you said, you know, "I would hope for kids and blah, blah", Then they really dug deep for you." (Magda)

These findings suggest that the attitudes of the medical professionals played an essential role in getting a diagnosis. In addition, the women were treated seriously

once fertility issues were mentioned. For these women differences in the time to reach a diagnosis was influenced by the willingness or desire of the doctors and specialists to pursue answers.

4.5.2 The Value of a Diagnosis

The surgeons were kind of like, we're sorry to tell you and I was like, hallelujah, I'm not a nutcase." (Magda)

Achieving a diagnosis was a massive step forward for the women. Not only did it bring relief as it validated their pain and symptoms, but it also brought about hope that it could be fixed, and their life with pain would end. All six women gave accounts of how relieved they were to find that the labels that had been put on them, by others and themselves, were not the case. It was like a life of stigma and disbelief had suddenly become unpicked.

"I was kind of like woke up when he said I was like, oh, thank God. Like I'm not crazy. Like it was just as like, oh, thank God, like huge amount of relief of like, ah, someone sees me. Someone has like, given me validation that I'm not just a drug seeker." (Sarah)

"Sort of relieved that I knew that there was actually something wrong and I wasn't mad. I think it was just knowing what it was. Was the big thing and knowing that yeah, okay, this is real. I'm not just imagining it." (Tee)

The women also felt they gained some power back which they felt they had lost trying to get answers. They were able to make connections with others who had endometriosis, research their condition, and then investigate their own treatment methods such as changing their diet, naturopathy, and herbal remedies. For Magda she noted how she changed and was kinder to herself, accepting that if she needed

to stay in bed for a day, it was ok. The diagnosis gave her an exemption for taking time out to rest. For Tee, her diagnosis gave her acceptance of the illness. She learned to live with her pain, accept it, and move on. She accepted it was a part of her life and seemed to be comfortable with that.

The findings also showed that the positive emotions that accompanied a diagnosis could also be quickly diminished. For Magda she felt she had put everything into gaining a diagnosis, and after three surgeries her hopes and dreams of being pain free were squashed. She experienced a short six months of feeling great with lots of excitement and hope for the future, only to have it all come crashing down.

"I was progressively getting better and better and it was like "Hello, normal world, this is what I'm like." You know, I was like working with a pelvic floor physiotherapist and making amazing progress. I was like back to playing basketball and just being like so excited. Yeah, it was pretty special time."

Very quickly her pain progressed once again, and with three surgeries already done, her specialist is unwilling to do anymore. She has now regressed emotionally into the cycle of concealment and isolation by staying at home, ignoring the situation, and not sharing her concerns with others. She mentioned how despite being daily incapacitated, she did not want to pursue any further help.

"So, I haven't really acknowledged you know, I've had little moments where it's crept in but I haven't really acknowledged because I put so much all of my eggs in a basket that if I saw a specialist, and I thought it was the best in the country, or the best, I know, like, this would be it and I would get my life back again."(Magda)

For Vanessa, she too felt the rollercoaster of hope and then despair as the surgery she had, has not helped her symptoms much at all. She noted how it was the

unknown that brought her fear. She was given little guidance as to what to expect after her surgery, and now that the pain has returned, she is unsure whether it was all normal or not. She also is afraid about quickly the disease may progress from here, and if this happens, what this means for her.

"But in terms of like after surgery, it's definitely not what I expected it to be. I thought surgery would take away all my problems and it would be fine. Yeah, but to be honest, it's yeah, it hasn't been fine. It's been pretty hard. I thought it would take away a lot of my pain and it hasn't." (Vanessa)

The narratives suggested that gaining a diagnosis brought on a mix of emotions for the women. Whilst it gave them hope, validation and relief, it also brought about disappointment, fear and frustration. Despite this, gaining a diagnosis was a real pivotal point for the women, one they still valued significantly as a part of their journey. For them they could accept the illness that had plagued them for years, and sometimes decades, and they could move on, gain some control and power back and make their own decisions about a way for the future.

4.6 What Now: Living with Endometriosis?

This section of findings details the women reflections on what life is like now after their diagnosis; what it is like on a day-to-day basis, what restrictions and challenges they face, and how they manage their symptoms. The emotional distress, even after a diagnosis is evident, and the reasons behind this are explored. Distressingly, the stigmatisation experiences continue, even after a diagnosis of endometriosis.

4.6.1 Living with Endo is Hard

"It's ruled my life."(Rachel)

The women varied in time since diagnosis. Some were diagnosed many years ago, and had exhausted all treatment options, whilst others have just had their first laparoscopy with endometriosis excised out. Despite the length of time with endometriosis all the women continue to face challenges and restrictions every day, in all aspects of their lives including work, exercise, relationships, social lives to name a few.

The women described their sadness that they could no longer exercise; for Rachel she loved to run, Tee enjoyed bowling and weights, whilst Gloria liked to surf and play netball. Continual pain also restricts three of the women from working. Sarah works for herself and so she is able to work around her symptoms, whilst Vanessa is able to work from home when she needs due to heavy bleeding and bloating so this is more comfortable for her. Life for Magda is quiet and simple. Her endometriosis prevents her from going out much, and when she does feel good she prefers to put the energy into her son.

"I don't really socialize very much. Just because I just, I don't feel well so often."

... "it's just isolating." (Magda)

For Rachel, she acknowledged that even now when her symptoms are better, she still continues to stay home a lot, avoiding social occasions. She felt this behaviour was so engrained in her from years of pain, that it had now become a learned behaviour. Sarah uses a variety of home remedies to get through her day. She keeps her diet pretty healthy and clean and uses a combination of ice baths and wheat bags to manage her inflammation and pain. She had made a conscious decision, partly due to the difficulty of managing her endometriosis, not to have children. For her, life is already hard enough, and having to care for a young person as well felt too difficult.

"Yeah, the idea of having children has just kind of like it's tough enough looking after yourself , so then I guess with being in the pain that I am. It was kind of like I don't know if I can even look after kids." (Sarah)

Vanessa describes her inability to go out like she used to as "Pissed off". She still tries to, but this is often accompanied by fear that she will have an attack of pain or start sporadically bleeding, which has been a problem for her recently. She spoke off always having to be prepared with pads, tampons, and painkillers. Likewise, Magda and Tee take painkillers daily to deal with their symptoms. For Magda she tracks her consumption using an app on the phone which ensures she takes them regularly, around the clock, also and helps to avoid confusion and possible overdose. This is something she fears with her use of medication.

The women reflected during the interview about the extent that endometriosis rules their lives. A strategy to help with the symptoms is continual planning, whether it be planning the painkillers, but also planning on calendars when their period is due, and to not 'double book' themselves during this time. Planning was a way for the women to gain some control back, something for a lot of times in their lives that they missed.

"And I remember from a really early age, I've always used calendars to mark when I had my period, so that I could, but you know, mind games think okay, I'm gonna be alright, for these couple of weeks. I don't have to worry about it now. But just in case that comes early that's when I need to start worrying about it. Like literally, even if I didn't have my period or didn't have the pain, that, it was with me. All the time. Yeah. Every day of my life, until I stopped getting periods." (Rachel)

For Sarah and Vanessa, only newly diagnosed, they still hold out hope that even further treatment may help them. They have follow-up appointments to attend to and will seek further advice then. For Gloria, after a partial hysterectomy, she is seeing a herbalist and has changed her diet to help manage her hormone imbalances and irritable bowel symptoms which now plague her. Rachel continued to have ongoing pain and unpleasant symptoms right up until a few years ago when she began to enter perimenopause. Magda, despite three operations, is impacted daily with pain and symptoms. She knows of a very specialised doctor in the states, that she said, "*if all her stars aligned*", would love to see. And for Tee, riddled with endometriosis, the doctors have said they can do no more. Her daily life too is compromised, however, despite her struggles, she does remain positive and upbeat, always hoping one day she can go bowling.

The findings showed that even post diagnosis, women continue to battle with the juggling of pain and bleeding, with their everyday life activities. The cycle of concealment and isolation continues, partly because the behaviour is so engrained partly, because the women still suffer with endometriosis symptoms.

4.6.2 The Perpetuation of Stigma

"If I say I'm not feeling well, because I have debilitating fatigue. Or like brain fog. That doesn't seem to resonate with people's assumption of what I should be experiencing with endometriosis."(Magda)

Medical professionals

It became clear during the analytical process that even after gaining a diagnosis, whilst the stigmatisation experiences for these women may have changed, they did not cease. The dismissal and trivialisation from medical professionals continued, particularly surrounding treatment options. For Magda she was met with

frustration that her specialist was disinterested in a further surgery. For her it reiterated that there was no concern or interest to help her.

"I said so there's nothing you're gonna do. You wouldn't go in and do another surgery to get rid of the endometriosis and he was like nah. And then I thought, okay, well there you go. This is it." (Magda)

Magda, Tee and Sarah also reflected on the fact that once they were diagnosed with endometriosis, it became trickier when they had other medical issues. These other medical issues were often dismissed by the medical professionals as being endometriosis, when in fact they were not. Magda experienced lots of gastro issues of which she said were dismissed by the doctors as endometriosis. Tee's enormous hernia was eventually found, after numerous visits to the doctor and A & E. And for Sarah, she continues to live with a pulling pain down the front of both legs. She is in the process of trying to find an answer, however this is being shadowed by her diagnosis of endometriosis.

Gloria continued to have pain after her diagnosis at 18 and for the next 21 years, was continually ignored and dismissed. She considered how having a diagnosis of endometriosis had its disadvantages:

"But it almost made it worse. Yeah. Because it was like, well it made it worse for the other things like you know, you had I know I had endo would they have picked up the IUD. Had I not had endo would they have noticed that growth earlier or done something about it." (Gloria)

Gloria's story was particularly upsetting to listen to, and for her, extremely distressing to tell. The story she told, portrayed such extensive and dreadful stigmatisation experiences, in particular the on-gong perpetuation of stigma. I felt it needed to be told in detail.

Gloria's Story

Unknown to Gloria, an IUD (inserted to manage her endometriosis symptoms) had actually been shot through her uterine wall into her bowel. For two and a half years she went from doctor to doctor, trying to get some help, only to be told it was her endometriosis and that there nothing they could do. When Gloria had an ectopic pregnancy years later that they could not find her IUD and decided it must have been misplaced. Another operation six months later found it in her bowel.

"For two and a half years, I had an IUD on my bowel, because they shot it through my uterus and all the pain from that I was always told either was in my head or was just endo related and to just find a way to live with it." (Gloria)

"And also, that whole thing like well, what am I going to do about it anyway, what's the point in complaining because you know, especially when I was having trouble being listened to it was like, well, nobody's gonna do anything anyway." (Gloria)

A few years later Gloria started to experience excruciating pain, so much that her ability to work as a nurse was becoming extremely difficult. At this time, she pushed for a referral to the gynaecologist team which was refused.

"At first they refused a referral to Gyni, the Gyni team refused the referral. And this was like after my IUD and everything. They just said that they didn't think I needed to be seen." (Gloria)

Gloria was in so much agony at work one day, her boss sent her to the emergency department at the closest hospital an hour away. There she was quickly dismissed and ignored as they discharged her and told her there was nothing wrong. After months of suffering, she plucked up the courage to go to the doctor and

convinced them to refer her once again. This time, the referral was accepted however she was met by a gynaecologist who refused to believe something was wrong.

At this point Gloria gave up and she left that appointment crying, with feelings of despair and helplessness. Her location in Northland meant resources were limited and she had seen the one public gynaecologist there was in the area. There were no more options, apart from moving into the private system which she could not afford. For a further two years she lived with the pain, giving up her job. She began to feel a hard object in her stomach, but due to the stigmatisation reactions she had endured, she delayed a further attempt for help. Eventually Gloria decided to pursue her concerns and convinced her nurse to refer her for a private ultrasound. It was then that they found a massive tumour which they thought was cancerous. Gloria eventually had surgery to remove this tumour.,

" So when I had the tumour, that only got picked up because I wanted to go for an ultrasound, it was in a lockdown. And I like I noticed there was something hard there, like that's not normal. And I noticed it, and I talked myself out of it for ages because I was like, the same thing. Like I'm just gonna be told there's nothing wrong with me. So, I left it for ages. I was like, well, nobody's gonna listen to me anyway." (Gloria)

The stigmatisation experiences had a substantial psychological impact on her. The emotional trauma she endured is summed up in the statements below.

"I think being not listened to makes you feel really powerless……And I think I probably do have anxiety now. Because, but not you know, but it's, yeah. One diagnosis. And like I think people with endo do have anxiety because it creates this whole thing where you're not listened to. And you question yourself and you're told it's all in your head. And then you start to think, oh, am I crazy? Am

I just Yeah, I think that's probably been one of the hardest things for me is like, Am I making it up? Am I attention seeking? Is it like, you know, and so you start to question yourself. Even to the point where it's like, do I have like mother issues or something, it all in my womb, like, do I have issues with my own mother, like, do I have to get sick so that people pay attention to me, is it psychological? Yeah, you know, in those moments when people were telling me there's nothing wrong." ..."So, people would just be like, oh, you've just got Endo. It's just your Endo. When it was actually other things. So, I didn't get treatment for some pretty serious things because it was just passed off as endo, scaring or whatever." (Gloria)

Family and Friends

Not only did the stigma from medical professionals continue after diagnosis, but findings found a different set of judgements and expectations came from the family and friends as well. Magda faced frustration when family and friends believed she should be instantly better after surgery, and she was not. They would reply with, *"oh, but you've had your surgery".* Magda also struggled because others believed pain should have been her only symptoms. The lack of education meant other symptoms such as fatigue and brain fog were not commonly recognised as legitimate symptoms of endometriosis. These judgements led to further withdrawal from Magda, as she then avoided discussing her persistent symptoms with friends and family; instead, she internalised them and withdrew.

"I guess because of the stigmas around it because, you know, like, the symptoms I have, you know, really pain should be the only symptom that I have. So, you know, according to anybody else. So, if I'm having if I say I'm not feeling

well, because I have debilitating fatigue. Or like brain fog. That doesn't seem to resonate with people's assumption of what I should be experiencing with endometriosis." (Magda)

Much as it was a relief for the women to gain a diagnosis, for most it was foreign disease that had little meaning to them or their family and friends. The lack of education and general awareness around endometriosis meant it was difficult for family members to understand just what the women were going through. This brought about frustrations for the women, and for some they just gave up explaining or talking about their condition to others. A common theme was that if others were educated about the disease, it certainly would have helped them cope with it themselves as they would have been able to share their experiences, instead of being met with confusion.

"This is this mystery illness that people just don't really know about. There's not a lot of education out there about it so people just kind of look at you a bit confused." (Sarah)

" Sometimes over the years I've got frustrated that it wasn't something that has a has a name that people you know, have sympathy for and some understanding of so that you know my life could have been a bit easier." (Rachel)

Reactions from Self

Despite a diagnosis, the women's actions did not change significantly. They described how relieved and validated they felt when they gained a diagnosis, however it seems the reactions from society were so deeply engrained in them, that they continued to behave with secrecy, conceal their pain and isolate themselves. As

mentioned earlier, this was partly to do with the ineffective medical treatments and feeling unwell, and the lack of knowledge people had about endometriosis, however it was also due to the internalised stigma they still felt. They still worried substantially about what people thought of them as a person in pain and could not do things others freely did. They worried they would be labelled as lazy or weak, or just making up excuses to get out of something.

The women in the study spoke about their lack of disclosure to others about their endometriosis. A pattern of selective disclosure was seen, with some not sharing their disease due to absence of knowledge many people had of the disease. They were often met with frustration due to the misinformation people had and felt unless you had experienced it, they felt it was not worth sharing due to the lack of understanding they had.

Rachel acknowledged that a diagnosis for her did not change her lack of openness about her illness. Rachel's children are 17 and 15, yet she is unsure after all this time whether they know she has endometriosis. During the interview she reflected back, visibly sad that she had not felt comfortable enough to share her illness with her wider family during the last 18 years. She was upset she had lived her life in secrecy and attributed her behaviour to the fear that they would judge her or not understand.

> *"So I think that was a relief, but having said that, you know, ever since I was diagnosed, it's not something that I was more open about it. I've always kept it really quiet. Always."..."I didn't want people judging me by the fact that I had this illness that they didn't understand, and quite possibly thought that I was overreacting about because they don't understand unless you experience it yourself. Or judging me for the fact that I used it as an excuse for things or that*

I was, you know, had, no tolerance of pain or that I any of that or that I was a negative person. Yeah, that was part of it. I think. So I think it's all of the above." (Rachel)

Gloria's family knew about her illness; however, she was hesitant to share this with others who do not have endometriosis. Gloria acknowledged that if she was to tell others, it would relive the emotional trauma she had been through, and that this was just too hard to do. She also felt they just would not understand. For her working as a nurse at a hospital, she even hid this from her medical colleagues, wherever possible. Gloria also reflected quite openly that the imprint of dismissal and trivialisation that she experienced from the medical professionals during her life, had been so internalised that they had left lasting effects on her behaviour.

"I definitely think my self-stigma came from the stigma I received from doctors and nurses and people. Yeah, I felt like a lot of my life. I felt like I don't want to bring it up. Because people just tell me I'm crazy." (Gloria)

Several of the other women reported not knowing or understanding their own secrecy associated with endometriosis. The ideas given by Griffith (2017) can be recognised and applied to my own findings. The lack of advertising, education and knowledge in the community can be attributed to the link endometriosis has with gender. Griffith proposed that since endometriosis is a disease of women's "reproductive parts" (p. 45), it does not fit within accepted cultural boundaries so is rarely discussed, making it a taboo issue. Women suffering with endometriosis feel discriminated against and obliged to remain silent. Their environment is one of structural violence, in which women face gendered oppression and a loss of equal standing with males, as well as with women who do not have endometriosis. It is

believed that if the disease affected men, it would be given importance and attended to with respect to funding, research and education (Griffith, 2017).

To conclude this section, it was clearly evident that even after a diagnosis, the stigmatisation experiences continue. Reactions from medical professionals and family and friends are still impacting how the women were living. In particular, the shame and embarrassment that the women have internalised during their journey to diagnosis is still affecting their emotional health. The women continue to feel fear, guilt, shame, and regret, as well as disappointment, despondency and hopelessness when they find there is no perfect treatment for endometriosis.

CHAPTER FIVE: Discussion

This study set out to explore the stigmatisation experiences of women with endometriosis in Aotearoa, New Zealand. This chapter begins with a brief summary of the findings. The key ideas that have emerged from the study are then discussed in relation to the literature and theories of stigma. Lastly the limitations of this study are considered alongside recommendations for future study.

5.1 Summary of Findings

For the six women interviewed stigma played out at all stages of their endometriosis journey. The narratives highlighted the emotional distress they experienced during their journey to being diagnosed with endometriosis. The women's journey to diagnosis was long and hard, and begun with distress associated with abnormal pain and bleeding, mainly during menstruation. Stigma experienced was connected to societal menstrual taboos, a lack of awareness and education about abnormal and normal menstruation, as well as a lack of knowledge about endometriosis. Trying to get answers for their abnormal symptoms was often met with dismissal and normalisation from medical professionals, and the women detailed the difficulty they had to access care and treatment in the public health system in Aotearoa, New Zealand.

Dismissal, normalisation, being silenced, trivialised and disregarded, all contributed to poor emotional health, as well as lengthy delays in diagnosis. The participants endured a range of feelings from being alone and isolated, to hopelessness, despondency and fear. Negative stereotypes and attitudes towards them were anticipated and internalised by the women, and this contributed to them giving up and withdrawing from seeking help. Instead, they lived in unnecessary

pain, and endured emotional suffering for many years before a diagnosis was found. The average time for the six women in this study to gain a diagnosis was 13.6 years.

Gaining a diagnosis was a pivotal point in the women's stories. They spoke of the validation and relief that they felt when they were diagnosed with an actual medical condition after years of feeling like it was "all in their head" or that they were just "weak" or a "complainer". The diagnosis gave the women a sense of control, power and hope and it helped to erase some of the stigmatisation they had experienced. Whilst the diagnosis brought a closure to the years of worry, despair, and fear, it too brought about an unexpected feeling of disappointment and frustration when treatment methods failed to be successful.

The final section of the findings concentrated on what it was like for the women after a diagnosis. The narratives unexpectedly highlighted the continuation of stigma that the women continue to face after a diagnosis. Despite being diagnosed the women were still in a vicious cycle of pain, stigma, and emotional distress that just kept evolving. A diagnosis brought about different forms of stigma associated with a lack of knowledge and understanding about endometriosis. The stigmatisation experiences from the past were so engrained in the women that they continued to behave with secrecy, conceal their pain from others, be selective about their disclosure and isolate themselves. The emotional trauma accompanying the stigma persisted, and many of the women continue to live in horrific pain with feelings of fear and hopelessness on a daily basis.

5.2 Stigma Experienced by Women with Endometriosis

Pryor and Reeder (2011) described four different manifestations of stigma experienced: public stigma, self-stigma, structural stigma and stigma by association.

For the women in this study self, public and structural stigma were discussed, whereas stigma by associate did not surface to the same extent. Figure 1 summarises the stigma experiences for women in this study. In contrast to Pryor and Reeder (2011) who position public stigma as the middle and organising stigma, I suggest that structural stigma is placed as the base for both public and self-stigma. Structural stigma was found to influence the public and self-stigma experienced at all levels. The sizes each of the types of stigmas in Figure 1 is deliberate - to illustrate roughly the degree of each type of stigma experienced. For example, structural stigma was found to be dominating and experienced much more frequently than the self-stigma. This section will unpack each of these stigma's briefly, in turn. However, it should be noted that the experiences of stigma at all levels are intertwined and the complexities of this are covered in sections 5.3 onwards.

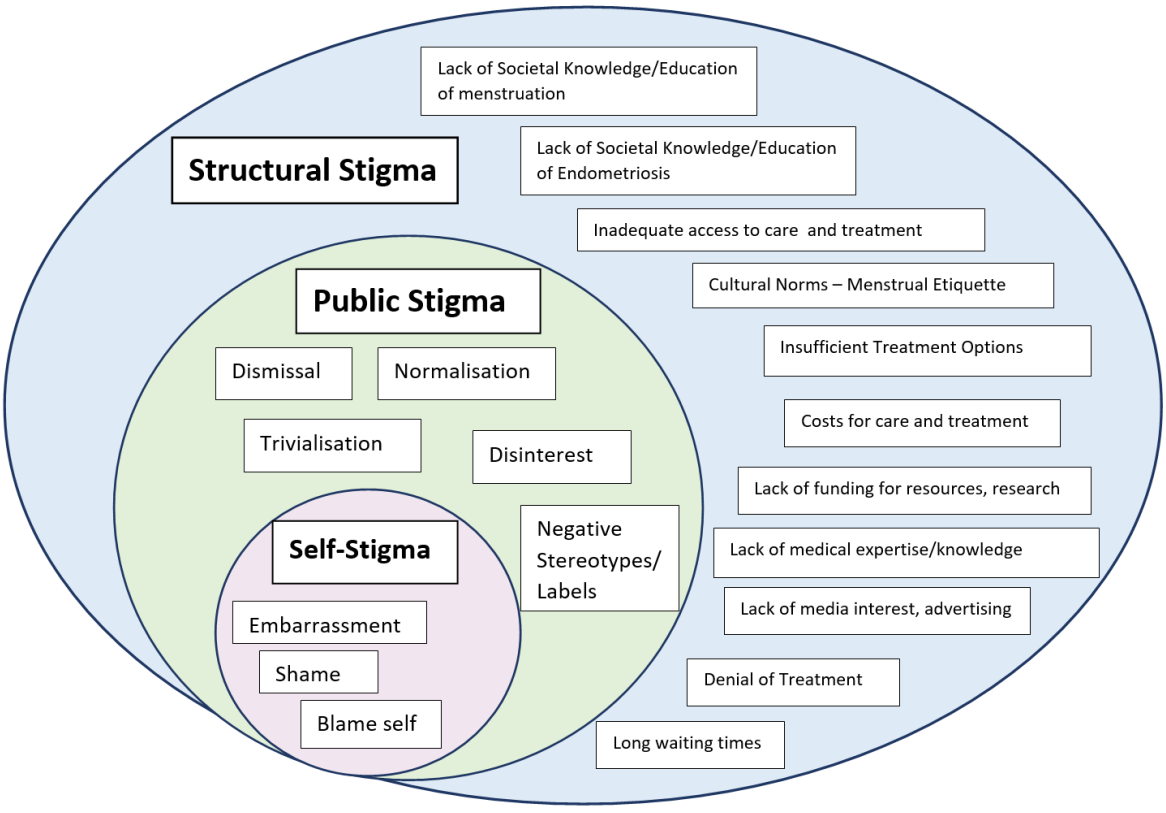

Figure 1: A representation of types of Stigma experienced by women with Endometriosis

5.2.1 Self-Stigma associated with Endometriosis

Self-stigma in endometriosis presented as feelings of guilt, embarrassment and shame when the women were unable to conduct activities that were commonly associated with the stereotypical female such as having children, household chores, or looking after their own children. Studies by Young et al. (2015), Griffith (2017) and Cox et al. (2003) also contribute to these ideas showing a direct link between gender stereotypes and stigmatisation. Noted was discrimination felt due to not fitting into society's neatly prescribed gendered roles, and in particular the loss of equal status which was felt due to this. Self-stigma also came from lack of knowledge of endometriosis, concealment of periods and pain at all stages of the endometriosis journey, associated stigma of menstrual blood, and stigma of being a sick person in pain. People with stigmatised conditions are acutely aware of the social devaluation, assigned by society, associated with their condition, which can lead to the internalisation and adoption of these negative views (Pryor & Reeder, 2011). Griffith (2017) noted that when women 'suffer in silence' as a result of stigma, feelings of isolation can be exacerbated, which in turn increases stress levels, disease progression and symptoms.

To cope with the stigma the women used coping mechanisms such as isolation, withdrawal, concealment and selective disclosure to reduce the potential of being seen as 'discreditable' and therefore discriminated against or devalued (Bos et al., 2013). According to Bos et al. (2013) these mechanisms are utilised to avoid public stigma but the stigmatising condition still exists and could be revealed which results in psychological distress for one with a stigmatising condition. The findings from this study illustrated this concept for endometriosis with women reporting diminished

feelings of self-worth and self-esteem due to feeling unheard, dismissed through other people's reactions.

The consequence is that women became withdrawn and isolated often giving up pursuing any form of help. This period of time where they left their pursuit of a diagnosis, and suffered in silence, often lasted for years and contributed to the delay in their diagnosis (Cox et al., 2003; Griffith, 2017). Many studies explicitly mention the link between concealment and isolation and the delay in diagnosing and treating endometriosis as being concerning (As-Sanie et al., 2019; Markovic et al., 2008; Matas-González et al., 2021; Sims et al., 2021). It is noted that these stigma experiences limit women's willingness to seek care, which delays diagnosis, treatment, and management and potentially causes symptoms exacerbations. This cycle of distress and behaviour is directly related to the stigmatisation experiences that they incur. These negative assumptions that the public adopt, need to be challenged, as they have a detrimental effect on the well-being of these women.

5.2.2 Public Stigma associated with Endometriosis

Public stigma is defined as the negative reactions the women experienced from society towards themselves as women with endometriosis (Bos et al., 2013; Jones & Corrigan, 2014; Pryor & Reeder, 2011). The participants in this study reported dismissal, normalisation, trivialisation, disinterest and labelling of negative stereotypes, mainly from health professionals. They also felt power imbalances associated with age, gender or socio-economic status. Power imbalances has been shown elsewhere within medical interactions (Lloyd et al., 2020) and a lot of research in endometriosis continues to highlight negative experiences with medical professionals (Denny, 2004; Matías-González et al., 2021; Moradi et al., 2014). In

Aotearoa ethnicity and Socio economic status(SES) continue to be highlighted as a social determinant of health, and this was clearly illustrated in the studies conducted by Sheridan et al. (2011) and Bécares et al. (2013) where it was noted that those with lower SES reported higher levels of chronic illness.

A very significant form of public stigma was education. This was evident in interactions with medical professionals, family and friends and then impacted on self-stigma. Endometriosis is a disease that is largely physically invisible relying on public knowledge of endometriosis, pain, menstruation being understood. The lack of understanding from their friends and family stemmed from a lack of knowledge and awareness that their friends or family had about the disease, and because of this they did not, or could not, support them. This is an example of where public stigmatisation reactions are directly influenced and linked to structural stigmatisation. It is these public reactions which caused significant distress and trauma for the women. To improve the emotional well-being of women with endometriosis, more must be done to educate and bring awareness about this disease to the general public so that they can begin to understand and support women who have endometriosis.

5.2.3 Structural Stigma associated with Endometriosis

Structural stigma is made up of societal conditions, cultural norms, and institutional policies that limit the opportunities, resources, and well-being of the stigmatised (Pryor & Reeder, 2011). The findings from this study illustrated many instances of structural stigma which acted as a barrier for the women to seek help and gain a diagnosis, all while their emotional health deteriorated. The lack of knowledge, awareness and education that society had about endometriosis had a

huge effect on the way the public reacted towards the women. The reactions medical professionals responded when the women presented for help were often very negative. This reiterated the ideas from As-Sanie et al. (2019) who proposed that the lack of disease awareness and education society has about endometriosis is a barrier to diagnosis. Whilst the women had limited knowledge and awareness about endometriosis they also felt there were a lack of knowledge in the medical world. The women reported many visits to GP's who did not even mention endometriosis as a possibility and dismissed their symptoms as other physical or psychological conditions. GP's also were often hesitant to refer the women on to specialists which delayed their diagnosis even further. The women living in smaller towns and cities were disadvantaged with limited access to specialists who had expertise in this area.

Hudson (2022) observes that the ambiguity and lack of knowledge surrounding etiology and sufficient treatment of endometriosis is due to a structural ignorance directly observed from cultural, structural and political forces. This "wilful ignorance" (p. 20) which includes the lack of funding, education and interest from government agencies surrounding this disease is thought to stem from processes of marginalisation and silencing. Hudson argues that endometriosis as a condition is marginalised primarily as it associated with undesirable historical constructions of menstruation and because it is 'women's' health issue, which in turn has contributed to this disease to being blatantly ignored and dismissed by those in political power. At a political level Australia has recognised the need for structural change within its policies and priorities, and so in 2017 it injected 16.07 million into endometriosis research, with the hope that prevention and cure for endometriosis is achievable (Australian Government Ministry of Health, 2018). In Aotearoa, New Zealand, the

same cannot be said. The 'Best Practice Guidelines' were developed by the Ministry of Health in 2020, with an aim to improve practitioner diagnosis and management, however no funding, resources, or even an action plan, have been implemented by the government since. The "Endometriosis Clinical Practice Guidelines" is also hoped to be adopted in Aotearoa New Zealand, as it is in Australia, however financial barriers have delayed the implementation. The lack of attention at a political level has real implications at a societal level (from time off work, fertility costs etc.). When no value or importance has been given to endometriosis at a political level, society also adopts these views and disregards the disease as well. This has huge implications for women with the disease. Unless education and knowledge regarding endometriosis improves, we will continue to have a disease that we know very little about, and because of this have inadequate diagnostic methods and treatments available. Women will continue to experience emotional distress, a decreased emotional well-being, a poor quality of life and symptoms such as depression and anxiety (Sims et al., 2021).

The last few years have seen an increase in general awareness of endometriosis at a practitioner level, and in society in Aotearoa New Zealand. This has solely been driven by advocacy groups, such as Endometriosis New Zealand which has successfully aimed to increase the profile coverage via social media, and in the national media. Tewhaiti-Smith et al. (2022) reports that this has played a role in the reduction in delay between symptoms onset and presentation. This is a pure example of where structural changes improve the diagnostic time for women with endometriosis in Aotearoa New Zealand.

Given the prevalence and health impact endometriosis has on women, their families and society, confusion exists as to why our society does not propose changes at a structural level such as funding, and more education and awareness surrounding this disease. It seems like an easy solution to end all of this trauma, yet little has been done to understand this enigmatic, mysterious disease which continues to have a debatable etiology, difficult diagnostic methods, poor and limited treatment options, and no cure.

Goffman (1963) clearly identified markers associated with marginalised groups that are contributing to stigma. In the case of endometriosis, the difficulties and barriers being faced by women are intrinsically tied to menstruation, pelvic pain and fertility. The fact that women still conceal their menstruation is a factor however, for endometriosis, the heavy periods add to the fear of leakage and "blemishes of individual character" (Goffman, 1963, p.4). The taboo's and cultural differences and understandings about concealment of period blood (Mondragon & Txertudi, 2019; (Tewhaiti-Smith et al., 2022) are not new concepts but it was surprising that the etiquette of menstruation is still encouraging women to conceal and not draw men's attention to menstruation in any way (Laws, 1990). Seear (2009) contends that this social etiquette is inextricably linked to sexual politics, in which women are required to conceal all signs of menstruation in order to regulate power relations between the sexes. Any violation of this menstrual etiquette has the potential to discredit women, making them susceptible to stigmatisation.

Women with endometriosis have symptoms of heavy bleeding and/or chronic pain; both of which can produce stigmatisation attitudes in two different ways. Heavy bleeding is associated with the stigmatising mark of menstrual blood, which

explained earlier, fits all three of Goffman's (1963) categories of stigma. The chronic pain women feel with endometriosis can also lead to stigmatisation due to the deviation it brings from societal norms (Kurzban & Leary, 2001; Phelan et al., 2008; Stangor & Crandall, 2000). Consequently, observers devalue and discredit those with chronic pain due to this failure to conform to a societal norm (De Ruddere & Craig, 2016).

Consistent with evolutionary biological theories of stigmatising behaviour outlined by Kurzban and Leary (2001), prejudice towards those who experience chronic pain is common. People's perceptions of others' contributions to their own and the community's well-being determine the degree to which they are valued, much as they did in the hierarchical social systems of our ancestors and early hominins (De Ruddere & Craig, 2016). According to Aste (2016), a woman with a chronic pain condition often has their pain dismissed, this is particularly so for a contested illness, or when it is a female chronic pain condition. For women with endometriosis, or unexplained chronic pain, they could be seen as a threat to survival or reproduction due to the perceived inability to fairly contribute to the survival of the group. In the case of unexplained chronic pain, scepticism about the veracity of the pain complaints and possible devaluation of the other person may result from a lack of a clear medical explanation for the pain or from a failure to fit with a restricted biological viewpoint centred on acute pain (De Ruddere & Craig, 2016).

Literature shows that people stigmatise "outgroup" members (De Ruddere & Craig, 2016). "In group" persons are those similar to the observer which could include relatives, friends, or similar ages, whereas "out group" people have distinct differences such as skin tones or cultures (O'Brien & Major, 2005). Women with

endometriosis or unexplained chronic pain could be considered to be outsiders or the “out group”. In the context of pain or suffering, observers have less empathy and altruistic desire for members of social out-groups than for members of in-groups, and "out group" members' pain complaints tend to be ignored or dismissed (De Ruddere & Craig, 2016).

Ruddere & Craig (2016) propose that observers which include the general public and all medical professionals attribute lower levels of pain to patients when a clear basis for their pain is not found. It is believed that they are less sympathetic and inclined to help, dislike the patients more, and suspect deception when no clear medical reason is found. Thus, observers dismiss or trivialise pain complaints and express doubt about credibility. For women without a diagnosis of endometriosis, this could account for the stigmatisation reactions they experience from family, friends and medical professionals. Consistent with evolutionary biological theories of stigmatising behaviour outlined by Kurzban and Leary (2001), prejudice towards those who experience chronic pain is common.

Endometriosis remains a mysterious, invisible illness. Gibbons (2000) found disbelief, ignorance and misunderstanding of chronic pelvic pain was displayed by others towards the women largely due to the invisibility of the pain. This stigma is thought to derive from issues of legitimacy, as the symptoms for an invisible disease are not discernible to others. Monsivais (2013) explains that when a person is faced with disbelief, a moral question about the persons character come into play. If the pain is not visible, it must be psychological, and voluntary, and so it is thought that it is an excuse for not participating in everyday life activities. Characterising this invisible pain to be a psychological condition, brings further stigma associated with

one having a mental illness. Pain sufferers were also seen to be weak, due to their inability to overcome their painful symptoms. For the women in this study, a big fear was just this; they feared that they would be labelled as being complainers, whiners, weak, lesser, or that they were overacting, being drama queens, crazy or hysterical. Resulting from this fear, the women hid the pain from their invisible illness. Instead of sharing their inability to complete household chores, look after the children, or complete their work-related roles, they remained silent. According to Monsivais (2013) this behaviour was adopted to protect their identity, which was at risk.

Inconclusive evidence about the etiology of endometriosis exists with a range of theories, including genetic factors, immune responses and the retrograde theory. This along with the lack of non-invasive diagnostic tests, the lack of a classification system and in-effective treatments class endometriosis as an ambiguous disease. Women with endometriosis can also present with huge variation in their symptoms, of which could easily be associated with many other illnesses (Hudson, 2021). These characteristics of endometriosis contribute to it being an illness that is shrouded in great uncertainty, which increases its potential for stigmatisation (Asbring and Närvänen (2002) and noted that "an illness that is not delimited to any specific organ, cannot be diagnosed in an objective way, and is difficult to treat often has a low status among doctors" (p. 149). Bean et al. (2022) further contributes to this idea with the suggestion that a chronic pain condition that has no clear biomedical reason, must be psychological, and thus is stigmatised.

There are some researchers that suggest framing endometriosis as a women's disease is not capturing the complexities of people who menstruate (e.g. (Laws, 1990)). However, this research has clearly highlighted that the pain associated with

endometriosis, the heavy bleeding, the guilt and shame expressed regarding the inability or worry about tasks that are traditionally feminine (e.g. caring for children) and fertility issues are still of significant concern and are impacting diagnosis times, societal attitudes, and how women live with endometriosis.

5.3 The influence of structural stigma on public and self-stigma

The conceptual model proposed by Pryor and Reeder (2011) which is shown in Figure 2, places public stigma at its centre core, proposing that public stigma is the foundation for the other types of stigma.

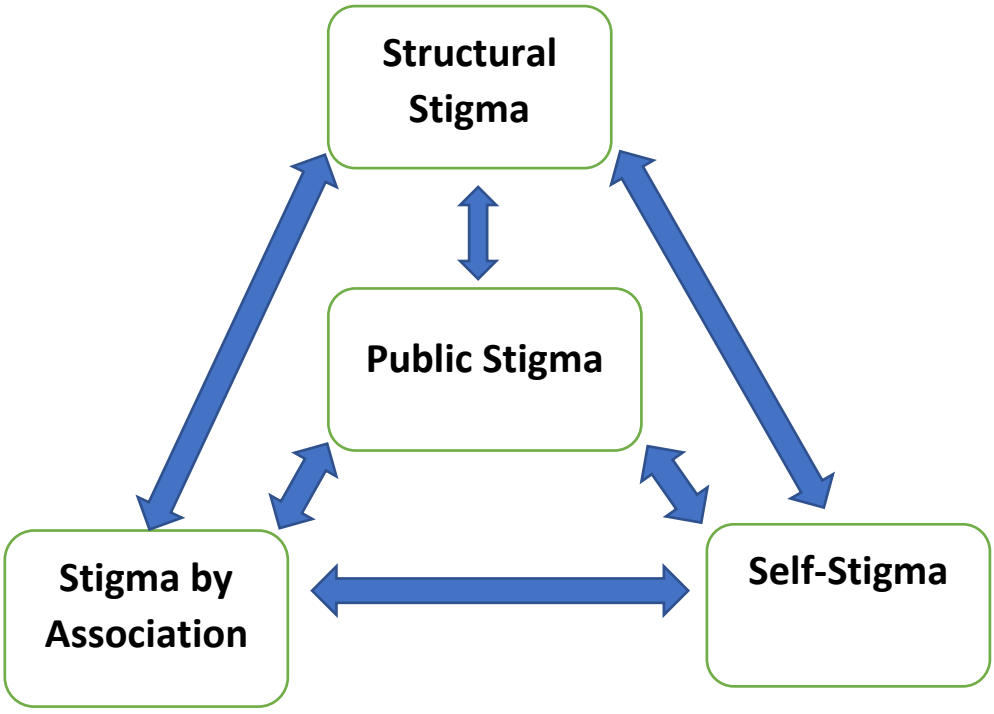

Figure 2. Pryor and Reader (2011) model. Redrawn from original diagram

In this study the experiences of structural stigmatisation seemed to dominate and impact the participants with endometriosis more so than the other types of stigma. Instead of public stigma being at the core of the other manifestations for women with endometriosis, structural stigma to be the foundation for public and self-stigma. I propose a new model as the data suggests structural stigma influenced

and induced the public stigma experiences, not the other way around as proposed by Pryor and Reeder. Without the public stigmatisation experiences that the women were exposed to, the self-stigma that they adopted would have been decreased. This relationships between structural, public and self-stigma is shown in Figure 3. Future research is needed to look at the different pathways.

Structural factors such as institutional policies such as laws, and practices of the health care system along with society's dominant cultural norms, and especially the lack of knowledge and awareness of the disease, played a key role in how society reacted to the women with endometriosis. Upon reflection it seemed obvious that the public stigma experienced, especially the reactions from medical professionals were directly resulting from structural stigma. The dismissal and normalisation, trivialisation and silencing that women had experienced could have been accounted for by the lack of education and knowledge the medical professionals had, as well as the engrained societal expectations and norms associated with women, menstruation and women's health. This research also demonstrates that structural forms of stigma exert strong, direct effects on the health of stigmatised individual. Structural stigma consisting of societal norms and expectations surrounding menstruation and gender stereotypes, along with a lack of awareness, education and funding and resources from political powers influenced society's views and ideations surrounding endometriosis. The reactions from friends, family, colleagues, and health professionals which included normalisation, dismissal, silencing, marginalisation, exclusion and a lack of understanding were a direct consequence of these structural forces.

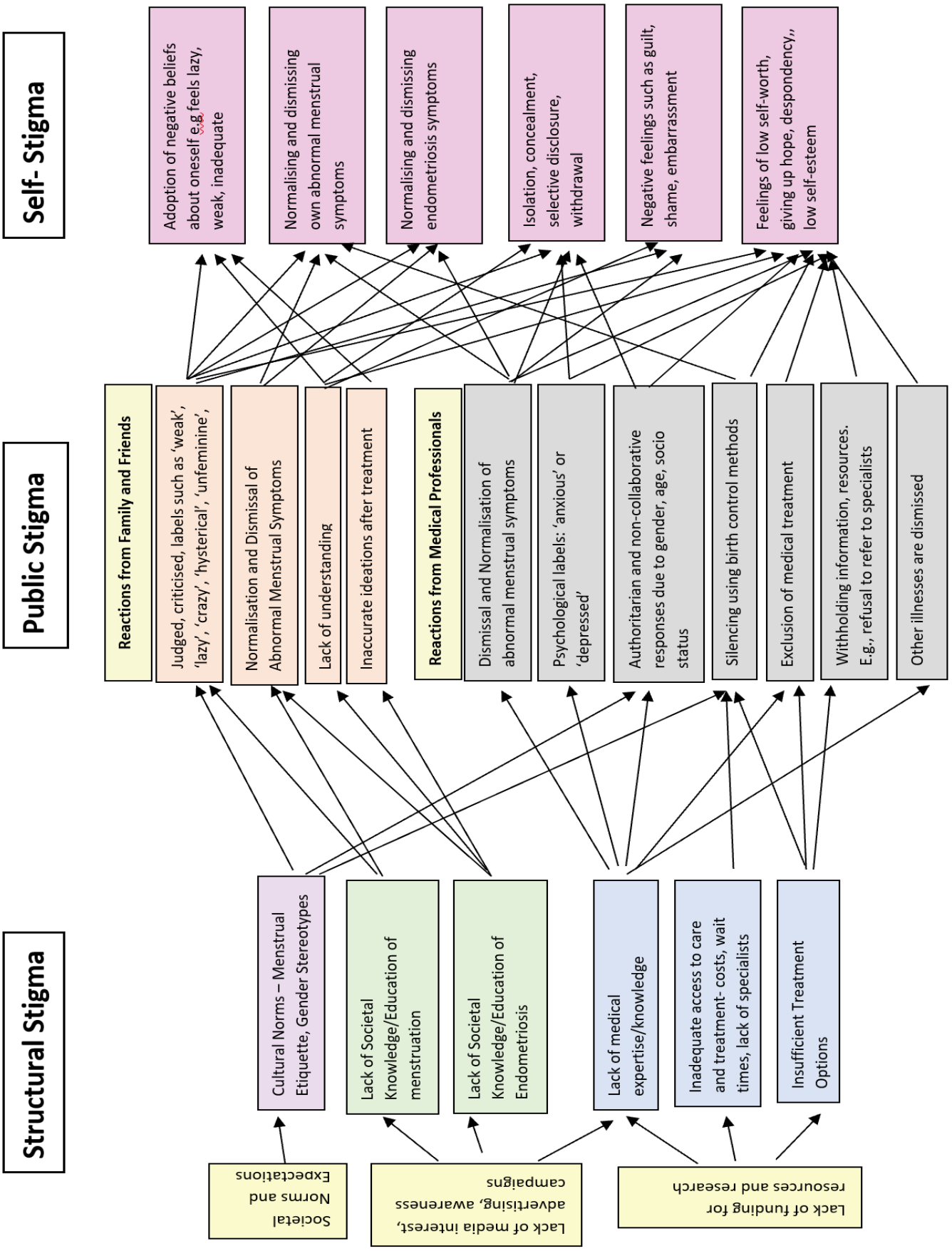

Figure 3: Stigma Experiences of Women with Endometriosis

Reactions then had a sequential effect on the behaviour of a women with endometriosis as they internalised these negative judgements and behaviours, agreed with them and then adopted them. The outcome was further emotional distress and a delay in help seeking behaviour as the women concealed and isolated themselves and their illness from others. To some extent, a bi-directional relationship, whereby self-stigma may feed into public, and public stigma influences structural stigma may exist. This model acknowledges this would occur to some extent, especially with the relationship between self-stigma and public stigma. An example of this would be the withdrawal and isolation one may show as a result of public disapproval or judgements, which in turn could create further negative thoughts and actions from the public, when perhaps they are seen to be lazy, weak or unsociable.

5.4 The Relationship between Stigma, Emotional distress and Delay in diagnosis

A bi-directional relationship was found between stigmatisation experiences, emotional distress, a delay in help seeking, and for diagnosis (Figure 4).

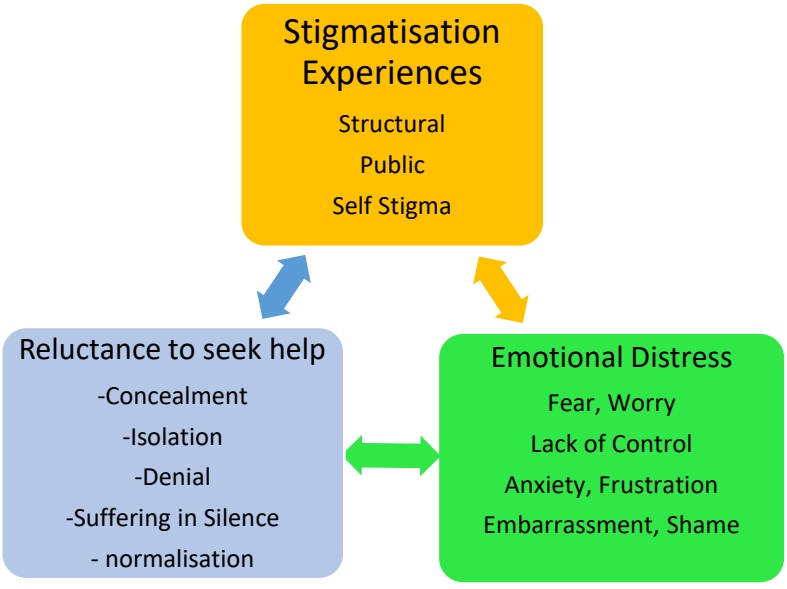

Figure 4: The relationship between Stigma, Emotional Distress and Help Seeking Behaviours

The internalised stigma produces feelings of shame and guilt, all which lead to reduced emotional well-being. The relationship between stigma, emotional distress and seeking help was also bi-directional due to the effect that not seeking any help had on the women's mental health, and on the stigmatisation experiences that were occurring. The delay in diagnosis, due to the secrecy and concealment which was adopted by the women, led to even more distress for the women. This behaviour also fuelled further stigmatisation reactions with the women being perceived to be weak or lazy when they withdrew from social activities or work commitments, which in turn prompted further judgements and negative attitudes towards them. These results are consistent with other findings where an association between chronic illness stigma and reduced help seeking behaviours and attitudes is seen (Barta & Kiropoulos, 2023; Hawkey et al., 2022; Holloway et al., 2007). This behaviour can be explained by the theory of Label Avoidance proposed by Jones and Corrigan (2014), which describes the avoidance or reluctance to seek medical care due to a fear of being labelled or stereotyped by others, and/or a personal fear of adopting a stigmatised label. Numerous studies have all shown an association between stigma and negative psychological well-being (Bos et al., 2013). Pryor and Reeder (2011) describes how when one internalises stigmatisation reactions from others, and adopts these opinions, applying them to one-self, their self-worth and self-efficacy is diminished.

5.5 Implications

This research has shown that women face tremendous hurdles, made up of many types of stigmatisation experiences in their journey to being diagnosed. The most dominant was structural stigma and involves social forces which create and

perpetuate our cultural views and societal expectations surrounding endometriosis and chronic pain. Structural stigma creates foundations for society which include education, funding, policies, and resources. I propose in this thesis, a new theory, one where structural stigma is dominant and influential of the other two primary stigma's experienced for women with endometriosis: public and self-stigma. This theory highlights the intersections and complexities of the stigma associated with endo. While more work is needed on the theory to expand it and to look at the pathways, different cultural lens and so on, the theory would allow health professionals and policy makers a starting point to start addressing structural issues.

The women experienced significant trauma in their journeys with endometriosis in this study, and even after a diagnosis many years later, this trauma did not dissolve. The implications of this are that practices must change as any preventable trauma is unacceptable. Being laughed at, not offered choices, dismissed in ED's to name a few, should not be happening. There is an awareness of women who struggle with infertility (the stress, pain, and trauma of this), but seemingly a lack of awareness of the impact of endo, until women cannot get pregnant. This study found a direct link between stigma, help seeking and emotional distress for women with endometriosis. It found that structural forms in the way of policies, legislations and resources are directly affecting a possible 1 in 10 women, in Aotearoa New Zealand, in a very damaging way. The time to gain a diagnosis for debilitating and terrible disease is far too long, and too many tears are being shed in between.

5.6 Future Research

Much more research is needed into endometriosis which would bring knowledge and awareness to everyone, as a way to understand, accept and define

this mysterious and debatable disease. Much more research is also needed into understanding the complex construct of stigma with women who have endometriosis. Our laws, policies, and priorities at a structural level differ considerably to our Australian neighbours, and hence it is likely our stigmatisation experiences differ as well. In the search for endometriosis-related stigma, only one other qualitative study, conducted by Matas-González et al. (2021), based on Latina women, was found. This study emphasised the importance of expanding research on this topic, particularly on other cultures and societies, worldwide, in order to better understand the cultural variables that may impact endometriosis related stigma as well as the consequences of feeling stigmatised as women living with a chronic and invisible condition.

Whilst much more research is needed worldwide, there is also a need for the research to be done in Aotearoa, New Zealand. Given I have proposed that structural forces exert influence on other stigmatisation reactions, more research is needed within New Zealand to gauge differences in different minority cultures and communities. Investigations could be done on our other ethnic groups such as Māori and Pacific Islander communities, given they have very different cultural views on topics related to endometriosis such as menstruation, menstruating women and gender specific roles within their communities. This would give valuable information about the role culture has regarding stigma and give more knowledge about how structural stigmas play a role in the health inequalities of our minority ethnic groups in Aotearoa New Zealand.

Given my findings signify expansive stigmatisation experiences from health professionals towards women with endometriosis, qualitative research investigating the views of doctors, nurses and specialists involved in endometriosis care is needed.

This research could capture their ideas and opinions surrounding endometriosis, particularly their own knowledge and awareness about the disease as well as their experiences with patients who present with endometriosis related symptoms. This could give a valuable insight into what creates and drives the stigmatisation reactions that medical professionals give.

5.7 Conclusion

Despite its high prevalence and well-documented effects on public health, the stigma associated with endometriosis is vastly understudied. This study found clear instances of self, public and structural stigma for women with endometriosis. The consequences of the stigma were decreased psychological well-being, diagnostic delays, concealment and isolation, and poorer outcomes physically. Structural stigma seems to be driving public and self-stigma for endometriosis. Individuals are living with endometriosis-related stigma and until stigma decreases these people will continue to be impacted. The complexity and multidimensional negative effects on timely care, treatment, and quality of life require further research.

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Appendices

Appendix A: Project Information

Stigma Experiences among Women with Endometriosis in Aotearoa New Zealand

INFORMATION SHEET

My name is Erica Collins and as part of my Master of Arts Thesis in Psychology, I am doing research about the experience of stigma that women with Endometriosis encounter in Aotearoa New Zealand.

Project Description and Invitation

Endometriosis affect roughly 1 in 10 women globally. This research is interested in exploring your experience of stigmatization associated with this disease. This Information Sheet will help you decide if you want to participate in this study. It outlines why I am doing the study, what involvement is needed from you if you wish to participate and what would happen at the completion of the study. Before you decide, you may want to discuss the study with other people such as partners, family, whānau, friends, or health providers.

Who can take part?

Inclusion Criteria

- Be over 18 years of age
- Have a laparoscopic confirmed diagnosis of Endometriosis
- Consider yourself to be in a good place to take part – i.e. in a place of well-being, no significant mental health distress.
- Currently residing in New Zealand
- Participants of any ethnicity are invited to participate; however, the interviews will be conducted in English

What would you be asked to do?

If you wish to take part, you will be invited to take part in two interviews at a time and place we both agree on. It is preferred these will happen face to face but given the current Covid-19 situation there may be a possibility of Zoom, or phone call interviews. Each interview should take no longer than one

hour. During the first interview I will ask you about your personal Endometriosis journey, and then in the second, ask you questions related to the stigma experiences you have faced associated with Endometriosis. You will be offered a $40 voucher/gift in recognition of your time.

Data Management

These interviews will be voice recorded with your permission. I will transcribe these recordings and give you a copy of the transcript which you can edit or make changes to if you wish. After reading the transcript you will be given a Transcript Release Authority form which, if you sign, gives me permission to use the information in my research. I will be reading through these transcripts to look for themes and patterns which will provide the data for my analysis.

Your confidentiality and privacy is important and therefore all names or identifying information will be removed from the transcripts, data and write up of the research. All personal information and data will be stored on a password protected computer and on a Massey University hard drive until the research is complete in February 2023, and then it will be deleted. An anonymous form of your transcript and coding will be stored indefinitely in Massey H drive as the data saved to Massey University's network is backed up, maintained and managed, secure, replicated and protected against viruses.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question,
- Ask for the recorder and/or video to be turned off at any time during the interview
- withdraw from the study at any time up to two weeks after the transcripts have been checked by yourself
- ask any questions about the study at any time during participation
- provide information on the understanding that your name will not be used unless you give permission to the researcher
- be given access to a summary of the project findings when it is concluded

Please contact the researcher or supervisor if you have any questions about the project.

Contact details below:

Researcher:	**Supervisor:**
Erica Collins	Kathryn McGuigan
[redacted]	K.Mcguigan@massey.ac.nz
[redacted]	09 414 0800, ext. 43115

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 22/15. If you have any concerns about the conduct of this research, please contact A/Prof Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800, x 43347, email. humanethicsnorth@massey.ac.nz

SUPPORT SERVICES

If the interviews raise issues that are particularly upsetting, I encourage you to use your personal support systems to talk through them. Often reliving an experience can be distressing, but sometimes there are benefits of talking with someone about it. Furthermore, your experience may help others who are experiencing something similar.

Mental health services – Where to get help

There's a range of resources and services available to help including phone and online services and information, as well as face to face support. Most services are free and provide information and confidential advice from trained professionals. If you're told that there is a waiting time for a service, please still reach out and make contact. Other supports can be put in place – ask what you can try in the meantime.

Helplines

- Need to talk? Free call or text 1737 any time for support from a trained counsellor.
- Lifeline – https://www.lifeline.org.nz/services/lifeline-helpline (0800 LIFELINE) or free text 4357 (HELP).
- Suicide Crisis Helpline – https://www.lifeline.org.nz/services/suicide-crisis-helpline (0508 TAUTOKO).
- Healthline – https://www.health.govt.nz/your-health/services-and-support/health-care-services/healthline
- Samaritans – https://www.samaritans.org.nz/
- Depression Helpline – https://depression.org.nz/contact-us/or free text 4202 (to talk to a trained counsellor about how you are feeling or to ask any questions).
- Vaka Tautua – Services offered in the languages of Samoa, Tongan, Cook Islands, Māori or English. Freephone 0800 OLA LELEI (652 535)

Endometriosis Support Groups

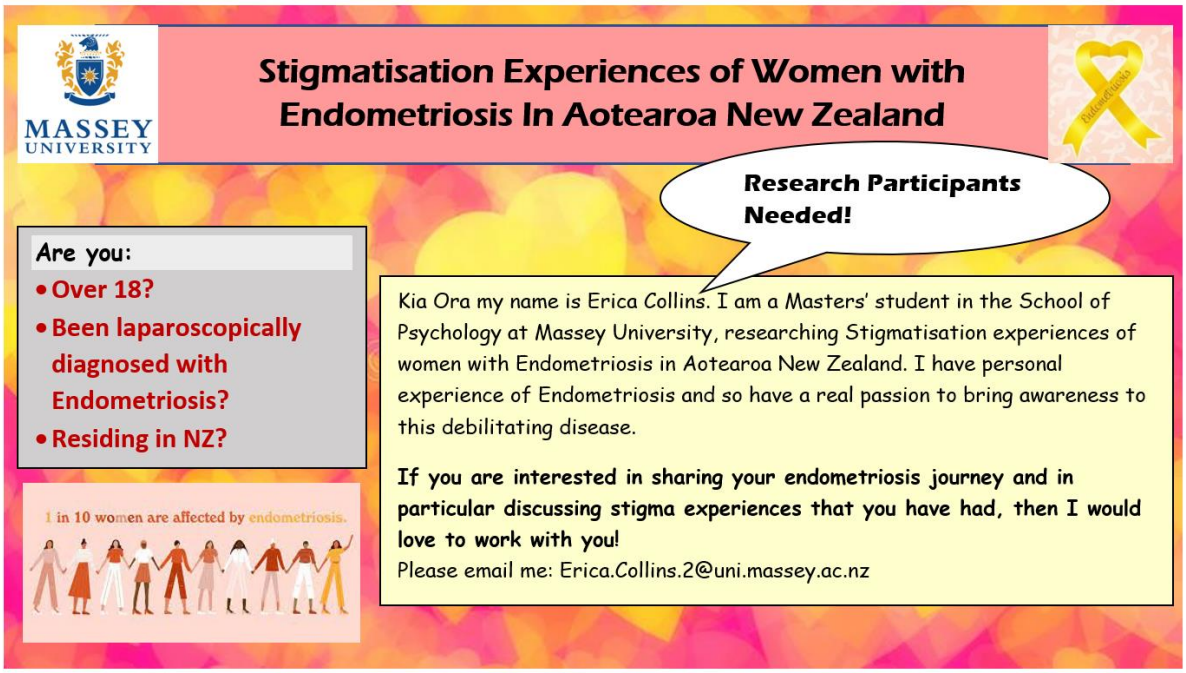
Endometriosis New Zealand

Endometriosis New Zealand provide information, help, support and advice on wellbeing.

Many people with endometriosis often feel isolated and overwhelmed. Sometimes it's helpful to talk to someone who 'gets it' and who can help you with an evidenced-based plan to address the issues you are facing. There are several ways to access information, help, support, or advice through the wellbeing service they offer.

Website: https://nzendo.org.nz/

Appendix B: Flyer



Appendix C: Consent Form

School of Psychology
Massey University
Private Bag 102-904
North Shore
Auckland 0745
Tel +64 9 414 0800 ext 43116
Fax +64 9 441 8157

PARTICIPANT CONSENT FORM

Exploring the stigmatization experiences of women with Endometriosis in Aotearoa New Zealand

I have read, or have had read to me, and I understand the Information Sheet. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw up to two weeks after I have released my transcript to be used in the study.

1. I agree/do not agree to the interview(s) being digitally audio-recorded
2. I understand that I can ask for the audio-recorder to be turned off at any point in the interview
3. I understand that the audio-recording will be destroyed once my interview has been transcribed
4. I understand that all information I give will be treated confidentially
5. I understand that I can read, discuss, and make edits to the transcript of my interview if I choose
6. I understand I will have access to a summary of the research at its completion
7. I understand and am happy to participate in the research under the conditions described in the Information Sheet provided.

Declaration by Participant:

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

Signature: _____ Date: _____

Appendix D: Interview Questions for Participants

INTERVIEW GUIDE- Questions for Participants

Concentrating on Endometriosis Journey

Demographic Questions

Name, Age, Ethnicity, Marital Status, Occupation, Age of Symptom Onset, Age of Diagnosis

Open Ended Questions:

- **Could you describe to me your journey to being diagnosed with Endometriosis?**
- **Tell me about how it is for you to live with endometriosis. Has endometriosis affected your life in any way?**
- **What strategies do you use to deal with your symptoms on a day-to-day basis?**
- **Could you describe any barriers you have come across to do with your diagnosis or treatment with endometriosis?**

Experiences of Stigma

Open Ended Questions:

- **Could you tell me about your early menstruation experiences?**
- **Could you please describe some of the reactions you get from family members, friends, or your partner when you share your symptoms or talk about your endometriosis?**
- **What is your experience of societal attitudes towards menstruation and endometriosis?**
- **Can you describe some of the reactions you have received from your doctor or specialist when you are visiting them for your endometriosis symptoms and/or treatment?**
- **Could you please describe any reactions you have received from colleagues surrounding your endometriosis?**

Appendix E: Full Interview Schedule

INTERVIEW GUIDE- Questions and prompts

This study will seek to explore stigmatization experiences women with endometriosis in Aotearoa New Zealand encounter, and in particular will investigate the plausibility of stigma as a factor influencing subordinate psychosocial well-being and diagnostic delay in women living with endometriosis. In doing so the proposed study will seek to answer the following questions:

1. How do women with endometriosis in Aotearoa New Zealand describe their experience of stigmatization?
2. How does experienced stigma influence help seeking behaviours for women with endometriosis in Aotearoa New Zealand?
3. How does experienced stigmatization impact the psychosocial well-being of women with endometriosis in Aotearoa New Zealand?

Concentrating on Endometriosis Journey

Demographic Questions

Name, Age, Ethnicity, Marital Status, Occupation, Age of Symptom Onset, Age of Diagnosis

Open Ended Questions/Prompts:

- **Could you please describe to me your journey to being diagnosed with Endometriosis?**

Prompts if needed: What made you seek help? Had you heard of endometriosis before your diagnosis? Did you understand what it was? How did it feel to be diagnosed with endometriosis? Did anything prevent you to seek help? What symptoms did you have? Who did you see to seek help? What treatment have you received for your endometriosis? Who did you see for treatments? (medical, surgical, psychological support, alternative therapies?)

- **Tell me about how it is for you to live with endometriosis**

Prompts: Could you describe your symptoms? Has endometriosis affected your life in any way? Are there aspects of your personal life that are affected? Or work life? Could you describe the affect endometriosis has had on your life? – physically, financially, emotionally. What are some of the emotions you feel when you think about your life with endometriosis? What sort of help have you sought with these emotions?

- **What strategies do you use to deal with your symptoms on a day-to-day basis?**

Prompts: How do you deal with your endometriosis on a day-to-day basis? What strategies do you use to cope? Who supports you? What do you do when you are having a bad flare up of endometriosis? How does it make you feel?

- **Are there any barriers you have come across to do with your diagnosis or treatment with endometriosis?**

Prompts: What has your experience been with the health system? How did it play a role in your diagnosis? Have you joined any support groups for your endometriosis? What sort of information did you receive when you were diagnosed with your endometriosis? Did you understand what endometriosis was when you were first diagnosed? How well do you think you understand endometriosis now?

Experiences of Stigma

- **Could you tell me about your early menstruation experiences?**

Prompts if needed: Was menstruation talked about in the home? By your mother? Friends? Did you feel like you had to hide your menstruation? Why? How did you feel when you were menstruating? Do you talk openly with your daughter(s) about menstruation? If no- why not?

- **Could you please describe some of the reactions you get from family members, friends, or your partner when you share your symptoms or talk about your endometriosis?**

Prompts if needed: Who do you tell? Are there particular people you disclose your endometriosis to, and why? Do you feel other people understand and are educated about what endometriosis is? How

do their reactions make you feel? How do you respond to their reactions? Do their reactions make you change your own behaviours in any way?

- **What is your experience of societal attitudes towards menstruation and endometriosis?**

  Prompts if needed: Do you feel easy to talk about these topics? What is your experience with the knowledge people have of these topics? Does your culture restrict the sharing of these topics in any way? What experiences have you had where you are treated differently because of your endometriosis or menstruation?

- **Can you describe some of the reactions you have received from your doctor or specialist when you are visiting them for your endometriosis symptoms?**

  Prompts if needed: Can you describe some of the reactions you have gotten from your doctor or specialist when you are visiting them for your endometriosis symptoms? How do these reactions make you feel? How did you respond to these reactions? Do you feel the doctors/specialists have a good understanding of what endometriosis is?

- **Could you please tell me about your endometriosis and the reactions you have received from colleagues?**

  Prompts: When have you needed to tell them about your endometriosis? How did they react? How do these reactions make you feel? Have their reactions made you change your own behaviours in any way?

Appendix F: Transcript Release Form

School of Psychology
Massey University
Private Bag 102-904
North Shore
Auckland 0745
Tel +64 9 414 0800 ext 43116
Fax +64 9 441 8157

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

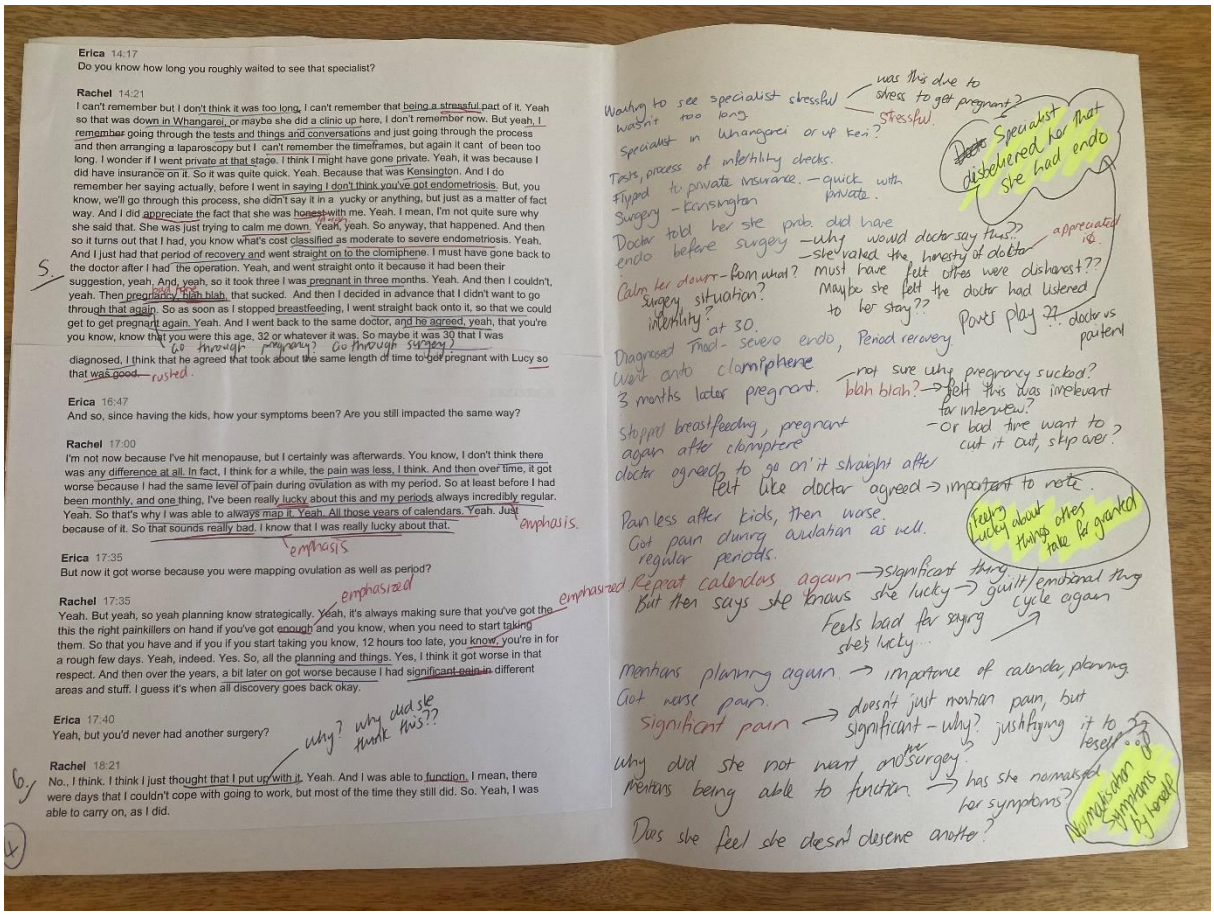
I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: ..... **Date:** .....

Full Name - printed .....

Appendix G: Exploratory Notes



Appendix H: Example of a Participant Experiential Theme (PET)

PET's Magda

PETS (Personal Experiential Statements) (Themes)	Experiential Statements (codes)	Quotes **having chronic illness is like staying afloat while carrying a heavy pack (pp. 15)** **it was like the rug got pulled out from underneath me (pp. 1)**
Abnormal symptoms were normalised by Others	Mum normalised the abnormal periods she had **Mum had bad symptoms, and also normalised her daughters due to thinking it was normal**	"Some people are like that". (pp. 1) "It's okay. You'll be okay" (pp .1) "don't put too much energy into it and just carry on". (pp. 3)
	Doctors normalised her pain	I ended up in emergency here. I had morphine up they put it up my bum because I couldn't hold anything down. And and he was like, Well, this is relatively normal (pp. 4) I remember like so out of it and just but him telling my friend that this is really totally normal (pp. 4) When you have every doctor replying with this as normal (pp. 4) "You know, how often you know, how many times do you go and pursue especially as a teen teen, you know, female, saying, hey, something doesn't seem right. And then saying, well, it is. So you just believe them." (pp. 3)
Normalisation of own pain	Normalising her own pain **Down-played her pain associated with her ruptured cyst**	I kept thinking this is like really making a big deal out of something that's not a big deal. I should just sit up and walk you know, like go find a good comfortable spot (pp. 1) It was just a cyst that ruptured. And that just happens sometimes (pp. 2) And you're kind of Yeah, you're fine enough, you know" (pp. 2) Yeah, again, would have had in my head that this is normal. (pp. 3) when I go back on my notes like diary notes, I think for real? was I really going through that?was I honestly it's it really that bad? I don't even believe that it's that bad. Im like was it really like that? (pp. 11)
	Didn't talk about it as she thought it was normal	"I don't think I was conscious of the fact that I wasn't telling everybody like by the way, this is really shit. This doesn't seem right because I just Yeah, again, would have had in my head that this is normal" (pp. 3)
	The pain was just what happens, unlucky	"And that just happens sometimes" (pp. 2)
	Thought everyone had painful periods	"So the fact that I'm having a response that other people can cope with. Yeah, I just remember thinking I can't understand how all of these women are having periods like this". (pp. 2) "I don't think I was conscious of the fact that I wasn't telling everybody like by the way, this is really shit. This doesn't seem right because I just Yeah, again, would have had in my head that this is normal" (pp. 3)
	Reassured herself about the pain symptoms	Would reassure herself that she was ok, and downplayed symptoms "And your kind of Yeah, you're fine enough, you know" (pp. 2)
The pain experienced was shocking, traumatic	Memories of Painful Periods	I thought I'll just probably die and I should tell somebody I'm dying so they know, because I just thought nobody can help me in this much pain and not die (pp. 4). "Like the rug got pulled out from underneath me" (pp. 1) "I just remember feeling like really, really bad pain" (pp. 1) "It was painful" (pp .1) I would have such bad pain that I literally thought like, well, if I'm going to the toilet, I'd bring my phone because I thought I'll just probably die and I should tell somebody I'm dying so they know, because I just thought nobody can help me in this much pain and not die. And I thought on the pain scale. I've always honestly thought that your pain scale from you know, one being not that bad. 10 I thought was death. I was like, Well, if you die then you've reached so much pain that your body will completely shut down on you. And so I'm yeah, just thought it was. Yeah, that (pp. 4).
	Memories of Pain after surgery	I was scared to fall asleep because I felt like I would die. (pp.8)
Medical Professionals dismissed symptoms, pain associated with endometriosis	Specialist refused to do further surgery despite her pain	I said so there's nothing you're gonna do. You wouldn't go in and do another surgery to get rid of the endometriosis and he was like nah. And then I thought, Okay, well there you go. That's it. (pp. 7)
	Other symptoms are quickly blamed on endometriosis	Oh, well, maybe you just have fibromyalgia (pp. 7) "I was having a lot of gastro problems from the ibuprofen. You see doctor saying, Oh, well, it's probably just your endometriosis" (pp. 12)

Appendix I: Example of Group Experiential Themes (GET)

	Sarah	Gloria	Rachel	Magda	Tee	Vanessa
Reactions from health professionals						
Dismissal, Trivalisation, Disbelief, Normalised, Not listened to						
Dismissed, trivalised, Didn't believe that she had endometriosis The invisible nature of the disease means doctors don't take it seriously Had no voice in her treatment plan- Wanted a hysterectomy much earlier, doctors wouldn't She felt the medical professionals would not listen Not being listened to, and being told you suffer from anxiety causes the anxiety, not Dismissal of the seriousness of the disease Other health issues were dismissed because she had endo, prevented diagnosis and Participant's own normalisation clouds the specialist's judgement Doctors normalised her pain Disbelieved her level of pain	The first gynaecologist basically just said to me, oh just go on the pill and it's not a big deal and just like totally because it's invisible, I guess, and they don't have, you know, unless you've actually got scans and stuff doctors would just say to me all this is normal just take brufen and panadol which did absolutely	And then I saw somebody down there. And same thing. He was an older male gynecologist. Yeah. I would have loved to have had a hysterectomy earlier. Yeah, I reckon if I'd had a hysterectomy From the moment I walked down, he decided he'd already decided what was there was nothing I think people with endo do have anxiety because it creates this whole thing where you're not So people would just be like, Oh, you've just got Endo. It's just your Endo. When it was actually other I went got sent to a gynecologist who told me my pain was just normal and I just needed to find a	my feeling was that there was no concern. And it was just a bugger and "I do remember her saying actually, before I went into surgery saying I don't think "And I think possibly she had thought, said that she didn't think I had it because of my sort of normalizing" (pp. 17) my feeling was that there was no concern. And it was just a bugger and something I "she questioned my level of pain" (pp. 16) "No, she didn't believe me"	I said so there's nothing you're gonna do. You wouldn't go in and do didn't want a hsyterecomy or birth control, hard to argue with doctors Oh, well, it might be something called endometriosis" (pp. 2) I ended up in emergency here. I had morphine up they put it up my bum	Yeah I remember changing Doctor three times , that obviously that was why Doctors wouldn't give hysterectomy when she asked years ago for pain.. if I I did ask when I went in there for the operation if they would do a It was like two minute or two minute chat which was basically like yes, we found one of the nurses was telling me oh, you need to go home, because we need the	It was like two minute or two minute chat which was basically like yes, we It was like two minute or two minute chat which was basically like yes, we
Disinterest - diagnosis						
doctors didn't seem interested in pushing for diagnosis Doctors disinterested unless it is related to fertility Medical team show disinterest in diagnosis due to difficulty, invasiveness, nuisance of Brushed off her symptoms as something else Lack of adequate questioning from medical professional resulted in delay of diagnosis	I was just trying to get something from a doctor and get them to actually diagnose with hormone stuff is like the worst, the worst (pp. 2) She was all about fertility and getting pregnant (pp. 2) all these different doctors that I've been to you know, first that was your family GP, then the other	From the from the medical side. I think there's, there's that kind of attitude. Like, you have to have	Got referred to gyno when in for infertility people don't necessarily ask the right questions" (pp. 17)	having kids. You could just have a hysterectomy. But it wasn't like there was no talk about the importance you want to have a baby, they'll put more energy into supporting your goal. Otherwise, they really just "Oh, you done having kids. You could just have a hysterectomy. But it wasn't have fibromyalgia (pp. 7) "I was having a lot of gastro	Doctor three times , that obviously that was why because I wasn't getting listened to. Otherwise I	
Power dynamics						
AGE Occupation, education Women	seriously when you were younger I think when I was in my 20s and 30s just kind of looked a little bit	He just didn't like that I was a nurse and then I was like health educated or something. He was Honestly, he should not be practicing. He hates women. I just felt like he hated me. From the		didn't know to kind of pursue further questioning" (pp. 2) Position of power medical team had prevented her from pursuing and having		
Judged/Labelled						
Felt Labelled by doctors Medical professionals labelled her as having anxiety/depression issues	And just a drama queen. Just a hypochondriac, (pp.3)I'm not just like, Yeah, this person is making this	I've had doctors tell me I have generalized anxiety, and I should go and see somebody for that and go on medication. And that's because I went with pain, and ... .There was a real long time there where it really affected me and		Felt judged as being 'difficult' or defiant by doctorIt also feels again like depressed" (pp. 12) At a later appt the same GP suggested that maybe symptoms are just because I there's a point in being the naggy patient" (pp. 4) "But		
Lack of knowledge						
GP knowledge Endo	I actually went to my doctor and I said, I suspect I have Endo. After saying this is my symptom. This is not through a medical professional that I had been to that said hey this sounds like this lets get some	Some of them. Yeah. Some of them definitely more so if they've had it, yeah, yeah. Yeah. anybody	I certainly don't remember any conversation about because of a friend who had it (p. 4)		I just continued just to be in pain, yeah. thinking this is just normal, whatever it is, was wrong (p. 1) But they didn't know why.	they sort of rule everything out and endo's not something that's everything out and endo's not something that's