The Barriers and Facilitators to the Diagnosis of Endometriosis in Aotearoa New Zealand

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Briana Wallis

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Abstract

Endometriosis is a debilitating chronic gynaecological disease that affects approximately 10% of people who menstruate worldwide. In Aotearoa New Zealand, it is estimated that 130,000 women have endometriosis, representing approximately 1 in 10 women who menstruate (Endometriosis New Zealand, 2022a). Endometriosis is a difficult disease to diagnose and currently the only definitive way to diagnose it is via laparoscopic surgery. Unfortunately, the journey to receiving a diagnosis is characterised by lengthy delays with many women experiencing long periods of time between symptom onset and receiving a diagnosis of the disease. Internationally it is estimated the diagnostic delay is an average of over 8 years, while in Aotearoa New Zealand a recent study found that the delay is diagnosis was an average of 8.7 years (Endometriosis New Zealand 2022a; Tewhaiti-Smith et al., 2022). The diagnostic delay of endometriosis is well-documented and widely reported in a number of qualitative and quantitative in the endometriosis space, however, there is a paucity of research that examines the reasons for the delay and ways to combat it. The aim of this research was to identify and develop a better understanding of the barriers and facilitators to the diagnosis of endometriosis in Aotearoa New Zealand by exploring women's accounts of their journeys to diagnosis. This research utilised online surveys to explore women's journeys to receiving a diagnosis of endometriosis in Aotearoa New Zealand and the barriers and facilitators they encountered. A total of 135 women took part in this research and answered a series of multiple choice and open-ended qualitative questions. Thematic analysis revealed five themes – the healthcare encounter, symptom concealment, education, taking control: advocacy, and the role of support. Each of these themes identified several barriers and facilitators across the individual, medical and societal levels. The findings of this research highlight that, in Aotearoa New Zealand, women experience challenging and often lengthy journeys to diagnosis and contributed new and unique insights to the barriers and facilitators women encounter on their journey to diagnosis and contributes to the limited literature on endometriosis available in the context of Aotearoa New Zealand.

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Chapter One: Introduction

What is endometriosis?

Endometriosis is a debilitating chronic gynaecological disease that predominately affects individuals assigned female at birth during their reproductive years (Bontempo et al., 2020; Johnson et al., 2017). Although the true prevalence of endometriosis is difficult to define, it is estimated that endometriosis affects approximately 10% of people who menstruate representing 179 million people worldwide. In Aotearoa New Zealand, it is estimated that 130,000 people will have endometriosis, representing 1 in 10 New Zealanders (Endometriosis New Zealand, 2022a; Ministry of Health 2022; World Health Organisation [WHO], 2021). It can affect people across all ethnic backgrounds and of any age, however, it most commonly affects women between the ages of 25 and 35 and in many cases, individuals will experience symptoms from their first period (11-15 years of age) (Wooster Hospital, 2019).

Endometriosis is a complex disease that is largely characterised by tissue similar to the endometrium, the lining of the uterus, growing outside of the uterus (Endometriosis New Zealand, 2022a). The ectopic endometrial-like tissue typically implants itself on the peritoneum and the organs within the pelvic region including the ovaries, fallopian tubes, bladder and the outside of the uterus. Although in some cases, the endometrial-like tissue has been observed on the pouch of Douglas (also known as the recto-vaginal pouch), bowel, lungs, gastrointestinal tract and abdominal surgical scars (Endometriosis New Zealand, 2022a; Lee et al., 2021; Sims et al., 2021; Young et al., 2015). The ectopic endometrial-like tissue behaves similarly to the endometrium which lines the uterus and responds to the reproductive hormones that trigger menstruation. Consequently, each month as the endometrium builds up, breaks down and bleeds during menstruation so does the ectopic tissue. However, unlike the endometrium in the uterus which leaves the body in the form of a period, when the ectopic tissue breaks down and bleeds, the blood and excess tissue cannot escape the body resulting in inflammation, cysts, chronic pain and a variety of other debilitating symptoms (Cox et al., 2003; Sikka & Brar, 2020; Sims et al., 2021; Young et al., 2015).

There are three types of endometriosis lesions that have been identified: superficial peritoneal lesions, endometriomas (ovarian lesions), and deeply infiltrating endometriosis (DIE). It is possible for an individual to have more than one type of endometriosis lesion at the same time (Franco-European Multidisciplinary Institute for Endometriosis [IFEM Endo], 2022). Superficial peritoneal lesions are the most common, accounting for approximately 80% of all endometriosis diagnoses. These lesions are small, superficial lesions that occur on the peritoneum (a membrane that lines pelvic organs and the wall of the pelvic cavity). Superficial peritoneal lesions typically infiltrate no deeper than 5 millimetres into the peritoneum and upon visualisation, they may appear as small patches of red, brown, black or white powder-like burns. It is widely believed that red lesions indicate active bleeding and inflammation; brown and black lesions indicate old bleeding; and white lesions indicate that a healing process has occurred (Giudice, 2010; IFEM Endo, 2022). Endometriomas, also known as ovarian lesions, are the second most common type of endometriosis lesion, accounting for approximately 17 to 44% of endometriosis diagnoses. These lesions form when ectopic endometrial-like tissue implants into the surface of the ovary. Upon visualisation, these lesions appear as dark brown fluid-filled cystic structures, therefore, they are often referred to as chocolate cysts (Hoyle & Puckett, 2022; IFEM Endo, 2022; Insight Endometriosis, 2022). Finally, deeply infiltrating endometriosis (DIE) is the least common endometriosis lesion, representing approximately 15-20% of all endometriosis diagnoses. DIE is an aggressive form of endometriosis characterised by hard fibrous lesions that infiltrate at least five millimetres into organs within or outside of the pelvic cavity, including the ovaries, fallopian tubes, bowel, bladder, rectum and lungs. In many cases, DIE leads to severe inflammation and the formation of scar tissue which in rare cases, can bond organs together (Advanced Gynaecology Melbourne, 2022; IFEM Endo, 2022).

In addition to endometriosis being identified by the type of lesion, the American Society of Reproductive Medicine (ASRM) developed a staging system to assess and classify the severity of the disease. This staging system includes four stages: stage 1 (minimal), stage 2 (mild), stage 3 (moderate) and stage 4 (severe). The stage is based on the size, location, depth, number, and type of lesion, however, it also takes into consideration the spread of ectopic tissue and which organs are involved (Endometriosis New Zealand, 2022a; Làgana et al., 2017; Lee et al., 2021). While the ASRM staging system provides healthcare providers with a useful tool to classify and describe the extent of a patient's endometriosis, it continues to attract criticism. The biggest limitation of this staging system is that the classification only considers the physical disease and does not take into account the severity of pain or the endometriosis-related symptoms the individual might be experiencing (Abokhrais, 2018; Cains et al., 1997; Lee et al., 2021). In other words, the stage of endometriosis does not necessarily correspond to the severity of symptoms, therefore, an individual with stage 1 endometriosis may experience debilitating symptoms that interfere with their quality of life while an individual with stage 4 may experience none (Endometriosis New Zealand, 2022a; Laganà, 2017; Lee et al., 2021). Another significant limitation of the ASRM staging system is that endometriosis can only be classified by a gynaecologist during a therapeutic or diagnostic laparoscopy.

Causes of Endometriosis

Following the identification of endometriosis in the 1860's, there have been many investigations into the cause of the disease resulting in multiple theories of aetiology. The four most widely accepted theories include retrograde menstruation, coelomic metaplasia, vascular and lymphatic metastasis, and immune dysfunction (Asghari et al., 2018; Denny & Mann, 2007). It is important to note that despite many years of research and various theories attempting to explain the aetiology of endometriosis, the true aetiology of the disease is not fully understood and remains largely unknown (Signorile & Baldi, 2010; Smolarz et al., 2021). I will briefly describe each theory in turn.

The theory of retrograde menstruation, proposed by Sampson in 1927, proposes that endometriosis occurs as a result of endometrial tissue which is shed during menstruation retrograding, or moving backwards, through the fallopian tubes and into the pelvic cavity. Once in the pelvic cavity, the misplaced tissue attaches itself to the wall of the pelvic cavity and establishes a blood flow subsequently forming lesions and cysts which respond to the hormonal changes that occur during the menstrual cycle (Sampson, 1927 in Signorile & Baldi, 2010; Smolarz et al., 2021). While Sampson's theory of retrograde menstruation is the most widely accepted theory for the development of endometriosis; it is important to acknowledge that this theory cannot fully explain the aetiology of endometriosis. This theory fails to explain the early onset of endometriosis in newly menarcheal or pre-menarcheal girls and it does not explain why endometriosis only occurs in approximately 10% of women while retrograde mensuration occurs in approximately 80% of women who menstruate (Ashgari er al., 2018; Bloski & Pierson, 2011; Smolarz et al., 2021). Additionally, the theory of retrograde menstruation fails to explain how endometriosis lesions occur in regions outside of the pelvic cavity such as on the lungs and diaphragm (Bloski & Pierson, 2011; Denny & Mann, 2007).

The coelomic metaplasia theory postulates that the formation of endometriosis occurs as a result of metaplasia of cells in the coelomic epithelium. In other words, endometriosis occurs as a result of the cells in the coelomic epithelium transform into endometrium inappropriately (Monga, 2006 in Denny & Mann, 2007; Signorile & Baldi, 2010). It is believed that metaplasia of the cells in the coelomic epithelium is triggered by the presence of hormonal or environmental toxins, or stress such as inflammation or irritation from retrograde menstruation (Bloski & Pierson, 2011; Signorile & Baldi, 2010). The coelomic metaplasia theory explains why only a small percentage of women have endometriosis despite approximately 80% of women having some degree of retrograde menstruation, as well as the occurrence of endometriosis in pre-menarcheal girls (Signorile & Baldi, 2010; Sourial et al., 2014). However, many researchers criticise this theory, as if coelomic metaplasia fully explained the aetiology of endometriosis then higher rates of endometriosis would be expected (Bloski & Pierson, 2011).

Another theory that has been proposed to explain the aetiology of endometriosis is the theory of vascular and lymphatic spread. As the name suggests, vascular and lymphatic spread proposes that fragments of endometrial tissue infiltrate the vascular and lymphatic systems and travel to parts of the body outside of the pelvic cavity via these systems (Denny & Mann, 2007; Bloski & Pierson, 2008). This theory is useful in explaining the presence of endometriosis in locations outside of the pelvic cavity such as the lungs, breasts, gastrointestinal tract, umbilicus, and abdominal surgical scars (Denny & Mann, 2007). However, researchers argue that as the incidence of endometriosis outside of the pelvic cavity is rare, this theory does not explain the primary cause of endometriosis (Bloski & Pierson, 2008).

The final theory, called altered immunosurveillance, proposes that endometriosis is associated with a dysfunctional immune system (Dmowski et al., 1998 in Bloski & Pierson, 2008). Within a normally functioning immune system, macrophages, T and B lymphocytes and phagocytes would normally identify, recognise, and destroy ectopic endometrial tissue as it does to other foreign material (Denny & Mann, 2007; Smolarz et al., 2021). However, as the theory of altered immunosurveillance postulates, in women with endometriosis, their immune system does not respond detect or eradicate the ectopic endometrial cells, allowing them to attach themselves within the pelvic cavity and establish a blood supply (Bloski & Pierson, 2008; Denny & Mann, 2007). While this theory takes a different approach to the theories of retrograde menstruation, coelomic metaplasia, and vascular and lymphatic spread, it is arguably supported by evidence indicating that women with endometriosis are more likely to experience other immune-related conditions such as eczema or allergies (Denny & Mann, 2007).

In addition to the various theories attempting to explain the aetiology of endometriosis, there are multiple risk factors that have been associated with the development of the disease (Sharif et al., 2018; Smolarz et al., 2021). The risk factors associated with endometriosis include early age at menarche (first cycle before age 11-13), short menstrual cycle length (<27 days), long menstrual flow (>7 days), Mullerian anomalies, outflow obstructions such as transverse vaginal septum or an imperforate hymen, low birth weight, lack of physical activity, exposure to endocrine disrupting chemicals and high consumption of red meat and trans-fats (Saha et al., 2015; Sharif et al., 2018; Smolarz et al., 2021). There also appears to be a genetic component to endometriosis as the disease seems to run in families. It has been estimated that women are up to 7-10 times more likely to develop endometriosis if there is a family history of the disease in their immediate family (Endometriosis New Zealand, 2022a; Saha et al., 2015). Additionally, it is important to note that a low BMI has been previously believed to be a risk factor of endometriosis; however, recent data suggests there is generally no association between low BMI and the incidence of the disease (Smolarz et al., 2021).

In summary, since endometriosis was first medically labelled, there have been various theories attempting to explain the aetiology of the disease and several risk factors have been identified. Despite this, many of the theories cannot fully explain the development of the disease, as such, it is assumed that the aetiology is multifactorial involving hormonal, immune and environmental factors so for the meantime the disease remains enigmatic (Endometriosis New Zealand, 2022a; Signorile & Baldi, 2010; Smolarz et al., 2021).

Treatment

There is currently no cure for endometriosis, therefore, the disease is overmedicalised and treatment is largely centred around suppressing and improving one's symptoms. The most common treatments used for endometriosis are hormonal treatments, laparoscopic surgery and pain management (Endometriosis New Zealand, 2022b; Guidice, 2010), which I will discuss in turn.

Hormonal treatment

Hormonal treatments are currently the most common for treatment of endometriosis and are considered the first line of treatment (Vannuccini et al., 2021). Endometriosis is an oestrogen dependent disease; therefore, a constant supply of oestrogen encourages ectopic endometrial-like tissue to grow and shed with menstruation and is necessary for the survival of endometriosis implants and lesions. The goal of hormonal treatments is to reduce or stop the production of oestrogen in attempt to inhibit the growth of endometriosis (Black and Fraser, 2012; Rafique & DeCherney, 2017). Hormonal treatments that rely on reducing the production of oestrogen include combined oral contraceptive pills, progestogens including progesterone-only oral contraception, contraceptive injection (Depo Provea) and intra-uterine devices including the Mirena, and Gonadotropin-releasing hormone (GnRH) analogues (Endometriosis New Zealand, 2022b; Rafique & DeCherney, 2017).

Combined oral contraceptives (the pill) contain both progestogen and oestrogen and are the most widely used form of hormonal treatment for endometriosis (BPAC, 2013). In circumstances where women are purely using the pill for birth control, they are advised to take the 21-day active pill followed by the 7-day inactive pill to mimic the natural menstrual cycle. However, when used for the treatment of endometriosis, women are advised to take the active pill continuously or semi-continuously meaning they either skip the inactive pills to prevent menstruation from occurring or skip them for three-six months before taking them to induce menstruation (BPAC, 2013; National Institute of Child Health and Human Development [NICHD], 2020). In endometriosis the ectopic endometrial-like tissue sheds and bleeds with menstruation resulting in inflammation, cysts, chronic pain and a variety of other debilitating symptoms, therefore, the theory behind taking the active pill continuously or semi-continuously is that menstruation ceases meaning the ectopic endometrial-like tissue should no longer shed and bleed, slowing the progression of the disease and helping to reduce inflammation and endometriosis-related symptoms (Family Planning, 2016; NICHD, 2020; Rafique & DeCherney, 2018). While the pill is effective in reducing endometriosis-related symptoms and slowing the progression of the disease, they are not always effective in treating endometriosis and have been used with varying degrees of success (Rafique & DeCherney, 2018).

Progestogen-only contraceptives are used as an alternative to combined oral contraceptives. This type of contraception is available in a variety of formations including progestogen-only oral contraceptive pills, the contraceptive injection (Depo Provera), contraceptive implants (the rod) and intrauterine implants such as the Mirena (Family Planning, 2016; Vannuccini et al., 2022). The use of Progestogen-only contraceptives inhibits ovulation and induces changes to the endometrium and the ectopic endometrial-like tissue responsible for endometriosis. This helps to inhibit inflammation, suppress endometriosis-lesions and provoke the death of endometrial cells, reducing the progression of the disease and improving endometriosis-related symptoms (Rafique & DeCherney, 2018; Vannuccini et al, 2022). Additionally, in instances where combined oral contraceptives and progestogen-only contraceptives are ineffective, GnRH analogues are typically used. GnRH analogues essentially work to suppress ovulation and reduce the production of oestrogen and progestogen by the ovaries inducing temporary menopause. As a result, ectopic-endometrial tissue and endometriosis lesions are no longer stimulated to grow which again reduces the occurrence of endometriosis-related symptoms (Küpker et al., 2002; Vannuccini et al., 2022).

Hormonal treatments are successful in slowing the progression of the disease and reducing endometriosis-related symptoms; however, they have been associated with many unwanted and adverse side effects. This includes gastro-intestinal disturbances, headaches and migraines, mood changes, weight changes, changes in libido, spotting or break-through bleeding, acne, depression, sleep disturbances, breast tenderness, excessive facial hair growth, bone mineral density loss and menopausal symptoms such as hot flushes (BPAC, 2013; NICHD, 2020; Vannuccini et al., 2022). Despite the many side-effects hormonal treatments are considered an integral component for treating endometriosis but require trial and error to establish the best option for women (Black & Fraser, 2012; Guidice, 2010).

Laparoscopic surgery

Currently, laparoscopic surgery is the only way to definitively diagnose endometriosis, however, it is also an effective treatment tool for reducing endometriosis-related symptoms such as pain and increasing women's fertility (BPAC, 2013). When undergoing laparoscopic surgery, a laparoscope is inserted through small incisions made below the belly button (naval) and on the lower abdomen so the internal organs in abdomen and pelvic cavity can be seen and endometriosis can be identified. During the surgery, if endometriosis is identified, then the surgeon will attempt to remove it using excision (removal of the ectopic tissue via cutting), ablation (destroying the ectopic tissue using diathermy), or a combination of both (Endometriosis New Zealand, 2022b, Guidice, 2010). The technique used to remove the endometrial-like tissue is decided by the surgeon and depends on the severity of the endometriosis and the size and location of the lesions; however, excision is preferred as it allows for the tissue to be sent for histological confirmation (Cheong et al., 2008; Endometriosis New Zealand, 2022b). While laparoscopic surgery is effective in improving women's symptoms, it may take weeks or months after surgery for symptoms to be alleviated (Endometriosis New Zealand, 2022b). Additionally, laparoscopic surgery does not treat the pathogenic mechanism of endometriosis, therefore the recurrence of endometriosis and women's symptoms is relatively high, with symptoms returning within one year for approximately 10-20% of women and within five years for approximately 40-50% of women (Black & Fraser, 2012; Cheong et al., 2008; Verecllini et al., 2014). As a result of the high rate of reoccurrence, this leads to women with endometriosis having multiple laparoscopies surgeries (Endometriosis New Zealand, 2013).

In cases where a woman's endometriosis is severe and pervasive, they may undergo a hysterectomy (removal of uterus) or an oophorectomy (removal of one or both ovaries) in addition to the excision or ablation of endometriosis. A hysterectomy is considered when a woman has long-standing painful and extensive endometriosis; while an oophorectomy is usually only considered when a woman's ovaries have been severely damaged by endometriomas (ovarian cysts) (Endometriosis New Zealand, 2022b; Ghai et al., 2020). Unfortunately, a hysterectomy or an oophorectomy is not always effective in treating the symptoms of endometriosis and there is a chance that one's symptoms will persist after removal given it will not cure endometriosis (Ghai et al., 2020).

Pain management

The final treatment for endometriosis that I will discuss is pain management which is often used in conjunction with other forms of treatment. Pain management includes the use of analgesics (pain relief), alternative and complementary treatments and self-management techniques (Endometriosis New Zealand, 2022c). Simple analgesics including paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and naproxen are believed to be effective in managing acute or mild pain associated with endometriosis, while strong analgesics (opioids) like codeine, tramadol and gabapentin which require a prescription are believed to be effective in managing severe and chronic pain associated with endometriosis (Maddern et al., 2020; NICHD, 2020). Despite the belief that analgesics are effective in managing pain associated with endometriosis, the reality is that many simple analgesics which can be purchased over the counter are ineffective in combating women's pain (Maddern et al., 2020). As a result, many women either find themselves in the emergency department several times a month or having multiple appointments with their general practitioner (GP) complaining about pain. However, due to the lack of awareness and lack of understanding of endometriosis, these women are often viewed as drug-seekers or attention-seekers and end up having their pain dismissed or downplayed by their healthcare providers while being denied the pain medication they require (Moradi et al., 2014; Huntington & Gilmour, 2005). Additionally, in discussing the use of analgesics to treat endometriosis, it is important to note that while analgesics can reduce or inhibit pain and can have an anti-inflammatory effect, they have no impact on the ectopic endometrial-like tissue or endometriosis lesions (Madderen et al., 2020; Mechsener, 2022).

It is also common for women with endometriosis to seek out more holistic pain management approaches and utilise alternative and complementary treatments and self-management techniques. These include dietary supplements, nutritional changes, exercise, meditation, yoga, herbal treatments, acupuncture, naturopathy and Chinese herbal medicine (Endometriosis New Zealand, 2022c; Mechsener, 2022). Women often turn to alternative and complementary treatments after experiencing dissatisfactory and negative interactions with healthcare providers and other methods of treatment are often trialled and adapted by women to suit their needs (Cox et al., 2003; Huntington & Gilmour, 2005).

Symptoms

Endometriosis is a complex multi-form disease which presents itself in a variety of ways and is associated with a wide range of symptoms. The most common symptom associated with endometriosis is pain. This includes pain during menstruation (dysmenorrhea), pain during or after sexual intercourse (dyspareunia), lower back pain and chronic pelvic pain (Endometriosis New Zealand, 2022; Grundström et al., 2015; van der Zanden et al., 2019). Other symptoms that frequently accompany endometriosis include heavy and irregular menstrual bleeding, fatigue and low energy, abdominal bloating, and bowel and bladder issues such as diarrhoea, constipation, pain with bowel movements, and pain with urination (dysuria) (Agarwal et al., 2019; Culley et al., 2013; Lamvu et al, 2020). Endometriosis has also been connected to compromised fertility with estimates suggesting that 30-40% of women with endometriosis suffer from sub-fertility or infertility (Cox et al., 2003; IFEM Endo, 2022).

Endometriosis symptoms vary significantly in intensity and severity from woman to woman, with some women experiencing no symptoms at all (asymptomatic) while others experience excruciating and debilitating symptoms. It remains a mystery as to why some women are symptomatic while others remain asymptomatic given research has shown that the stage of the disease does not correlate with the symptoms an individual present with or the severity their symptoms (Grundström et al., 2015; Kissel and Sourouni, 2019). Additionally, while the presentation of endometriosis is highly variable, the symptoms tend to be cyclical in nature, that is, they occur during menstruation. While women may experience their symptoms while they are not menstruating, the intensity of symptoms remains most severe during menstruation (Agarwal et al., 2019; IFEM Endo, 2022).

Diagnosis

How is endometriosis diagnosed?

In gynaecological practice, endometriosis is a problematic and complex disease to diagnose. It cannot be identified or diagnosed with a simple blood test and diagnosis based on symptoms alone is unreliable. This is because endometriosis is associated with a wide range of non-specific symptoms which vary from person to person and overlap with various gynaecological and nongynecological conditions such as adenomyosis, irritable bowel syndrome (IBS), urinary tract infections, ovarian cysts, pelvic pain and pelvic inflammatory disease (Berker & Seval, 2015; Hunt et al., 2021).

At present, laparoscopic surgery is the gold standard for diagnosing endometriosis. Laparoscopic surgery is a surgical procedure performed under general anaesthesia, which involves a laparoscope being inserted through small incisions made below the belly button and on the lower abdomen so the internal organs in the abdomen and pelvic cavity can be visualised, endometriosis lesions can be identified, and a small biopsy of tissue can be taken for histological confirmation (Endometriosis New Zealand, 2022b; Hunt et al., 2021; Pascoal et al., 2022). Although laparoscopic surgery is considered a minimally invasive procedure, there is a 7.5% risk of minor complications and a 1.4% risk of major complications occurring. Additionally, laparoscopic surgery is also used to treat endometriosis, therefore, at the time of diagnosis a surgeon may decide to excise any lesions or cysts they find meaning it can take weeks or even months for women to fully recover following a laparoscopic surgery – especially if endometriosis is found and excised (Endometriosis New Zealand, 2022b; Hunt et al., 2021).

Unsurprisingly, laparoscopic surgery for diagnostic purposes must be performed by a gynaecologist or another surgeon who is trained in identifying endometriosis. However, in Aotearoa New Zealand, like many other countries, before a woman can receive the diagnostic surgery, they must first be referred by their GP to a gynaecologist who will assess their symptoms and perform tests to establish whether they fit the criteria for receiving the surgery (American Society for Reproductive Medicine [ASRM], 2012). Generally, individuals will be referred through to a gynaecologist in the public system. However, in the case where individuals have health insurance, they may have their GP refer them to a private gynaecologist; or they may simply choose to self-refer and refer themselves to a private gynaecologist of their choosing (ASRM, 2012; Endometriosis New Zealand, 2022b). However, in both the private and public system, despite having received a referral to a gynaecologist, getting an appointment with these specialists to determine the next steps and set a date for surgery can take months, even years (Rea et al., 2020).

Although laparoscopic surgery is the gold standard and is the only reliable and definitive way to diagnose endometriosis, recently there has been a shift towards clinical diagnosis of endometriosis which combines clinical history and symptoms with physical examination to diagnose the disease (Pascoal et al., 2022; Riazi et al., 2015). A detailed clinical history focusing on the most common symptoms of endometriosis and the severity of said symptoms should be taken when an individual presents to their healthcare provider with symptoms consistent with endometriosis. The clinical history should consider both gynaecological symptoms such as pain during menstruation (dysmenorrhea), pain during or after sex (dyspareunia), pelvic pain and infertility; and non-gynaecological symptoms such as fatigue and low energy, bowel and bladder issues and back pain (Agarwal et al., 2019; Pascoal et al., 2022). While symptoms associated with endometriosis are generally indicated in initial assessments, there are limitations to the accuracy of clinical history and symptoms in predicting a diagnosis. For instance, the way an individual perceives and communicates their symptoms is variable and highly subjective; and subjectivity in healthcare providers' assessment of their patient's symptoms may impact diagnostic accuracy. Additionally, common symptoms of endometriosis such as pain, bowel and bladder issues, and infertility overlap with several gynaecological and nongynecological conditions which may lead to misdiagnoses (Hunt et al., 2021; Pascoal et al., 2020). For these reasons, endometriosis cannot be diagnosed on clinical history and symptoms alone and must be used alongside other diagnostic methods such as physical examination.

There are several methods of physical examination that can be used to help guide a diagnosis of endometriosis. This includes pelvic examination and imaging techniques such as transvaginal (TV) ultrasound and magnetic resonance imaging (MRI) (Pascoal et al., 2022; Wee-Stekly et al., 2015). Pelvic examinations are conducted on women when their history and symptoms suggest a possible diagnosis of endometriosis and typically involve abdominal palpitation and internal examination. Abdominal palpation cannot identify whether an individual has endometriosis, although, it may help identify any anatomical abnormalities and tender areas; while internal examinations can help identify the presence of lesions or cysts on the vagina and cervix as they can be visualised if present (American Society for Reproductive Medicine, 2012; Hunt et al., 2021; Pascoal et al., 2022). There is limited benefit with using pelvic examination in the diagnosis of endometriosis. Pelvic examinations, particularly those involving abdominal palpitation and internal examination are unreliable as it is not possible to feel endometriosis lesions or cysts unless a sizable cyst has formed; and the absence of lesions and cysts on the vagina or cervix during internal examination does not mean an individual does not have endometriosis as it may be present in other unobservable areas. Additionally, for some women, having to undergo a pelvic examination can be extremely confronting and it can be a painful experience, especially for those experiencing high levels of pelvic pain (Hunt et al., 2021; Pascoal et al., 2022). In comparison to pelvic examinations, imaging techniques such as TV ultrasound and MRI provide a better option for visualising endometriosis and are less invasive (Pascoal et al., 2022). TV ultrasound and MRI are particularly useful for detecting endometriomas and DIE; however, they have limited value in identifying adhesions and superficial lesions as they lack sufficient resolution (BPAC, 2013; Hsu et al., 2010; Wee-Stekly et al., 2015).

Diagnostic delay

Endometriosis is a complex multi-form disease which presents itself in a myriad of ways and is associated with a wide range of symptoms. It is a difficult disease to diagnosis and currently the only definitive way to diagnose endometriosis is via laparoscopic surgery as there are no accurate non-invasive diagnostic tests and imaging techniques add little value (Hunt et al., 2021; Pascoal et al., 2022). Unfortunately, the journey to diagnosis is charactered by lengthy delays with many women experiencing long periods of time between symptom onset and receiving a formal diagnosis of the disease (Dixon et al., 2021; Lamvu et al., 2020; Wren & Mercer, 2021).

The diagnostic delay of endometriosis is well-documented and widely reported in a number of qualitative and quantitative studies. In Aotearoa New Zealand, a recent study by Tewhaiti-Smith et al. (2022) found that the average time between initial presentation of symptoms and receiving a diagnosis of endometriosis is 8.7 years; while internationally, it is estimated that the average the delay between symptom onset and receiving a diagnosis of endometriosis remains an average of over 8 years (Endometriosis New Zealand, 2022a; Wren & Mercer, 2021). The delay in diagnosis has been associated with a range of consequences, including an increase in the number and severity of symptoms and it can exacerbate decreases in physical, psychological and social well-being (Lamvu et al., 2021; Pettersson & Berterö, 2020). Additionally, lengthy diagnostic delays can adversely affect reproductive capabilities and result in delayed access to appropriate treatment; often meaning women are left to deal with their symptoms, some of which are painful and not well-understood by others (Pettersson & Berterö, 2020; Sims et al., 2021).

Endometriosis in Aotearoa New Zealand

There is a surprising lack of accurate data and statistics on endometriosis, chronic pelvic pain and polycystic ovary syndrome (PCOS) (Tewhaiti-Smith et al., 2022). There is even less data for women who were not assigned female at birth or of non-heterosexual women. In addition, there is very little information for Māori, Pasifika, and other ethnic minorities in Aotearoa New Zealand. A cross-sectional survey conducted by Tewhaiti-Smith et al. (2022) found that of 800 people, 12.1% of respondents were Māori. The barriers and facilitators to healthcare in Aotearoa New Zealand are linked to the social determinants of health (e.g., socioeconomic status, biological factors, culture and ethnicity, population based services) (Anisman, 2016; National Advisory Committee on Health and Disability, 1998). This suggests that ethnicity, where you live and other factors external being a woman may act as a barrier to women receiving a diagnosis of endometriosis.

Chapter Two: Literature Review

The focus of this chapter is to provide a review of the current literature in the endometriosis space surrounding women's experiences of receiving a diagnosis of endometriosis, specifically, the facilitators and barriers they encounter while on their journey to diagnosis. In order to provide effective healthcare to women, including lesbian, bisexual, queer women and transgender men (individuals who are born biologically female and identify or present as male), research that examines their experiences in their own voices is needed (Lawson & Marsh, 2017). Historically, healthcare research has typically excluded the lived experiences of women and their voices, resulting in a limited understanding of women's health experiences (Lawson & Marsh, 2017). This is especially true for research on menstruation, reproductive health and conditions that affect women such as endometriosis and polycystic ovary syndrome. In the endometriosis space, the current body of literature has an abundance of research exploring the scientific and medical aspects of endometriosis. However, there is limited research which explores women's lived experiences of endometriosis, and there is even less research which explores their journey to receiving a diagnosis. While scientific and medical knowledge regarding endometriosis is important, the missing perspective of women can be detrimental to the care they receive, which is evidenced by the diagnostic delay of endometriosis (Young et al., 2018).

In the existing body of literature in the endometriosis space, the diagnostic delay of endometriosis is well-documented by a number of qualitative and quantitative studies. However, there appears to be a very limited number of studies that explore the reasons for the diagnostic delay and ways to reduce it (Ballard et al., 2006; van der Zanden et al., 2020). The current body of research in the endometriosis space that explores the women's experiences and perceptions of the diagnostic delay predominately focuses on their experiences of receiving a diagnosis of and living with endometriosis (Ballard et al., 2006; Cox et al., 2003b; Fernely, 2021; Grogan et al., 2018; Lamvu et al., 2020; Moradi et al., 2014; Wren & Mercer, 2021; van der Zanden et al., 2021; Zale et al., 2020) and their interactions with healthcare providers (Cox et al., 2003a; Grundström et al., 2017; Pettersson & Berterö, 2020; Young et al., 2020). Further, there appears to be a few qualitative studies which explore the diagnostic delay from the perspective of healthcare providers, focusing on their experiences of diagnosing women with endometriosis (Dixon et al., 2021; Grundström et al., 2017; van der Zanden et al., 2020; Zale et al., 2020). While there is a limited body of research in the endometriosis space that explicitly focus on the reasons for the diagnostic delay and possible ways to reduce it, the existing literature identifies several barriers and facilitators to the diagnosis of endometriosis from the perspective of the women themselves and healthcare providers. As such, in this chapter, I will explore the facilitators and barriers that have been identified by prior research. I will start this chapter by discussing the barriers that have been identified. Following this, I will discuss the facilitators that have been identified before concluding the chapter by providing an outline of this research, including the research aims and objectives.

Barriers to diagnosis

Prior research suggests that the diagnostic delay of endometriosis is extensive, however, there is a lack of research which explicitly explores the reasons for the delay, that is the barriers women experiences on their journey to receiving a diagnosis. While there is a lack of research that explicitly explores the reasons for the delay, there have been several studies which explore women’s experiences and perspectives of the diagnostic delay, focusing on their experiences of living with endometriosis and receiving a diagnosis, as well as their interactions with healthcare providers. This body of research suggests that the reason for the diagnostic delay is complex with several factors contributing to the delay, highlighting the normalisation and dismissal of symptoms, symptom concealment, ineffective clinical practice and lack of knowledge as factors contributing to the diagnostic delay and acting as barriers for women while seeking a diagnosis. Each of these factors will be discussed in detail below.

Normalisation and dismissal

A common theme identified in the current body of literature regarding the diagnostic delay of endometriosis is the normalisation and dismissal of endometriosis-related symptoms. One of the earliest studies exploring the diagnostic delay of endometriosis, conducted by Ballard et al. (2006) described the women in their study as perceiving their disruptive periods as an extreme normality, considering themselves unlucky to have bad periods rather than seeing themselves as unwell. Similarly, Moradi et al. (2014) highlighted women's accounts of not taking their symptoms seriously and normalising their severe pain and symptoms as a normal part of menstruation. Although, Moradi et al. (2014) did not explore why the women in their study did not take their symptoms seriously or why they normalised them.

While there is evidence suggesting that women, themselves, normalise and dismiss their endometriosis-related symptoms, there are several studies which highlight women's experiences of frequently having their symptoms normalised and dismissed by their healthcare providers. Ballard et al. (2006) was the first to uncover women's experiences of having their symptoms normalised and dismissed by healthcare providers. In their findings, Ballard et al. (2006) described woman's perceptions of disbelief surrounding the genuineness or severity of their symptoms when interacting with healthcare providers and highlighted their experiences of being told that their pain was normal and something they would have to learn to cope with. Similarly, Grogan et al. (2018) found that women frequently perceived that their symptoms were not taken seriously by their healthcare providers and that they were not believed even when they stressed the severity of their symptoms.

These findings from Ballard et al. (2006) and Grogan et al. (2018) are supported by several studies that describe women’s encounters with healthcare providers who made them feel like they were overreacting or overexaggerating, making a fuss over nothing, imagining their symptoms or that they had a low pain threshold (Denny & Mann, 2008; Grogan et al., 2018; Grundstrom et al., 2017). It was common for women to encounter healthcare providers who positioned their symptoms as a normal feature of menstruation or as painful periods, suggesting their symptoms are something that they should be able to deal with as they are part of being a woman (Denny & Mann, 2008; Pettersson & Berterö, 2020; Young et al., 2015). This was made clear by Pettersson and Berterö (2020) who described women's experiences of having healthcare providers attribute their symptoms to normal menstruation without examining whether there were any underlying causes; and Denny and Mann (2008) who discussed women's experiences of repeatedly visiting GPs only to be told that they were unlucky to suffer from period pain and being given pain killers or oral contraception which rarely made a difference to their symptoms. Having healthcare providers normalise and dismiss their symptoms as painful periods was especially true for younger women (Wren & Mercer, 2021). This was supported by Moradi et al. (2014) who reported that younger women are more likely to have their symptoms normalised and dismissed, with the majority of teenagers in their study describing that their healthcare providers did not take their symptoms seriously, did not believe them and thought that they were making up stories to get attention.

The normalisation and dismissal of symptoms and the idea of menstrual pain as a normal part of being a woman and something to be lived with was not only confined to healthcare providers, or the women themselves, but was compounded by women’s family, friends and colleagues being equally doubtful of the symptom's women experienced (Denny & Mann, 2008). A systematic review conducted by Young et al. (2015) highlighted that when women revealed their symptoms to those closest to them, including, family members, friends, teachers or colleagues, their experiences were dismissed and normalised as something that all menstruating women must endure. This was supported by Moradi et al. (2014) who highlighted women's experiences of repeatedly being told by family and friends that pain and bleeding was normal; and van der Zanden et al. (2021) who described women frequently being told by their family and friends that their complaints were within a normal range or that they were just unlucky to have pain. This was problematic as van der Zanden et al (2021) also suggested that their participants’ help seeking behaviour was largely influenced by the interpretation of their complaints, not only by them, but also by family and friends, in particular their mothers.

Symptom concealment

There are several studies that attribute the diagnostic delay, in part, to the concealment of menstrual difficulties and endometriosis-related symptoms. Ballard et al. (2006) found that women rarely disclose their early experiences of pain to their family and friends. The participants in this study largely attributed the concealment of their symptoms to feelings of embarrassment and not wanting to be perceived as weak or as unable to cope with what they believed was normal period pain. This was supported by a more recent study by

Grogan et al. (2018) who discussed that their participants concealed their symptoms from family, friends, and work colleagues. Grogan et al. (2018) went on to suggest that the women in their study encountered a lack of understanding and empathy from their family, friends and colleagues and shared their concern about being labelled as a hypochondriac or as unable to handle normal period pain; and reported that many women felt as though others did not perceive endometriosis as a legitimate illness. Additionally, Fernely (2021) discussed how the women in her study experienced, to some degree, the social stigma, and shame of being labelled a complainer and often being seen as unable to cope with or exaggerate their menstrual concerns. Fernley (2021) suggested that this stigma creates additional barriers for women, resulting in them staying silent due to cultural or societal beliefs that menstrual pain is normal.

Ineffective clinical practice

Another common theme identified in the current body of literature regarding the diagnostic delay of endometriosis is ineffective clinical practice by healthcare providers, including, misdiagnoses (Lamvu et al., 2020; Moradi et al., 2014), overmedicalisation (Ballard et al., 2006; Fernely, 2021), delayed or incorrect referrals (Zale et al., 2020; Wren & Mercer, 2021; van der Zanden, 2021), and ineffective communication (Cox et al., 2003a; Lamvu et al., 2020; Young et al., 2020). I will discuss these in turn.

Previous research highlights that women with endometriosis frequently receive a number of misdiagnoses before they are diagnosed with endometriosis. Lamvu et al. (2020) found that women were diagnosed with conditions such as anxiety, depression, and irritable bowel syndrome before receiving a diagnosis of endometriosis. This is supported by the findings of Moradi et al. (2014) found that women's endometriosis was frequently misdiagnosed and mistreated as appendicitis, ectopic pregnancy, pelvic pain, or inflammatory disease. The women in these studies suggested that their doctors misdiagnosed or mistreated their endometriosis as they did not believe their symptoms, or they lack knowledge (Lamvu et al., 2020; Moradi et al., 2014). Further, Denny and Mann (2008) suggest that misdiagnoses may be due to GPs reluctance to accept women’s symptoms as gynaecological, while Grundström et al. (2017) suggests that healthcare providers are more focused on finding an easy explanation for women’s symptoms. In addition to misdiagnoses, Ballard et al. (2006) and Fernely (2021) highlighted healthcare providers’ reliance on hormonal birth control to regulate or control their periods and suppress or provide relief for their symptoms instead of seeking the underlying cause of their issues. A common feature reported in the studies exploring the diagnostic delay and women’s interactions with healthcare providers, is women having to see multiple GPs before receiving a referral to specialist care (Ballard et al., 2006; Cox et al., 2003a). Almost all of the women who participated a study by Cox et al. (2003a), spoke about encountering doctors who refused to give referrals to specialists as they did not believe their symptoms or concerns. This was supported by Wren and Mercer (2021) who described women's experiences of healthcare providers’ hesitancy to refer them to specialists following the presentation of endometriosis-related symptoms; and van der Zanden et al. (2021) who described several women’s experiences of having GPs refrain from giving them a referral. Similarly, Ballard et al. (2006) found that the delay in receiving a referral from a GP to a specialist varied from one month to 22 years, with women having to attend multiple appointments with their GP before receiving a referral. This is concerning as the GPs in a study conducted by Zale et al. (2020) suggested that not referring a woman with symptoms of endometriosis to a specialist ultimately hinders their journey to diagnosis.

Additionally, many women encounter ineffective communication when interacting with healthcare providers which was evidenced by women's feelings of being unheard. In their findings, Moradi et al. (2014) described the ineffective communication women often encountered while interacting with their healthcare providers. They highlighted women's accounts of healthcare providers who did not want to listen to their concerns and had no time to answer their questions. Similarly, Young et al. (2020) described many women’s accounts of encountering healthcare providers who did not listen to them or denied them the opportunity to contribute their knowledge in their interactions; and Cox et al. (2003) spoke of women who spent years attempting to locate a doctor who would listen to them. While Lamvu et al. (2021) suggested that women’s accounts of not being heard by their healthcare providers is concerning as it not only affects their journey to diagnosis but can also impact their ability to cope with a chronic condition.

Lack of knowledge

Finally, many of the studies in the current body of literature regarding the diagnostic delay of endometriosis attribute the delay in diagnosis, in part, to a lack of knowledge about endometriosis by healthcare providers. In speaking with GPs, van der Zanden et al. (2020) found that many GPs discussed limitations to their knowledge about endometriosis and they recognised that their training, in regard to endometriosis, had been limited. Similarly, when speaking with GPs Zale et al. (2020) revealed a lack of education of endometriosis among healthcare providers, which they attributed to a lack of general training and misperceptions about the disease. This is supported by Petterson and Berterö’s (2020) findings which demonstrated that women perceived healthcare providers as lacking a general awareness of endometriosis as they repeatedly encountered issues with healthcare providers not knowing the cause of their symptoms; and further investigations by Zale et al.

(2020) which highlights women's encounters with healthcare providers who lacked the knowledge to properly diagnose and manage the disease.

Additionally, several studies highlighted healthcare providers sharing myths and misinformation surrounding endometriosis which they attributed to a lack of knowledge. The women who participated in Denny and Mann's (2008) study spoke of interactions with GPs who repeated myths about endometriosis that they knew to be untrue such as that having a baby would cure their symptoms or that they were too young to have endometriosis. This is supported by Pettersson and Berterö (2020) and Cox et al. (2003a) who had similar findings and suggested that women frequently received treatment based on medical myths including that periods are normally heavy and painful, endometriosis can be cured by pregnancy, hysterectomy or birth control, endometriosis always equals infertility, and menopause stops endometriosis.

While a key theme in many studies was the lack of knowledge demonstrated by healthcare providers, several studies also highlighted that the women, themselves, lack of knowledge of endometriosis as did the general population. This was evidenced in Wren and Mercer (2021) who described women's accounts of feeling clueless about endometriosis and their concerns over the lack of information in the public domain. Similarly, Fernely (2021) described that many of their participants had not heard about endometriosis prior to their diagnosis and believed that there was a significant lack of community awareness of the condition; and Moradi et al. (2014) reported that many women had not heard about endometriosis prior to their diagnosis and there was a lack of information regarding endometriosis among their family, friends, schools and workplaces.

Facilitators to Diagnosis

To date, much of the existing literature exploring the diagnostic delay of endometriosis has failed to explore the reasons for the delay and ways to combat it. However, there are several studies which explore women's experiences and perspectives of the diagnostic delay, focusing on their experiences of living with endometriosis and receiving a diagnosis, as well as their interactions with healthcare providers. These studies have outlined several reasons for the delay, albeit implicitly. Similarly, there are a few studies which have implicitly identified several ways to combat the diagnostic delay, that is, facilitators to the diagnosis of endometriosis. The facilitators this research has identified can be attributed to three key themes, that is, self-advocacy, support and increased knowledge, all of which will be discussed in detail below.

Self-advocacy

Several studies in the current body of literature regarding the diagnostic delay of endometriosis highlight women taking control, or self-advocacy, as a factor that may reduce the diagnostic delay. This is a common theme that is discussed in relation to women's interactions with healthcare providers. In their study, Cox et al. (2003a) described women's accounts of taking control after deciding they would no longer continue to tolerate being treated poorly by healthcare providers. Cox et al. (2003a) described how after deciding to become more assertive, the women sought information, forced their doctors to listen to their concerns and requested referrals to specialist care; and when women encountered healthcare providers who would not listen to them, they would switch providers until they received the care, they believed they deserved. Similarly, Zale et al. (2020) highlighted that after years of feeling dismissed and ignored by their healthcare providers, many of the women who participated in their study ultimately became their own advocate. In doing so, the women in this study conducted their own research and sought additional medical opinions which enabled them to successfully receive a diagnosis of endometriosis and the treatment they desperately needed.

These findings are supported by Wren and Mercer (2021) who briefly discussed women's need for persistence when interacting with GPs in order to feel heard and establish access to specialist care; and Cox et al. (2003b) who suggested that women's decisions to become assertive and take control was dictated by their decisions to not be dismissed by healthcare providers and their need to convince their GPs that their symptoms were not normal. Additionally, the idea of women taking control as facilitating their journey to diagnosis was further supported by van der Zanden et al. (2021) who, in talking with GPs, found that GPs were more willing to refer women who were assertive and made demands during their appointments in comparison to women who were more passive.

Part of women taking control in their interactions with healthcare providers involved self-diagnosis which was emphasised by Moradi et al. (2014) who described that several women in their study resorted to self-diagnosis. In their findings, Moradi et al. (2014) outlined that several women in their study were able to self-diagnose due to a known family history of endometriosis, information on the internet, friends who were knowledgeable about endometriosis and from their interactions with other women who had been diagnosed with endometriosis; and indicated that self-diagnosis helped speed up their journey to diagnosis. However, while Moradi et al. (2014) indicated that self-diagnosis could help speed up women's journey to diagnosis, they did not explore why this was the case.

Increased knowledge

In contrast to the literature which attributed a lack of education about endometriosis to the diagnostic delay, several studies suggested that increasing education about endometriosis may facilitate the diagnosis of endometriosis. In a study by van der Zanden et al. (2021), women were asked whether they had any suggestions for decreasing the diagnostic delay of endometriosis. In their responses, the women highlighted increases in healthcare providers’ education about endometriosis and providing them with skills to correctly interpret their symptoms. Similarly, the women who participated in a study by Moradi et al. (2014) suggested increases in education among healthcare providers as well as increasing understanding in the general population as helpful actions to decrease the diagnostic delay. The idea that increasing education of endometriosis as improving the diagnostic delay was further supported by Lamvu et al. (2020) who suggested that decreases in the delay are possibly driven by improvements in healthcare providers’ education and awareness of the disease.

Beyond increases in healthcare providers’ education, the prior research also identified increases in the education of the women themselves surrounding endometriosis serves to decrease diagnostic delays. This was evidenced by Young et al. (2015) who highlighted women's experiences of seeking information about endometriosis and developing their knowledge. Young et al. (2015) suggested that the women in their study increased their knowledge, or education, about endometriosis so they could begin to make sense of their experiences and evaluate the validity of healthcare providers’ statements. Similarly, the women who participated in a study conducted by Cox et al. (2003a) increased their knowledge by recording their symptoms, realising that their symptoms were cyclical in nature and had a basis in physiology. Having increased their knowledge about their symptoms, the women in this study started to believe what their bodies were telling them, and they started to reject what they were being told by healthcare providers who were dismissive of them.

Support

Finally, several studies in the current body of literature regarding the diagnostic delay of endometriosis highlight the role support plays in reducing the diagnostic delay. Denny and Mann (2008) were the first to indicate the role of support in reducing the diagnostic delay; suggesting that delays in diagnosis may be reduced by improvements of GPs attitude towards women presenting with endometriosis symptoms. This was further supported by Fernley (2021) who described several women's accounts of encountering supportive healthcare providers. In their findings, Fernley (2021) suggested that positive interactions, characterised by support and empathy, had powerful consequences for the women, transforming their entire diagnostic experience. Similarly, Grundström et al. (2017) described women's accounts of being acknowledged and supported by their healthcare providers. They suggested that when encountering supportive healthcare providers, the women in this study no longer felt like they had to convince their healthcare provider of their symptoms and they could share exactly how they felt without being judged and were more likely to be honest about their symptoms. Additionally, Zale et al. (2020) found, in talking with GPs, that it was important for healthcare providers to establish supportive relationships with women who are experiencing symptoms of endometriosis as it plays a significant role in empowering women while on their journey to diagnosis.

Outside of supportive interactions with healthcare providers, several studies emphasise the importance of receiving support from others while on the journey to diagnosis. For instance, Fernely (2021) suggested that while some women receiving support from their healthcare providers, many of their participants utilised online spaces, including support groups, to received support from others. Similarly, van der Zanden et al. (2021) emphasised the importance of support by suggesting that when women were supported by their mothers and partners, they were more likely to consult a healthcare provider for their complaints when they felt something was wrong. Further, van der Zanden et al. (2021) highlighted that for young women, the opinion of their mothers turned out to play an important role in how they viewed their symptoms which influenced the time it took them to consult a healthcare provider.

My Research

While the diagnostic delay of endometriosis is well-documented and widely reported in the current body of literature in the endometriosis space, there is a paucity of research that examines the reasons for the delay and ways to combat it. In the current body of research, there are several studies which focus on women's perceptions of the diagnostic delay and their interactions with healthcare providers, as well as several studies which explore the diagnostic delay from the perspective of healthcare providers. Although these studies do not explicitly explore the reasons for the diagnostic delay and ways to combat it, they do implicitly identify several barriers and facilitators that women encounter on their journey to receiving a diagnosis. This body of research suggests that the normalisation and dismissal of symptoms, symptom concealment, ineffective clinical practice, and lack of knowledge are barriers women encounter on their journey to diagnosis; while suggesting that self-advocacy, support and increased knowledge act as facilitators. Despite this small body of research highlighting several facilitators and barriers, there is still a dearth of research which privileges women's experiences of their journey to receiving a diagnosis and the facilitators and barriers they encounter.

Additionally, like much of the current literature in the endometriosis space, the small body of research that examines the reasons for the diagnostic delay and ways to combat it has been conducted overseas, in international healthcare settings. The majority of these studies have been conducted in Australia, Netherlands, the United Kingdom and the United States of America whose healthcare settings may differ from the setting here in Aotearoa New Zealand. Women are entitled to healthcare that meets their diverse needs. Currently, in Aotearoa New Zealand, the diverse healthcare needs of women are not being effectively met which is reflected in the current outcomes for women with endometriosis and the diagnostic delays they experience. Perhaps this is a result of the current literature in the endometriosis space not providing evidence of or reflecting the experiences of women with endometriosis in Aotearoa New Zealand; or perhaps it is because the barriers and facilitators women encounter while on the journey to receiving a diagnosis of endometriosis in Aotearoa New Zealand and what it means to them are not well understood. Therefore, there is a need to conduct Aotearoa New Zealand based research that specifically explores women's journeys to diagnosis and the facilitators and barriers they encounter.

The aim of this research is to identify and develop a better understanding of the barriers and facilitators to the diagnosis of endometriosis in Aotearoa New Zealand by surveying and exploring women's accounts of their journeys to diagnosis. In doing so, the objectives of this research are as follows:

1. To understand women's pathways to receiving a diagnosis of endometriosis in Aotearoa New Zealand.
2. To identify and understand the barriers women encounter on their journey to receiving a diagnosis of endometriosis in Aotearoa New Zealand.
3. To identify and understand the facilitators women encounter on their journey to receiving a diagnosis of endometriosis in Aotearoa New Zealand.

Chapter Three: Methods

The aim of this research was to develop an understanding of the facilitators and barriers to the timely diagnosis of endometriosis in Aotearoa New Zealand through a qualitative exploratory survey.

In this chapter, I outline the philosophical perspective of this research and provide an overview of how the research was conducted. This chapter will begin by discussing the critical realist ontological and social constructionist epistemological perspectives that underpin this research and the way in which these philosophical positions relate to my research aim. Following this, I will discuss in detail the practical method of how I went about collecting the data. This will include a discussion of how the survey was developed and how the participants were recruited. I will then discuss ethical considerations and reflexivity before finishing by outlining the analytical approach I took when interpreting the data.

Theoretical Perspective

My ontological stance for this research is critical realism. Critical realism is based on the premise that there is an external physical world that exists independent of our awareness and consciousness of it; that is, it assumes an objective reality (Crotty, 1998). However, critical realists also recognise a social world; and accept that we become conscious of the world and can begin to make sense of it through our engagement with the world (Crotty, 1998). In this sense, our understanding of the world and knowledge of reality is constructed from our experiences and is socially influenced (Al-Ababneh, 2020; Bukowska, 2021). Critical realists acknowledge the existence of both an external physical world that exists independent of human consciousness and a social world that consists of knowledge that is socially influenced. Both the physical and social world consists of real objects or ‘things’ that exist regardless of whether we see or experience them. While these objects or ‘things’ may be challenging to directly observe, they have causal powers and can be observed through the effects that they may cause (Burr, 2015). This is the case for physical aspects of endometriosis which can be observed through the participant’s experiences. The critical realist approach allows me to accept that the participants’ experiences were a reflection of their reality, acknowledging how the women made sense of their experiences of receiving an endometriosis diagnosis within the broader social context in which these experiences arose (Sayer-Jones & Sherman, 2022).

Despite subscribing to a critical realist ontology and accepting that there is a physical reality which exists independent of whether I see it or not, I also acknowledge that we construct the world and make sense of it socially, through shared meanings that we assign to reality. As such, this research was conducted through a social constructionist lens. Social constructionism challenges the way that knowledge is acquired in mainstream psychology; rejecting claims that knowledge is obtained from the generation and testing of hypotheses. Instead, social constructionism posits that knowledge and understanding are created and maintained through social interaction via description, explanation and language (Burr, 2015; Gergan, 1985). As social constructionism considers knowledge and understanding to be constructed socially, social constructionists place an emphasis on social interactions and shared understandings; and are primarily concerned with the ways people describe and explain the world they live in, and how they construct meaning of their life events and experiences (Crotty, 1998). From the constructionist view, understandings of the world are constructed through social processes and interaction, therefore, knowledge is formed from shared understandings. However, shared understandings are not necessarily maintained over time as they remain open to changing perspectives and are contested and redefined across changing cultural and historical contexts (Galbin, 2014; Gergan, 1994). For this reason, social constructionists recognise multiple ways of understanding and encourage researchers to consider alterative perspectives rather than attempting to form truths about a so-called objective reality (Andrews, 2012; Burr, 2015).

Additionally, it is important to acknowledge that social constructionism considers language as a fundamental aspect in the construction of knowledge. While social constructionists posit that knowledge is constructed socially through description and explanation, language does more than simply describe and explain reality. Instead, language is viewed as shaping reality (Crotty, 1998). However, language gains its meaning from the context in which it is used, therefore, it is not neutral. Social constructionists are, therefore, interested in the way people interpret the world within specific linguistic, social and cultural contexts as norms, beliefs, values, traditions and attitudes vary across different cultural groups and social contexts, hence, meaning and understanding are likely to differ across contexts (Burr, 2015; Gablin, 2014; Schwandt, 1997).

Now that I have explained the theoretical assumptions, I will outline my understanding of endometriosis. From an ontological perspective, I understand endometriosis as a physical disease caused by the presence of endometrial cells in sites outside of the uterus, usually in the pelvic cavity which can be observed during, for example, a laparoscopy. In this sense, I view endometriosis as physical matter, existing in the physical world, regardless of whether we experience it or not, and independent of our observations of it. However, on the other hand, I also understand endometriosis as a term used to describe the bodily disturbances, or symptoms, that are experienced by women with these ectopic endometrial cells. In this sense, I view the symptoms associated with the physical features of endometriosis as socially constructed. That is, the meaning and understanding attributed to the symptom's women experience are constructed through language and socially agreed upon. Therefore, my understanding is that the critical realist ontological perspective supports the physical aspects of endometriosis; while the social constructionist epistemology that I subscribe to accounts for how individuals construct meaning of the symptoms associated with the physical features of endometriosis. Consequently, in order to capture both the physical reality and subjective nature of endometriosis, a qualitative survey was decided on.

An advantage of online qualitative surveys is that offers flexibility to address a range of research questions including research from peoples experiences or meaning-making practices. Further, it enables participants from diverse geographical setting to participate in the research which is particularly important when conducting research in the context of Aotearoa New Zealand (Braun et al., 2021). Braun et al. (2021) highlight the value of qualitative surveys for rich and complex data and suggest that qualitative surveys allow researchers to address the research topic with a ‘wide-angle lens’ that enables them to capture differing experiences and perspectives. As such an online qualitative survey with a mix of closed questions and open-ended questions was most appropriate to explore if the barriers and facilitators identified in the literature are relevant to women in Aotearoa New Zealand but also allowing them to tell their stories.

Procedure

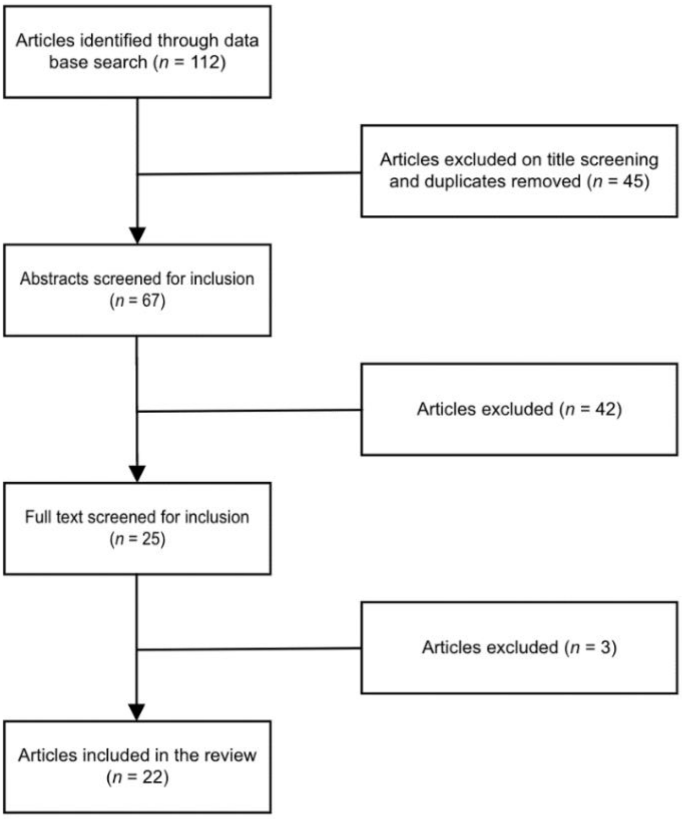
To the best of my knowledge, there was no existing questionnaire or survey that I could employ that would produce data relevant to the research aims. There are certainly measures to capture the quality of life (e.g., the Endometriosis Impact Questionnaire and Endometriosis Health Profile-30) but none that explore the barriers and facilitators to diagnosis (Moradi et al., 2019; Tiringer et al., 2022). Therefore, I developed an online survey to capture information relevant to the research aims under the guidance of my supervisor. In the sections to come, I will describe the research process. I will start by describing the first phase of the survey production – a systematic review that was conducted to identify the facilitators and barriers established by prior research. I will then describe the survey development, how participants were recruited, and I will specify how the data was collected.

Step 1: Systematic review

I conducted a systematic review of the literature in the endometriosis space to identify the facilitators and barriers to the diagnosis of endometriosis that had already been established and discussed in prior research. The search strategy I implemented for identifying relevant studies to be included in the systematic review is summarised below in Figure 1.

Figure 1

Systematic Review Search Strategy



An exhaustive search for potentially eligible studies was conducted through a literature search using a combination of the key terms ‘endometriosis’, ‘diagnosis’, ‘delay’, ‘late diagnosis’, ‘diagnostic delay’, ‘path to diagnosis’, ‘journey to diagnosis’, ‘facilitators’, ‘barriers’, ‘women’s experiences’, ‘healthcare interactions’, ‘qualitative’, ‘interview’, ‘survey’, ‘focus-group’, and ‘in-depth’. The databases used for the literature search were Google scholar and the Massey University Library database. I also searched the Journal of Clinical Gynaecology and Obstetrics, the Mendeley database and the reference lists of the studies that were initially included in the review to identify additional studies for inclusion.

A total of 112 studies were identified as a result of the literature search. These were uploaded to my library on Mendeley, a reference management software, to be screened for inclusion in the systematic review. The screening process began with removing any duplicates and screening the titles to exclude those that did not seem relevant. Following this, I read the abstracts of the remaining 67 studies and removed any that did not appear to fit the inclusion criteria. The 25 articles that remained after the abstract readings were then read in full to assess their eligibility against the inclusion criteria which resulted in the exclusion of three articles as they were concerned with the diagnostic tools for diagnosing endometriosis. The following criteria were used to determine whether a study would be included in the review for establishing the facilitators and barriers to the diagnosis of endometriosis:

1. **Types of studies:** The systematic review included primary/empirical research studies (qualitative, quantitative and mixed methods) and secondary research (systematic reviews and meta-analysis).
2. **The research aims:** Studies were included if they were concerned with women's journey to diagnosis, women’s experiences of diagnostic delays, women’s

experiences with endometriosis, women's interactions with healthcare professionals, healthcare professionals' perspectives of diagnostic delay, or facilitators and barriers to the timely diagnosis of endometriosis. Additionally, studies were excluded if they concentrated on diagnostic tools, tests or equipment.

3. **Types of participants:** Studies with participants who identified as having endometriosis (i.e., confirmed via laparoscopy, histological confirmation, self-identified, or assumed by a healthcare provider) or as healthcare professionals who were responsible for treating or diagnosing patients with endometriosis were included. Additionally, studies were not excluded for the age, ethnicity/race, or socioeconomic status of participants.
4. **Geographical context:** Due to limited research, this review included studies conducted in other countries. However, studies were excluded if they were not published in English.
5. **Time frame:** There were no time-frame restrictions for studies.

A total of 22 studies were identified to be included in the systematic review. To review each of the studies and establish the facilitators and barriers to the diagnosis of endometriosis that had been identified by prior research, I developed an extraction sheet. The extraction sheet was used to identify the aims, sample and sampling methods country of origin, methodology and data analysis, and any facilitators and barriers discussed in the results. I applied the extraction sheet to each of the studies and collated the information in an excel spreadsheet.

As a result of the systematic review, a total of 22 facilitators and barriers occurring at the individual level, 23 facilitators and barriers occurring at the medical level, and 13 facilitators and barriers occurring at the societal level were identified. A summary of the facilitators and barriers that were identified have been included in the appendices (see appendix A).

Step 2: Survey development

Using the facilitators and barriers identified in the systematic review as a guide, I developed a series of questions that would allow me to capture data relevant to the research aims. This process was complicated and involved many discussions with my supervisor to decide on wording, organisation of sections, order of sections, when to give closed options and when to create open ended questions. Due to the nature of survey research, questions cannot be modified during data collection and unlike interviews, there is no opportunity to ask clarifying questions. Therefore, when conducting survey research, the wording of the questions is crucial (Braun et al., 2021). In order to achieve maximum clarity with my survey questions, I presented the questions in a variety of ways. This included follow up questions that asked the women to elaborate or explain their answer in more detail, closed question that were followed up with opened-ended questions that allowed the women to clarify their answer in their own words, and providing examples of the issues I wished them to discuss, in brackets after the question (Braun et al., 2021). Further, I needed to consider the length of the survey as this can impact the overall results. Typically, qualitative surveys tend to be short, however, Braun et al. (2021) suggest that longer qualitative surveys require shorter responses to each question to sustain quality in answers and reduce risk of question fatigue. As this survey was a longer qualitative survey, I grouped the questions addressing similar issues into sub-sections to help with the overall clarity and flow of the survey.

A word version of the survey can be located in Appendix B In total, I developed 90 items to be included the survey which were split across five sections: demographics (8 items), journey to diagnosis (13 items), facilitators and barriers occurring at the individual level (13 items), facilitators and barriers occurring at the medical level (21 items), and facilitators and barriers occurring at the social level (35 items). The demographics section contained a series of questions about participants age, gender, self-identified ethnicity, geographic location, whether they have received a diagnosis of endometriosis via laparoscopy, and the stage of their endometriosis. The purpose of the demographic questions was to provide a clearer picture of the participants; and it provided an opportunity to ensure that the participants fit the inclusion criteria. Moreover, the intention was to use the demographic data gathered as a lenes through which to view the survey data and to look for patterns amongst different groups of participants. The journey to diagnosis section contained a series of questions specific to the participants' personal journeys to receiving a diagnosis of endometriosis in Aotearoa New Zealand. This section was designed to gather additional background information about the participants that was relevant to the research questions; and included questions about symptoms, interactions with healthcare providers, and the time taken to receive a diagnosis.

The final three sections of the survey were concerned with the facilitators and barriers that the participants encountered on their journey to receiving a diagnosis of endometriosis. As mentioned above, these questions were guided by the facilitators and barriers identified in the systematic review. The series of questions relating to the facilitators and barriers that occur at the individual level pertained to education/knowledge (4 items), normalisation and dismissal (3 items), and empowerment (5 items). The questions concerning the facilitators and barriers that occur at the medical level pertained to misdiagnosis (6 items), referral (5 items), perceived education of healthcare providers (4 items), and interactions with healthcare providers (5 items); and finally, the questions relating to the facilitators and barriers that occur at the societal level pertained to education and awareness (4 items), health education in schools (7 items), normalisation and dismissal of symptoms (6 items), empowerment (2 items), myths (7 items), stigma (6 items) and culture (2 items). Additionally, each of these sections contained a question that would enable participants to share any additional information that they felt was relevant; opening the possibility of uncovering unexpected data that might otherwise have been overlooked.

Once the survey questions had been established and I had decided on the format, the survey was created using the Qualtrics software with help from the IT department at Massey University. I piloted the survey on the online platform to ensure it ran smoothly and that there were no grammatical errors or issues with the flow of the survey. The survey was piloted by four independent testers. These individuals were women who fit the inclusion criteria for participation in the study. The independent testers completed the survey and provided feedback on all aspects of the survey, including structure, length, response options, coherence and clarity of the questions, and technical aspects such as format and visual display. During the piloting phase, the average time to complete the survey was 40 minutes.

Step 3: Recruitment

Participants were recruited from two endometriosis support groups on the social media platform Facebook. These support groups were the Australian and New Zealand women with endometriosis support group and the Endometriosis New Zealand group. These Facebook groups were chosen because they are centred around endometriosis and supporting women who live with the disease. There was no limitation to who could be a part of these groups, however, their followers were typically women living with endometriosis or people who knew someone with the disease.

The administrators of the respective pages were contacted via private message and asked if an advertisement (see Appendix C) could be shared on their page with the intention of recruiting members of the group. The administrators of both groups agreed to share the advertisement and survey link. It did take longer than anticipated to receive a response from the administrators; however, as I contacted them a few weeks before the survey was released this did not cause a delay in the recruitment of participants. Participants were also recruited from the Endometriosis New Zealand website, Facebook and Instagram as the advertisement and survey link were also shared there. This was particularly useful as it enabled the survey to be advertised on a broader scale. Recruiting in this manner follows the principles of purposive sampling, which allows for the recruitment of participants who can provide in-depth and specific information about the phenomenon of interest; while also allowing for the recruitment of a sample in terms of sociodemographic factors such as socioeconomic status, age, ethnicity, level of education, employment status and geographical location (Palinkas et al., 2015).

The recruitment of participants was further enhanced by using snowball sampling. In this instance, I shared the advertisement and survey link via my personal Facebook and Instagram pages in the hopes that individuals with endometriosis in my informal social network would see the posts. I also encouraged those within my social network to share the advertisement. Subsequently, the advertisement was shared 21 times on Facebook and 44 times on Instagram, opening new possibilities for recruitment. Snowball sampling, as a method of recruitment, is particularly useful when recruiting difficult-to-identify or ‘hidden’ populations such as those with endometriosis. In choosing to utilise snowball sampling, I knew it was possible that my family and friends knew people with endometriosis, and I was hopeful that their sharing the advertisement would help reach a broader audience of women that I, otherwise, would not have access to. Further, without the people who shared the advertisement, I do not know how successful this project would have been.

Step 4: Data collection

The data was collected using the online survey that I developed (as detailed above). The advertisement that was shared for recruiting the participants contained a link to the survey which was run through the Qualtrics Information Systems administered by Massey University. When participants clicked the survey link, they were redirected to an information sheet (see Appendix D) which provided them with a detailed introduction to the research. This included a brief description of the project, an overview of the inclusion criteria, what participation would entail, the risks and benefits of participation, how the data would be managed, participant rights, and the contact details for the researcher (myself) and the research supervisor.

At the end of the information sheet, the participants were asked to provide consent for their survey responses to be included in this research project. Although the survey was self-administered and the participants submitting their survey responses implied consent, the participants were still required to give consent. The participants’ consent was obtained using the following statement: “by clicking NEXT you are consenting to take part in this research having read the information sheet and understanding your rights as a participant”. From that point, the participants could complete the main body of the survey, which consisted of 5 sections: demographics, journey to diagnosis, and facilitators and barriers occurring at the individual level, the medical level and the societal level (as described earlier).

The survey was comprised of open-ended and closed questions (see Appendix B). The open-ended questions did not demand long, detailed accounts of the participants' experiences, instead, they offered participants the opportunity to respond in their own words. The open-ended questions provided qualitative data which could be analysed by thematic analysis; allowing for a richer understanding of the participants’ experiences and the possibility for new or unexpected understandings that might have otherwise been overlooked to be uncovered. The closed questions in the survey included multiple choice questions, Likert scales and matrix questions; and involved participants selecting an answer from a set of pre-determined answers. This provided data which could be quantified and analysed by content analysis. Additionally, with all questions, the participants were asked to respond based on their personal journey to diagnosis; and I was aware that not all of the facilitators and barriers that the survey addressed would be relevant to the participants’ experiences. This was accounted for by allowing participants to select ‘not applicable’ or having the option to leave the answer blank.

As the survey was online, the participants were able to complete the survey in their own time. The survey was set up, so the participants' responses were automatically saved as they progressed through the survey; allowing participants to complete the survey in more than one sitting. Despite participants' progress being automatically saved, their responses were not recorded until they submitted them upon completion of the survey. This not only served to ensure that incomplete responses were not recorded; but allowed participants to easily withdraw their participation. Additionally, upon completion of the survey, the participants were offered the opportunity to enter in a draw to win a $100 Prezi card. In order to enter, they were required to click on a link which would them to a separate questionnaire that asked for their details. This questionnaire was separate from the online survey to ensure that their details could not be matched up with their survey responses. Although the data collection went smoothly, I feel it is important to disclose that I did encounter an issue when closing the survey. Initially, it was planned for the survey to remain open for 4 weeks; however, due to an error the survey remained live after this period for an additional 4 weeks. Although this was not detrimental to the research as it simply meant that more participants ended up completing the survey.

Ethical Issues

This research was assessed through the Massey University research ethics process and deemed to be ‘low-risk’. As a low-risk study, this research was not subject to a formal ethics review from the Massey University Human Ethics Committee. Instead, this project was peer-reviewed for risk and required the completion of a Low-Risk Notification form which needed approval from the Massey University Ethics Committee. The letter of approval can be viewed in Appendix E.

Despite being deemed ‘low-risk’, this research was conducted in accordance with the principles outlined in the Massey University code of ethical conduct for research, teaching and evaluations involving human participants. This was consulted when thinking through the ethics and were referred to as required during the research process. The key ethical considerations that were identified during the peer-review process pertained to autonomy and respect for persons, confidentiality and privacy, and avoidance of harm alongside cultural responsibility outlined by principles of Te Ara Tika. As the number of Māori and Pasifika women with endometriosis in Aotearoa New Zealand is not known, I planned for this research to be inclusive of all women who have received a diagnosis of endometriosis regardless of their ethnicity. As there was the potential for women of different ethnicities and cultures to participate in this research, I needed to ensure that the research was conducted in a way that was sensitive and responsive to cultural diversity. To ensure the research was conducted in a culturally competent manner, I used the Te Ara Tika Guidelines for Māori research to inform the ethics behind this research; and aligning with the Massey University code of ethics, I strove to implement the principles of Te Tiriti o Waitangi where appropriate to promote equality and partnership.

The participants were recruited via social media. This was achieved by advertising the survey on endometriosis support groups on Facebook, the Endometriosis New Zealand social media pages and website. The administrators of the respective pages were contacted and asked to share the advertisement and link to the survey. The advertisement and survey link were also shared on my own Facebook and Instagram pages; and this was further shared by numerous friends and family members on these platforms. The advertisement included adequate information about what participation would entail, the inclusion criteria for participation and my contact details in case anyone wished to contact me with questions. When potential participants clicked the survey link, they were provided with an information sheet (Appendix D) that presented all relevant information in plain language and understandable terms, to enable them to make a fully informed decision about participating. Before participants could begin the survey, they were required to click a button indicating that they were consenting to participation having read the information sheet and understanding their rights as a participant.

The survey was completely anonymous and did not ask any questions that would directly produce any information that the participants could be identified by (i.e., name, date of birth). However, as the participants were offered the opportunity to enter a prize draw for participating, they were required to provide their name and email address. This information was collected and stored separately from the main survey data; therefore, it was not attached to the participants' survey responses in any shape or form. Further, any personal information or identifying aspects were excluded from the data during analysis to ensure anonymity; and the data was stored on password protected devices.

During the peer-review process, this study was deemed to pose no significant risk of harm to participants and the researcher. However, I recognise that the participants disclosed sensitive information and due to the challenges of living with endometriosis, I am aware that participating may have been an emotional experience and it may have been difficult for participants to share some aspects of their journey. Although, I also recognise that giving participants an opportunity to share their experiences and journey to receiving a diagnosis may have been therapeutic as it allowed them to share their thoughts, feelings, emotions and experiences. Additionally, to support the participants, the information sheet included a list of free and easily accessible resources. This included information about free support services for people with endometriosis and New Zealand based mental health services that they could easily access.

When constructing the survey, I tried to be considerate and careful with the wording of questions and I remained sensitive to the fact that some of the questions may have brought up negative or unresolved emotions. It was made clear that participants did not have to answer any questions they did not feel comfortable responding to and that they could complete the survey in more than one sitting – enabling them to take as many breaks as needed. It was also made clear that the participants were free to withdraw from participating at any stage without penalty simply by exiting the browser they were completing the survey on and that uncompleted responses would be deleted when the survey closed.

Data Analysis

The closed-ended questions were analysed using descriptive statistics. As this research was an exploratory study, the data produced from the closed-ended questions were analysed using frequency data. The mean and standard deviation were calculated for questions such as “what is your age?” and frequency counts were expressed as percentages for other questions such as “prior to receiving a diagnosis, what were your primary symptoms?”. The focus was on the qualitative responses to give context and richness to the findings.

Thematic analysis is the chosen method of data analysis for the open-ended questions research. Thematic analysis is a flexible approach to data analysis which involves exploring and interpreting patterns of meaning (themes) across qualitative data sets in an organised and structured manner to generate new insights and answer research questions (Braun & Clarke, 2013; Nowell et al., 2017). It is a particularly useful approach when seeking answers to researcher questions concerned with people’s experiences, views and perceptions, and questions related to understanding and the construction of meaning as it provides rich and detailed yet complex accounts of the data (Nowell et al., 2017; Terry et al. 2017). However, it involves more than generating themes that simply summarise the participant's account; instead, thematic analysis moves beyond description to interpretation, whereby the analysis interprets and makes sense of the data (Braun & Clarke, 2006; 2013; Maguire & Delahunt, 2017).

Thematic analysis appreciates that the interpretation of the data and the themes that arise are constructed by the researcher. As such, researcher subjectivity is acknowledged and embraced as an integral part of the analysis process (Braun & Clarke, 2020; Terry et al., 2017). In this sense, while I attempted to present the data for what it was, I acknowledge that with thematic analysis, you cannot enter a theoretical vacuum and recognise that the interpretation of the data is inevitably shaped by my social position, lived experiences and the theoretical assumptions of the research. Therefore, in using thematic analysis it is important to acknowledge the theoretical framework that informs the research as it has implications for the analysis (Braun & Clarke, 2006; 2020; Terry et al., 2017). As such, it should be made clear that the theoretical assumptions of this research fit with thematic analysis as it accepts that the participants accounts reflect their lived-realities and experiences while also recognising that there are multiple realities and understandings and interpretations of reality (Andrews, 2012; Burr, 2012; Terry et al., 2017).

Braun and Clarke (2006) suggest that thematic analysis involves six stages: familiarisation, code generation, initial theme development, reviewing themes, defining and naming themes, and finally writing the analysis. However, as thematic analysis is a flexible approach to data analysis, there are multiple ways it can be approached, therefore, it is important to specify that for this research, I employed an inductive version of thematic analysis whereby the coding and theme development was directed by the content of the data instead of a pre-determined coding system (Braun & Clarke, 2006; Terry, 2017). Additionally, it is important to note that during the data analysis, I followed the six stages outlined by Braun & Clarke (2006), however, I applied them flexibly as I moved back and forth between the stages when necessary.

The first stage of analysis involved becoming familiar with the data. I exported the participants responses into a word document and began reading through the data. During the first read, I began to generate ideas around the participant’s journeys to diagnosis and the facilitators and barriers they encountered. During the second and third read, I highlighted any keywords or phrases that were of significant interest and noted down any key ideas that stood out or came to mind while I was reading. As I became familiar with the data, I recognised data that reflected literature I had read while writing the literature review and conducting the systematic review to establish the survey questions, however, I also began to see patterns that were not reflected in the current research which I interpreted as salient.

The second stage of analysis involved generating codes. To do this, I re-read the data, paying particular attention to the annotations I had made during the first stage of analysis and made note of possible codes on a piece of paper and highlighted any quotes in the data that were interesting or reflected the codes that I had written down. While generating the initial codes, I did not impose a limit on the number of codes that data could entail, therefore, the codes were iterative. Following this, I synthesised and refined the codes to form a succinct list of codes which I considered most relevant to the study and could be used as potential themes. During this process, I gave more significance to codes that appeared most frequently in the data; however, at the same time there were several codes that appeared less frequently that I deemed significant. After deciding on the codes, to make things easier when developing the themes and writing the analysis, I collated the key ideas, words and quotes relevant to each code in a Microsoft word document. As I was doing this, it became clear that several of the codes addressed similar aspects of the data and could be combined which helped to further refine the codes. By the end of the coding stage, I had conceptualised 14 distinct codes.

Once the data had been coded, I began to form initial themes. To do this, I looked for similarities and related meaning across the codes and grouped the codes based on what they appeared to be communicating to form themes. During this process, I organised the codes into seven initial overarching themes and identified relevant sub-themes. As some of the codes overlapped with one another, it took several attempts to decide on the initial themes and produce a thematic map.

The fourth stage of analysis involved reviewing the initial themes that I had generated. This stage involved evaluating the relationships between the themes and sub-themes and analysing how well they reflected the data. During this process, I realised that two of the initial overarching themes - ‘normalisation and dismissal’ and ‘judgment and stigma’ - had similar meanings to the subthemes under other overarching themes. As such, there was no clear distinction between them, therefore, I decided to delete ‘normalisation and dismissal’ and ‘judgment and stigma’ as overarching themes and merged them with the appropriate subthemes and created new subthemes where necessary. After reviewing the themes, I was left with five overarching themes, each with several subthemes.

The fifth stage of analysis involved further refining the themes. To do this, in a new Microsoft word document, for each overarching theme, I wrote down the sub-themes and corresponding codes, collated the data for the sub-themes according to the codes, provided a description for each theme, provided useful quotes and wrote a reflection on the overall theme. This helped to ensure that there was no overlap and that they were not too diverse or restrictive, however, it also meant I knew what each theme meant and how I would discuss it when writing the results. Once I was happy with the sub-themes for each overarching theme, I proceeded to tentatively name each theme, which I finalised once I had finished writing the results. When naming the themes, I stayed close to the meaning of the data, and I used participants quotes where possible.

The sixth and final stage of analysis consisted of writing the results section where I elaborated on the writing I did for each theme when defining and naming the themes and sought to interpret and explain each theme beyond the data in relation to the overarching research questions.

Reflexivity

Qualitative research is inherently subjective, in that researchers bring with them their own values, experiences, beliefs, judgement, biases, practices and assumptions to the research process (Berger, 2013). If left unchecked, these can shape how the data is interpreted and have an impact on the overall outcome of the research, therefore, reflexivity is a crucial component of the research process when conducting qualitative research. Reflexivity is used in qualitative research to ensure that the interpretation of the data and outcome of the research is not affected by the researcher's background. It requires researchers to be critical of their assumptions, experiences and positioning and be aware of the impact these could have on the different stages of the research process (Alvesson & Sköldberg, 2000; Berger, 2013).

In terms of what reflexivity means for me, as a researcher, is that it is important for me to recognise and acknowledge my presence as an active participant in the research process and to consider how this research is inevitably linked to who I am and my prior experiences. In conducting this research, I am a Pākehā, cis-gendered, heterosexual, non-disabled, middle-class woman in her mid-twenties and have lived in Aotearoa New Zealand my whole life. Throughout the duration of my studies, I have become extremely passionate about women’s health and increasing awareness around issues such as endometriosis, polycystic ovary syndrome and infertility. With respect to endometriosis, my interest in this topic does not come from personal experience with the disease as I do not have endometriosis, but rather, it comes from the lack of awareness around women’s health and the desire for the disease to be recognised and taken more seriously given it affects 1 in 10 women in Aotearoa New Zealand.

Given I have not received a diagnosis of endometriosis, I recognise that in conducting this research, I am considered an outsider to the experiences of living with endometriosis, and I am aware that my reality is different to that of the participants. In qualitative research, presenting as someone outside of the lived experiences of the participants has the potential to create a barrier between the researcher and the participants (Dwyer & Buckle, 2009). However, given this research utilised online qualitative surveys for data collection rather than face-to-face interviews or focus groups, my outsider status did not seem to have an impact on what the participants were willing to share or the quality of the data. Additionally, I believe that my outsider status did not limit my appreciation for or representation of the participants' experiences. Despite not being diagnosed with endometriosis, I am not a stranger to the disease as I have witnessed the difficulties friends and family members have faced in their journeys with endometriosis; and as a woman I have experienced difficulties with menstruation, some of which are similar to those with endometriosis such as heavy bleeding, irregular periods and healthcare providers’ reliance on birth-control. The reason I am disclosing this information is because while I have not had the same experiences as the participants; my experiences have given me the ability to empathise with the participants and recognise their strength as they embarked on their journey with endometriosis. Moreover, in reading the participants accounts, as I do not have first-hand experience in living with endometriosis, I was unable to compare the participants accounts to personal experience meaning I took the participants accounts for what they were (Dwyer & Buckle, 2009).

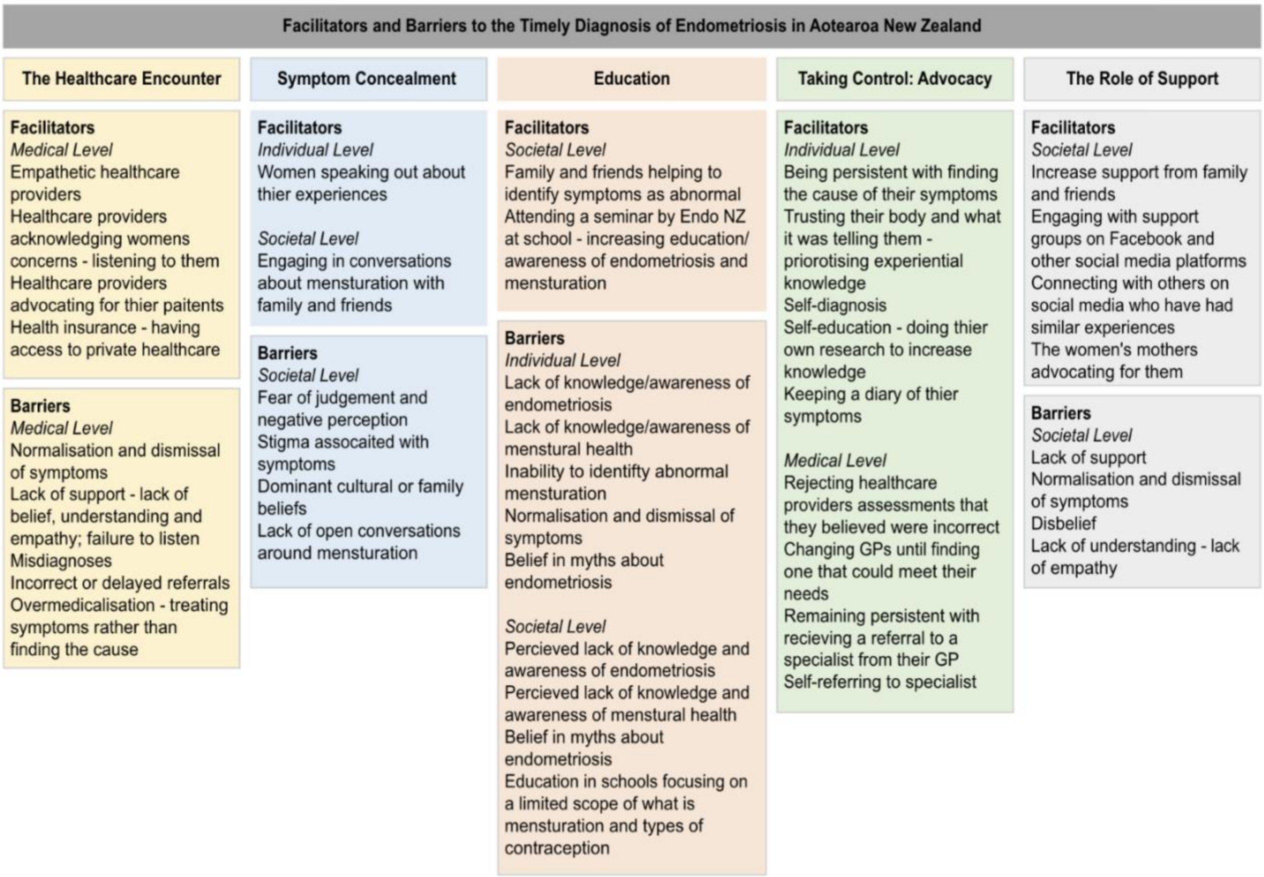
Another issue that arose during the research process in terms of reflexivity and remaining critical of my position pertained to the emotions I experienced when reviewing prior literature and reading the participants accounts when analysing the data. Reading women's accounts of the difficulties that they experienced on their journey to receiving a diagnosis and the difficulties they continue to face in their day-to-day lives of living with endometriosis was an emotional task and I found it to be mentally exhausting. I felt a deep sense of sadness, frustration and anger that these were the experiences that real-life women living in Aotearoa New Zealand experienced and continue to experience and I needed to be careful not to let those emotions shape my interpretation of the data. In saying that, at the same time I was greatly appreciative and in awe of the women who participated in this research, and I admired how open, honest and real were when sharing their accounts as it allowed me to have greater insight into their reality and lived experiences.

Chapter Four: Findings

The aim of this research was to establish an understanding of the facilitators and barriers to the timely diagnosis of endometriosis in Aotearoa New Zealand. In the process of analysing the data, it became clear that the women had similar experiences on their journey, with many of them encountering the same facilitators and barriers evidenced in both the qualitative responses and the frequency of responses. This chapter starts by describing the women's sociodemographic characteristics and their pathway to diagnosis primarily using the quantitative data. The subsequent sections outline the five key themes. Figure 2 gives a visual representation of the main barriers and facilitators which is education, however, I begin with discussing 'the healthcare encounter' which explores the women's interactions with their healthcare providers where most of the barriers and facilitators occur at the medical level. This is followed by 'symptom concealment' which explores the ways the women concealed their symptoms and explores the stigma surrounding endometriosis-related symptoms and menstruation, 'education' which explores the knowledge and awareness surrounding endometriosis, 'taking control: advocacy' which explores the way the women took control and empowered themselves on their journey to diagnosis, and finally, 'the role of support' which explores the support the women received on their journey to diagnosis.

Figure 2

Thematic Map



Facilitators and Barriers to the Timely Diagnosis of Endometriosis in Aotearoa New Zealand

The Healthcare Encounter

Facilitators
Medical Level
Empathetic healthcare providers
Healthcare providers acknowledging womens concerns - listening to them
Healthcare providers advocating for thier paitents
Health insurance - having access to private healthcare

Barriers
Medical Level
Normalisation and dismissal of symptoms
Lack of support - lack of belief, understanding and empathy; failure to listen
Misdiagnoses
Incorrect or delayed referrals
Overmedicalisation - treating symptoms rather than finding the cause

Symptom Concealment

Facilitators
Individual Level
Women speaking out about thier experiences

Societal Level
Engaging in conversations about mensturation with family and friends

Barriers
Societal Level
Fear of judgement and negative perception
Stigma assocaited with symptoms
Dominant cultural or family beliefs
Lack of open conversations around mensturation

Education

Facilitators
Societal Level
Family and friends helping to identify symptoms as abnormal
Attending a seminar by Endo NZ at school - increasing education/ awareness of endometriosis and mensturation

Barriers
Individual Level
Lack of knowledge/awareness of endometriosis
Lack of knowledge/awareness of menstural health
Inability to identifty abnormal mensturation
Normalisation and dismissal of symptoms
Belief in myths about endometriosis

Societal Level
Percieved lack of knowledge and awareness of endometriosis
Percieved lack of knowledge and awareness of menstural health
Belief in myths about endometriosis
Education in schools focusing on a limited scope of what is mensturation and types of contraception

Taking Control: Advocacy

Facilitators
Individual Level
Being persistent with finding the cause of their symptoms
Trusting their body and what it was telling them - priorotising experiential knowledge
Self-diagnosis
Self-education - doing thier own research to increase knowledge
Keeping a diary of thier symptoms

Medical Level
Rejecting healthcare providers assessments that they believed were incorrect
Changing GPs until finding one that could meet their needs
Remaining persistent with recieving a referral to a specialist from their GP
Self-referring to specialist

The Role of Support

Facilitators
Societal Level
Increase support from family and friends
Engaging with support groups on Facebook and other social media platforms
Connecting with others on social media who have had similar experiences
The women's mothers advocating for them

Barriers
Societal Level
Lack of support
Normalisation and dismissal of symptoms
Disbelief
Lack of understanding - lack of empathy

Sociodemographic Characteristics

The sociodemographic characteristics of the women are summarised below in Table 1. Of the 135 women who completed the survey, 134 identified as women (99.3%) and one participant did not specify their gender (0.7%). The women ranged in age from 18 to over 50 years, with half of the respondents aged between 20-29 years (50.4%). Of the 135 women, 114 identified as New Zealand European (84.4%), seven identified as Māori (5.2%), four identified as Samoan (3.0%), one identified as Indian (0.7%) and eight identified as other (5.9%). Additionally, of the eight participants who identified as other, one identified as Dutch, one identified as German, one identified as mixed Chinese-European, one identified as French, one identified as Australian, one identified as Māori-European, and one as South African.

Table 1

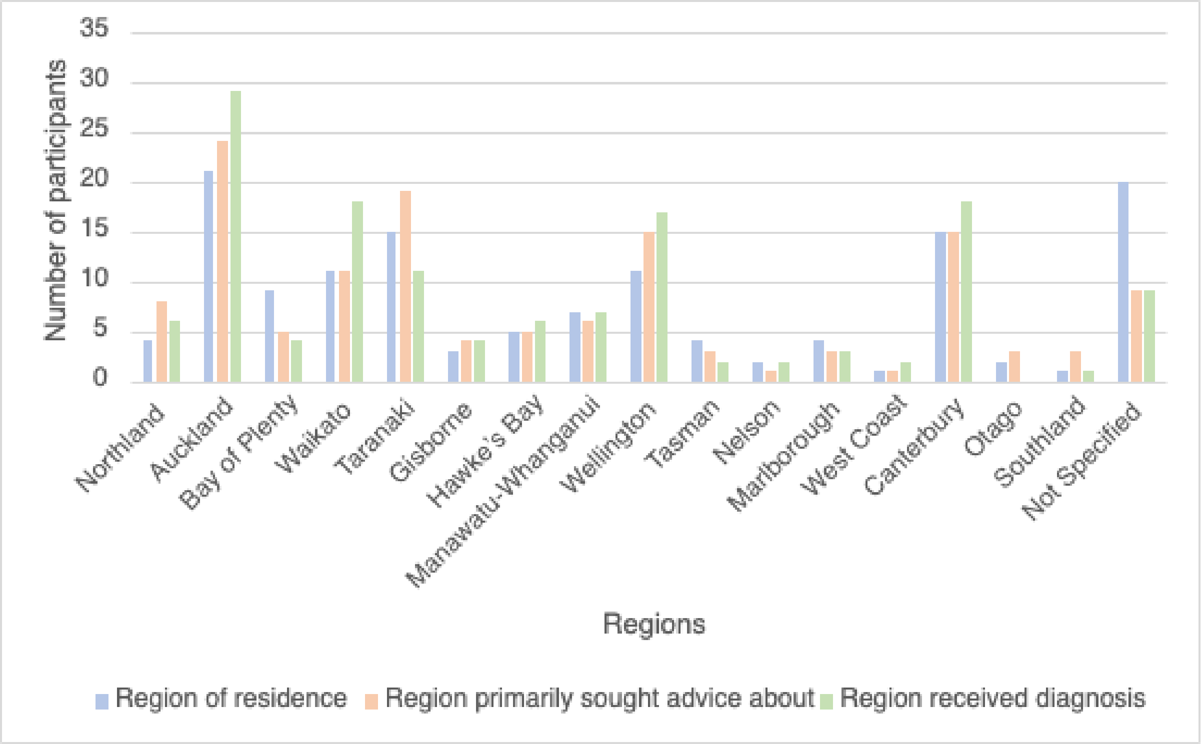
Sociodemographic Characteristics of the Participants

	Participants, n (%)		
	Overall (n=135)	Confirmed via laparoscopy (n=116)	Not confirmed via laparoscopy (n=19)
Gender			
Woman	134 (99.3)	116 (100)	18 (99.3)
Man	-	-	-
Not Specified	1 (0.7)	-	1 (0.7)
Age (years)			
18-19	3 (2.2)	1 (0.9)	2 (10.5)
20-29	68 (50.4)	55 (47.4)	13 (68.4)
30-39	43 (31.9)	39 (33.6)	4 (21.1)
40-49	18 (13.3)	18 (15.5)	-
50+	3 (2.2)	3 (2.6)	-
Ethnicity			
New Zealand European	114 (84.4)	98 (84.5)	16 (84.2)
Māori	7 (5.2)	6 (5.2)	1 (5.3)
Samoan	4 (3.0)	3 (2.6)	1 (5.3)
Indian	1 (0.7)	1 (0.9)	-
Other	8 (5.9)	7 (6.0)	1 (5.3)
Not Specified	1 (0.7	1 (0.9)	-

At the time of completing the survey, all the women resided in Aotearoa New Zealand, with the majority of the women living in Auckland (15.6%), Canterbury, (11.1%), Taranaki (11.1%), Waikato (8.1%) and Wellington (8.1%) (see Figure 3). Consistent with this data, when the women were asked in which region they primarily sought advice from healthcare providers about their symptoms, the majority of the women (62.2%) reported seeking advice from healthcare providers in Auckland (17.8%), Taranaki (14.1%), Wellington (11.1%), Canterbury (11.1%) and Waikato (8.1%). Similarly, when the women were asked which region they received their diagnosis of endometriosis in, the majority of the women (68.8%) reported receiving their diagnosis in Auckland (21.5%), Waikato (13.3%), Canterbury (13.3%), Wellington (12.6%) and Taranaki (8.1%). This indicates that some of the women received their diagnosis in a region that they did not primarily seek healthcare advice about their symptoms.

Figure 3

Summary of Regional Differences



Clinical presentation

This section discusses the women's clinical presentations of endometriosis. Most of the women reported getting their first period by the time they were 13 years old (69.6%) and began experiencing endometriosis-related symptoms by the time they were 19 years old (68.9%) (see Table 2). The majority of the women reported that they experienced endometriosis-related symptoms for less than 1 year (34.8%) and 1-2 years (35.6%) before seeking medical advice (see Table 2).

Table 2

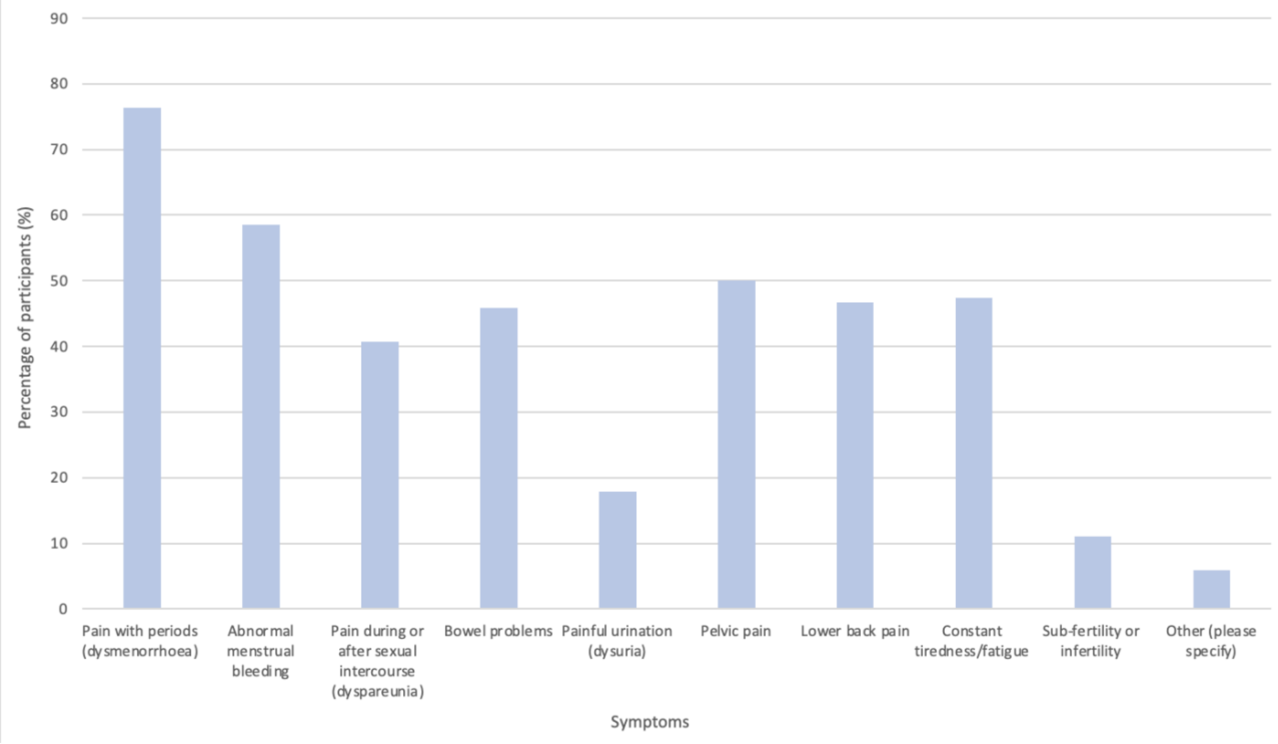
Participants' Clinical Presentation

	Participants, n (%)		
	Overall (n=135)	Confirmed via laparoscopy (n=116)	Not confirmed by laparoscopy (n=19)
Age at first period, years			
Under 10	1 (0.7)	1 (0.9)	-
10-11	41 (30.4)	38 (32.8)	3 (15.8)
12-13	52 (38.5)	45 (38.8)	7 (36.8)
14-15	28 (20.8)	24 (20.7)	4 (21.1)
16+	13 (9.6)	8 (6.9)	5 (26.3)
Age when symptoms began, years			
Under 15	51 (37.8)	46 (39.7)	5 (26.3)
15-19	42 (31.1)	36 (31.0)	6 (31.6)
20-24 years	28 (20.8)	21 (18.1)	7 (36.8)
25-29 years	10 (7.4)	9 (7.8)	1 (5.3)
30+ years	4 (3.0)	4 (3.4)	-
Time experiencing symptoms prior to seeing GP, years			
Less than 1	47 (34.8)	35 (30.1)	12 (63.2)
1-2	48 (35.6)	45 (38.8)	3 (15.8)
3-4	21 (15.6)	21 (18.1)	-
5+	15 (11.1)	14 (12.1)	1 (5.3)
Not specified	4 (3.0)	1 (0.9)	3 (15.8)

The most common symptoms that the women reported experiencing prior to receiving a diagnosis were painful periods (76.3%), abnormal menstrual bleeding (58.5%), pelvic pain (51.4%), lower back pain (46.7%), fatigue (47.4%), bowel problems (45.9%) and pain during or after sexual intercourse (40.7%) (summarised in Figure 4). This was consistent for the women who had a confirmed diagnosis via laparoscopy and participants whose diagnosis had not been confirmed via laparoscopy.

Figure 4

Participants' Main Symptoms Prior to Diagnosis

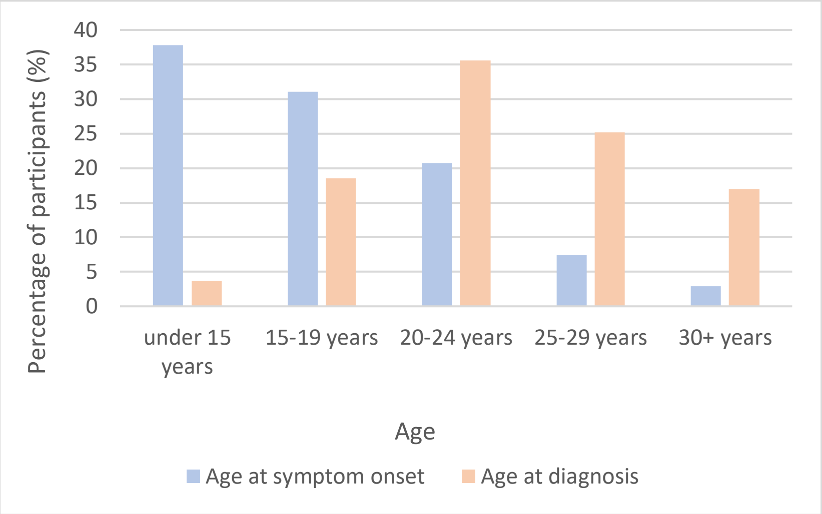


Diagnostic Experience

This section summarises the women's diagnostic experience. Most of the women were between the age of 20-29 years (60.8%) when they were diagnosed with endometriosis (see Figure 5). It is promising that 40% of women reported that it took less than 1 year (17.8%) or 1-2 years (22.2%) to receive a diagnosis, however, there were still 23.7% that took 9+ years from the initial conversation with a healthcare provider about their symptoms until receiving a diagnosis of endometriosis (see Table 3).

Figure 5

Average Age at Symptom Onset and Receiving Diagnosis



Of the 135 women that completed the survey 116 women (85.9%) had their diagnosis confirmed via laparoscopic surgery and 18 women self-identified that they had endometriosis without surgical confirmation (these are still included in the data). When these 116 women were asked to identify the stage of their endometriosis, it was surprising that almost one quarter (24.1%) did not know (or were not told) their stage of diagnosis (see Table 3). It should be noted that the stage at diagnosis does not mean the women will stay at this stage and pain does not necessarily increase with stage (it is based on the number of lesions, location, and depth of infiltration). In terms of their interactions with healthcare providers, 95 women (70.4%) reported discussing their symptoms with multiple GPs and surprisingly only 37% of women were diagnosed with visits to one specialist (see Table 3). Therefore, it is taking multiple visits with many healthcare professionals before the majority of women are getting diagnosed – almost 20% of women require visits with 4 or more GPs before endometriosis was even mentioned as a possibility.

Table 3

Participants' Diagnostic Experience

	Participants, n (%)		
	Overall (n=135)	Confirmed via laparoscopy (n=116)	Not confirmed by laparoscopy (n=19)
Approximate time to receive diagnosis, years			
Less than 1 year	24 (17.8)	16 (13.7)	8 (42.1)
1-2 years	30 (22.2)	26 (22.4)	4 (21.1)
3-4 years	14 (10.4)	12 (10.3)	2 (10.5)
5-6 years	18 (13.3)	18 (15.5)	-
7-8 years	14 (10.4)	13 (11.2)	1 (5.3)
9+ years	32 (23.7)	30 (25.9)	2 (10.5)
Not specified	3 (2.2)	2 (1.7)	1 (5.3)
Discussed symptoms with multiple GPs			
Yes	95 (70.4)	82 (70.7)	13 (68.4)
No	38 (28.1)	32 (27.6)	6 (31.6)
Not specified	2 (1.5)	2 (1.7)	-
Number of different GPs visited			
1	-	-	-
2	25 (28.5)	20 (17.2)	5 (26.3)
3	42 (31.1)	38 (32.8)	4 (21.1)
4	7 (5.2)	5 (4.3)	2 (10.5)
5+	21 (15.6)	19 (16.4)	2 (10.5)
Not specified	40 (29.6)	34 (29.3)	6 (31.6)
Time before GP mentioned possibility of endometriosis, years			
<1	41 (30.4)	31 (26.7)	10 (52.6)
1-2	32 (23.7)	28 (24.1)	4 (21.1)
3-4	15 (11.1)	15 (12.9)	-
5+	43 (31.9)	40 (34.5)	3 (15.8)
Not specified	4 (3.0)	2 (1.7)	2 (10.5)
Number of visits with GP before referral to specialist			
1	16 (11.9)	8 (6.9)	8 (42.1)
2-3	39 (28.9)	35 (30.2)	4 (21.1)
4-5	28 (20.7)	25 (21.6)	3 (15.8)
6-7	15 (11.1)	15 (12.9)	-
8-9	5 (3.7)	3 (2.6)	2 (10.5)
10+	31 (23.0)	29 (25.0)	2 (10.5)
Not specified	1 (0.7)	1 (0.9)	-
Number of specialists seen before diagnosis			
1	50 (37.0)	45 (38.8)	5 (26.3)
2	49 (36.3)	41 (35.3)	8 (42.1)
3	24 (17.8)	19 (16.4)	5 (26.3)
4	4 (3.0)	4 (3.4)	-
5+	5 (3.7)	4 (3.4)	1 (5.3)
Not specified	3 (2.2)	3 (2.6)	-
Stage of endometriosis			
Stage 1	25 (18.5)	19 (14.1)	6 (4.4)
Stage 2	28 (20.7)	25 (18.5)	3(2.2)
Stage 3	24 (17.8)	23 (17.0)	1 (0.7)
Stage 4	22 (16.3)	21 (15.6)	1 (0.7)
Unsure	33 (24.4)	28 (20.7)	5 (3.7)
Prefer not to say	3 (2.2)	-	3 (2.2)

Consistent with the number of professionals required and the average time to diagnosis, the majority of women reported that it took either <1 year (30.4%), 1-2 years (23.7%), or 5+ years (31.9%) before their GP mentioned endometriosis as a possible cause for their symptoms (refer to Table 3). Additionally, many of the women reported having either 2-3 visits (28.9%), 4-5 visits (20.7%), or 10+ visits (23.0%) with their GP before they received a referral to a specialist. Once receiving a referral to a specialist, 50 women (37.0%) reported visiting one specialist, 49 women (36.3%) reported visiting two specialists, 24 women (17.8%) reported visiting three specialists, four women (3.0%) reported visiting four specialists, and five women (3.7%) reported visiting 5+ specialists before receiving a diagnosis of endometriosis.

The quantitative data clearly illustrates the diagnostic delay the women experienced on their journey to diagnosis and starts to highlight some of the barriers they faced. These barriers are further unpacked in the following themes which also explore the facilitators the women encountered.

The Healthcare Encounter

This theme is centred around women's healthcare encounters on their journey to diagnosis. It explores women's interactions with healthcare providers including negative interactions where healthcare providers normalised and dismissed symptoms and showed a lack of support and understanding, and the less frequent positive interactions that women experienced. It also explores the ineffective clinical practice the women encountered including misdiagnoses, incorrect and delayed referrals, healthcare providers who seemed more concerned about treating the symptoms than finding the cause and the difference between private and public care.

Interactions with Healthcare Providers

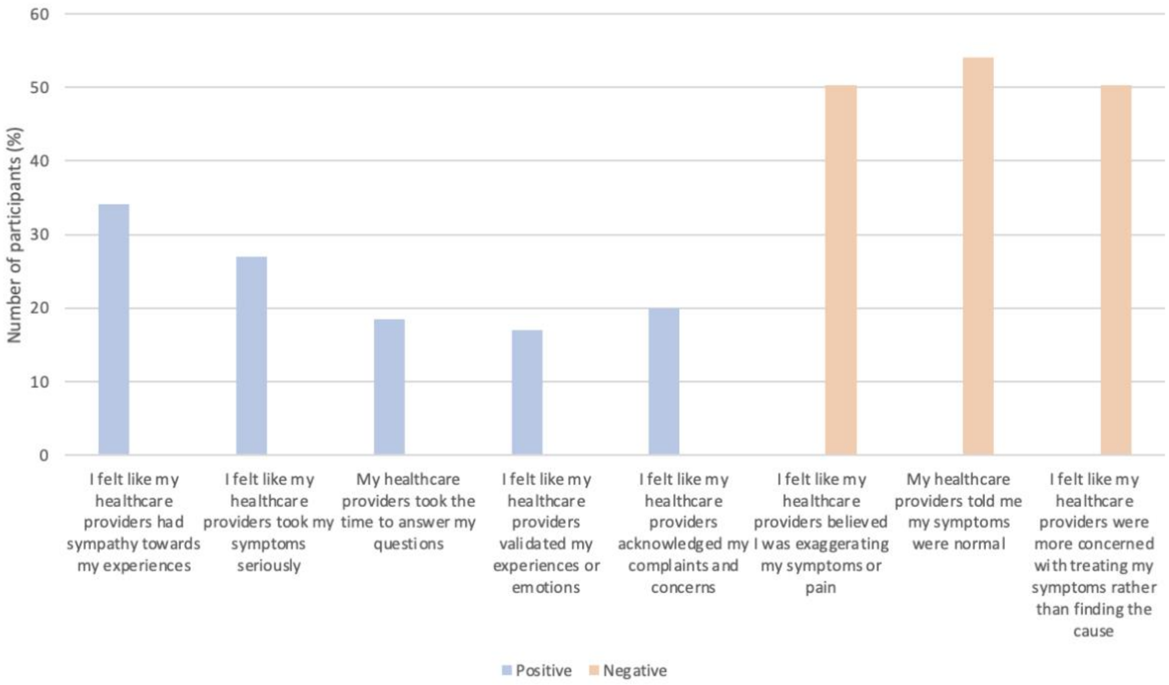
Reflecting on their interactions with the healthcare providers that they encountered on their journey to diagnosis, the women described both positive and negative interactions. The barriers were highlighted with many women describing a ‘struggle’ characterised by disbelief, normalisation, dismissal, and a lack of support. However, a minority of women spoke of positive encounters which highlighted the role that healthcare providers play in facilitating the diagnosis of endometriosis. Where healthcare providers were sympathetic, listened to and acknowledged the women’s concerns and complainants, provided support and advocated for them, a diagnosis was facilitated. It is telling that only 33% of women were extremely satisfied or satisfied with their interactions with healthcare providers and 66% were unsatisfied or extremely unsatisfied.

Normalisation, Dismissal and Disbelief

In the women’s accounts, it became clear that the normalisation and dismissal of endometriosis-related symptoms by healthcare providers was one of the major barriers that women frequently experience on their journey to diagnosis. The women described their healthcare providers repeatedly tell them that their symptoms were normal symptoms for women to experience during menstruation (Figure 6). There was no difference to those who felt judged (52%) compared to those who were not (46%). However, as Figure 6 illustrates, the percentage of women having positive interactions is lower than those having negative interactions.

Figure 6

Frequency of Positive and Negative Interactions with Healthcare Providers



There were many qualitative responses to medical interactions, for instance, *"I was told at 14 years old that it is what periods were like for some girls/women so took what I had as normal and I was one of the unlucky ones"*, while others stated *"...I was told that all women were different, and this was just what some ladies experience during their period"* and *"I was told by several GPs that my symptoms were normal for women to experience."* This was especially true for women's complaints of pain which were frequently dismissed as 'normal period pain'. For example, one woman stated *"initially when I was in A&E I was seen by male nurses and doctors who told me that I was experiencing period cramps, even after I had advised them that I was bedridden for 24 hours before going to the hospital because of the pain. It felt as though the pain I was in was being written off as 'not that bad'"* while another said she received *"comments like we all get period pain, it's normal, just nodding and saying nothing".* This idea of menstrual pain and other symptoms as being a normal experience for women during menstruation was not confined to healthcare providers but was also something the women reported being told by family and friends: *"My family said that I was being dramatic and lots of women handle period pain without needing to see a doctor"* and *"I think the idea that periods are painful was widespread between all my friends and family..."*

Consequently, for many women, the symptoms they were experiencing were positioned as something they would have to live with, therefore, they needed to learn how to deal with it. For instance, one woman stated "*I know this is about healthcare, but another barrier I faced was doctors and other women telling me that I should just suck it up because women have been dealing with this for thousands of years and it's not a big deal, we are just supposed to deal with it"* while other women said *"male doctor told me the symptoms were in my head, and I needed to just get on with it"* and *"because I was being told it was normal, I just accepted that and thought that it was in my head, and that I had to push through."*

Lack of Support

In addition to the normalisation and dismissal of endometriosis-related symptoms, the women's accounts of their interactions with healthcare providers also detailed a lack of support. The lack of support was demonstrated through a lack of belief, understanding and empathy from the healthcare providers that the women interacted with; and further delayed women from receiving a diagnosis of endometriosis.

When discussing their symptoms with healthcare providers, most of the women reported experiencing a lack of belief. Far too often, the women's accounts described healthcare providers who did not believe what they were saying, and they were made to feel like they were not taken seriously despite stressing the severity of their symptoms and the impact their symptoms had on their day-to-day lives. For example, one woman said "*I* *felt unsupported and as though they didn't believe me, which meant that I didn't have the confidence to advocate for myself. I'd had very little interaction with doctors at all before I started suffering from endometriosis symptoms in my teens, so naturally thought the doctors would know what they were talking about and that they would help me. How wrong was I...*" while another stated "*it felt like my GP did not take me seriously even when I repeatedly told them that the pain was excruciating and meant I couldn't go into uni or hang out with my friends. It is extremely disheartening."*

Additionally, in their accounts, many women reported encountering healthcare providers who did not listen to them; with many of the women describing feeling like their concerns were falling on deaf ears during the consultation process. For instance, one woman said *"(the doctors) didn't listen to what I said, felt like they thought they knew my body better than me"* while another commented "*it felt like my GP didn't listen to what I was saying. Repeatedly had the same conversations time and time again.*" This was also depicted in the women's accounts where they reported knowing that something was wrong but kept being dismissed with one woman stating, "*I knew something was seriously wrong but was dismissed by GPs*" while another remarked "*I did not dismiss my symptoms at all, I knew I had endo but GP kept blowing me off."* These experiences left many women feeling hopeless, ignored, invisible, diminished and like they had to fight to be taken seriously: *"I never felt empowered. I felt diminished, ignored and eventually like death would be better than the shitty experience of pain, blood, nausea and sleep deprivation that I was experiencing day in and day out."*

The women also reported experiencing a lack of understanding when interacting with their healthcare providers, which was demonstrated by a lack of empathy towards the women's experiences. For example, one woman stated "*my GP told me that I was a stupid* *little girl, to get over myself and see mental health help – not medical help when I presented with symptoms at 13 years old. I went to the ER on a regular basis, where I was also dismissed and gaslit"* while other women commented *"my GP showed absolutely no empathy towards my experience and told me I just needed to get on with it. There needs to be more respect for women's experiences and greater learning about endo by GPs as they are normally the first point of contact"* and *"one GP made me feel as though I was just attention seeking and wasting his time. He showed zero empathy."* Consequently, this made the women feel like they were exaggerating or imagining their symptoms, that they were a hypochondriac, that it was all in their heads or that they simply had a low pain tolerance:

> *"Because the GP told me it was all in my head, I thought I couldn't handle my period like everyone else and I was made to feel like I had a very low pain tolerance."*
>
> *"Doctors were dismissive of my concerns, refused to explore issues further, made me feel like I was exaggerating/making things up."*
>
> *"... I also had male GPs who made me feel as if I had a low pain threshold and what I was experiencing was normal, I was just a wuss."*
>
> *"The doctors were dismissive of the pain that I was in, making me feel like I was being a hypochondriac, oh you're back again (eye roll), 'I just don't know what you want me to do for you'..."*

Positive Interactions

In contrast to the negative interactions with healthcare providers whereby women experienced a lack of belief, understanding and empathy and their symptoms were normalised and dismissed; the women also spoke of positive encounters. In the women's accounts of positive interactions, healthcare providers were sympathetic towards their experiences, listened to and acknowledged their concerns and complaints, provided support and advocated for them; all of which helped to facilitate the diagnosis of endometriosis. In their accounts of positive interactions, the women discussed feeling acknowledged by their healthcare providers, that is, they felt listened to, believed and validated. For instance, one woman stated *"...it wasn't until I finally saw a general surgeon... that I finally had a turning point. He validated my experiences, listened to me, met me where I was at and swiftly referred me into the public health system to be seen... it was amazing to actually have a doctor that believed in me and the suffering that I had been experiencing for so many years. I was fobbed off, disbelieved, given prescriptions for the contraceptive pill and generally told to just get on with it by so many others, but that one consultation with the general surgeon who believed me help me to believe in myself and know that my experiences are valid. I will always be grateful to him"* while another stated *"endometriosis was impacting my studies negatively and someone suggested I go to family planning as the doctors there are focused on women's health. This appointment was the best appointment I had as I felt listened to, validated and encouraged to continue fighting for a diagnosis, especially after the doctor referred me to a gynaecologist."*

When healthcare providers listened and were sympathetic towards women's experiences and acknowledged their concerns and complaints, the women no longer felt like they had to convince healthcare providers of the legitimacy of their symptoms. This helped the women to believe in themselves, made their self-esteem grow and gave them the confidence to return when they needed additional healthcare which was a crucial facilitator for some of the women on their journey to diagnosis: *"my GP has always taken my concerns seriously so I felt empowered and confident to go back to her when the pain got worse as I knew I wouldn't be dismissed."* However, these experiences were not shared by all of the women with 46 women (34.1%) reporting feeling like their healthcare providers had sympathy towards their experiences, 27 women (20.0%) reporting feeling like their healthcare providers acknowledged their concerns and complaints, and 23 women (17.0%) reporting feeling like their healthcare providers validated their experiences and emotions (see Figure 6).

In addition to feeling acknowledged by healthcare providers, several of the women's accounts described encountering healthcare providers who advocated for them. In their accounts, it became clear that the healthcare providers who advocated for their patients were predominantly GPs who were well educated on endometriosis and women's health, were practitioners at family planning or practiced complementary or alternative medicine such as naturopaths. These healthcare providers advocated for their patients by arming them with information and supporting them on their journey to diagnosis as well as giving them confidence to keep fighting for a diagnosis. For example, one woman stated *“a nurse at the sexual health clinic advocated for me and bolstered my confidence about listening to my body”* while another said *“I went to a naturopath out of desperation to get relief from symptoms due to previous GPs just sending me away with more birth control and over the counter painkillers that did not work. My naturopath was the first healthcare provider to tell me my pain was not normal. She then gave me the information of how endo needed to be diagnosed and that my ultrasound was not enough. She essentially told me what to ask from my GP and that knowledge really empowered me to advocate for myself. Next GP visit I got my referral.”*

The women in this study that experienced positive interactions with healthcare providers considered themselves “lucky” to have encountered a healthcare provider who was supportive, listened to them and made them feel acknowledge, were sympathetic towards their experiences and advocated for them. For instance, one woman commented "*I personally have been incredibly lucky to have a great GP! Without this GPs original thoughts, I would have had no idea about endometriosis or that... what I was experiencing isn't normal"* while another stated *"I feel I was incredibly lucky compared to others with my experiences and the time to receive my diagnosis. I believe I had a GP who took me and my symptoms seriously and was committed to finding the cause. I also felt like I was lucky to see a gastroenterologist who suggested I might have endometriosis after his testing came back clear. I also feel lucky I saw a good gynaecologist who knew a lot about endometriosis and quickly diagnosed me through laparoscopy."* However, these women considered themselves lucky and were appreciative to have received a level of care that was not available to all of the women as positive interactions appear to be the exception to the rule: "*I was very happy with the healthcare I received from my healthcare providers, but am aware that this seems to be the exception."*

Ineffective Practice

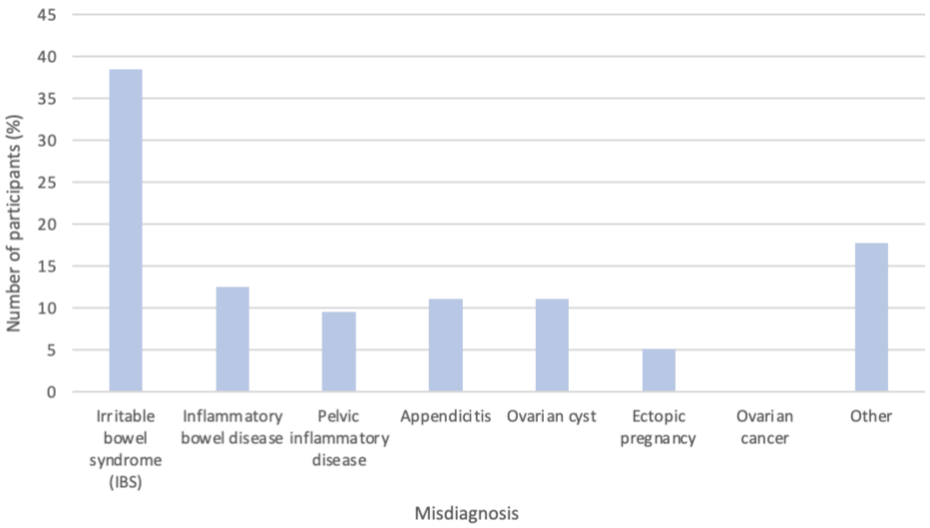
One of the major barriers for women which occurred at the medical level was what they perceived as ineffective clinical care in terms of the treatment they received. Many of the women (70.4%) reported repeated consultations with GPs for a diverse range of symptoms which could be attributed to endometriosis. During their consultation with healthcare providers, the women often perceived their GPs as having a lack of knowledge about menstrual health (59.3%) and endometriosis (70.4%) which often resulted in a failure to consider the women's symptoms as gynaecological. The women reported that in these instances, they received misdiagnoses and frequently received referrals to medical specialists who were not gynaecologists. Additionally, they were often prescribed pain medication and contraceptive pills in an attempt to reduce their symptoms without any real attempt to uncover the cause of their symptoms.

Misdiagnoses

The majority of the women in this study spoke of being misdiagnosed with many different illnesses, both physical (59.0%) and mental (30.4%), on their journey to receiving a diagnosis of endometriosis. Prior to receiving a diagnosis of endometriosis, the most common symptoms the women in this study experienced were painful periods, abnormal menstrual bleeding, pelvic pain, fatigue, bowel problems, lower back pain and pain during or after sexual intercourse (refer to Figure 4). Yet, many of the women reported that healthcare providers frequently attributed their symptoms to ‘common diagnoses’. The qualitative data indicates that women were commonly misdiagnosed with conditions such as irritable bowel syndrome (IBS) (38.5%) (see Figure 7). However, the quantitative data also suggests that women were misdiagnosed with sexually transmitted infections (STI’s), urinary tract infections (UTI’s), food intolerances and hormonal imbalances despite their failure to explain all the symptoms the women were experiencing.

Figure 7

Physical Misdiagnoses Participants’ Received



Alternatively, healthcare providers would blame women's symptoms on their weight or a poor diet. Additionally, in some instances, women reported that their healthcare providers attributed their symptoms to mental health disorders such as anxiety (20.6%) and depression (18.5%) despite their symptoms having clear physical manifestations which were linked to menstruation.

> *"Healthcare providers were insistent that my symptoms were related to an STI, IBS and/or anxiety."*

> *"...medical advice was that I was overweight, and my diet was poor and that was the reason for the severe symptoms."*

> *"The original GP would diagnose me with UTIs when testing was negative, felt like she wanted to give it a 'common diagnosis' quickly..."*

In the case of misdiagnoses, the women felt like their healthcare providers were focused on finding an easy explanation for their symptoms without exploring them further. While some of the misdiagnoses could be plausible explanations for some of the symptom's women were experiencing such as IBS and UTIs, others seemed ridiculous to the women with one woman stating, *"they repeatedly sent me for AIDs tests and STI tests that caused extreme distress to me and my husband who were both faithful to each other..."* In these instances, healthcare providers seemed reluctant to accept the women's symptoms as gynaecological and many of the women felt that their healthcare providers failed to recognise their symptoms as being related to endometriosis (87.4%) or consider endometriosis as a plausible explanation for their symptoms (56.3%).

Unsurprisingly, in the women's accounts, it became clear that GPs were primarily responsible for misdiagnosing the women's endometriosis with 83.5% of the women who received a misdiagnosis being from a GP. However, women also received misdiagnoses from ED doctors, gynaecologists, gastroenterologists and psychologists.

Delayed or Incorrect Referrals

The majority of the women expressed that they experienced painful symptoms for a number of years before their GP referred them to specialist care (see Table 3). In this sense, despite the presence of endometriosis-related symptoms, the women's GPs seemed hesitant to refer these women to specialist care, with many of the women (67.4%) left feeling like their GP delayed referring them to a specialist.

In their accounts, many of the women described a 'struggle' with their GP where their concerns were dismissed, and their symptoms were normalised. Several women felt like their GPs failed to consider their symptoms gynaecological and did not want to go down the route of endometriosis which many women found frustrating and often lengthened their journey to diagnosis. For instance, one woman stated, *"it's like they wouldn't/didn't want to go down the route of endometriosis and refer me"* while another exclaimed *"the disinterest some of the doctors had towards my symptoms was shocking and their refusal to refer me was frustrating and made me feel like I was overreacting even though I knew I wasn't."*

The major facilitator identified in aiding a timely diagnosis was the women taking on more control and advocacy for themselves. Some of the women spoke about taking specialist care into their own hands by demanding a referral from their GP. For example, one woman said *"I spent years backwards and forwards with the drs to try and get to the bottom of my symptoms, I had many tests. Finally, my mum stepped up and said what about endo. I was told 'I don't believe you have endometriosis but can refer you if that's what you want to do'"* while another stated *"... I deliberately decided to keep pestering my GP until* *they granted me a scan and referred me to a specialist. I just kept coming back and complaining about my symptoms on a regular basis and then at the final appointment I directly suggested endo and a referral."* Alternatively, other women simply referred themselves to a specialist who they believed could help them. *"I discussed (my symptoms) with my mum as she had endometriosis and adenomyosis, and (she) was a strong advocate for me including in us self-referring to a specialist as we didn't get offered a referral from either of the two GPs I saw"* and *"I wrote to the Oxford Clinic in Christchurch after I got violently sick and couldn't move my bowel. I then 'ditched' my doctor and paid to see a specialist privately."*

However, for many women, receiving a referral to a specialist did not ensure immediate diagnosis of endometriosis. Instead, once receiving a referral to a specialist, nearly half of the women (48.1%) felt like they were faced with a lengthy wait time before they were able to have an appointment with the specialist and many women (60.7%) reported having an appointment with more than one specialist before they received a diagnosis of endometriosis. In many instances, this was due to the women receiving referrals to specialists who were not gynaecologists, including gastroenterologists, psychologists, orthopaedic specialists, urologists, rheumatologists, endocrinologists and neurologists which prolonged their journey to receiving a diagnosis.

Treating Symptoms Rather Than Finding the Cause

Another barrier that many of the women in this study encountered on their journey to receiving a diagnosis which became apparent was the copious amounts of medications that had been prescribed by their GPs to treat their symptoms. In many cases, the women described their healthcare providers as being quick to prescribe medication that targeted their symptoms rather than attempting to find out why they were experiencing the symptoms in the first place. One woman said, *"doctors suggested putting me on birth control at the age of 15 to control the symptoms but were not willing to look into the cause of the symptoms"* while others stated, *"I was often given different medications to stop my symptoms rather than discovering the root cause"* and "*...people are put on pills too quickly and its always a band-aid fix which can actually make things worse in my experience and birth control …can just help with symptoms sometimes..."* The women felt that while medications are useful for the symptoms sometimes, their doctors used medications instead of seeking further tests for endometriosis. In this sense, while the prescription of medications to treat the symptoms acts as a barrier to receiving a diagnosis, the medication acts as a facilitator to get through the pain.

In other words, many of the women in this study felt that their healthcare providers relied on birth-control and other medication as a band-aid for their symptoms. The medication may have masked their symptoms, but this was a temporary solution as they were only able to ignore their problems for a few years before they were back at square one. *"...my symptoms were centred around my period, so I got put on hormonal birth control that stopped my period and consequently my main symptoms of pain, so I ignored the fact for a few years as well. But when I came off birth control my symptoms were still there, so it was only a temporary fix for my symptoms, and I had made no progress."* Despite the frustration at healthcare providers' reliance on hormonal birth control and pain relief to treat symptoms rather than finding the cause of women's symptoms, for many women, taking medication helped them get through each day. However, the over prescription and failure to establish the cause of women's symptoms is problematic as the women were not given any explanation for the causes of their symptoms which reflects healthcare providers' lack of concern for and unwillingness to acknowledge women's health issues and contributed to further delays in diagnosis for women.

"I'm lucky I had insurance": Private Healthcare

It is not uncommon in research about endometriosis for women who get diagnosed relatively quickly to say they are lucky. This luck is often to do with access to private healthcare therefore is considered a facilitator. There was a minority of women who considered themselves 'lucky' in this study when it came to the healthcare they received. In most cases, this related to women encountering healthcare provides who were supportive, listened to their concerns and advocated for them; all factors that facilitated diagnoses of endometriosis, however, this was framed as luck not a human right. Although for many women, they considered themselves 'lucky' in the sense that they could access private healthcare through their health insurance or by paying for private care out of pocket. This meant they were able to access more knowledgeable and specialist care in a faster manner and laparoscopic surgery was far more accessible which helped facilitate a diagnosis of endometriosis.

> *"I would like to say I am certain the only reason I was taken seriously, and things escalated quickly for me towards my diagnosis was because I had private health insurance which would cover seeing a specialist and potential surgery. I don't think my symptoms were severe enough for the public system to consider them a priority. I'm lucky I had insurance – my GP referred me straight away when she realised this and gave me a range of options on who the best surgeons would be. Within 2 months, I was having surgery and I was diagnosed with stage 4 endometriosis."*

> *"Having private health insurance made such a big difference because I was able to be seen and then have surgery within months."*

> *"My experience was very different because I had private healthcare. I went from initial consult to surgery within 4 months. There is a real double standard in the system that I was heard and listened to and got the healthcare I needed because I have insurance while others wait in pain."*

Thus, not having access to private healthcare was clearly a barrier as one woman said "*barriers for people is definitely got to be what they have access to. Most people can only access their GP and then get a referral to a specialist publicly but if that doesn't work out for them there isn't much they can really do after that"*. The women receiving care within the public health system collectively felt like their experiences were not deemed as important or urgent enough by medical professionals that believed endometriosis was not acknowledge as a serious condition or as a priority, *"the public health system needs to acknowledge just how severe endometriosis is. I don't think they prioritise it enough, because it isn't considered a fatal disease. However, it severely impacts quality of life, and people often forgo opportunities because it would be too much in addition to living with endometriosis..."*

Summary

This theme explored the women's interactions with healthcare providers while on their journey to diagnosis. The main barriers women encountered were negative interactions with healthcare providers, with many of the women describing a 'struggle' characterised by the normalisation and dismissal of their symptoms, disbelief, and a lack of support. Additional barriers were misdiagnoses, delayed or incorrect referrals and having healthcare providers prescribe copious amounts of medication in an attempt to treat their symptoms without finding the cause. It became abundantly clear that negative interactions with healthcare providers acted as significant barriers for the women while on their journey to diagnosis. On the other hand, positive interactions with healthcare providers were identified as a facilitator to the diagnosis of endometriosis. Some of the women described positive interactions where healthcare providers were sympathetic, listened to and acknowledged their concerns, provided them with support and advocated for them; and it became clear that having health insurance and access to private healthcare increased the likelihood of having a positive encounter. Having positive encounters validated the women and meant they no longer felt like they needed to convince their healthcare providers of the legitimacy of their symptoms resulting in a huge sense of relief.

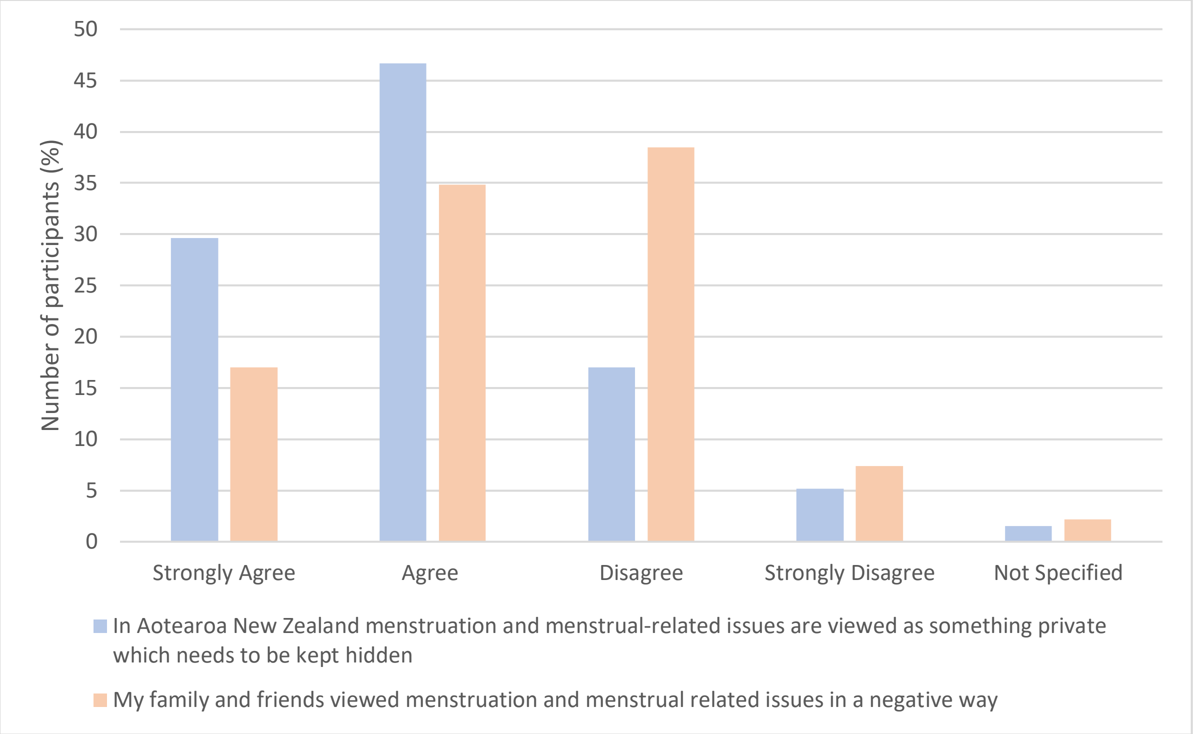
Symptom Concealment

Another significant barrier that contributes to the diagnostic delay of endometriosis is symptom concealment. This theme unpacks the ways women with endometriosis concealed their symptoms prior to receiving a diagnosis and explores the stigma surrounding endometriosis-related symptoms and menstruation that occurs at a societal level.

The majority of the women (76.3%) believe that menstruation and menstrual-related issues are perceived as something private which needs to be kept hidden in Aotearoa New Zealand (see Figure 8). However, there was almost an even split between women who strongly agreed/agreed (51.8%) that their family and friends viewed menstruation in a negative way and those who strongly disagreed/disagreed (45.9%)

Figure 8

Societal Attitudes Towards Menstruation and Menstrual-Related Issues



Unsurprisingly, many of the women described instances where they concealed their menstrual cycle and their endometriosis-related symptoms from family, friends and other members of society. When asked why they concealed their menstrual-cycle and symptoms, the women's responses highlighted three key reasons for concealment. These were fear of judgement and negative perception, fear of the stigma associated with their symptoms, and lastly, due to dominant cultural or family beliefs.

Fear of Judgement and Negative Perception

The idea of menstruation and endometriosis-related symptoms as being perceived negatively by women's family and friends became clear when the women were asked whether they believed that their family and friends perceived menstrual-related issues, including endometriosis, in a negative way; with over half of the women (53.0%) stating that was the case.

In their accounts, many of the women spoke directly about their fear of being judged or perceived negatively by their family, friends and other members of society such as other women, teachers, colleagues and employers. It became clear that they were concerned that if they spoke openly about the difficulties that they were experiencing with menstruation and endometriosis-related symptoms then they would be labelled as a hypochondriac, weak or unable to handle normal period pains. For example, one woman stated, "*I believed people would think I was just overexaggerating and weak and had a low pain tolerance which isn't the case"* while another said, "*"I didn't want to cry wolf over something when it might have been seen as me being too weak and just not dealing with it."* Additionally, many of the women were concerned that people would think they were "*always complaining, making it up or being dramatic"* if they spoke about their symptoms and they didn't want to draw attention to themselves. For instance, one woman commented "*I didn't want people always thinking I was just being dramatic about periods and wanting attention*" while others stated, "*I didn't want to come across as dramatic, hysterical or using my period as an excuse...*" and "*I was overly concerned with what other people would think, didn't want to draw attention I guess.*" As a result, many of the women felt the need to conceal their symptoms and hide their experiences from others as a means of protecting themselves. As one woman put it, *"I learnt to hide my symptoms and pain, became very good at acting and also very good at lying about why I couldn't do something to protect myself."*

Additionally, many of the women described instances where they received negative backlash and a lack of support from their family and friends, as well as other members of society when they attempted to share their reality and inform them of the symptoms they were experiencing. For instance, one woman stated *"when I shared my symptoms, I was ashamed as was made to feel like I was being a drama queen or trying to get out of school* *from the staff and my parents"* while another said, *"when I tried to talk to my family and friends I was told that I was being dramatic and lots of women handle period pain without needing to see a doctor."* This served to reinforce a negative cycle, where the women continued to conceal their symptoms from family, friends and other members of society such as colleagues, teachers and employers; and unfortunately, for many women, this continued after they had received a diagnosis of endometriosis.

"The Symptoms were Embarrassing": Endometriosis and Stigma

In addition to women concealing their symptoms due to a fear of judgement and being perceived negatively by family, friends and other members of society, the women in this study also concealed their symptoms due to the stigma associated with menstruation, and by extension, endometriosis. Most of the women that participated in this study (63.0%) reported feeling that in Aotearoa New Zealand, there is an unspoken belief that women should feel embarrassed or ashamed about menstruation and menstrual-related issues such as painful periods, irregular or excessive bleeding, and digestive issues such as bloating, constipation, diarrhoea and gas. In their accounts, many of the women discussed that they concealed their symptoms such painful sex, excessive bleeding and bowel and bladder issues because they believed they were embarrassing symptoms to have. For instance, one woman stated "*the symptoms were embarrassing. If I said how painful it was people generally didn't believe me and said I was being dramatic*" while another commented "*I dismissed pain during intimacy and kept it to myself because I was embarrassed and thought, I was the problem...*" Moreover, one woman described feeling like "*there is a lot of shame in society relating to women's issues*" and claimed that they were extremely private with the difficulties they were facing because they did not want to be discriminated against:

"...I was so private because I did not want to be hit with the discrimination that would come with being more open about it."

Many of the women that participated in this study believed that the stigma surrounding menstruation and menstrual-related issues is linked to a lack of open communication surrounding menstruation and menstrual-related issues, and society's view that menstruation is taboo, shameful, disgusting and something that should not be discussed in public. For example, one woman said "*stigma starts from beliefs instilled in us at an early age. We need to start discussing menstruation and endometriosis openly... the more we talk about it, the easier it will be to lift the stigma*" while another claimed, "*stigma around periods occurs because we are told early on that periods are yucky and gross and something that women need to keep to themselves.*" Despite the majority of women in this study reporting that they experienced stigma in one way or another on their journey to diagnosis, a minority of women reported that they never experienced stigma. However, these women were quick to attribute this to the fact that they believe there are not enough conversations about menstruation or endometriosis for them to have experienced stigma. For example, one woman said "*there aren't enough conversations being had for me to truly feel that there is a stigma, but I do believe there is stigma... I just haven't experienced it...*" while another said "*I never shared my struggles wide enough to experience stigma. I wish I had.*"

Cultural and Family Beliefs

In the women's accounts, it also became clear that in some instances they concealed their symptoms prior to receiving a diagnosis of endometriosis due to dominant cultural or family beliefs surrounding menstruation. In their accounts, some women discussed concealing their symptoms as a result of cultural beliefs. For instance, one woman who identified as Māori stated "w*ith Māori having your period is tapu – so I never really spoke about it because it was such a hard topic to try and bring up"* while another who identified as Chinese-New Zealand European stated "*Chinese are very patriarchal and dismissive of women and girls. So, there was just a general underlying belief that as a woman/girl I should just be quiet and not complain. We also don't talk about periods really and Chinese women are generally expected to suffer, at least in our family."* Additionally, another woman stated *"I believe my culture was a factor, just have to suck it up and get on with it. Girls/women have a big responsibility in caring for the family and can't stop for anything."* In these instances, the concealment of symptoms was not necessarily due to stigma, but rather because menstruation is simply something which is not spoken about.

Alternatively, some of the women in this study concealed their symptoms due to their family beliefs. In their accounts, these women explained that in their family they did not openly speak about menstruation or menstrual-related issues that could be attributed to endometriosis which resulted in women not having the opportunity to discuss the symptoms they were experiencing. For example, one woman stated "*...there are several women in my family who've experienced endometriosis. However, it still wasn't really spoken about."* while another said *"As a teenager I thought that everyone else experienced the same with their periods as I watched my Mum throw up from pain during her periods and then head to work. She didn't talk about it so I just endured my pain thinking it was normal. We have a family culture of women just going about their life through pain or illness and ignoring their bodies too, so that was a factor."*

Additionally, there were some instances where the women reported receiving encouragement from their family members, usually mothers and grandmothers, to not discuss or disclose their concerns around menstrual pain and irregularities as well as other symptoms that they were experiencing which could later be attributed to endometriosis after they made attempts to speak about their experiences. For instance, one woman said "*extended family (especially my Grandma) always told me that I shouldn't complain and that we keep these sorts of things to ourselves. She said that pain with periods is normal and part of being a woman and that it was normal to have to take time off school and go to bed"* while another said, "*I was told it wasn't lady like to talk about these things and that I should just carry on."* This supports the age-old belief that menstruation is to be hidden and kept a secret; however, it is problematic as it acts as a barrier to the diagnostic delay of endometriosis.

Speaking Up

Despite the stigma surrounding menstruation and menstrual-related issues, dominant cultural and family beliefs and the fear of judgement and being perceived negatively, some of the women chose to speak up about the difficulties they were experiencing and fought to be heard. Speaking up and finding a group of people who understand was a facilitator when advocating for getting a diagnosis. When these women started to speak up and demand to be heard, they found it to be quite liberating and they found that they were able to discover a community of people who had been impacted by similar experiences. For instance, one woman said "*I actually found that when I started to talk about it, rather than keep my experiences hidden I was surprised to find just how many other people had been impacted by similar experiences, either with themselves, their spouse, or other family members/friends. Once the stigma was lifted, I felt more free and ready to move forward and get answers from healthcare professionals*" while another commented "*in speaking with a friend who had been diagnosed, I realised I wasn't alone and what I was experiencing wasn't normal and something could be done about it.*"

In finding a community of people who had been impacted by similar experiences to their own, the women had found a safe space where they could communicate openly with other women who could empathise with them were sympathetic to their situation and could empathise with them. Becoming immersed in these communities, which were usually online, helped remove any stigma or break down any fears the women had and allowed them to learn, share and discuss information and experiences all of which helped facilitate the diagnosis of endometriosis. As one woman stated, "*online endometriosis groups were great, talking to actual people who were experiencing the same thing allowed me to learn heaps and eventually get diagnosed*" while another said, "*once I finally talked with my friends about what I was experiencing, one friend in particular encouraged me to seek medical assistance, she had experienced the same, knew that what was happening to me wasn't normal and helped me realise that it wasn't embarrassing."* Moreover, in the women's accounts, it became clear that after being exposed to the menstrual experiences of their family and friends (37.0%) and being given an opportunity to share their menstrual experiences and symptoms with their family and friends (34.1%) many of the women felt empowered to seek advice from healthcare providers.

Summary

This theme demonstrated that in Aotearoa New Zealand, there is a stigma attached to menstruation, and endometriosis. Despite being in the 21st century, it was perceived that society viewed menstruation as taboo, shameful, disgusting and something that should not be discussed in public; and was influenced by dominant cultural and family beliefs. The attitudes people hold towards menstruation and menstrual-related issues meant that many of the women put on a brave face and kept their symptoms and experiences to themselves. In many cases, the women concealed their symptoms as to not be judged or perceived negatively by their family, friends, and other members of society and to avoid being labelled as hypochondriac, weak or unable to handle period pain. However, this acted as a barrier to the diagnosis of endometriosis. Conversely, when the women spoke out about their experiences and engaged in conversations about menstruation with their family and friends, this helped to remove the stigma and break down any fears that the woman had and encouraged them to seek help which helped to facilitate the diagnosis of endometriosis.

Education

This theme explores the education and awareness of endometriosis and menstrual health as a barrier to the timely diagnosis of endometriosis in Aotearoa New Zealand. It unpacks the knowledge and awareness surrounding endometriosis – taking into consideration the women's own knowledge and awareness as well as the perceived knowledge and awareness of healthcare providers, family and friends, and the general population of Aotearoa New Zealand. It also explores the myths surrounding endometriosis and the education of menstrual and sexual health in schools.

Lack of Knowledge and Awareness

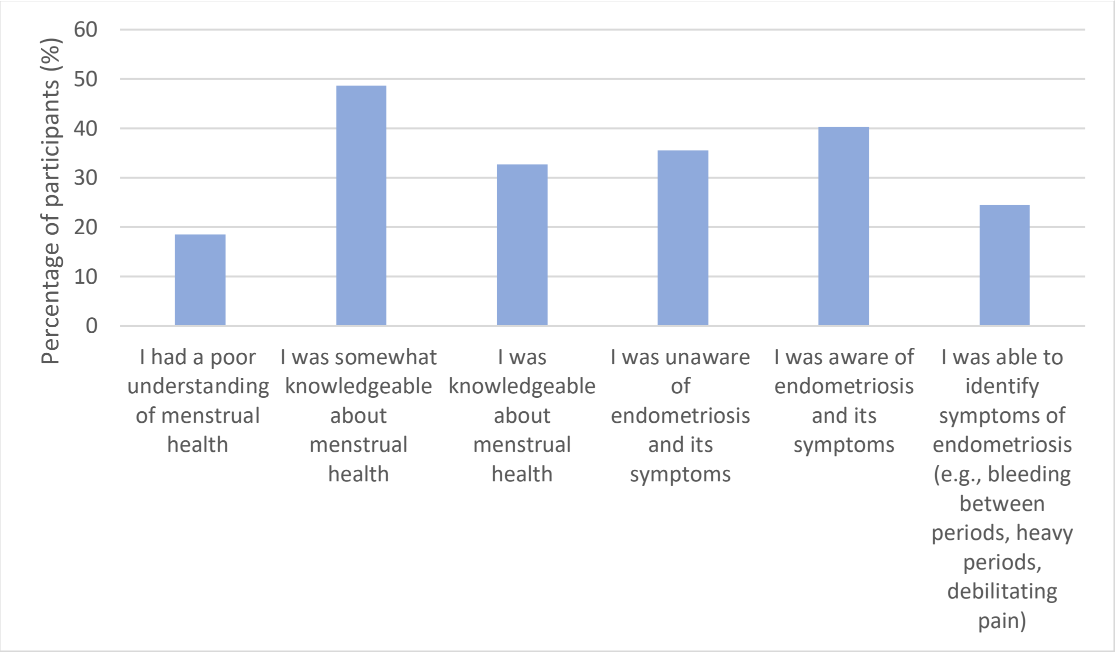
In the women's accounts, it became clear that a perceived lack of knowledge and awareness surrounding endometriosis and menstrual health was one of the most significant barriers to the diagnosis of endometriosis. The women described a lack of knowledge and awareness surrounding endometriosis and menstrual health as occurring across three different levels – the individual, the medical and the societal level – which will be discussed in turn below.

Individual Level

In their reflections of their knowledge and awareness of endometriosis and menstrual health prior to receiving a diagnosis, it became clear that many of the women believed they had a lack of knowledge and awareness. In their accounts, 113 women (87.7%) commented on their knowledge and awareness of menstrual health, while 119 women (88.1%) commented on their knowledge and awareness of endometriosis. Of the 113 women who commented on their knowledge of menstrual health, 18.5% felt like they had a poor understanding, 48.7% felt like they were somewhat knowledgeable, and 32.7% felt like they were knowledgeable. Of the 119 women who commented on their knowledge and awareness of endometriosis, 40.3% were aware of endometriosis and its symptoms, 35.5% were unaware of endometriosis and its symptoms, and only 24.4% were able to identify symptoms of endometriosis (see Figure 9).

Figure 9

Individual Awareness of Menstrual Health and Endometriosis



In the women's accounts, it became clear that for many of the women, a lack of knowledge and awareness meant that they experienced difficulties distinguishing between 'normal' and 'abnormal' menstruation and they failed to consider their symptoms as being related to endometriosis. For instance, one woman stated, "*other than the one public* *speaker that visited my high school years ago that talked to us about endometriosis for 45 minutes, I had no understanding of endometriosis. I thought that the symptoms I was experiencing were normal problems women were just unlucky to have and had to deal with*" while others said "*I knew cramping was normal and heavy flow was common in many women, so I thought that I was in the normal range*", "*I believed my symptoms were normal and just something I had to put up with*" and "*I didn't truly appreciate the level of period pain that I was experiencing was abnormal*". As a result, many of the women did not feel the urge to seek advice about their symptoms from their healthcare providers and continued to live with their symptoms for numerous years before realising their symptoms were not normal.

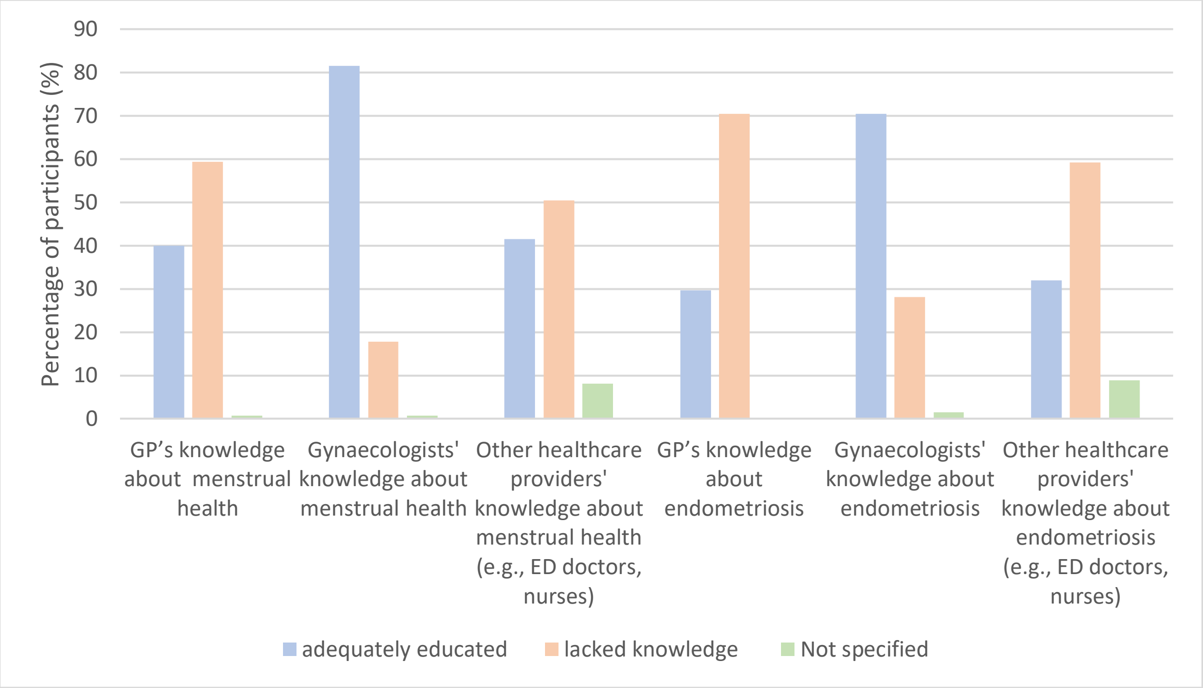
In addition, a lack of knowledge and awareness about endometriosis and menstrual health meant that many of the participants were quick to normalise and dismiss their endometriosis-related symptoms. In their accounts, the women described normalising and dismissing their symptoms in various ways, including, downplaying the severity of their symptoms (45.2%), not taking their symptoms seriously (21.5%), considering themselves unlucky to have their symptoms as opposed to 'unwell' (48.1%%), considering menstrual irregularities to be a normal experience for women (45.9%), considering their symptoms to be 'normal' period pain (55.6%), and believing their symptom were something woman just had to endure (45.2%). Additionally, several of women spoke about dismissing their symptoms after comparing their experiences to those of other women. For example, one woman stated, "*I used to think other girls must have it worse than I coz I probably just had a normal experience*" while others said, "*... I did have a friend who was diagnosed with endometriosis and I did not think I was as bad as her, so I never considered it for myself even though my symptoms were bad*" and "*I was aware that other woman experienced much* *more discomfort than I did, so I dismissed my own symptoms for several years*". Despite normalising and dismissing their symptoms in various ways, it became apparent that they all link back to the women having a lack of knowledge and awareness of endometriosis and menstrual health.

Medical Level

While the women in this study viewed healthcare providers as people who should have superior knowledge and awareness of endometriosis and menstrual health, most of the women described encountering healthcare providers who they perceived as lacking adequate knowledge and awareness of endometriosis and menstrual health (see Figure 10).

Figure 10

Perceived Education of Healthcare Providers



Over half of the women perceived GPs (59.7%) and other healthcare providers such as nurses and emergency department (ED) doctors (54.7%) as lacking knowledge of menstrual health, while the majority of the women (82.1%) perceived gynaecologists as being adequately educated. Similarly, most of women perceived GPs (70.4%) and other healthcare providers such as nurses and ED doctors (65.0%) as lacking knowledge of endometriosis, while most of the women perceived gynaecologist (71.4%) as being adequately educated.

In their accounts, the women described their experiences of a lack of support and understanding from their healthcare providers and having their healthcare providers normalise and dismiss their symptoms; and reported receiving multiple misdiagnoses and delayed or incorrect referrals – all of which can be attributed to a lack of education and awareness of endometriosis and menstrual health. Additionally, the majority of the women (88.1%) felt like their GPs failed to consider their symptoms as being related to endometriosis which is consistent with the participants claims that they perceived their GPs as having a lack of knowledge and awareness of endometriosis and menstrual health.

Several women commented that they do not expect GPs to know everything about endometriosis and mensural health but when GPs were perceived as having insufficient knowledge about endometriosis and menstrual health this creates a barrier to diagnosis. As GPs are the first point of call for women on their journey to receiving a diagnosis, meaning they essentially pose as gatekeepers for accessing gynaecologist, who are perceived as more knowledgeable. This is illustrated by the following quote: *“I like and respect my GP, the issue was more that they did not seem adequately educated on endometriosis or abnormal periods, and so did not refer me or mention endo for two decades, until I pushed to get referred, which makes sense as my GP is older and probably not well educated at the time about endo.”*

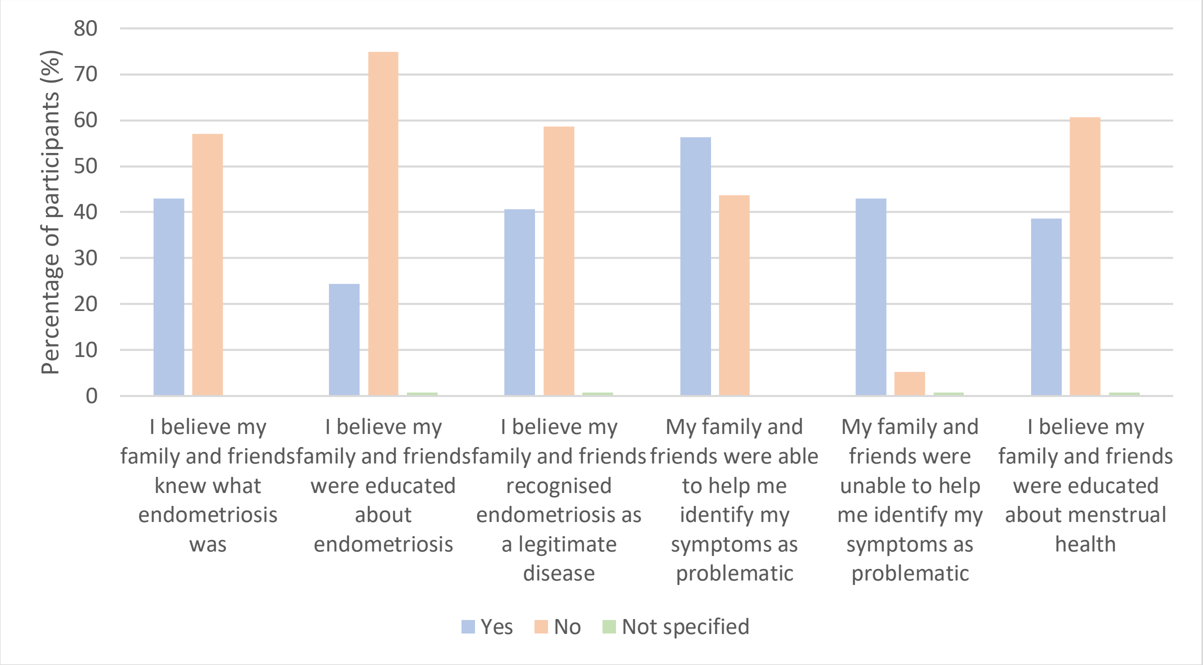
Societal Level

When reflecting on their perception of the general knowledge and awareness of endometriosis in Aotearoa New Zealand, 99 women (73.3%) believed there was a lack of education, while 106 women (78.5%) believed there was a lack of awareness. Similarly, when reflecting on their perception of the knowledge and awareness of menstrual health, 97 women (71.9%) believed there was a lack of education and 99 women (73.3%) believed there was a lack of awareness. With endometriosis being a disease that affects approximately 1 in 10 women in Aotearoa New Zealand, some of the women expressed that the lack of awareness and education around endometriosis, and by extension, menstrual health was inexcusable. For instance, one woman stated "*people do not know what endometriosis is unless you take the time to explain what it is. It's not good enough*" while another said "*it is barely recognised anywhere as much as it should be given that it is 1 in 10 women who have it. It's very inexcusable for this to not be common knowledge.*"

In the women's accounts, it became clear that their family and friends played an important role in facilitating the diagnosis of endometriosis in the sense that many of the women's family and friends helped them identify their symptoms as abnormal (60.7%) and encouraged them to seek advice from their healthcare provider. For instance, one woman stated, "*one friend in particular encouraged me to seek medical assistance, she has experienced the same and knew that what was happening to me wasn't 'normal'*" while another said, "*speaking to my mum (ex-nurse) she suggested the pain and symptoms were not normal and suggested I go and see my GP*". Unfortunately, the ability of women's family and friends to help assist them in identifying their symptoms as problematic or abnormal is intrinsically linked to their level of education and awareness of endometriosis and menstrual health. When reflecting on their family and friend's knowledge and awareness of endometriosis prior to them receiving their diagnosis, the majority of the women in this study perceived their family and friends as lacking knowledge and awareness (see Figure 11).

Figure 11

Perceived Education of Family and Friends



Less than half of the women (43.0%) believed their family and friends knew what endometriosis was, and even less believed that their family and friends were educated about endometriosis (24.4%) and menstrual health (38.5%). Therefore, within the women's circle of family and friends, a lack of education and awareness of endometriosis and menstrual health poses as a barrier to the diagnosis of endometriosis, while, on the other hand, increased education and awareness appeared to facilitate the diagnosis of endometriosis.

However, in saying that, several of the women believe that endometriosis has become more recognised in Aotearoa New Zealand over the recent years, with one woman stating, "*it is much more recognised than it was 5 years ago*" and another claiming, "*it is* *becoming a disease that is more regularly talked about in NZ*". Although, the education and awareness of endometriosis and menstrual health in Aotearoa New Zealand still has a way to go with one woman claiming, "*I believe the education and awareness has gotten a lot better in recent years, although there is still a lot of work that needs to be done*". It is clear that more education is needed at all levels so that it can be removed as a barrier and act as a facilitator.

Belief in Myths

Both prior to and after receiving a diagnosis of endometriosis, the women in this study encountered many myths about endometriosis. In their accounts, the women described encountering myths about endometriosis predominantly at the medical and societal level; and largely attributed the belief in myths to a lack of education and awareness of endometriosis and menstruation.

In the women's accounts of their interactions with the healthcare providers they encountered on their journey to diagnosis, many of the women described experiences of having their healthcare providers, mainly GPs, repeat myths about endometriosis which they now know are untrue. The myths that the women's healthcare providers commonly referred to related to three key areas – symptoms, epidemiology and treatment. For instance, one woman stated *"my doctor said "you don't have heavy or painful periods, so you don't have endometriosis"* while others said, *"my doctor told me that I was not in enough pain to have endometriosis"*, *"the gynaecologist told me that he believed I was too young and what I was experiencing was simply a normal part of the growing up stage"*, *"I was told that I would be too young to have anything wrong and my periods would settle down as I got older which was not the case"* and "*my gynaecologist kept telling me that the only way to solve endometriosis is to be pregnant and that I would have less pain etc. if I had* *a baby".* When healthcare providers referred to myths about endometriosis, the women felt that their healthcare providers had a lack of knowledge of the disease. Moreover, having their healthcare providers refer to myths made the women feel like their problems were not taken seriously and that their discomfort was completely disregarded as part of being a woman, all of which contributed to the diagnostic delay. Additionally, for some women, the suggestion that their pain would be solved if they got pregnant was perceived as offensive, particularly in instances where they were struggling with conceiving or were in a situation where it was not plausible to have a child at that point in time.

Similar to their experiences with healthcare providers, prior to (and after) receiving a diagnosis of endometriosis, over half the women (58.5%) described encountering family who would refer to myths about endometriosis when they engaged in conversations about their symptoms and experiences. In these instances, the myths about endometriosis that the women encountered related directly to their symptoms. In their accounts, many of the participants described being repeatedly told by their family and friends that "*periods are meant to be painful, it's normal*" (78.5%), that "*it's normal for your period to be irregular*" (54.8%), and that "*heavy periods are completely normal*" (57.8%). The women also reported being told by their family and friends that struggling with menstrual pain meant they had a low pain tolerance (49.5%), that it is normal for sex to be painful – particularly when it is for the first time (41.5%) and that menstrual pain is just psychological - "*it's all in your head*" (26.5%). Having their family and friends refer to myths about endometriosis – particularly in relation to their symptoms - was discouraging for many of the women as it served to normalise and dismiss their symptoms and experiences, leaving many of them feeling like their family and friends did not believe them. This was problematic as it caused many of the women to doubt themselves which resulted in them delaying seeking advice from healthcare providers – consequently contributing to a delay in diagnosis.

When the women were asked why they believed the myths and misinformation surrounding endometriosis existed, their responses could be attributed to a lack of education and a lack of conversations about endometriosis and menstrual health. This is illustrated in the women's accounts with one woman stating *"because for so long, these illnesses were never spoken about. No one shared anything for the ear it was shameful or that you were a faulty woman. Especially in the older times, the idea was to 'suck it up and move on' no one talked about it"* while others claimed, *"it's a topic that is not talked about publicly, therefore myths tend to hang around longer", "lack of education and women's pelvic issues are seen as gross and rude to talk about... so people don't want to engage with things and make sure they are aware or educated" and "menstrual health isn't taught or discussed well enough, so it is shrouded in myths and mystery".*

Education in Schools

In their accounts, the majority of the women discussed the education they received during their time at school regarding menstrual and sexual health; and it became clear that for many of the women, their educational experiences of menstrual and sexual health created a barrier to the timely diagnosis of endometriosis. Upon reflection of the education of menstrual and sexual health they received during their time at school, over half of the women (70.0%) reported feeling unsatisfied with the education they received. In their accounts, the women reported predominately learning about menstruation (79.4%) and contraceptive methods (73.8%) as part of their education of menstrual and sexual health. However, only a minority of the women reported learning about sex, specifically what to do if experiencing pain during sex (15.9%), how to differentiate between abnormal and normal menstruation (11.1%) and menstrual related issues such as endometriosis and PCOS (7.9%). Additionally, in their descriptions of their educational experiences, the women reported receiving most of their education of menstrual and sexual health during their time at intermediate (48.9%) and high school (73.35). Although, a minority of women reported receiving some degree of menstrual and sexual health education while at primary school (8.1%).

It became clear that the women's education of menstrual and sexual health focused on a limited scope, confined predominately to the more traditional aspects of menstrual and sexual health. Consequently, many of the women failed to learn about menstrual and pelvic pain, menstrual related issues (e.g., endometriosis and PCOS), how to recognise their symptoms as abnormal, what do if they experience any abnormal symptoms, how they can manage any symptoms they experience, and lastly, who they can go to for support and information. This left many of the women with gaps in their education, contributing to the lack of knowledge and awareness; and it became clear that many of the participants felt they were let down by the education they received. For example, one woman stated "*there wasn't any resources given out at school about healthy cycles or endometriosis. I was unaware and if I had been given these at school, I may have been able to seek the right help even if it wasn't from the GP*" while others said "*I would have preferred to learn about menstruation and the difference between normal/abnormal instead of learning how to put a condom on a wooden banana because why do men always need shit done for them? Woman have enough to worry about and aren't educated enough! It's disappointing*" and "*I watched a video of a woman giving birth and a teacher putting a tampon in a glass of water and told us not to wear undies that were too tight. That's pretty much a summary of my education around women's health. Sorry what?!*".

In their accounts, a minority of the women spoke about attending a seminar run by Endometriosis New Zealand as part of their menstrual and sexual health education at school. These women believed this seminar was instrumental in facilitating their diagnosis of endometriosis as it helped them recognise their symptoms as abnormal and led them to seek advice from their GPs. For instance, one woman stated "*if it wasn't for my high school bringing someone in to teach us about endometriosis, I would not have gone to my GP with that idea, and it would have taken longer to get my diagnosis*" while others said "*it was through a person who came to our class once and gave a presentation that I learnt about endometriosis and first thought that it could potentially be something I had*" and "*I believe that the seminar I saw when I was younger was instrumental in me finally making the step to seeing my doctor...*".

The women's accounts highlighted the importance of young women receiving a comprehensive education about menstrual and sexual health during their years at school. Many of the women believed that comprehensive education of menstrual and sexual health plays an integral role in increasing people's knowledge and awareness of menstrual and sexual health which can help facilitate the diagnosis of endometriosis. For instance, one woman stated "*I think it is incredibly important that education starts in schools and is not only about menstrual health and abnormalities but making young women feel empowered to seek help and keep going until they get helped*" while another said "*education about menstrual health and associated disorders at the beginning of puberty would go a significant way in improving awareness in both those who menstruate, as well as their friends and family. Knowing what symptoms are normal and what are not, would give people who menstruate more confidence in seeking help when it is needed, rather than enduring significant discomfort for extended periods of time.*"

Summary

This theme explored the knowledge and awareness of endometriosis and menstruation in Aotearoa New Zealand across all three levels – the individual, the medical and the societal; and it became abundantly clear that a lack of knowledge and awareness posed as a significant barrier to the diagnosis of endometriosis in Aotearoa New Zealand. In their accounts, the women reported having a lack of knowledge and awareness of endometriosis and menstruation which meant they struggled to distinguish between 'normal' and 'abnormal' menstruation. As a result, many women were quick to dismiss their symptoms and continued to live with their symptoms for years before finally seeking advice from their healthcare providers. Further, the women described the education they received while at school, which focused on a limited scope, confined predominately to the more traditional aspects of menstrual and sexual health such as 'what is menstruation and 'types of contraception' which left gaps in many of the women's knowledge. Having a lack of knowledge and awareness, meant the women relied on their family and friends to help them identify their symptoms as abnormal, however, the ability of their family and friends to help identify their symptoms as abnormal is intrinsically linked to their level of knowledge and awareness. In many cases, the women perceived their family and friends as lacking knowledge and awareness which limited their ability to help and contributed to the diagnostic delay. In terms of the medical level, the women frequently described negative encounters with healthcare providers who they perceived as lacking knowledge and awareness, which is problematic especially in the case of GPs, as they are the first point of call for women on their journey to diagnosis. The lack of knowledge and awareness of endometriosis and menstruation in Aotearoa New Zealand was further highlighted by many of the participants believing in myths about endometriosis and having their family, friends and healthcare providers refer to myths. However, on the other hand, when the women's knowledge and awareness of endometriosis increased whether that be through self-education, interactions with others or through programs such as those run by Endo NZ, this helped facilitate the diagnosis of endometriosis as it empowered the women to seek help and gave them to confidence to question their healthcare providers and make demands.

Taking Control: Advocacy

This theme explores the ways the women in this study took control and empowered themselves on their journey to receiving a diagnosis; and it became clear that women taking control and advocating for themselves was a significant facilitator to the diagnosis of endometriosis.

It became clear that, for many of the women, they eventually reached a point on their journey to diagnosis where they felt like they needed to make a change and empower themselves by taking control of the situation to find the cause of their symptoms, receive a diagnosis and treatment. For example, one woman stated *"... I'd had enough of the chronic pain that I'd been in for 18 years, someone had to take charge and I decided I wasn't taking no for an answe*r" while another said, "*I needed to know instead of being put on pill after pill which badly affected my health and happiness and quality of life so I did my own research and took control*".

In their accounts, the women spoke of several different ways they took control and empowered themselves on their journey to receiving a diagnosis. These included being persistent with finding the cause of their symptoms (46.7%), trusting their body and it what it was telling them and prioritising their experiential knowledge (31.3%), self-diagnosing themselves with endometriosis (20.7%), rejecting healthcare providers' assessments that they believed were incorrect (31.1%), changing their GP until they found one that could meet their needs (25.1%) and remaining persistent with receiving a referral from their GP (39.3%). These strategies can be categorised into four main categories – self-education, self-diagnosis, GP shopping and self-referral – which will be discussed in more detail below.

Self-Education

In the women's accounts, it became clear that for many of the women, the first step they took to take control and advocate for themselves was by researching their symptoms and increasing their knowledge of menstrual health. Over half the women (74.8%) described doing their own research about the symptoms they were experiencing to increase their knowledge in the hopes of finding an answer. The women described "*reading books, reading a lot of books...*", conducting google searches, listening to podcasts, searching Instagram and Facebook, watching YouTube videos, joining online support groups, talking to family and friends who menstruate, and speaking to people who were experiencing similar symptoms or had been diagnosed with a menstrual-related issues such as endometriosis and PCOS. After conducting their own research about their symptoms and increasing their knowledge of menstrual health, over half the women (57.8%) suspected that endometriosis was the cause of their symptoms. Additionally, these women suspected endometriosis was the cause before their healthcare providers suggested it as a possibility.

As a result of doing their own research about the symptoms they were experiencing and increasing their knowledge about menstrual health, the women began to trust their bodies and what their bodies were telling them. It also enabled the women to exert more control over their situation as it placed them in a position where they were able to advocate for themselves when interacting with their healthcare providers. In this sense, doing their own research and increasing their knowledge gave the women the confidence to make suggestions, question what their healthcare providers were saying, and to push for their embodied knowledge to be recognised and taken seriously. Moreover, the women were able to demand that their healthcare providers listened to their concerns and took them seriously. This is illustrated in the following accounts:

> *"If there's anything I've learnt throughout this whole journey to diagnosis, is that you have to advocate for yourself. I was able to successfully advocate for myself and make demands once I had done my own research and learnt to trust my body and what it was telling me."*

> *"Once I finally believed in myself that it had to be and could not be anything else, I was finally able to verbalise all of the symptoms that I hadn't actually realised were symptoms for many years. Once I did my own research about all of those various symptoms, I was then able to take a list of them with frequency and severity to my appointments and make demands."*

Self-diagnosis

Another way the women took control and empowered themselves on their journey to receiving a diagnosis was by diagnosing themselves with endometriosis. In the women's accounts, it became clear that self-diagnosis wasn't something they did lightly, instead the participants turned to self-diagnosis after feeling like they had been failed by their healthcare providers. For instance, one woman stated "*I turned to self-diagnosis because I was repeatedly blown off by my GP, I'm not sure whether it was because I was a young teenage girl or because he just couldn't be bothered. My symptoms, along with my mum's history was enough of a tell*" while others said, "*I turned to self-diagnosis because nobody was listening to me – they gave me ultrasounds, MRIs, blood tests etc... and I kept saying* *that it won't show endometriosis, but they refused to send me for a laparoscopy*", "*I self-diagnosed because I was getting nowhere with everything else. They kept testing me for STIs or giving me antibiotics for a UTI or even appendicitis when I went to the emergency department. I was not admitted to gynaecology and was sent home with tramadol and A referral for a pelvic ultrasound*" and "*I self-diagnosed because my symptoms were identical to a diagnosed friend. I just assumed I had it and stopped bothering medical professionals because I felt like I wasn't getting listened to.*" While diagnosing themselves with endometriosis meant the participants diagnosis was not confirmed or definitive, some of the women felt a sense of relief and empowerment in finally having an answer for their symptoms and confirmation that they were not being dramatic or imagining their symptoms. However, in the case when the women diagnosed themselves with endometriosis, it became clear that, for some, their journey to diagnosis did not end with self-diagnosis. Instead, some of the women spoke of bringing their self-diagnosis to the attention of their GPs and demanding a referral to a specialist who could confirm their diagnosis.

As a part of diagnosing themselves with endometriosis, several of the women reported keeping a diary of their symptoms in an attempt to figure out for themselves what was happening to their bodies. For instance, one woman stated "*deep down I knew something was wrong. I ended up writing a 4-page document showing all my family history, tests I'd had, symptoms etc. A GP finally listened to me then*" while another said "b*ecause my family and doctors didn't believe me, I decided to start recording all my symptoms including frequency and severity so I would have a record to show them. When I did research about the symptoms I was experiencing, I thought I might have endometriosis, so I talked to a friend that I knew had been diagnosed. It was after this I diagnosed myself and demanded* *it to be confirmed by the doctor*". By keeping a diary of their symptoms, this meant the women had a detailed record to show their healthcare providers, which is important as it gave them the agency to demand a referral to a specialist, diagnosis and treatment.

GP Shopping and Self-Referral

For many of the women, taking control and empowering themselves on their journey to diagnosis involved becoming more assertive in their interactions with healthcare providers; and it became clear that one way they did this was by GP shopping and demanding referrals to specialists of their choice or referring themselves.

In their accounts, the women described approaching their healthcare providers armed with as much information as possible after doing their own research and increasing their knowledge, the participants made their demands and insisted on being heard and taken seriously by their healthcare providers. If the women felt like their healthcare providers were not listening to them or were not taking their concerns seriously, the women would go on to seek advice from a different healthcare provider. This was particularly true for GPs, with the majority of the women (70.4%) reporting switching GPs until they found one who could meet their needs. However, in some cases, the women's region of residence limited their ability to 'shop around' for another GP. For example, one woman stated, "*I live in a geographically isolated area, so it was hard to get to a doctor and I didn't get much choice of what doctor I saw*."

Moreover, when reflecting on their encounters with healthcare providers, many of the women spoke of experiencing painful symptoms for a number of years before their GP referred them to specialist care and receiving referrals to specialists that were not gynaecologists which often lengthen their journey to diagnosis. In their accounts, some of the women spoke of their persistence in receiving a referral to a specialist from their GP.

However, in some instances, the women spoke about their decision to refer themselves to specialists that they believed would be able to provide them with the care they needed after dealing with healthcare providers who were unsympathetic to their experiences and did not listen to their concerns. For instance, one woman stated "*lots of research and talking to other people with endometriosis made it obvious it aligned with all of my symptoms...When I came to the conclusion that it was endometriosis, I researched the best gynae for treating endo in my area and went to them for a confirmed diagnosis. Over 10 years of battling GPs for a referral I never got one, so I took matters into my own hands*". For the women who referred themselves to a specialist of their choosing, the self-referral gave them a sense of empowerment and control over their situation and helped speed up their journey to receiving a diagnosis.

Summary

After a long struggle, many of the women eventually reached a turning point on their journey to diagnosis where they decided to take control and empower themselves, which was identified as a major facilitator to the diagnosis of endometriosis in Aotearoa New Zealand. In their accounts, the women described the several ways they were able to take control and empower themselves. However, the most common ways they did this was by educating themselves, diagnosing themselves with endometriosis, becoming more assertive in their interactions with healthcare providers and referring themselves to specialists. In their accounts, many of the women described researching their symptoms and increasing their knowledge about menstrual health. This placed them in a position where they were able to advocate for themselves during interactions with healthcare providers as it gave them the confidence to question what they were being told and to push for their embodied knowledge to be recognised and taken seriously. After doing their own research, some of the women diagnosed themselves with endometriosis and requested their healthcare providers confirm their self-diagnosis. Additionally, after doing their own research, armed with as much information as possible, the women approached their healthcare providers and insisted on being heard and taken seriously. In instances where they felt like their healthcare providers were not listening to them or taking them seriously, they would change providers until they found one who could meet their needs.

The Role of Support

This theme is centred around the support women received from others while on their journey to diagnosis. It explores the lack of support that women frequently encountered from others, including family and friends, which posed as a barrier for women on their journey to diagnosis. However, it also explores the role of increased support which encompasses women's accounts of encountering others who validated their experiences, showed compassion and advocated for them, which helped facilitate their diagnosis of endometriosis.

Lack of Support

In the women's accounts, it became clear that a lack of support from others, including family and friends, was a major barrier that was frequently experienced by the participants while on their journey to receiving a diagnosis of endometriosis. When reflecting on their interactions with their family, friends, and individuals in their professional and wider social circles, the women described the lack of support as a 'battle' characterised by the normalisation and dismissal of their symptoms, disbelief, and a lack of understanding, which will be discussed below in more detail.

Normalisation, Dismissal and Disbelief

Reflecting on their interactions with those closest to them while on their journey to receiving a diagnosis of endometriosis, over half of the women (57.8%) described feeling like those closest to them did not believe the severity of their symptoms. This included their immediate family (33.1%), extended family (35.3%), friends (51.1%), peers at school or university (39.1%), and work colleagues (42.9%). This was illustrated in the women's accounts with one woman stating, "*I feel as though some women struggled to believe how my period could be so bad since they experienced their own without any problems*" while another said, "*I felt like my mum, sisters and most of my friends did not believe the severity of my symptoms as they didn't experience any problems*."

In addition, many of the women also described their experiences of having those closest to them normalise and dismiss their symptoms prior to receiving a diagnosis. Over half of the women (52.6%) described having their family, friends and people in their professional and wider-social circles repeatedly tell them that their symptoms were "*normal symptoms for women to experience during menstruation*" and "*part of being a woman*". For example, one woman stated "*I was always being told by my family that my symptoms were normal and just my period so get over it. Stop being so dramatic*" while others said "*I faced other women telling me that I should just suck it up because women have been dealing with this for thousands of years and it's not a big deal, we are just supposed to deal with it*" and "*every woman has her own experience and hearing another woman say she has pain or other symptoms will trigger an 'oh yeah, I get that, but you know, you just have to get on with it' response. I got this a lot from people I worked with.*"

In the women's accounts, it became clear that encountering a sense of disbelief and repeatedly having their symptoms normalised and dismissed by those closest to them was difficult for the women to endure, resulting in many of the women feeling dismissed (41.5%) and unheard (52.6%). Additionally, being repeatedly told that their symptoms were normal symptoms for women to experience during menstruation and having their family and friends question the legitimacy of their symptoms meant that many of the women started to doubt themselves and question whether they were being dramatic or over-exaggerating their symptoms as their family and friends were suggesting. For example, one woman stated, "*family thought I was being a hypochondriac so I started to feel like it was all in my head*" while others said "*the way my family and friends would react made me feel like maybe I was overreacting or being dramatic. I started to think that maybe I was making it up and my symptoms were in my head*" and "*my family was pressuring me not to be dramatic as they didn't believe my symptoms or pain and thought I was making it up. This made me start to doubt myself.".* Having their family and friends not believe their symptoms and attribute them to 'normal menstruation' meant that in addition to having to fight to be heard and believed by their healthcare providers, the women also had to fight to be believed in their own homes. Moreover, this discouraged some of the women (36.3%) from seeking help as they had the opinion that if they could not get their own family and friends to believe them, what chance would they have in getting a healthcare provider to believe them. The impacts of disbelief and dismissal from others are summarised below in Table 4. In the participants' accounts, it became clear that as a result of disbelief and dismissal from others, many of the women believed their symptoms were something they would just have to put up with (61.5%) and that they were not being heard (52.6%). Additionally, many participants identified that disbelief and dismissal from others had a negative effect on their mental health (48.1%).

Table 4

Impacts of Disbelief and Dismissal From Others

	Participants (n= 135)	
	N	%
Impacts		
I thought my symptoms were something I would just have to put up with	83	61.5
I felt like I was not listened to (not heard)	71	52.6
It negatively affected my mental health	65	48.1
I felt like I could not disclose the real reason for taking sick leave	60	44.4
I felt dismissed	56	41.5
I felt like I could not socialise as much as I would have liked to	53	39.3
It discouraged me from seeking help	49	36.3
It negatively impacted my intimate relationships (e.g., dating, marriage)	45	33.3
I had to give up my extracurricular activities/hobbies (e.g., sports, music)	39	28.9
I took leave without pay	23	17.0
I lost friends	21	15.6
Other	4	3.0
Not applicable	11	8.1

In addition, while the women experienced disbelief, normalisation and dismissal from both men and women, several of the women expressed that it was far more damaging when other women were dismissive of their experiences. For example, one woman stated "*another woman dismissing you is far more damaging than a man and some women seem to exist to tear each other down*" while others said "*In general I think the response from most women is a knee-jerk reaction of 'oh well we all have to put up with that' or 'shhh don't talk about that' or 'someone else has it worse, so stop complaining' which is quite harmful*" and "*I think the women who don't experience bad menstrual symptoms make the ones that do feel dramatic. I also think women are competitive and some women that experience menstrual related issues invalidate other women with these issues because they want to come off as 'worse off'. It's belittling and so toxic.*"

Lack of Understanding

In addition to encountering disbelief and the normalisation and dismissal of their symptoms by those closest to them, the women's accounts also detailed a lack of understanding from their family, friends and people in their professional and wider-social circles. While it was clear that the participants experienced a lack of understanding in several ways and differed from woman to woman, a lack of understanding was predominantly demonstrated by those closest to the woman showing a lack of empathy towards their experiences. This is illustrated in the following accounts:

> *"When I would tell my mum about what was happening she would tell me to 'stop complaining' and 'suck it up'."*
>
> *"Until my hysterectomy at age 32, my family/friends had no empathy for me because I looked 'so well'."*
>
> *"I had no help at home or encouragement to rest if I was sick. If I was lying on the floor in pain, then family members would just step over me and go about their day."*
>
> *"Family and friends, they had no idea what it was like – they had it easier than I so didn't have an understanding of what I was going through, so it felt like they had no sympathy towards my experiences."*
>
> *"My dad believed that I should just get up and go for a big walk that, that would make me feel well enough to carry on with my day."*

Similar to their experiences with the healthcare providers they encountered on their journey to diagnosis, having those closest to them show no empathy towards their experiences made many of the women feel like they were exaggerating or imagining their symptoms, that they were a hypochondriac, that it was all in their head or that they simply had a low pain tolerance. Additionally, having those closest to them show a lack of empathy towards their experiences left many of the women feeling invisible, unheard, ignored, and like they had to fight to be taken seriously which negatively impacted their mental health.

For instance, one woman stated "*I suppose when you have no support from your family or friends and hear all these comments that you're exaggerating or being dramatic you feel really isolated and belittled. It really messes with your mental health because the more you hear them the more that you believe them."*

In their accounts, it became clear that the majority of the women (69.9%) thought that the women in their lives were more understanding and supportive in comparison to the men in their lives. These women spoke of women as being more understanding and empathetic even if they did not have endometriosis as they experience menstruation themselves. For instance, one woman stated "*because most women can directly relate to the experience. Even though we all have different experiences of menstruation, it's something we collectively understand*" while others said "*because women actually experience it and if they have endo they can sympathise and empathise with you*", "*if women have experienced more severe symptoms like this themselves or are naturally more empathetic then they are understanding*" and "*even if they don't have long, heavy or painful periods they are still able to understand the mental, emotional and physical impacts*".

However, some of the women (30.1%) were not convinced that the women in their lives were more supportive than the men in their lives. For example, one woman stated, "*men will never experience menstruation, therefore I think men are more sensitive towards women experiencing it*" while others said, "*I think because men don't experience it, most response is based on what their partner (if in a relationship with a female partner) experiences or maybe a sister whose said something previously, otherwise they had no other reference and take it at face value*", "*... I found many other women judgmental. Men are more accepting that they can't really understand and just empathise that what you're going through is shit*" and "*I think women put up with more stuff and just carry on as normal and* *expect everyone else to as it's still normal, unless they personally experience issues themselves. Whereas men have possibly dated someone with menstrual issues and have seen first-hand how debilitating it can be.*"

Increased Support

In their accounts, many of the women encountered a lack of support in their interactions with healthcare providers characterised by the normalisation and dismissal of their symptoms, disbelief and a lack of understanding. Similarly, many of the women encountered this same battle with those closest to them, sometimes even in their own homes. As a result, many of the participants described feeling isolated and alone in their experiences, further exacerbating the negative impacts of their symptoms and experiences on their mental health. However, in contrast to the women's accounts which highlighted the lack of support that many of the women encountered while on their journey to diagnosis, some of the women spoke of the support they received from those closest to them.

In the women's accounts, it became clear that supportive relationships, with those closest to them, characterised by empathy, understanding and concern helped facilitate the women's journey to diagnosis. The importance of support from those closest to them, specifically, family and friends, was emphasised by several of the women. It was clear that the women depended on their support systems during negative interactions with healthcare providers and experiencing symptoms flare ups. Having people around them who were supportive and empathetic towards their experiences meant the women felt less isolated and having people show understanding meant the participants did not feel alone in their experiences. For example, one woman stated, "*My supervisor (a woman) was incredibly supportive... I also started dating an amazing man whose mother is a sexual health nurse and who understands endo. So, I had both of them in my corner too. Having their support* *was incredible"* while others said, *"I could talk about things with my mum which was brilliant, and although my brother and I didn't talk about the nitty gritty much he tended to know when I needed to just lie down and watch a movie with him so he met me where I was at"* and *"I had never met anyone affected by menstrual issues prior to my diagnosis, when I was diagnosed I was told it was hereditary, which made me feel more alienated as I don't know anyone in my family who suffers from it... Post diagnosis I have met so many women who understand or suffer from some sort of menstruation issues and this is what makes me feel most comfortable and supported..."*

When discussing the role of support, it became clear that for some women, their mothers played an important role in supporting them while on their journey to diagnosis. Several of the women described their mothers advocating for them, particularly in their interactions with healthcare providers. It became clear that the women and their mothers worked collaboratively to convince their healthcare providers to listen to their concerns, take their symptoms seriously and refer them to a specialist. For example, one woman stated "*my mum, having endo herself, was fantastic at advocating for me and pushing for me to be taken seriously..., if it hadn't been for her pushing forward to get me help and teaching me how to advocate for myself when I was younger, I'd hate to think where I would be now"* while others said, "*my mum was a massive advocate for me and pushed me to self-refer to specialist and keep telling my GP that something was wrong*" and "*I was helped by a lot by mum who has endometriosis. She thought that I had endometriosis as well and she was right. Even when I downplayed my symptoms and accepted the responses from healthcare professionals that it was normal, my mum continued to advocate for me and helped me see a gynaecologist who specialised in endometriosis.*"

Some of the women required their mothers to advocate for them while on their journey to diagnosis because their symptoms appeared when they were young and were often dismissed by their healthcare providers. For example, one woman stated "*You don't need to get checked out yet you are only young, your periods won't be like this forever*" while other said "*I've been told I was too young (we first went to the doctors at age 11 for symptoms)*" and "*I was told that I would be too young to have anything wrong and my periods would settle down as I got olde*r." Additionally, some of the participants' mothers had endometriosis themselves and suspected endometriosis as the cause of their daughters' symptoms. As such, they advocated for their daughters as they knew the process for receiving a diagnosis and what to expect.

In addition to receiving support from those closest to them, several of the woman described utilising endometriosis support groups on Facebook and other social media platforms despite not having received a diagnosis of endometriosis. These women described joining online support groups and connecting with women on Instagram who shared content about endometriosis and their own journeys to diagnosis, as it offered them an opportunity to connect with others who understood their experiences and could empathise with them. This allowed the women to escape from those in their lives who showed a lack of support and understanding. Moreover, it provided a space for the women to share their experiences and ask advice from others with endometriosis or who have knowledge about endometriosis, which not only helped the participants to feel supported and validated but also provided them with useful tips and guidance while on their journey to diagnosis. As one woman put it, "*online support groups were helpful, talking to actual people who were experiencing the same thing and hearing from other people who had similar experiences to me was super comforting. Being able to talk to someone who had been through something* *similar provided a massive sense of relief as I knew it confirmed it was not in my head*" while another said "*social media was huge for me. Following accounts that discussed endo and joining Facebook groups for people with endo helped empower me to speak more about it...*" After years of experiencing a lack of support from their family, friends and healthcare providers, the support the women received from online support groups reduced the women's feelings of isolation and meant they finally felt heard and believed.

Summary

This theme explored the support women received from those closest to them while on their journey to diagnosis. Many of the women described encountering a lack of support from others, including their family and friends, which was characterised by the normalisation and dismissal of their symptoms, disbelief and a lack of understanding. A lack of support meant many of the women started to doubt themselves and question the legitimacy of their symptoms and whether they were being dramatic or over-exaggerating as their family and friends were suggesting. It also left many of the women feeling invisible, unheard, ignored and like they had to fight to be taken seriously which negatively impacted their mental health and discouraged them from seeking help as if they could not get the support from those closest to them, what chance would they have of getting a healthcare provider to support them. From these accounts, it became abundantly clear that, in Aotearoa New Zealand, a lack of support is a significant barrier to the diagnosis of endometriosis. In contrast, the women who received support characterised it by having others validate their experiences, showing compassion and empathy, and advocating for them. While some women received support from those closest to them, many of the women described receiving support from online support groups and endometriosis communities. From these accounts, it became clear that receiving support from others acts as a facilitator to the diagnosis of endometriosis in Aotearoa New Zealand.

Chapter Five: Discussion

The aim of this research was to develop a better understanding of and identify the barriers and facilitators to the diagnosis of endometriosis in Aotearoa New Zealand. The analysis revealed a similar journey for the women, with the barriers and facilitators they encountered relating to five key themes – the healthcare encounter, symptom concealment, education, taking control: advocacy, and the role of support (Figure 2, page 58). This research illustrates that the barriers and facilitators to receiving a diagnosis of endometriosis in Aotearoa New Zealand occur at the individual level, medical level and the societal level. This is similar to previous research that implicitly identified several barriers and facilitators to diagnosis occurring at an individual and medical level (Ballard et al., 2006; Wren & Mercer, 2021). However, the barriers and facilitators that this research identified at the societal level were unique to this research, as previous research failed to explore this aspect of the diagnostic delay with the exception of support and the normalisation and dismissal of women's symptoms.

The purpose of this chapter is to provide a summary of the findings of this research and consider the findings in relation to previous research. It will highlight the barriers and facilitators women encounter on their journey to receiving a diagnosis of endometriosis in Aotearoa New Zealand and discuss the new information this research contributes to the existing literature. Additionally, I will consider the implications of this research before discussing the limitations and suggestions for future research and provide a concluding summary.

Barriers to Diagnosis

This research identified several barriers to the diagnosis of endometriosis in Aotearoa New Zealand that occurred across the individual, medical and societal level. The barriers identified in this research include a lack of education, normalisation and dismissal of symptoms, ineffective clinical practice, a lack of support, and symptoms concealment.

The most common barrier women encountered on their journey to diagnosis as identified by this research is a lack of education characterised by a lack of knowledge and awareness surrounding endometriosis and menstrual health. This barrier is perhaps the most significant barrier identified by this research and occurred across all three levels – individual, medical and societal. Consistent with prior research, at the individual level, many of the women reported a having a lack of education surrounding endometriosis and menstrual health prior to receiving their diagnosis of endometriosis (Fernely, 2021; Moradi et al., 2014; Wren & Mercer, 2021). The women's lack of education contributed to the women normalising and dismissing their symptoms and meant they often had difficulties in identify their symptoms as 'abnormal'. While a lack of education at the individual level is problematic as it often means women delay presenting to healthcare providers at symptom onset, a lack of education at the medical level is deemed more problematic. At the medical level, a lack of education was characterised by women's experiences of having healthcare providers normalise and dismiss their symptoms and receiving ineffective clinical care. This finding builds on that of previous work which suggested that healthcare providers had a lack of knowledge surrounding both endometriosis and menstrual health which influenced the level of care they provided (Pettersson & Berterö, 2020; van der Zanden et al., 2020; Zale et al., 2020). This research has shown that a lack of education at the individual and medical level has the most impact on the women's journey to diagnosis, however, it has also shown that a lack of education at the societal level is problematic in its own right. A lack of education at the societal level is problematic considering the role women's family and friends play in helping them identify their symptoms as problematic or abnormal. This finding is similar to the findings of Moradi et al. (2014) who suggested a lack of information among patients' family and friends contributed to the diagnostic delay.

Additionally, consistent with the findings of previous research, this research suggests that the lack of education often meant that women, themselves, and their healthcare providers believed myths about endometriosis and menstruation (Cox et al., 2003a; Denny & Mann, 2008; Petterson & Berterö, 2020). Although, this was not limited to the individual and medical level, as this research also suggested that the women's family and friends believed in myths about endometriosis, a finding that is unique to this research. Unlike the previous research discussing the barriers to the diagnosis of endometriosis, the findings of this research suggest that the lack of education at the individual and societal level can be attributed to the education people receive during their time at school. The menstrual and sexual health education the women within this research received focused on a limited scope confined predominately to the more traditional aspects of menstrual and sexual health, such as, 'what is a period' and types of contraception. However, this research cannot attest to the reason for the limited education the women received, and the education healthcare providers receive during their training as this was outside the scope of this research.

In relation to a lack of education, a prominent barrier women frequently encountered on their journey to diagnosis at the individual, medical and societal level was the normalisation and dismissal of their symptoms. At the individual level, women, themselves, were often quick to dismiss their symptoms typically attributing their symptoms to “normal period pain” and considering themselves unlucky to have their symptoms as opposed to being unwell. At the medical level, the women reported having healthcare providers repeatedly tell them that their symptoms were normal for women to experience during menstruation. This was particularly true for their complaints of pain which were dismissed as “normal period pain”. Although, this was not confined to the medical level, as over half (52.6%) of the women had similar experiences with family, friends and people in their professional and wider social circles repeatedly dismissing their symptoms. These findings are consistent with prior research from both women’s and healthcare providers’ perspectives suggesting that both women and healthcare providers dismiss endometriosis-related symptoms as a normal part of menstruation (Ballard et al., 2006; Denny & Mann, 2006; Grogan et al., 2018; Moradi et al., 2014; Pettersson & Berterö, 2020); and highlighted women’s accounts of repeatedly being told by their family and friends that their symptom were normal (Denny & Mann, 2006; Moradi et al., 2014; van der Zanden et al., 2021).

In the women's accounts, they frequently described their perception of receiving ineffective clinical care from their healthcare providers, which encompassed misdiagnoses, delayed or incorrect referrals and overmedicalisation, barriers specific to the medical level. Similar to the conclusions reached in previous studies, the women in this study reported being misdiagnosed with conditions like anxiety (20.6%), depression (18.5%), and irritable bowel syndrome (38.5%) before finally receiving a diagnosis of endometriosis (Ballard et al., 2006; Lamvu et al., 2020; Moradi et al., 2014). The women often believed their healthcare providers were focused on finding an essay explanation for their symptoms (Grundstrom et al., 2017) and perceived them as being reluctant to accept their symptoms as gynaecological (Denny & Mann, 2008). Many of the women expressed their frustrations with receiving delayed referrals to specialist care (67.4%), and in some instances, receiving referrals to specialists who were not gynaecologists which lengthened their journey to diagnosis. This finding is supported by several studies which spoke of women encountering healthcare providers who were reluctant to refer women to gynaecologists, especially if they were of young age (Ballard et al., 2006; Cox et al., 2003a; van der Zanden et al., 2020; van der Zanden et al., 2021; Wren & Mercer, 2021). It is possible that the delayed or incorrect referrals occurred as a result of limitations in GPs education, as suggested by the women in this study, which is further supported by Pettersson & Berterö (2020) who suggested that a lack of knowledge among healthcare providers was made clear by incorrect diagnoses and delayed referrals. Additionally, the women described their healthcare providers as being quick to prescribe medication in an attempt to supress their symptoms rather than attempting to find out the underlying cause, which is consistent with the findings of Ballard et al. (2006) and Fernely (2021).

Another prominent barrier women encountered on their journey to diagnosis was a lack of support from both healthcare providers and those closest to them, including family and friends. At the medical level, in their interactions with healthcare providers, the women described a lack of support which was charactered by disbelief, a lack of empathy and understanding, and a failure to listen. Far too often, in their accounts, the women described encountering healthcare providers who did not believe what they were saying, did not take them seriously and made them feel like they were exaggerating or imagining their symptoms, that it was all in their heads or that they were simply a hypochondriac. Unfortunately, the women also reported similar encounters at the societal level with their family and friends expressing disbelief towards their symptoms and demonstrating a lack of understanding and empathy. While the lack of support at the societal level was not surprising, this finding is relatively unique to this research as it is an aspect that is largely missing from the current literature in the exploring the diagnostic delay of endometriosis. However, the lack of support at the medical level is consistent with previous research highlighting the disbelief healthcare providers show towards women's symptoms (Cox et al., 2003a; Fernely, 2021; Young et al., 2018; Young et al., 2020) and emphasising women's encounters with healthcare providers who made them feel like they were overexaggerating (Denny & Mann, 2006; Grundström et al., 2017).

The findings of this research suggest that many women concealed their symptoms from others, which had been identified as a notable barrier to the diagnosis of endometriosis. Consistent with previous research, the women in this research concealed their symptoms due to a fear of judgement and being perceived negatively (Ballard et al., 2006; Fernely, 2021; Grogan et al., 2018). However, the women in this research also described concealing their symptoms due to the stigma associated with menstruation and dominant cultural or family beliefs surrounding menstruation. While symptom concealment can be attributed to the individual level, it is largely influenced by societal beliefs and attitudes towards menstruation. Across various cultures, menstruation is associated with various taboos and negative attitudes; and it is typically viewed as something that should be kept private (van Lonkhuijzen et al., 2020). This sentiment was evident in the findings of this research, with the women reporting that in their families, they did not openly speak about menstruation or menstrual-related issues. Further, the women’s family members, usually their mothers and grandmothers, encouraged them to not disclose or discuss their concerns around menstrual pain and irregularities as well as the symptoms they were experiencing.

Facilitators to Diagnosis

This research identified several facilitators to the diagnosis of endometriosis in Aotearoa New Zealand that occurred across the individual, medical and societal level. The facilitators identified include support, increased education, increased communication about menstruation, and finally, women taking control.

Previous research has suggested that one way of reducing the diagnostic delay of endometriosis is by increasing education surrounding endometriosis and menstrual health (Lamvu et al., 2020; Moradi et al., 2014; van der Zanden et al., 2021). These studies largely focus on education at the medical level, suggesting that increases in healthcare providers' education and awareness and providing them with the skills to correctly interpret women's symptoms is helpful in reducing the diagnostic delay of endometriosis (Lamvu et al., 2020; Moradi et al., 2014; van der Zanden et al., 2021). Similar to these findings, although not at the medical level, the findings of this research suggest that increases in women's education surrounding endometriosis and menstrual health plays an integral role in facilitating the diagnosis of endometriosis. Having knowledge and awareness of endometriosis and menstruation, meant the women were able to trust what their bodies were telling them and placed them in a position where they were able to use their knowledge to advocate for themselves when interacting with healthcare providers. Consistent with the findings of Cox et al. (2003a) and Young et al. (2015), the women who participated in this research increased their education about endometriosis and menstrual health by doing their own research about their symptoms and menstruation. Further, several women reported recording their symptoms in an attempt to figure out for themselves what was happening to their bodies.

The findings of this research suggest that when women have increased education surrounding endometriosis and menstrual health, they are able to take control and become more assertive in their interactions with healthcare providers, which was identified as a facilitator. Consistent with previous research, the women in this research took control by remaining persistent with finding the cause of their symptoms, keeping a diary of their symptoms, self-diagnosis, and seeking a healthcare provider who could meet their needs (Cox et al., 2003a; Cox et al., 2003b; Wren & Mercer, 2021; Zale et al., 2020).

Additionally, the findings of this research suggest that when women encounter support from healthcare providers and those closest to them, including family and friends, this helps to facilitate their journey to diagnosis. In this research, supportive interactions at the medical and societal level were characterised by women receiving sympathy towards their experiences, having their concerns acknowledged and complaints heard, and in some instances, having others empathise, show understanding and advocate for them. Having their healthcare providers and people around them be supportive and empathic towards their experiences meant the women in this research felt listened to, believed and validated. Moreover, they no longer felt alone in their experiences or that they had to convince their healthcare providers of the legitimacy of their symptoms. This is consistent with previous research by Grundström et al. (2017) and Zale et al. (2020) who found that when women were supported, particularly by their healthcare providers, they no longer to need to convince others of their symptoms and they could share exactly how they felt without being judged. Further, this is consistent with the findings of Denny and Mann (2008) and Fernely (2021) who found that support has powerful consequences on women’s journeys to diagnosis and may serve to reduce the diagnostic delay.

An aspect of support that was unique to this research was that of advocacy. This research highlighted several accounts of women having their mothers and healthcare providers advocate for them on their journey to diagnosis. As it was rare for women to encounter healthcare providers who advocated for them, these women often considered themselves lucky as this seemed to be the exception to the rule. Only one past study has discussed advocacy, suggesting the importance of women, particularly those who are young, being supported by their mothers in their interactions with healthcare providers as their symptoms are often dismissed due to their age (van der Zanden et al., 2021). Additionally, similar to the findings of Ferney (2021), this research found that women in this research often relied on support from online support groups while on their journey to diagnosis. These groups offered them an opportunity to connect with others who could empathise with them, allowing them to escape from a lack of support and understanding from others in their lives.

The final facilitator identified by the findings of this research is women speaking up about the difficulties they were experiencing, despite the stigma associated with menstruation and menstrual related issues. This facilitator is a unique finding central to this research as, to the best of my knowledge, women speaking up has not been discussed as a facilitator in previous research. This facilitator is relevant to both the individual and societal level, with the findings of this research indicating that several women spoke out about their experiences and engaged in conversations about menstruation with their family and friends. After being given an opportunity to share their menstrual experiences with others and being exposed to the menstrual experiences of their family and friends, many women felt empowered to seek advice from healthcare providers. Further, when these women spoke up, they were able to discover a community of people who had been impacted by similar experiences which helped to break down any stigma or fears the women had surrounding their experiences.

Implications and Strengths of This Research

The strength of this research is that it provides useful insights into the barriers and facilitators women encounter on their journey to receiving a diagnosis of endometriosis in Aotearoa New Zealand; an aspect largely missing from the previous literature. This research highlights several barriers and facilitators which occur across an individual, medical and societal level; and indicates that the barriers and facilitators are complex and multifaceted. In demonstrating the complexity of the barriers and facilitators, an implication of this research is that to reduce the diagnostic delay, we need to address the barriers while also implementing strategies to increase the facilitators. While it is not as simple as mapping the facilitators onto the barriers, this research does suggest that increasing the education and reducing the stigma surrounding menstruation and, by extension, endometriosis, may target the diagnostic delay of endometriosis in Aotearoa New Zealand.

The lack education among women themselves, healthcare providers and the general population is a barrier in its own right, however, it also influences several other barriers across all three levels. At the individual and societal level, the barriers and facilitators identified by this research can be linked to people’s knowledge and awareness of endometriosis and menstrual health which is influenced by the education they have received. When reflecting on their educational experiences, many of the women described receiving poor education surrounding sexual and menstrual health, as such, this research offers insight to the need for increasing people’s education. One way we can do this is by introducing comprehensive sexual and menstrual health education while people are young. Implementing education at a young age may facilitate change at both the individual and societal level by addressing some of the barriers women currently experience on their journey to diagnosis. At the individual level, increases in education may serve to reduce the normalisation and dismissal of women’s symptoms, increase women’s ability to identify their symptoms as abnormal and reduce the influence of myths surrounding menstruation and endometriosis. At the societal level, an increase in education may improve others understanding of endometriosis allowing them to be more empathetic and supportive, while simultaneously targeting the normalisation and dismissal of women’s symptoms and their ability to recognise women’s symptoms as abnormal and encourage them to seek advice.

Specific to Aotearoa New Zealand, the use of more holistic models of health such as Te Whare Tapa Wha (Mark & Lyons, 2010) or the Biopsychosocial-Spiritual model (Jasemi et al., 2017) can improve interactions for both women and be an accessible resource for healthcare providers to use. Currently, endometriosis is overmedicalised within a largely biomedical framework. Endometriosis is diagnosed surgically, and the main line of treatment is treating the physical symptoms (Endometriosis New Zealand, 2022b; Guidice, 2010). The use of holistic models of health can look to reduce the overmedicalisation of endometriosis by implementing patient-centred care that takes into consideration the lived experiences of women with endometriosis and the impact it can have on all facets of a woman’s life. An aspect that is often overlooked by the biomedical approaches. In addition to this, changes at the medical level may be enhanced by further development of the education and support for healthcare providers. This may include further professional development focussing on women’s health and encouraging healthcare providers to engage with the current literature in this space that considers women’s lived experiences.

At the medical level, the positive effects that increases in healthcare providers' education has on a women's journeys to diagnosis has been highlighted by the findings of this research. In their accounts, a minority of women deemed themselves 'lucky' to have found a healthcare provider who was supportive, empathetic, acknowledged their concerns and advocated for them or had the ability to access private healthcare which is consistent with the findings of Grundström et al. (2017). Further, this research suggested that women's age and ethnicity acts as a barrier to their diagnosis. While this reflects many health statistics of Māori and Pasifika peoples, it did not explore what the impact of women's sociodemographic characteristics have on the healthcare they receive while on their journey to receiving a diagnosis of endometriosis.

Aligned with an increase in education, if people have more knowledge and awareness of endometriosis and menstruation, this may encourage them to discuss menstruation and their own menstrual experiences more openly. However, the findings of this research highlight that menstruation and, by extension, endometriosis, are shrouded in stigma and negative sentiments which influence people's willingness to engage in these conversations. Goffman (1963 in Seear, 2009) defines stigma as socially undesirable or unwanted characteristics. The characteristics that are deemed undesirable vary between cultures and historical periods, and people who express such characteristics are often stigmatised against. This is particularly true for menstruating women, with several studies confirming that there is a stigma surrounding menstruation that makes it social unacceptable for women to talk about their menstrual experiences (McHugh, 2020; Seear, 2009). Currently, for women, discussing their experiences of menstruation can have adverse impacts as it may result in increased discrimination and prejudice and reinforce the existing stigma surrounding menstruation (Seear, 2009; van Lonkhuijzen et al., 2022). While this research highlights the existence of stigma surrounding menstruation, it is not something that this research explored in detail, therefore, it is difficult to discuss the true impacts of stigma on women's journeys to receiving a diagnosis of endometriosis in the context of Aotearoa New Zealand.

The strength of this research suggests is that it clearly identifies the barriers and facilitators and what could be done to decrease barriers and increase facilitators, building on the survey conducted by Tewhaiti-Smith et al. (2022) which suggests that addressing the lack of education and the stigma surrounding menstruation and endometriosis may be instrumental in targeting the diagnostic delay in Aotearoa New Zealand. However, as the barriers and facilitators identified by this research are complex and extensive, it is important that any attempts to reduce the barriers and increase the facilitators must consider change across the individual, medical and societal levels.

Limitations and Suggestions for Future Research

This research contributes to the current literature surrounding endometriosis in the context of Aotearoa New Zealand. While it advances knowledge of the barriers and facilitators women encounter on their journey to receiving a diagnosis of endometriosis, there remains several avenues for future research to further develop our understanding of the barriers and facilitators women face which I disucss

As discussed above, this research identified the education surrounding endometriosis and menstrual health as both a significant barrier and facilitator to the diagnosis of endometriosis. A lack of education was apparent across the individual, medical and societal level, however, this research failed to explore the reasons for the lack of education and did not consider how we can address this issue. As such, further research should be conducted focusing on the education surrounding endometriosis and menstrual health in Aotearoa New Zealand at all three levels. Such research should explore the reasons for the gap in education whether that be related to stigma or beliefs surrounding menstruation, or the education adolescents receive in school regarding endometriosis and menstrual health. Additionally, it should also explore how we can increase the education surrounding endometriosis and menstrual health in the context of Aotearoa New Zealand. Furthermore, a key finding of this research was the perceived lack of education of healthcare providers. However, this discussion was limited and came from the perspective of the women. As such, this research does not reflect healthcare providers' perspectives of their knowledge and awareness of endometriosis and menstrual health, therefore, it would be interesting to explore this aspect from the perspective of healthcare providers and the impact this has on their practice.

Another limitation of this research was that the rate of participation of ethnic minorities, including Māori, Pasifika and Asian was underrepresented when compared to the total population as a whole. The majority of the women who participated in this research identified as New Zealand European, or Pākehā (84.4%), while only 5.2% of the women identified as Māori, 2.9% of the women identified as Pasifika, and 0% of the women identified as Asian. This demonstrates parity with the total population of Aotearoa New Zealand given Māori, Pasifika, and Asian people represent 17.1%, 8.1%, and 15.1% of the population, respectively (Statistics New Zealand, 2019; 2022). Currently, there is very little known about the prevalence or experiences of endometriosis in the Māori, Pasifika and Asian populations, whether this is due to women not being diagnosed due to a lack of access or engagement with healthcare services, which for Māori is limited for various historical and contemporary reasons (Tewhaiti-Smith et al., 2022), or alternative reasons which remain unknown due to the lack of research. As such, further research should focus on the barriers and facilitators women encounter on their journey to receiving a diagnosis of endometriosis in Aotearoa New Zealand, in relation to ethnic minority populations. This research is important as it could provide new insights and comparative data with the Pākehā population, which made up the majority of the participants in this research. Further, such research may highlight barriers and facilitators that are unique to those who identify as Māori, Pasifika or Asian and whether these differ to those of the Pākehā population, an aspect that this research failed to explore.

Conclusion

The aim of this study was to identify and develop a better understanding of the barriers and facilitators to the diagnosis of endometriosis in Aotearoa New Zealand by exploring women's accounts of their journey to diagnosis. This research employed a qualitative survey to explore the barriers and facilitators women encounter on their journey to diagnosis. The findings of this research highlight that, in Aotearoa New Zealand, women experience challenging and often lengthy journeys to diagnosis characterised by complex barriers at the individual, medical and societal level. The barriers identified include normalisation and dismissal of symptoms, lack of support, ineffective clinical practice, symptom concealment, lack of conversations around menstruation, and a lack of education. The findings of this research also suggest that there are facilitators at the individual, medical and societal level that have a positive influence on women’s journey to diagnosis and ultimately help them receive a diagnosis. The facilitators identified include positive healthcare interactions, increased support, conversations about menstruation and one's menstrual experience, women taking control, advocacy, and increased education. The findings of this research are consistent with the findings of previous research, however, this research contributed new and unique insights to the barriers and facilitators women encounter on their journey to diagnosis and contributes to the limited literature on endometriosis available in the context of Aotearoa New Zealand.

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Appendices

Appendix A: Outcome of Systematic Review

	Aim	Setting, Sample	Methods	Facilitators and Barrier to Diagnosis
Ballard et al. (2006)	To investigate the reasons women experience delays in the diagnosis of endo and the impact of this	*Setting* Hospital pelvic pain clinic; Southeast England *Sample* 32 women, aged 16 47 years	Interviews; Thematic analysis	***Barriers*** Inability to make clear distinctions between a "normal" and "abnormal" menstrual experiences Women normalising and dismissing their symptoms GPs normalising and dismissing symptoms Embarrassment and fear of being seen as unable to cope Intermittent hormonal suppression of symptoms (prescribing birth control) Non-discriminatory diagnostic investigations
Bullo (2018)	To identify dis/empowerment caused by discourses in the healthcare and social environment of women as manifested in their accounts of endometriosis experiences	*Setting* Invitation via social media; United Kingdom *Sample* 21 women, aged 27 to 53 years	Face-to-face and online interviews; Discourse analysis	***Facilitators*** Empowerment in the forms of knowledge particularly surrounding one's own body Keeping a diary of symptoms ***Barriers*** Miscommunication Normalisation and dismissal of symptoms Misdiagnosis Disbelief caused by the lack of knowledge or understanding of her condition in her social and professional circle Doctors gate keeping from diagnostic procedures resulting in disempowerment Women's lack of agency in encounters with HCPs Dismissal of symptoms as normal from the social/professional circle where women interact

	Aim	Setting, Sample	Methods	Facilitators and Barrier to Diagnosis
Cox et al. (2003)	To describe aspects of a study that was conducted to determine women's needs for information related to laparoscopy for endometriosis	*Setting* Invitation via mail sent to members of the Endometriosis Association (Vic) Inc. and the Epworth Endometriosis Centre database; Australia *Sample* 61 women, aged 20-64.	Focus groups; Thematic analysis	***Facilitators*** Becoming assertive and taking control Keeping a careful diary to work out for themselves what was happening and to have a record to show the doctor Realising cyclical nature of symptoms and that their symptoms were clearly based on physiology Rejecting what they were being told by those who were dismissive of them Locating the consultant that they wanted to go to and insisted on getting a referral from their GP ***Barriers*** Feeling like a victim of HCPs disbelief and trivialisation Misdiagnosis and mistreatment
Fernley (2020)	To expose and synthesise the collective themes of diagnostic experience	*Setting* Accounts located through Google search engines (had to be an Australian autobiographical account); Australia *Sample* Online written accounts from 49 women	Online autobiographical accounts; Thematic analysis	***Barriers*** Pain normalisation Non-referrals to pelvic/endo specialists Misdiagnosis Dismissal Patient self-dismissal and non-Disclosure Women suffering in silence Constant doctor dismissal Judgement from family, partner, friends, or educators Lack of community awareness Myths and misinformation Lack of endometriosis informed GPs "dr google" Doctor disbelief in pain levels or symptoms Attitude of "women's problems" Negative doctor relationships Patient is overreacting or too Sensitive Belief “it's all in the head and psychological

	Aim	Setting, Sample	Methods	Facilitators and Barrier to Diagnosis
Grogan et al. (2018)	To understand women's experiences of coping with endometriosis, and impact on their lives	*Setting* Invitation via UK based endometriosis charity website; United Kingdom *Sample* 34 women; aged 22 to 56 years	Online questionnaire; Inductive thematic analysis	***Barriers*** Lack of support from healthcare professionals Feeling let down by healthcare professionals Women felt their symptoms were not taken seriously by HCPs and that they were not believed Being told they just have painful periods Concealing symptoms from friends, family and work colleagues concerned not to be labelled as a hypochondriac or as unable to handle normal period pains
Grundström et al. (2017)	To identify and describe the experience of healthcare encounters among women with endometriosis	*Setting* A university and a central hospital clinic; Sweden *Sample* 9 women; aged 23 to 55 years	Interviews; Interpretive phenomenological analysis	***Facilitators*** HCPs acknowledging patients - they felt confirmed and visible Feeling of being listened to and visible - no longer had to try and convince HCPs of their symptoms ***Barriers*** Disbelief Lack of knowledge Treated with ignorance by HCPs HCPs attitude that women exaggerated or imagined their symptoms or had low pain thresholds HCPs focused on finding an "easy explanation" - infections, miscarriage, IBS HCPs resorting to normalising and trivialising the problems Some women perceived HCPs as distant and nonchalant HCPs lacked basic knowledge about endometriosis

	Aim	Setting, Sample	Methods	Facilitators and Barrier to Diagnosis
Lamvu et al. (2020)	To explore women's journeys to an endometriosis diagnosis, experience with endometriosis pain, and interactions with healthcare practitioners	*Setting* Invitation via for members of MyEndometriosisTeam and advertisements via MyEndometriosisTeam Facebook page; United States (70%), Other – United Kingdom, Australia, New Zealand, South Africa, Canada, Ireland (30%) *Sample* 451 women, aged 19 to 60+ years	Online survey; Statistical analyses	***Facilitators*** Public awareness Physican awareness Improved education ***Barriers*** Receiving other diagnoses before endometriosis Poor consistency between treatment goals and practitioner's goals Age - younger women experience longer delays Not having symptoms take seriously by doctors (particularly for younger girls) Not being able to differentiate between "normal" and "abnormal" menstrual experience Patient's feeling like they aren't being heard Poor communication with practitioner relying on internet to retrieve information about their condition

	Aim	Setting, Sample	Methods	Facilitators and Barrier to Diagnosis
Moradi et al. (2014)	To explore women's experiences of the impact of endometriosis and whether there are differences across 3 groups	*Setting* 23 women from a dedicated Endometriosis Centre at one public hospital in Canberra and 12 women from the community; Australia *Sample* 35 women, aged 17 to 53 years	Focus groups; Thematic analysis	***Facilitators*** Sympathetic doctors that were understanding and took the time to address the patient's concerns ***Barriers*** Misdiagnosis and mistreated for appendicitis, ovarian cyst, ectopic pregnancy, pelvic inflammatory disease and ovarian cancer Women normalising their severe period pain or other symptoms Women did not take their symptoms seriously Women did not share or talk with others about their symptoms because of shame Family and friends telling them that pain and bleeding were normal Doctors misdiagnosing or mistreating women Doctors normalising women's symptoms - 'normal', 'not serious' Doctors not believing women Doctors lacking knowledge Difficulty accessing a gyno or specialist who understood endometriosis Long surgery lists Doctors not listening to women's concerns, having no time to answer questions Doctors not taking teens symptoms seriously - not believing them and thought they were making up stories just to get attention Women's lack of information about endo
Soliman et al. (2017)	To quantify the time to diagnosis among women with endo in the US and to identify patient- and physician-related factors affecting delay	*Setting* Invitation via online advertisements; United States *Sample* 638; aged 18-49 years	Online cross-sectional survey; Univariate analysis	***Facilitators*** Women seeking medical attention soon after experiencing symptoms ***Barriers*** Ethnicity Age – younger age at symptom onset associated with longer delay

	Aim	Setting, Sample	Methods	Facilitators and Barrier to Diagnosis
van der Zanden et al. (2020)	To identify barriers and facilitators to the timely diagnosis of endometriosis from the GPs perspective	*Setting* Invitation via advertisements placed at 29 group practices; Netherlands *Sample* 43 general practitioners	Focus groups; Content analysis	***Facilitators*** *Professional experience and competence* Recent case or training enhances awareness *Patient characteristics* Fast referral in case of infertility Patient engagement promotes referral Non-Western European background more easily referred *Collaboration* Reporting on endo as incidental finding may increase awareness ***Barriers*** *Professional experience and competence* Low sense of urgency for timely diagnosis Limited experience with endometriosis; limited knowledge and skills related to endo Insufficient training and literature *Patient characteristics* Not returning to the GP when initiated treatment fails Young women less likely considered for pathological condition *Guideline factors* Lack of GP guideline *Collaboration* Lack of understanding gynos diagnostic/treatment options Low frequency of reporting on endo in correspondence letters Lack of knowledge in other medical specialists

	Aim	Setting, Sample	Methods	Facilitators and Barrier to Diagnosis
Wren & Mercer (2021)	To explore young women's experiences of an endometriosis diagnosis in order to gain a better understanding of the impact of this process and the role and importance of support structures	*Setting* Invitation via advertisements on Facebook; United Kingdom *Sample* 9 women	Online interviews; Interpretive phenomenological analysis	***Facilitators*** Persistence – the need for persistence with clinical staff, in order to feel heard and to eventually establish access to specialist gyno services. ***Barriers*** Ineffective clinical practices - *c*linicians remained hesitant to refer women to specialist care routes and believed HCPs had little concern for the origin and potential exacerbation of symptoms Age-based dismissal - younger women getting dismissed
Young et al. (2020)	To investigate how women navigate knowledge and power within the medical encounter to receive healthcare that assists them in managing endometriosis	*Setting* Invitation via advertisements. After 20 interviews purposive sampling was applied to ensure diversity; Victoria, Australia *Sample* 26 women; aged 20 to 54 years	Face-to-face or telephone interview; Thematic analysis	***Facilitators*** Deciding not to put up with any aspect of healthcare they were not happy with Knowing your own body and when something isn't right Self-diagnosis of endo via google, medical journals, support groups etc - then requesting formal diagnosis from doctors Self-advocacy - to ensure needs are met Changing doctors - to find one that could assist them ***Barriers*** Doctors lack of expertise - perceived lack of knowledge about endometriosis among doctors Normalisation of women's pain and discomfort Doctors favouring their own perspective despite women's efforts to convince them of the validity of their own knowledge Women doubting knowing their own body when experiencing symptoms, they could not explain Doctors unwilling to diagnose Doctors thinking women are too young for endo GP reluctant to refer or refused to refer to gyno feeling like doctors not listening to them and denying them an opportunity to contribute their embodied knowledge while exerting their own power and knowledge Feeling like doctors not believing what they are saying

Appendix B: Survey Questions

Demographic Information

1. What is your gender?
   - ○ Woman
   - ○ Man
   - ○ Transgender
   - ○ Non-binary
   - ○ Other (please specify) ___________________

2. What is your age?
   - ○ Under 20 years
   - ○ 20-29 years
   - ○ 30-39 years
   - ○ 40-49 years
   - ○ 50+ years

3. Which ethnic group do you belong to?
   - ○ New Zealand European
   - ○ Māori
   - ○ Samoan
   - ○ Cook Islands Māori
   - ○ Tongan
   - ○ Niuean
   - ○ Chinese
   - ○ Indian
   - ○ Other (please specify) _________________________

4. Which region do you currently live in?
   - ○ Auckland / Tamaki-makau-rau
   - ○ Bay of Plenty / Te Moana-a-Toi
   - ○ Canterbury / Waitaha
   - ○ Gisborne / Te Tai Rāwhiti
   - ○ Hawke's Bay / Te Matau-a-Māui
   - ○ Manawatu-Whanganui
   - ○ Marlborough / Te Tauihu-o-te-waka
   - ○ Nelson / Whakatū
   - ○ Northland / Te Tai Tokerau
   - ○ Otago / Ōtākou
   - ○ Southland / Murihiku
   - ○ Taranaki
   - ○ Tasman / Te Tai-o-Aorere
   - ○ Waikato
   - ○ Wellington / Te Whanga-nui-a-Tara
   - ○ West Coast / Te Tai Poutini

5. Have you received a confirmed diagnosis of endometriosis via laparoscopy?
   - ○ Yes
   - ○ No

6. What is your last known stage of Endometriosis?
    - Stage 1
    - Stage 2
    - Stage 3
    - Stage 4
    - Unsure
    - Prefer not to say

7. In which region did you receive your diagnosis of endometriosis?
    - Auckland / Tamaki-makau-rau
    - Bay of Plenty / Te Moana-a-Toi
    - Canterbury / Waitaha
    - Gisborne / Te Tai Rāwhiti
    - Hawke’s Bay / Te Matau-a-Māui
    - Manawatu-Whanganui
    - Marlborough / Te Tauihu-o-te-waka
    - Nelson / Whakatū
    - Northland / Te Tai Tokerau
    - Otago / Ōtākou
    - Southland / Murihiku
    - Taranaki
    - Tasman / Te Tai-o-Aorere
    - Waikato
    - Wellington / Te Whanga-nui-a-Tara
    - West Coast / Te Tai Poutini

8. Prior to receiving a diagnosis of endometriosis, in which region did you primarily seek advice from a healthcare provider about your symptoms?
    - Auckland / Tamaki-makau-rau
    - Bay of Plenty / Te Moana-a-Toi
    - Canterbury / Waitaha
    - Gisborne / Te Tai Rāwhiti
    - Hawke’s Bay / Te Matau-a-Māui
    - Manawatu-Whanganui
    - Marlborough / Te Tauihu-o-te-waka
    - Nelson / Whakatū
    - Northland / Te Tai Tokerau
    - Otago / Ōtākou
    - Southland / Murihiku
    - Taranaki
    - Tasman / Te Tai-o-Aorere
    - Waikato
    - Wellington / Te Whanga-nui-a-Tara
    - West Coast / Te Tai Poutini

Journey to Diagnosis

9. Approximately how old were you when you got your first period?
    - Under 10 years
    - 10-11 years
    - 12-13 years
    - 14-15 years

   - 16+ years

10. Approximately how old were you when you started experiencing symptoms of endometriosis?
    - Under 15 years
    - 15-19 years
    - 20-24 years
    - 25-29 years
    - 30+ years

11. Approximately how long did you experience symptoms before seeking advice from your GP?
    - Less than 1 year
    - 1-2 years
    - 3-4 years
    - 5+ years

12. What was your primary symptom/s prior to diagnosis? (Select all that apply)
    - Pain with periods (dysmenorrhoea)
    - Abnormal menstrual bleeding
    - Pain during or after sexual intercourse (dyspareunia)
    - Bowel problems
    - Painful urination (dysuria)
    - Pelvic pain
    - Lower back pain
    - Constant tiredness/fatigue
    - Sub-fertility or infertility
    - Other (please specify) ____________________________

13. Do you have a known family history of endometriosis?
    - Yes
    - No

14. Did you discuss your symptoms with multiple GPs?
    - Yes
    - No

15. If yes, approximately how many different GPs did you visit?
    - 2 GPs
    - 3 GPs
    - 4 GPs
    - 5+ GPs

16. Approximately how many times did you visit your GP to discuss your symptoms before receiving a referral to a specialist?
    - 1 visit
    - 2-3 visits
    - 4-5 visits
    - 6-7 visits
    - 8-9 visits
    - 10+ visits

17. After initially visiting a GP about your symptoms, approximately how long was it until a healthcare provider mentioned that you might have endometriosis?
    - Less than 1 year
    - 1-2 years
    - 3-4 years
    - 5+ years

18. Did you suspect you might have endometriosis before your healthcare provider brought it up as a possibility?
    - Yes
    - No

19. How old were you when you received a diagnosis of endometriosis via laparoscopy?
    - Under 15 years
    - 15-19 years
    - 20-24 years
    - 25-29 years
    - 30+ years

20. Approximately how many years did it take you to receive a diagnosis of endometriosis after initially presenting to a healthcare provider with symptoms?
    - Less than 1 year
    - 1-2 years
    - 3-4 years
    - 5-6 years
    - 7-8 years
    - 9+ years

21. Prior to receiving a diagnosis of endometriosis, what different healthcare providers did you interacted with? (e.g., GP, gynaecologists, psychologists, naturopaths, dieticians)

Facilitators and Barriers occurring at the Individual Level

Education/Knowledge

22. Reflecting on your own education and knowledge prior to receiving a diagnosis, which of the following statements are applicable to you (select all that apply):
    - I had a poor understanding of menstrual health
    - I was somewhat knowledgeable about menstrual health
    - I was knowledgeable about menstrual health
    - I was unaware of endometriosis and its symptoms
    - I was aware of endometriosis and its symptoms
    - I was able to identify symptoms of endometriosis (e.g., bleeding between periods, heavy periods, debilitating pain)

23. Prior to receiving a diagnosis, I did my own research about the symptoms I was experiencing
    - Yes
    - No

24. If you did your own research, how did you go about it? (e.g., self-help books, google search, Instagram etc.)

25. Is there anything else you would like to share about your education/knowledge about endometriosis and menstrual health prior to receiving a diagnosis?

Normalisation and Dismissal

26. Past research has identified the normalisation and dismissal of endometriosis-related symptoms as a barrier to receiving a timely diagnosis of endometriosis. If you dismissed or normalised your symptoms prior to receiving a diagnosis, please indicate in which ways you did this (select all that apply)
    - I downplayed the severity of my symptoms
    - I considered myself ‘unlucky’ to have these symptoms rather than considering myself ‘unwell’
    - I considered menstrual irregularities to be a normal experience for women
    - I considered my symptoms to be ‘just period pains’
    - I believed my symptoms were something women just had to endure
    - I did not take my symptoms seriously
    - Other (please specify) _______________________

27. If you felt like you dismissed or normalised your symptoms in any other ways, please specify the ways in which you did so

28. If you dismissed your symptoms, please explain why you did this? (e.g., thought my symptoms were normal, didn’t want to be seen as being dramatic, etc.)

Empowerment

29. Below is a list of factors that indicate higher levels of empowerment, assertiveness and control for women who are on their journey to diagnosis. Are any of these relevant to your journey to diagnosis (select all that apply)
    - I sought help from a healthcare provider in a timely manner
    - Prior to receiving a diagnosis, I was persistent with finding the cause of my symptoms
    - I self-diagnosed myself with endometriosis
    - I was persistent with receiving a referral from my GP
    - I kept changing my GP until I found one that could meet my needs
    - I trusted my body and what it was telling me
    - I rejected healthcare professional's assessments that I believed were incorrect
    - I prioritised my experiential knowledge (and knowing when something was not right)

30. If you self-diagnosed yourself, why did you turn to self-diagnosis? Did you ask your healthcare provider to confirm your self-diagnosis? Do you believe this sped up the process of getting a confirmed diagnosis of endometriosis and why?

31. If you kept changing your GP until you found one that could meet your needs, approximately how many GP’s did you see?
    - 1
    - 2
    - 3
    - 4
    - 5+

32. On your journey to receiving a diagnosis, was there a ***specific instance*** or ***turning point*** where you felt like you had to take more control or become more assertive (e.g., I felt like I was not being listened to, after being continually dismissed)
    - Yes
    - No

33. If yes, please elaborate on this instance or turning point and what you did to take more control or become more assertive.

Section Summary

34. In this section, you were presented with a range of facilitators and barrier to the timely diagnosis of endometriosis which occur at the individual level that have been identified by past research. Is anything else you would like to share?

Facilitators and Barriers occurring at the Medical Level

Misdiagnosis

35. Was your endometriosis ever misdiagnosed as a different physical condition (e.g., IBS)?
    - Yes
    - No

36. If your endometriosis was misdiagnosed, what diagnoses did you receive? (Select all that apply)
    - Irritable bowel syndrome (IBS)
    - Inflammatory bowel disease
    - Pelvic inflammatory disease
    - Appendicitis
    - Ovarian cyst
    - Ectopic pregnancy
    - Ovarian cancer
    - Other (please specify): ______________________________

37. Was your endometriosis ever misdiagnosed as a mental health condition?
    - Yes
    - No

38. If your endometriosis was ever misdiagnosed as a mental health condition, what diagnoses did you receive? (Select all that apply)
    - Anxiety
    - Depression
    - Other (please specify): ____________________________

39. If you received a misdiagnosis, what healthcare providers misdiagnosed you? (Select all that apply)
    - GP
    - ED doctor
    - Gastroenterologist
    - Gynaecologist
    - Psychologist
    - Psychiatrist

○ Other (please specify): ___________________________
○ Not applicable

40. I feel like the healthcare providers who misdiagnosed me failed to consider endometriosis as a possible diagnosis

1	2	3	4
(Strongly Agree)			(Strongly Disagree)

Referral

41. I feel like my GP delayed referring me to a specialist (e.g., gynaecologist)

1	2	3	4
(Strongly agree)			(Strongly disagree)

42. Once receiving a referral to a specialist, I feel like I was faced with a lengthy wait time before I was able to have an appointment with said specialist

1	2	3	4
(Strongly agree)			(Strongly disagree)

43. Prior to receiving a diagnosis, did you receive a referral from your GP to a specialist who was not a gynaecologist (e.g., gastroenterologist, psychologist etc.)?
    ○ Yes
    ○ No

44. If yes, please specify what types of specialists you received referrals for.

45. How many specialists did you have to see before you received a diagnosis of endometriosis?
    ○ 1
    ○ 2
    ○ 3
    ○ 4
    ○ 5+

Perceived Education of Healthcare Providers

46. Reflecting on your journey to receiving a diagnosis, how educated/knowledgeable did you perceive the healthcare providers you interacted with? (Please select all that apply)
    ○ I believe the **GP's** I encountered were **adequately educated** about **menstrual health**
    ○ I believe the **GP's** I encountered l**acked knowledge** about **menstrual health**
    ○ I believe the **specialists** I encountered were **adequately educated** about **menstrual health**
    ○ I believe the **specialists** I encountered **lacked knowledge** about **menstrual health**
    ○ I believe the **GP's** I encountered were **adequately educated** about **endometriosis**
    ○ I believe the **GP's** I encountered **lacked knowledge** about **endometriosis**
    ○ I believe the **specialists** I encountered were **adequately educated** about **endometriosis**
    ○ I believe the **specialists** I encountered **lacked knowledge** about **endometriosis**

47. Looking back, I feel that my GP failed to recognise my symptoms as being related to endometriosis

1 2 3 4
(Strongly agree) (Strongly disagree)

48. My healthcare provider referred to myths about endometriosis
    - Yes
    - No

49. If yes, please specify the myths your healthcare provider referred to (e.g., teens are too young to have endometriosis etc.)

50. Do you feel like your healthcare providers belief in such myths had any unexpected consequences for you? If so, please specify (e.g., would not give me a referral, told me I wouldn't have endometriosis)

Interactions with Healthcare Providers

51. Below is a list of interactions women with endometriosis commonly experience during interactions with their healthcare providers. Prior to receiving a diagnosis of endometriosis, did you experience any of the following while interacting with your healthcare providers? (Select all that apply)
    - I felt like my healthcare providers had sympathy towards my experiences
    - I felt like my healthcare providers took my symptoms seriously
    - I felt like my healthcare providers believed I was exaggerating my symptoms or pain
    - My healthcare providers told me my symptoms were normal
    - My healthcare providers took the time to answer my questions
    - I felt like my healthcare providers validated my experiences or emotions
    - I felt like my healthcare providers acknowledged my complaints and concerns
    - I felt like my healthcare providers were more concerned with treating my symptoms rather than finding the cause.

52. Did the healthcare providers you interacted with ever make you feel like you were being judged?
    - Yes
    - No

53. If yes, what do you believe made you feel like this (e.g., negative attitudes from healthcare providers, lack of support etc)

54. Overall, how satisfied were you with your interactions with healthcare providers?

1 2 3 4
(Extremely Satisfied) (Extremely Unsatisfied)

55. Do you have any additional comments to make about your interactions with healthcare providers?

Section Summary

56. In this section, you were presented with a range of facilitators and barrier to the timely diagnosis of endometriosis which occur at the medical level that have been identified by past research. Is anything else you would like to share?

Facilitators and Barriers occurring at the Societal Level

Education and Awareness

57. Thinking about Aotearoa New Zealand in general, which of the following statements do you agree with (select all that apply)
    - I believe that in Aotearoa New Zealand, there is a lack of education about menstrual health
    - I believe that in Aotearoa New Zealand, there is sufficient education about menstrual health
    - I believe that in Aotearoa New Zealand, there is a lack of awareness around menstrual health
    - I believe that in Aotearoa New Zealand, there is sufficient awareness around mensuration health
    - I believe that in Aotearoa New Zealand, there is a lack of education about endometriosis
    - I believe that in Aotearoa New Zealand, there is sufficient education about endometriosis
    - I believe that in Aotearoa New Zealand, there is a lack of awareness around endometriosis
    - I believe that in Aotearoa New Zealand, there is sufficient awareness about mensuration

58. Thinking about your family and friends prior to your diagnosis of endometriosis, which of the following statements do you agree with (select all that apply)
    - I believe my family and friends knew what endometriosis was
    - I believe my family and friends were educated about endometriosis
    - I believe my family and friends recognised endometriosis as a legitimate disease
    - My family and friends were able to help me identify my symptoms as problematic
    - My family and friends were not able to help me identify my symptoms as problematic
    - I believe my family and friends lacked education about menstrual health
    - I believe my family and friends were sufficiently educated about menstrual health

59. Do you have any additional comments to make about the education and awareness of endometriosis in Aotearoa New Zealand?

Health Education at School

60. Did you receive health education while you were at school?
    - Yes
    - No

61. As a part of your health education at school, did you learn about any of the following (select all that apply):
    - Menstruation
    - How to differentiate between abnormal vs normal menstruation
    - Menstrual-related health issues (e.g., endometriosis, polycystic ovary syndrome etc)
    - Contraceptive methods
    - Sex – in particular what to do if you experience pain during sex

62. At which school levels did you receive sex education? (Select all that apply)
    - Primary school
    - Intermediate
    - High school

63. Which type of high school did you attend?
    - Co-ed (boys and girls)
    - All girls
    - Other (please specify e.g., home schooled) ________________________

64. If you attended a co-ed school, did the boys learn about menstruation?
    - Yes
    - No

65. Overall, how satisfied were you with the sex education you received while in school?

1	2	3	4
(Extremely Satisfied)			(Extremely Unsatisfied)

66. Do you have any additional comments regarding health education in schools?

Normalisation and Dismissal

67. Prior to receiving a diagnosis, did you feel that any of the following groups did not believe your symptoms (select all that apply):
    - Immediate family
    - Extended family
    - Friends
    - Peers at school/university
    - Work colleagues
    - Other (please specify – e.g., sports teams, clubs) _____________________
    - Not applicable

68. Why do feel that those particular groups did not believe your symptoms? (Select all that apply)
    - I was made to feel like they did not believe the severity of my symptoms
    - I was made to feel like I was exaggerating
    - They dismissed my complaints
    - They were insensitive about my experiences
    - They expressed that my symptoms were part of being a woman
    - They expressed the belief that one should keep their issues to themselves (particularly menstrual issues)

- Other (please specify) ___________________________
- Not applicable

69. In what ways do you think the disbelief or dismissal of others impacted you? (Select all that apply)
    - I felt dismissed
    - I felt like I was not listened to (not heard)
    - I thought my symptoms were something I would just have to put up with
    - It discouraged me from seeking help
    - It negatively affected my mental health
    - I took pay without leave
    - I felt like I could not disclose the real reason for taking sick leave
    - I lost friends
    - I felt like I could not socialise as much as I would have liked to
    - I had to give up my extracurricular activities/hobbies (e.g., sports, music)
    - It negatively impacted my intimate relationships (e.g., dating/marriage)
    - Other (please specify) __________________________
    - Not applicable

70. Generally speaking, do you think that women are more understanding than men when it comes to menstruation and menstrual-related issues?
    - Yes
    - No

71. Please elaborate why you believe that women are more understanding than men:

72. Please elaborate why you believe that women are not more understanding than men:

Empowerment

73. Prior to receiving a diagnosis, did any of the following factors contributed to you feeling empowered to share your symptoms and seek help? (Select all that apply)
    - I was given the opportunity to share my menstrual experience with my family and friends
    - I was exposed to the menstrual experience of my family and friends
    - My family and friends encouraged me to seek advice about my symptoms
    - I was able to disclose the real reason for taking sick leave
    - I felt understood by my school/workplace
    - I felt supported by my school/workplace
    - I was able to disclose and discuss my issues with my work colleagues
    - Not applicable

74. Is there anything else that you can think of that helped facilitate empowerment on your journey to receiving a diagnosis?

Myths

75. The following is a list of myths related to endometriosis and menstruation that society perpetuates which have been identified by past research. Do you feel any of these myths contributed to the diagnostic delay you experienced on your journey to receiving a diagnosis (Select all that apply)
    - It is normal for periods to be extremely painful (menstrual pain is normal)
    - Irregular periods are common
    - Heavy bleeding on your period is normal
    - Teens are too young to have endometriosis
    - Every women’s experience of pelvic pain is the same
    - Menstrual pain is just psychological
    - Struggling with menstrual pain means you have a low pain threshold
    - Painful periods are the price women pay to be able to have children
    - Endometriosis only affects western/white women
    - It is normal for sex to be painful for women – particularly the first time
    - Having difficulties walking after sex just means you had good sex
    - Not applicable

76. Are there any other endometriosis-related myths that you have been exposed to?

77. Why do you think these myths exists?

78. Prior to receiving a diagnosis, did your family and friends refer to any myths relating to endometriosis or menstruation?
    - Yes
    - No

79. What types of myths did your family and friends refer to? (e.g., it is normal for women to experience pain with menstruation, irregular periods are common)

80. I believe that schools/workplaces contribute to the spreading of misinformation and myths about menstruation and menstrual-related issues

1	2	3	4
(Strongly agree)			(Strongly disagree)

81. Is there anything else you wish to share relating to the topic of myths in relation to endometriosis and menstruation?

Stigma

82. I believe that in Aotearoa New Zealand, there is an unspoken belief that women should be embarrassed or ashamed about menstruation and menstrual-related issues

1	2	3	4
(Strongly agree)			(Strongly disagree)

83. I believe that in Aotearoa New Zealand menstruation and menstrual-related issues are viewed as something private which needs to be kept hidden

1	2	3	4
(Strongly agree)			(Strongly disagree)

84. Prior to receiving a diagnosis, I feel that my family and friends viewed menstruation and menstrual related issues in a negative way

1	2	3	4
(Strongly agree)			(Strongly disagree)

85. Prior to receiving a diagnosis, I felt discriminated against because of menstruation or menstrual related issues
    - ○ Yes
    - ○ No

86. Why do you feel like you were discriminated against? (e.g., excluded from social circles)

87. Is there anything else you wish to share relating to the topic of stigma in relation to endometriosis and menstruation?

Culture

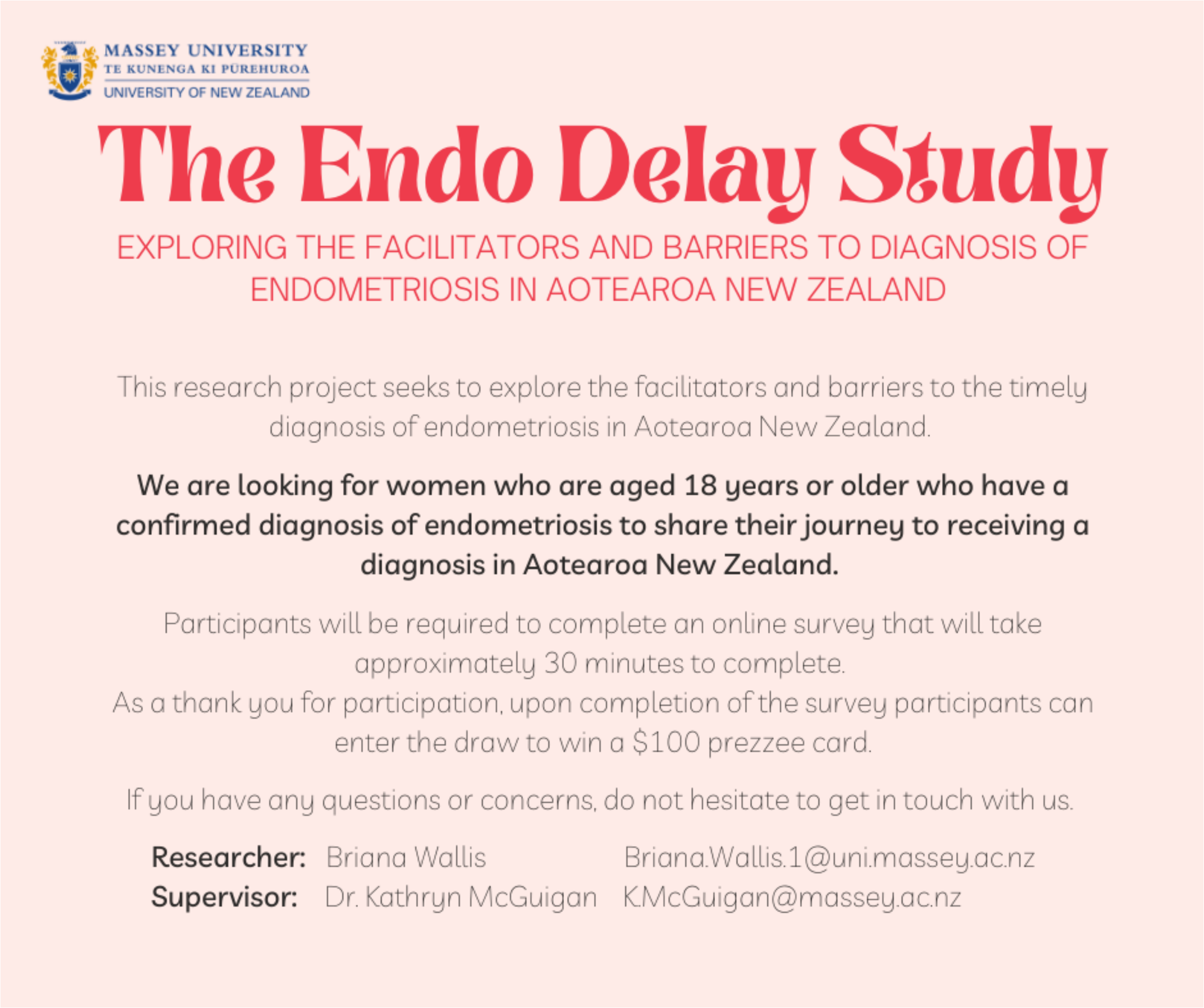
88. Below is a list of various cultural factors that could influence one's journey to receiving a diagnosis. Do you believe any of these have impacted your journey to diagnosis (select all that apply)
    - ○ Religious beliefs
    - ○ Healthcare beliefs (e.g., western, traditional, eastern or alternative medicine)
    - ○ Beliefs about the causes of illness and disease
    - ○ Cultural beliefs about menstruation
    - ○ Beliefs about sexuality, fertility and childbirth
    - ○ Language barrier
    - ○ Gender roles
    - ○ Role within family (i.e., role of members, hierarchy, key-decision makers)
    - ○ Understanding of symptoms
    - ○ The way illness and pain are experienced and expressed
    - ○ Lack of or difficulty accessing culturally-specific resources
    - ○ Where you seek help
    - ○ How you ask for help
    - ○ When you first sought help from a health professional
    - ○ Not applicable

89. Is there anything else you wish to share about your cultural beliefs and how they may have impacted your journey to receiving a diagnosis of endometriosis?

Section Summary

90. In this section of the survey, you were presented with a range of facilitators and barriers to the timely diagnosis of endometriosis which occur at the societal level that have been identified by past research. Do you feel like there is anything else you would like to share?

Appendix C: Advertisement



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The Endo Delay Study

EXPLORING THE FACILITATORS AND BARRIERS TO DIAGNOSIS OF ENDOMETRIOSIS IN AOTEAROA NEW ZEALAND

This research project seeks to explore the facilitators and barriers to the timely diagnosis of endometriosis in Aotearoa New Zealand.

We are looking for women who are aged 18 years or older who have a confirmed diagnosis of endometriosis to share their journey to receiving a diagnosis in Aotearoa New Zealand.

Participants will be required to complete an online survey that will take approximately 30 minutes to complete.
As a thank you for participation, upon completion of the survey participants can enter the draw to win a $100 prezzee card.

If you have any questions or concerns, do not hesitate to get in touch with us.

Researcher:	Briana Wallis	Briana.Wallis.1@uni.massey.ac.nz
Supervisor:	Dr. Kathryn McGuigan	K.McGuigan@massey.ac.nz

Appendix D: Information Sheet

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

RESEARCH INFORMATION SHEET

Exploring the facilitators and barriers to diagnosis of endometriosis in Aotearoa New Zealand

Kia ora, my name is Briana Wallis and I am doing my Masters of Arts at Massey University. This information sheet is to give you more information so you can decide if this survey is something you might want to complete. If you have any questions, please email me or my supervisor, Kathryn (our details are at the end of this sheet).

Project Description

My research is interested in seeing what barriers and facilitators are contributing to diagnostic delays for endometriosis here in Aotearoa, New Zealand. The questions for the survey are based on the limited research from Aotearoa and internationally and will ask you to indicate what barriers you have faced on your journey to diagnosis. I also am interested in what helped you get your diagnosis. There will be chances for you to tell more of your story in open-ended questions throughout the survey.

Participant Identification and Recruitment

The study is being advertised on three endometriosis support/community group pages on Facebook, with the permission of each group's administrator. Anyone who is interested in participating in the research is invited to complete this survey. If you know anyone else who might be interested in participating, and meets the inclusion criteria, please feel free to pass the details of this survey on.

Inclusion criteria for the study include:

- Participants must be over the age of 18 years of age
- Participants must have a confirmed diagnosis of endometriosis by a gynecologist
- Participants must have received their diagnosis of endometriosis in Aotearoa New Zealand

The survey is in English.

If you participate, what will you be required to do?

If you decide to participate in this study, please complete the online survey that follows this information page You can complete the survey in your own time, and it will take approximately 20-30 minutes to complete. The survey will be open until 31 July, 2022.

The survey consists of five sections which ask questions about your background information (demographics), journey to diagnosis, facilitators and barriers to the diagnosis of endometriosis which occur at the individual, medical and societal levels. Your identity will remain anonymous, and you will only be known as a participant number. However, if you would like to go into the draw to win a $100 Prezi card, you will be asked for an email address at the end of the survey. This will be stored separately to your other survey answers.

As you complete the survey, your progress will be automatically saved, meaning you do not have to finish the survey in one sitting, and can take time to think about how you would like to answer any of the questions

You are free to withdraw from the study at any time. To do this, simply close your browser window the survey is presented on without submitting your responses. While your progress will be automatically saved, your responses will not be recorded, and your progress will be deleted when the survey closes.

Risks and Benefits

It is not anticipated that involvement in this study will involve any risks or discomfort to participants. In fact I hope this research will give us a unique perspective to the barriers and facilitators to diagnosis here in Aotearoa. However, due to the challenges of living with endometriosis, we know that it may be difficult to share some aspects of your journey and it is possible that this may be an emotional experience. As such, there is no pressure to share anything you do not want to. If you do not feel comfortable responding to a question or feel the question is irrelevant to your journey, you can either leave the answer field blank or select the 'not applicable' option. I have included a list of free supports available and I encourage you to utilize your own support networks:

- Endometriosis New Zealand – http://nzendo.org.nz/helping-you/
- Need to talk? - free call or text 1737 any time for support from a trained counsellor
- Lifeline Aotearoa – 0800 543 354 (0800 LIFELINE) or free text 4375
- Healthline – 0800 611 116
- Suicide Crisis Helpline – 0508 828 865 (0508 TAUTOKO)

Data Management

All personal information and data collected during this study will be stored securely on a password-protected network that only myself, the researcher, and my supervisor, Dr Kathryn McGuigan, will be able to access. All data will be destroyed once the project is completed in February 2023. I will be responsible for making sure that your data will only be used for the purposes mentioned in this information sheet.

Participants' 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;
- Withdraw from the study up until you submit your responses;
- Ask any questions about the study at any time during participation;
- Provide information on the understanding that your name will not be used;
- Be given access to a summary of the project's findings when it is concluded.

Thank you for taking the time to enquire about this project and to read this information sheet. We greatly appreciate your consideration of this invitation, and we welcome your participation in this study. If you have any questions about the project, please do not hesitate to reach out to either myself, or my supervisor, Dr Kathryn McGuigan, at the details below.

Researcher: Briana Wallis
Email: Briana.Wallis.1@uni.massey.ac.nz

Supervisor: Dr Kathryn McGuigan
Email: K.Mcguigan@massey.ac.nz

Statement of Ethical Approval

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

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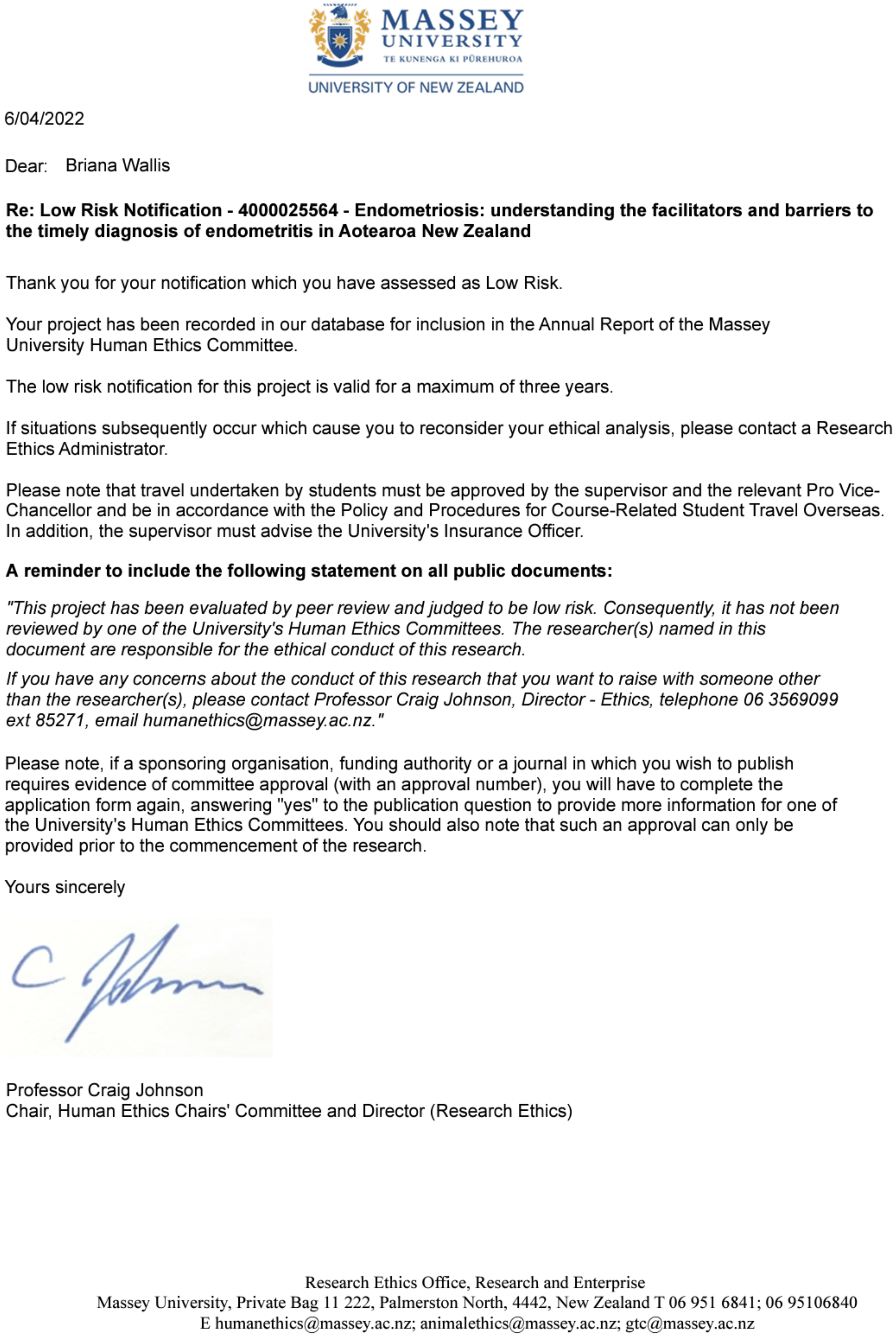
This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Prof Craig Johnson, Director, Research Ethics, telephone 06 356 9099 x 85271, email humanethics@massey.ac.nz.

Appendix E: Low Risk Ethics Notification



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6/04/2022

Dear: Briana Wallis

Re: Low Risk Notification - 4000025564 - Endometriosis: understanding the facilitators and barriers to the timely diagnosis of endometritis in Aotearoa New Zealand

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

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

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

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

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

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

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

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

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

Yours sincerely

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

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