“It feels like an uppercut to the uterus”: Exploring the Impact Painful Sex has on Women's Sexuality due to Endometriosis.

A thesis presented in partial fulfilment of the requirements for the degree of Master of Science (by thesis)

in

Psychology

at Massey University, Albany,

New Zealand

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2021

Abstract

130,000 women have endometriosis in New Zealand, with an estimated 70% of these women experiencing pain during or after sex (Adamson et al., 2010). There is limited research in New Zealand exploring women with endometriosis experiences of painful intercourse and its impact on them as a woman and their sexuality. Research has focused predominantly on the medical factors that affect women with endometriosis sexuality rather than taking a holistic approach. It is critical to explore the impacts painful intercourse have on women with endometriosis to better support them. This study aimed to explore women living with endometriosis experiences of painful intercourse and the impact this has on their sense of femininity and sexuality taking a feminist approach which privileges the women's voices and stories. Ten women with endometriosis took part in two semi-structured interviews and created a timeline of painful menstruation and sexual intercourse. In the first interview, participants discussed their endometriosis journey and created a timeline. In the second interview, participants discussed their experiences of painful intercourse, the impact, and the ways they cope. A structural narrative analysis was used to explore how the women storied their endometriosis journey alongside their experiences of painful intercourse. It was essential to capture the women's diverse and unique experiences and make meaning of their narratives. The analysis revealed the following narrative points, which consist of narrative subthemes. 1) something isn't right – pain, normalisation of pain and the turning point, 2) who am I as a woman living with endometriosis and painful intercourse? – sexual function, sexual relationships, fear and anxiety towards future sexual interactions and impact on their sense of femininity and, 3) what does this mean for their sexuality and them as a woman? The findings indicate that painful intercourse associated with endometriosis impacts women’s sexual relationships, self-worth, femininity, feminine roles, and sexuality. However, there was less impact on women’s sexual function. These findings are essential for future research methods and intervention strategies to support women living with endometriosis.

Acknowledgements

I want to thank my supervisor, Dr Kathryn McGuigan, for your support and guidance throughout this year. Your devotion and commitment to me has been appreciated. You exceeded any expectations I had of a supervisor, and you pushed me to do the best I could do. I will always be thankful for this amazing experience we got to share.

I want to thank my parents Stuart West and Sam West, for being the most incredible parents. Thank you for your endless amount of support, guidance, and love you both give to me. You have both always supported my dreams and pushed me to be the best version of myself. Without you both, I would not be where I am today. I hope you are both proud of me.

I want to thank my partner Reece Lane. Thank you for the always being there for me and supporting me in whatever I choose to do in life. Thank you for making me laugh endlessly and teaching me not to take life too seriously.

I want to thank my two best friends Steph Green and Meghan Mappledoram. These two beautiful people have been my absolute rock since the day I met them both. Thank you to you both for your endless amount of support, encouragement, and friendship.

I want to say thank you to my grandparents Vic Franklin, Jeannette Franklin, and Joyce West. You all have been so supportive and encouraged me to strive for my dreams.

Lastly, I want to thank the women who participated in my research. Thank you for sharing your experiences and stories with me. I wish you all the best of luck in your endometriosis journey in the future.

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Chapter One

Introduction

Many women expect there to be pain with menstruation. There are over-the-counter anti-inflammatory drugs readily available in many supermarkets, pharmacies and health stores that provide short term relief from menstrual pain, reinforcing the notion that period pain is normal (Markovic et al., 2008). Additionally, the media portray women who menstruate as vibrant and energetic, suggesting that the pain and discomfort experienced by women should be manageable. Medical professionals have also been found not to take women's pelvic pain seriously. Women are then left to distinguish whether their period pain is normal or not, and then need to try to convince a medical professional that they require further medical attention. This can be exemplified with endometriosis, which is a chronic inflammatory disease with symptoms including period pain, chronic pelvic pain and sub-fertility or infertility (Giudice, 2010).

A significant impact of the pain associated with endometriosis is painful sexual intercourse, but this is a difficult topic to bring up with medical professionals. Many women with endometriosis face this challenge, as well as the burden and consequences of living with this disease. This research will explore how women with endometriosis live, and how they live with the symptom of painful sexual intercourse. Furthermore, this research will explore the impact pain with intercourse has on the women's sexuality and femininity.

This chapter will outline what endometriosis is, the symptoms associated with endometriosis, the treatment options and what it is like for women living with this disease. The chapter will then finish with a discussion on painful sexual intercourse and the research objectives for this study.

What is endometriosis?

It is estimated that 176 million girls and women worldwide are affected by endometriosis, with 130,000 women affected in New Zealand. Thus approximately 1 in 10 women in New Zealand will have endometriosis (Adamson et al., 2010). It is diagnosed most commonly during a women's reproductive years (25-35 years), but often women will experience severe pain from their first periods (11-15 years of age). Endometriosis is a chronic gynaecological disease where tissue like the endometrial develops outside the uterus. The endometrial-like tissue is located commonly in the pelvis, around the ovaries, fallopian tubes, the uterosacral ligaments, on the outer surface of the uterus and in the pouch of Douglas (also known as the recto-vaginal pouch) (Giudice, 2010). It can also be found in rarer sites including the bowel, bladder (De Cicco et al., 2011), intestines, abdominal scars (Huang et al., 2013), diaphragm and lungs (Nezhat et al., 2012). The endometrial-like tissue that is misplaced responds similarly to the endometrium in the women's menstrual cycle. Therefore, during a women’s menstruation when the endometrium shreds this also stimulates the endometriosis to grow, break down and then the tissue to bleed. This blood and excess tissue cannot escape the body and leads to internal bleeding ultimately causing inflammation, pain and the formation of adhesions and cysts inside the women's body. These adhesions and cysts are commonly located in the pelvis area but can start to form in other parts of the women’s body too.

Medical aetiology

Identification of endometriosis in the 1860's caused numerous investigations on the cause of the disease. This resulted in several aetiology theories attempting to explain and better understand the pathogenesis of endometriosis (Asghari et al., 2018). The Sampson’s Retrograde Menstruation Theory is the most widely accepted biomedical theory for the development of endometriosis (Sasson & Taylor, 2008). This theory proposes that the occurrence of retrograde menstruation allows the ectopic endometrium to be carried back through the woman's fallopian tubes, ovaries, and the pelvic cavity, where it can embed itself, grow, and cause the development of endometriosis. It is argued that this is possible by a pressure gradient originating from dyssynergia uterine contractions (Vercellini et al., 2014). This misplaced tissue then forms lesions and cysts, which stimulates a chronic inflammatory reaction in response to hormonal change, resulting in the formation of scar tissue, adhesions, and pain (Asghari et al., 2018). However, this theory cannot explain the early onset of endometriosis in premenarcheal girls. Still, Brosens et al. (2013) hypothesise that neonatal uterine bleeding is the initial retrograde reflux. Since retrograde menstruation is common in women who menstruate, to some degree, this does not explain why some women do not get endometriosis and some do.

The Coelomic Metaplasia Theory proposed by Iwanoff (1898) and Meyer (1903) suggests that endometriosis derives from the metaplasia which is the changing from one type of cell to another type of cell. Thus, metaplasia of specialised cells is thought to occur within the mesothelial lining of the visceral and abdominal peritoneum. Hormonal or environmental toxins are believed to be able to stimulate the transformation of peritoneal cells into endometrium-like tissue (Maruyama & Yoshimura, 2012). This theory explains how prepubertal and adolescent girls who have not menstruated have been diagnosed with endometriosis. However, Sasson and Taylor (2008) argued that if this aetiology were the primary cause of endometriosis, then we would see an increased incidence with aging, like metaplasia in other organs. The Embryonic Rest Theory is similar; however, it proposes that the Mullerian fragments in the recto-vaginal area differentiate into endometrial glandular cells (Maruyama & Yoshimura, 2012). Because embryonic cell rests of Mullerian origin are present in woman and men, this theory could explain the rare cases where males have been diagnosed with endometriosis in their bodies. De Ziegler et al. (2010), argues that the embryonic rest theory explains the occurrence of endometriosis within families and why some women with endometriosis experience severe pelvic pain from the beginning of their menstruation. Nevertheless Sasson and Taylor (2008), argued that this theory would then involve the assumption that these embryological rests continue to adulthood. Yet, this theory still has not been confirmed.

The last theory, called Lymph Vascular Metastasis Theory suggests that while travelling through the blood vessels or the lymphatic system, the endometrial fragments could travel to other parts of the body (Sasson & Taylor, 2008). This theory could explain endometriosis found in rarer sites such as the brain, skin, or eye. Sasson and Taylor (2008), argue that the endometrial fragments transferred by the lymphatic system contributes to the development of endometriosis. Yet, the rare incidence of hepatic and thoracic endometriosis, means that the lymphatic system is not likely the primary mechanism that spreads endometriosis around the body. Consequently, proposing that women with endometriosis may experience immunological defects or dysfunction. Laganà et al. (2013), research has shown women with endometriosis have abnormal functioning of macrophages, T and B lymphocytes and activity of natural killer cells which would usually detect and expel excess menstrual tissue and endometrial cells. It has been speculated that as the endometrial fragments enter the pelvic cavity they have the ability to escape the immune system. This theory is not excluded because research has shown that women with endometriosis have the possibility of abnormal endometrial fragments and immune system. Therefore, some theories of the aetiology of endometriosis are favoured over others. However, there is still not a proven aetiology.

Endometriosis can only be diagnosed through surgery. The American Society has developed a staging system for Reproductive Medicine to assess the severity of the disease (Canis et al., 1997). The staging system includes four stages, from minimal to severe. They are measured by the size, depth, and place of the endometriotic lesions found during laparoscopy surgery. This staging system can be useful in the treatment and management of infertility. However, the stages correlate poorly with the extent and severity of endometriosis and the severity of pain symptoms which make it difficult to provide adequate treatment (Greene et al., 2016). Endometriosis symptoms include pain with periods (dysmenorrhoea), chronic pelvic pain, pain during or after sexual intercourse (dyspareunia), bowel and bladder issues, sub-fertility or infertility and fatigue (Bulletti et al. 2010). Women have described their pain like a knife turning in their ovary or like sitting on needles (Denny, 2004a). These symptoms vary a great deal from woman to woman - some women do not have any symptoms at all and do not know they have the disease. Others may have debilitating pelvic pain, cramps and associated pain continuously. There is no explanation why some women may have symptomatic or asymptomatic endometriosis because research has indicated that the amount of endometriosis found and the individual's symptoms do not necessarily correlate with the severity of the disease making the disease difficult to treat and somewhat of a mystery (Greene et al., 2016). Due to the variety of symptoms, signs, locations of endometrial-like tissue, ambiguous diagnosis and varying treatments, the efforts made to estimate the prevalence of endometriosis in a woman is distorted (Huang et al., 2013). Women also report being told they have endometriosis without having had surgery, so this also suggests the true prevalence is unclear.

Treatments

The most common treatments used for endometriosis are hormonal, surgical, pain management and self-management practices (Olive & Pritts, 2001). As endometriosis is an estrogen-depend disease, the hormonal treatments concentrate on altering the women's hormones and menstrual cycle to produce a pseudomenopause or pseudopregnancy where the woman stops ovulating (Huang, 2008). In each of these situations, the endometrium wall becomes thin and inactive, which hinders the growth of endometrium-like tissue and can alleviate the symptoms of endometriosis. Hormonal treatments include the oral contraceptive pills, progestogens, Mirena and other hormonal agents which many have harmful side effects (Kennedy et al., 2005). For example, synthetic androgens such as danazol increase the concentration of free testosterone to produce a hypoestrogenic state and inhibit the endometrial growth (Selak et al., 2001). Common side effects include dark hair growth on a woman’s face, chest or back, acne, weight gain and it may affect cholesterol levels (Selak et al., 2001). Gonadotrophin releasing hormone (GnRH) analogues stops the production of oestrogen and induces amenorrhoea. Thus, the women can experience side effects such as hot flushes, vaginal dryness, breast tenderness, insomnia, and depression (Busacca et al., 2001). The other problem associated with these hormonal treatments is that they only relieve pain in the short term and are a temporary solution for women with endometriosis (Huang, 2008). Despite these issues’ hormonal treatments are a vital part of a women's endometriosis treatment plan but require trial and error to work out the best option for them as hormones affect every woman differently.

Another treatment option is to remove the endometrial-like tissue, adhesions, and cysts surgically via two different procedures: 1) excision surgery which involves cutting the endometrial-like implants away from the surrounding tissue and 2) coagulation which involves burning the endometrial-like implants with laser technology (Nezhat et al., 1986). Both types of surgeries are used individually or can be combined. Research has shown that excision surgery is the most effective treatment to alleviate endometriosis symptoms compared to coagulation (Vercellini et al., 2014). Surgery does relieve pain, but it does not affect the pathogenic mechanisms of endometriosis. Thus, the recurrence of woman's symptoms is frequent with reports of 40% to 50% recurrence rates at 5-year-follow-up when there has been no postoperative treatment used. Also, approximately half of the woman who had surgery required analgesics and/or hormonal therapy within 2-years (Vercellini et al., 2014). In these cases, pain related symptoms from endometriosis continued after surgery, and side effects from hormonal treatments and pain medication becomes intolerable. A hysterectomy, which the woman's uterus gets removed, and an oophorectomy, which is the removal of one ovary or both ovaries, may be considered as a final treatment. However, women need to be made aware that this is not a cure and that with definitive surgery there is a chance that symptoms may persist after the removal, with reports of 5 – 15% reoccurrence of endometriosis (Ghai et al., 2020). It is disheartening for many women, but even young women in their early

20’s have had hysterectomies to relieve their pain associated with endometriosis. Furthermore, the pain that follows surgery often has a long recovery time and attempting to figure out what works best for each individual woman is time-consuming. These factors can lead to further discouragement for those with endometriosis.

Analgesia is pain medication used to help with the management of pain caused by endometriosis. Painkillers such as paracetamol and ibuprofen are effective drugs for acute pain. For chronic pain, opiate-based drugs are used such as codeine, tramadol, and gabapentin. Opiate drugs have severe side effects, including sedative, drowsiness effects, and constipation (Martínez et al., 2013). Endometriosis associated pain can last for hours, days or even months, resulting in many women relying on opiate-based drugs for pain management. Many women end up in the emergency department of a hospital several times a month or have multiple doctor appointments complaining about pain and requiring opiates regularly to help manage the pain (Krebs & Schoenbauer, 2019). The lack of understanding towards this disease, even in the medical profession, can contribute toward women being seen as attention-seekers or drug seekers. Many medical professionals also imply that women’s endometriosis pain is merely insignificant or that it is inside the women's head or even a ploy for obtaining opiate-based drugs (Krebs & Schoenbauer, 2019). Being labelled as drug-seekers can be profoundly devasting for women's careers and psychological health, as well as physical health, especially when they are in severe pain and denied pain medication.

When symptoms persist after many different treatments, women tend to take a more holistic approach to manage their pain, and they seek alternative therapies. There are many alternative therapies used by women which has shown to help improve endometriosis symptoms, these include, but not limited to: 1) Chinese herbal medicine can help reduce the formation of cysts, alleviate menstrual pain and pelvic pain (Zhao et al., 2018), 2) healthy diets and lifestyle changes can increase women's energy levels and they can learn to influence their symptoms through different lifestyle changes (Karlsson et al., 2020), 3) physiotherapy can help woman strengthen their pelvic floor muscles, exercises for relaxation and massages to help alleviate pain associated with endometriosis, especially bladder, bowel issues and pain during or after intercourse (Kumari, 2018), 4) yoga, certain yoga poses can alleviate pain during menstruation and pain associated with endometriosis (Gonçalves et al., 2017), and 5) naturopathic medicine has been used to regulate menstruation, balance hormones, and alleviate painful menstruation and menorrhagia (Reid et al., 2019). Although there has been numerous clinical research done on the above treatment's efficacy in relieving endometriosis and have shown promising results, there is still not a cure for endometriosis. Therefore, treatment plans for endometriosis are based on alleviating symptoms and improving the women’s quality of life, rather than curing the disease.

The treatment process can be strenuous and feel like it is never-ending. All the above treatments may only provide temporary to no relief from pain, whereas for some, they may significantly reduce pain. However, research has shown that the recurrence rate of woman's symptoms and lesions is 40% to 50% at a 5-year-follow-up (Vercellini et al., 2014). The persistence of symptoms and recurring pain after months, even years of multiple rounds of treatment is hugely taxing on women. Living in constant pain can be associated with feelings of despair, disappointment and hopelessness. Medical professionals who voice that there is not much else they can do for the women also results in the development of mental disorders and worse cases, even suicide (Huntington & Gilmour, 2005). Nevertheless, many women do not let the disease control them, but instead make significant changes to their lifestyles after the limitations of surgery and hormonal treatments to take back their control and manage their pain.

“Women’s problems” and diagnostic delays

Historically, the typical endometriosis patient profile was a “career women" who was a woman who delayed childbearing and was at greater risk for endometriosis as older women allowed menstrual tissue to build up as they experienced a more significant number of cycles throughout their lives. Also, these women were heterosexual and from middle-to-upper class (Jones, 2015). This victim-blaming approach led to medical professionals telling the woman to stay home and fall pregnant as a solution to the women's suffering (Carpan, 2003). Despite this outdated notion and being offensive, it has been proven that there is no difference between the incidence of endometriosis in women who have not been pregnant and the women who have (Moen & Muus, 1991). The mystery and myths surrounding endometriosis persisted, and the frequent ignorance and misdiagnoses from medical professionals led to disturbing interventions. These included prescribing women tranquilisers to cure a disease that the medical doctors described as a problem in a woman's head (Shohat, 1992). Painful periods and endometriosis-associated pain were seen as fake, signs of a neurotic personality or fate of being a woman (Shohat, 1992). Some women in today’s society are still told by medical professional or families that getting pregnant will treat endometriosis or that the pain is all in their head (Denny, 2004a). It is shameful that a disease that causes 10% of the population to be in severe pain and has deliberating symptoms is still classed as the fate of being a woman by some medical professionals.

Nancey Peterson, the director of the endometriosis treatment programme and endometriosis advocator, said:

> *"If a man had a disease that causes him to be unable to father a child, to have unbearable pain during sex and unbearable pain during bowel movements [which was] treated by feminising hormones and surgery, endo would be declared a national emergency in this country"* (Shohat, 1992, p. 62)

The quote demonstrates the medicalisation of endometriosis and that within the social order women existed primarily to be wives/mothers in society. It highlights the inequalities women faced and unfortunately, in today's society women with endometriosis still face many challenges regarding diagnosis, treatment, as well as, the significant impact living with this disease has on women's lives. Dominant views that period pain is normal contributes to delays in diagnosis (Ghai et al., 2020). Women report that it can take years until they receive a diagnosis of endometriosis. The average delay from symptoms onset to receiving an official diagnosis is ten years because the journey to receiving a diagnosis is strenuous and complicated (Endometriosis Foundation of America, 2018). A major barrier to the management of endometriosis is diagnostic delays which can lead to many years of suboptimal treatments and possible disease advancement. To be diagnosed definitively with endometriosis women must undergo a surgical assessment by laparoscopy or in rarer conditions by laparotomy (Olive & Pritts, 2001). This is done by gynaecologists and getting access to these specialists can take months even years.

Ballard et al. (2006) reported that the first challenge women face to getting a diagnosis is that they must distinguish whether the pain they are experiencing is 'normal' or 'abnormal. Having painful periods from the start of their menstruation and the societal views that it is normal for women to experience pain tends to let women consider their pain as normal. Although many women recognise that their pain is problematic and causes disruption to their lives, they perceive this as an extreme of normality and delay seeking medical attention. Secondly, Hudelist et al. (2012), explains that once women have established that their pain is ‘abnormal’ and turn to medical advice, the next challenge is to make the GP believe them. Often, women are told that their symptoms associated with menstrual pain is ‘part of being a woman’ or that there ‘is nothing wrong’ with them and that they are simply ‘unlucky’. Menstrual pain is normalised and medical professionals treat the pain as if it is a physiological process of menstruation, rather than something pathological. For example, Denny (2004a) reported that many of the women first went to their GP in their teenage years with menstrual pain and were either prescribed the contraception pill or told they were ‘just unlucky’. Therefore, not having a medical professional believing the pain is legitimate can cause the women to feel like it is in their head and not seek medical attention again, thus delaying diagnosis and not receiving treatment, so the disease progresses.

Furthermore, not all GPs agree that mild endometriosis is a disease or that it should be treated. Cox et al. (2003), reported that 70% of the patients who told their GPs that they suspected they had endometriosis, 24% were ignored or the GP disagreed with their self-diagnoses, 15% were reluctantly referred to a specialist, and 26% were immediately referred to a specialist. Additionally, Ballard et al. (2006) found that because women require a laparoscopy for a definitive diagnosis, they also require a referral from their GP to secondary care. These referrals may vary from one month to 22 months and many women reported that they had to visit their GP numerous times before they received a referral to the gynaecologist. Another factor contributing to diagnosis delay for women with endometriosis is that many women are misdiagnosed due to other medical conditions mimicking endometriosis such as irritable bowel syndrome, pelvic inflammatory disease (Seaman et al., 2008), sciatica, uterine fibroids, polycystic ovary syndrome and pelvic floor dysfunction (Mao & Anastasi, 2010). For example, a study conducted by Bontempo and Mikesell (2020), reported that 75.2% of women living with endometriosis were misdiagnosed; with 95.1% being diagnosed with another physical health condition, 49.1% diagnosed with a mental health problem and 44.6% reported both. In this respect, the denial of appropriate treatment expresses how the medical system is failing to understand and assist women with endometriosis and delaying diagnosis.

Another factor contributing to delays is the long process of trial and error of different treatments as not all are effective. Ballard et al. (2006) reported that before a definitive diagnosis of endometriosis, many women were prescribed oral contraceptive drugs by their GPs. Some women reported that the oral contraceptive pill offered them relief from their symptoms; however, some reported side effects that worsened the pain (Denny, 2004a). Thus, women sought further medical advice and treatment options, but again a hormonal treatment was prescribed. This process is ubiquitous and may take up to years. Once women have been persistent in their primary health care with chronic pelvic pain that is not responding to medical treatments, then they are referred to get an ultrasound (Ballard et al., 2006). Also, many of the test’s women are subjected to do not help diagnose endometriosis initially. Ultrasounds scans can detect ovarian endometriosis (endometriomas), but they are a poor measure for nonovarian pelvic endometriosis. The undetected endometriosis reassures the GPs that further investigation or treatment is not required (Staal et al., 2016). Additionally, imaging and biomarkers can be useful at detecting endometriosis, but they are unable to identify superficial peritoneal lesions. Thus, they are unable to provide a definitive diagnosis

(Staal et al., 2016). These negative tests can further place doubts in the woman's head about their symptoms as well as doctors and the women's social groups who reinforce the normalisation of period pain. When a woman does eventually receive a laparoscopy to investigate endometriosis, the most common reasons are the women’s wish to have a definitive diagnosis, they are unresponsive to different hormonal and medical treatment, subfertility, or infertility and persistent or increasing symptoms indicating the disease is progressing (Moradi et al., 2014). Usually, by this point, the disease has progressed rapidly due to being undetected for years, and the women have a higher risk of recurrence and infertility.

Furthermore, people that do not identify as women such as nonbinary, trans men and genderqueer people who have ovaries and a uterus can also have endometriosis. These people are even more likely to find it challenging to receive a diagnosis than cis-women because of the transphobic norms in biomedicine (Nadal et al., 2012). This reinforces the notion that endometriosis is constructed around the patient file of a woman that is white, middle-to-upper class and straight (Jones, 2015). Additionally, it is important to consider the influence ethnicity, income and education factors have on women’s accessibility to sought medical attention for pain. Research suggests that women who have a lower socio-economic background are less likely to seek medical help as they believe their pain would not be taken seriously by medical professionals (Markovic et al., 2008). Barriers are also experienced by minority women such as language, costs, and transport to access medical care services, further delaying diagnosis (Markovic et al., 2008). Therefore, ceasing the delay in diagnosis is critical for all woman living with endometriosis because access to treatment is essential to be able to live well with this disease.

Upon diagnosis

According to Denny (2004a) after receiving a definitive diagnosis women reported feeling a sense of relief, validation and in some cases, anger towards the earlier inferences from doctors that their complaints and symptoms were psychological or ‘made up’. The diagnosis brings relief by allowing women to talk about their symptoms, gain knowledge to understanding endometriosis and to seek appropriate treatment options. Also, a diagnosis allowed women to access social support groups or organisations, to connect with other women who are living with the disease. Facchin et al. (2017), reported that the negative aspects of receiving a diagnosis were women discovered that there was no cure for endometriosis and no guarantee of successful treatment. Because receiving a diagnosis of endometriosis does not always lead to a reduction in symptoms, and there is a lack of information about this disease. The lack of information, support and relief from symptoms can cause frustration, confusion, anxiety and hopelessness among women as well as mistrust in medical professionals.

Living with endometriosis

In women's accounts of their experiences with endometriosis, pain is the most discussed subject and is the biggest concern for women living with endometriosis (Huntington & Gilmour, 2005). According to Huntington and Gilmour (2005), women's experiences of pain were still dismissed by medical professionals even after their diagnosis. Denny (2009) found that medical professionals held concern for the women's pain, but they rarely asked the women about their experience of pain, or how it is affecting their lives. Thus, women's concerns and pain are still ignored within the clinical setting, just as it was before receiving a diagnosis, reinforcing the need for women to construct their experience in a way that legitimatises their pain.

There are significant implications that arise in everyday life for women with endometriosis including time off work, tensions in intimate relationships, being too tired to socialise, and low self-esteem (Markovic et al., 2008). Persistent symptoms frequently lead to women taking time off work or school, which can affect the women's income or career progression. It can be embarrassing for women to discuss why they are absent from work, especially if their working environment is male dominant (Jones et al., 2004). Women's social lives and activities are compromised as social events are cancelled frequently due to debilitating symptoms. Some women try organising their social events around their menstrual cycle to try and take control of their disease but can be difficult due to the unpredictability of symptoms (Denny, 2004a). Women must have social support systems in place to help them cope with living with the disease such as family and friends but some women discover that these support systems diminish upon diagnosis. The unpredictability of endometriosis, no cure, diverse effectiveness of treatment options and the consequences of untreated symptoms lead women to feel disempowered and that their disease controls their life (Markovic et al., 2008). This is reinforced by multiple encounters with medical professionals who do not take women's pain seriously, and many women find themselves being disbelieved, accused of exaggerating and being neurotic, even by friends and family (Denny, 2004b). This enhances women's feelings of frustration, hopelessness, confusion and loss of control over their bodies and lives. Consequently, it is reported that women with endometriosis have higher risk of developing depression and anxiety, which can delay their diagnosis further because medical professionals often associate women's pain and symptoms with psychological factors (Cox et al., 2003). Endometriosis associated pain and the taxing symptoms have been the reason for several relationships to break up (Denny & Mann, 2007). Overall, endometriosis can affect every aspect of women's lives.

Painful sexual intercourse

It is common for women with endometriosis to experience pain with intercourse. Research reports that 30 – 70% of women with endometriosis experience dyspareunia (painful intercourse) suggesting that many women are experiencing sexual distress caused by endometriosis, which may interfere with conception, intimate relationships, and self-esteem (Pluchino et al., 2016). Sexual intimacy is an integral part of an intimate relationship, so the impact of endometriosis is considerable on sexuality, identity as a woman and the relationship (Pluchino et al., 2016). Vercellini et al. (2011) reports that there is a 9-fold increased risk of women with endometriosis experiencing dyspareunia compared to women without endometriosis. Dyspareunia is defined as genital pain occurring before, during or after penile penetration that is not exclusively due to the lack of lubrication (Fritzer et al., 2013). There are two types of dyspareunia: (1) superficial dyspareunia, where pain occurs at the vaginal introitus at initial penetration, and (2) deep dyspareunia, where the pain is in the abdomen with deep vaginal penetration (Fritzer et al., 2013). The definition of dyspareunia is medicalised and heterosexist. It does not include women who are bisexual or lesbian experiences of pain during intercourse and sexual intimacy. Throughout this research, I will be using the terms of painful sexual intercourse or painful sex instead of dyspareunia because the term dyspareunia focuses on the belief that sex must involve penile penetration. This therefore would exclude lesbians, bisexual woman and people that have non-woman gender identities, who may not engage in penile penetrative intercourse but still experience painful sexual intercourse.

Pain during intercourse is caused by the stretching of scarred endometrial tissue or from the pressure placed on lesions, enlarged ovaries or adhesions during penetration (Elmerstig et al., 2008). For some women, this is described as 'discomfort', 'being uncomfortable' and ‘intense cramps’ (Jones et al., 2004). The pain may affect women’s sexuality, as the pain is often severe, lasting not just during sexual intercourse but many hours afterwards, with some women afterwards not being able to move due to the crippling pain (Buster, 2013). Pain during or after intercourse impairs women’s quality of sexual life by reducing sexual desire, sexual arousal, orgasms, and frequency of intercourse (Hämmerli et al., 2018). Interruption during intercourse for women with endometriosis is frequent due to pain, severe cramps, and possible bleeding, which can also disturb the mood and decrease sexual motivation (Hämmerli et al., 2018). Pain with intercourse can result in behaviours such as avoidance of intercourse; however, some women still engage in sexual intercourse despite the pain due to trying to conceive, feelings of guilt, embarrassment, and the notion that this is what sex is supposed to feel like (Elmerstig et al., 2008). The pain during sex can last for hours afterwards, making sexual contact not a pleasant experience for these women. Women begin to fear having pain during or after sex resulting in them avoiding sexual intercourse altogether (Fritzer et al., 2013). This fear also decreases a women's sexual arousal, desire and lubrication, which in turn affects the relationship (Elmerstig et al., 2008). All of these factors can lead to sexual intimacy issues with partners as well as effect women's sexuality.

Sex is a sensitive subject and can be embarrassing to talk about, especially if you believe there is something wrong or not working correctly. Therefore, identifying painful intercourse as a symptom of endometriosis can be difficult as many women do not voluntarily discuss personal information to their doctor. Supporting this Weijts et al.

(1993) reported that many women were reluctant to discuss problems relating to their sexuality as were the gynaecologists. One reason for reluctancy to discuss sexual issues is the numerous encounters women have had with medical professionals who have disregarded their pain during intercourse as ‘this is normal for women’ or ‘there is nothing we can do’. Another reason is that pain with intercourse has been normalised by informal discussions with medical professionals and society. These strengthen women's beliefs that painful intercourse is normal and justifies why only 1/3 of women suffering from distressing severe sexual problems seek professional assistance (Vercellini et al., 2011). This suggests that many women suffer in silence and do not receive the medical treatment they require, further impacting their relationships and sexuality.

The treatments associated with reducing pain during and after sex consist of changing sexual positions that allow women to control the depth of penetration, such as missionary position, which helps reduce the pain (Denny, 2004a). For some women, sexual positions only reduce pain to a certain extent and require pain medication to cope. Pain medication includes paracetamol, codeine, and tramadol, and as mentioned above, they have many unpleasant side effects such as decreased sexual arousal and desire. Excision surgery for endometriosis has reported to reduce pain during intercourse and improve the quality of a woman's sexual life. However, excision surgery requires a high level of surgical skill and may only partially or temporarily be effective. Hormonal treatments have been used to relieve pain during intercourse and are a favoured treatment as they are efficient, safe, and cost effective (Vercellini et al., 2012). Conversely, pharmacological therapies and hormonal medication does not work in one out of three women, and the side effects can hinder sexual desire and arousal, further reducing the frequency of intercourse episodes per week (Vercellini et al., 2012).

Painful sexual intercourse can affect aspects of women's lives that are socially constructed and defined as feminine. Traditionally, feminine women are heterosexual and are expected to act and look a certain way that men deemed as attractive. Historically, unfeminine women were assumed to be lesbian because they acted and presented themselves in a way that men believed to be unattractive and inappropriate (Lenskyi, 1994). Thus, for women with endometriosis who experience painful intercourse and unattractive symptoms these high standards of feminine are more difficult to research. There is a lack of knowledge and research on the association between the endometriosis symptom painful intercourse and a women's sexuality and sense of femininity.

With the large number of women affected by endometriosis, I believe it is vital to research this area. Women sharing their stories, will allow us to learn and understand how women represent endometriosis and painful intercourse. It will also allow us to view the way the women talk about it affecting their sexuality and sense of femininity. The contradicting information on menstruation and painful sex regarding whether it is normal or not normal has a significant impact on the way women construct their experiences. Therefore, the purpose of this research is to explore women living with endometriosis experiences of painful sexual intercourse and the impact this has on their sense of femininity, sexuality and what it means to be a woman. I believe that women living with endometriosis who have experienced or experiencing painful sexual intercourse will have a diminished sense of femininity and have a negative attitude towards their sexuality. I believe that these women will have affected areas regarding sexuality, such as sexual function, sexual relationships, and views on themselves as a woman. This research will give women with endometriosis a voice to share their stories and an insight into what it is like for these women to deal with an invisible disease that causes pain in something so intimate.

Research aims

The research aims of this project are to explore women with endometriosis experiences of painful sexual intercourse and the impact this has had of their sexuality and sense of femininity.

Objectives

The impact painful sexual intercourse has on a women's sexuality.

1) If a woman is experiencing painful intercourse, how does she understand her experiences if she has been told it is normal or not normal?
2) What do women do when they are told painful intercourse is not normal?
3) How does painful intercourse affect a women's sexual relationship?
4) How does painful intercourse affect a women's sexual function?
5) What happens to the future of women's sexuality?

The impact of painful sexual intercourse has on women's sense of femininity.

6) Does painful intercourse affect women's feminine roles?
7) How do women understand her experience of painful intercourse regarding her femininity?
8) How does this impact the view the women have on themselves as a woman?

Chapter Two

Literature review

This chapter begins with a summary of the history of sex, discussions on the suppression of female sexuality and how female sexuality has been socially constructed. I will discuss the definitions around sexuality and the multidimensional holistic definition that this research will be using. Next, I will outline the theoretical background of the fear-avoidance model to explain why many women with endometriosis experience pain during or after sex and result in avoiding intercourse. I will explore the literature around women's experiences of endometriosis, specifically the impacts that painful sexual intercourse has on women's sexual lives. I then highlight the societal expectations of women in relationships evolving around sex and the issues that women living with endometriosis encounter in their intimate relationships due to painful intercourse. Finally, I outline how women with endometriosis cope with painful intercourse.

History of female sex

Sex has had a long history of social control and taboo. In medieval times, there were three things that people feared: the devil, hunger and women (Baumeister & Twenge, 2002). Women were a source of anxiety for men that continued until the twentieth century. It was believed that menstruation and female sexuality had deleterious effects on a woman's intelligence as they contributed to female disorders such as nymphomania, hysteria and masturbation which were viewed as a threat to a woman's health and life (Baumeister & Twenge, 2002). Medical professionals and men had unusual beliefs to why women developed these disorders. One belief was that a woman who chose an academic life would result in the blood shutting off from her uterus to the brain, causing depression and infertile. Another belief was that if a woman read inappropriate novels or listened to romantic music, this would cause female disorders such as masturbation and hysteria (Baumeister & Twenge, 2002). Medical professionals believed that to treat these female disorders; they should remove the women's offending sexual organs. Initially, leeches were placed on the women's vulva and anus, or the clitoris was cauterised. This then led to even more bizarre interventions in the 1860's such as a clitoridectomy which was the removal of the clitoris. Interestingly, the medical professionals who made these interventions were males; yet these same medical professionals did not use the same treatment of removing the males sexual organs to treat male disorders such as masturbation, infertility or sexual disorders. These procedures are highly unethical, yet they still occur in today’s society in various parts of the world.

McGee (2005), reported that there are 21 countries in east, west, and central Africa as well as Indonesia, Malaysia and Middle Eastern countries that still perform female circumcisions. The most common age for girls to receive this procedure is between 4 and 10 years old. The least severe ritual circumcision consists of pricking the clitoral hood to release a drop of blood. One of the more severe procedures includes the removal of the whole clitoris, including clitoris glands and labia, and is called a clitoridectomy. Infibulation is the most severe procedure which involves excising the clitoris and labia of a girl then the edges of the vulva are stitched back together, leaving a small hole to urinate and menstruate from. This prevents a girl from having intercourse, and in their first sexual intercourse experience the male breaks these stitches from penetration. These procedures are hazardous, and the countries that carry out these procedures do not have the appropriate medical instruments causing problematic consequences such as shock, infection, haemorrhaging, HIV and AIDS. Women experience adverse psychological effects such as depression, terror, anxiety and humiliation. The reasoning behind female circumcision is to control female sexuality, to gender normalise, maintain the patriarchal structure and to rid women from sexual desire and disorders (Rodriguez, 2008). It is speculated that by removing the women's clitoris this will remove the organ which produces promiscuity and female sexuality. These procedures are highly controversial and inhumane, and no women should have to go through genital mutilation. They highlight the extreme rules and measures society has used to suppress female sexuality.

Throughout the early twentieth century, society held the belief that women had less sexual desire than men, and that men had the right to sexual intimacy because they had more sexual urges than women. This created double standards among women and men. Women were looked upon as sexual objects and inferior to men in all aspects of living, including work, politics, marriage, and sexual lives. Medicine during this time focused predominantly on men’s experiences and behaviours. The female clitoris was viewed as an anatomical homolog to the penis that was made of the same tissue and responded sexually in a similar manner (Small, 1992). These findings constructed the male body as superior and generated general standards for measuring all human sexuality. As a result, when gender-related differences occurred and could not be given a male comparison, they were often presented as female deficiencies or dysfunctions (Lenskyi, 1994). Medical discourses surrounding women's bodies have also included themes of volatility and control, especially concerning their sexuality and menstruation (Young et al., 2019). Women's sexuality was constructed as volatile and in need of control, if uncontrolled, then women would become distracted from their assigned reproductive roles (Ussher, 2003).

Feminists critiqued these texts and argued that sole purpose of a woman is not simply to reproduce, be a stay-at-home wife/mother or/and to just have penetrative sex with men (Scully & Bart, 2003). Women were expected to partake in sexual intercourse but not to enjoy sex, and hardly any consideration was given to female sexual pleasure. When women were not able to have intercourse or achieve a clitoris orgasm, they were shamed, resulting in many women suffering in silence as they had a lack of education on sexual intercourse. These women were also often misdiagnosed with hysteria, but many were suffering from chronic illnesses that irritated organs during intercourse (Angel, 2010). Women are shamed by the language of medicine and the typical female functions that have been pathologised, leading women to blame themselves for their illness. Daniluk (1993), study on women's experience of sexuality reported that many women felt the medical professionals and medicine had influenced their experiences of sexuality. For example, a woman with cervical cancer had an unnecessary hysterectomy because she was told that her cancer was due to her being promiscuous in her younger years, resulting in her blaming herself for her illness (Daniluk, 1993). Also, medical texts described menopausal bodies as decayed and not worthy of medical attention, further impacting a woman's sexuality (Young et al., 2019). Past medical texts have persistently defined female sexuality as inferior to male sexuality and that women must submit to the male, further suppressing female sexuality. Naturally, women resented being viewed sexually but often were made to feel unattractive or not worthy when they did not comply. The suppression of female sexuality in society during these times have led to long-lasting effects on female sexuality.

Furthermore, it was not only the medical literature that suppressed female sexuality but also education. Sex education predominately focused on female anatomy rather than female sexuality. The traditional models of sexual education normalised the notion that sex is not for pleasure, and women are made to reproduce, thus suppressing female sexuality. Feminists have critiqued the traditional sex education models that were evolved around biology, puberty, and reproduction. It emphasised the risks and dangers of intercourse, lacked attention to relationships, and only addressed vaginal penetration with no empathises on homosexuality sexual acts or woman's pleasure (Cameron-Lewis & Allen, 2013). Feminist have argued that the emphasis on risk and danger has left little room for women to explore pleasure, desire, and their sexuality (Fine, 1988; Measor et al., 2000; Alldred, 2007). This has made it difficult for women to know how to go about achieving pleasure from sex and positive attitudes towards one's sexuality.

Feminists fight for female sexuality

The first wave of feminism in the early twentieth century acknowledged that the suppression of female sexuality was a problem and recognised the gendered and sexualised dimensions of research (Shulman, 1980). These feminists focused on the connection between women and male sexuality rather than focusing on women's sexuality as it affected other institution like motherhood. It was not until a few years later when the subject of sex and power were analysed by feminists again. Betty Friedan, a famous feminist who wrote *The Feminine Mystique* in 1963, begun the discussion around sex discrimination and led the second wave of feminism (Friedan, 2010). Friedan explored the idea that women outside their traditional roles could find personal fulfilment and initiated the fight of sex discrimination (Friedan, 2010). Discussions among women around male supremacy, woman as sexual objects, sexual experiences and their needs started to increase rapidly. Naturally, women resented being sexualised and not taken seriously.

The formation of radical feminist groups allowed many women without political experience to join and voice their experiences and resentments (Shulman, 1980). Men were the so-called experts on women and were the authors of many journals, articles and books about women's sexual behaviour and sexuality. Women did not play a significant role in constructing their sexual paradigm, but the feminist racial groups allowed women to take back control and become experts in women's sexuality. Daniluk (1993) expressed that at first it was a challenge for women to present their sexual behaviour and sexuality as they had to free their minds from a male orientation that they have lived with for years. In 1968 the feminist movement had its first national demonstration with 60 feminists who highlighted the judgement towards women as sexual objects. Feminists spoke about what women went through to get abortions, how sex outside marriage women was punished, that a women's sexuality was held responsible for rape and their cry for freedom. In 1969 a group of feminists were granted 20 pages in the *Home Journal* to present feminist ideas. Subsequently, many articles were written by feminists acknowledging sex, contraception, sexual politics, women's liberation, female problems such as loss libido, female sexual dysfunctions, and treatments for sexual intimacy (Studd & Schwenkhagen, 2009). This tremendous outpour of literature encouraged women to examine their bodies, inside and out, not to feel ashamed and to free them from the bias and control of the male medical establishment. During this time many more feminist movements were organised such as a movement for reproductive freedom, women's self-help movement from California and broader women's health movement which all strived to reclaim the control back over women's bodies (Shulman, 1980). Feminist questioned the traditional definitions of women's sexuality, sexual satisfaction and sexual health in which were traditionally defined by men.

The feminist rebellion carried on further, and women began to re-examine, through a woman’s point of view, the definitions and beliefs about sexuality. Feminists discovered that they could help a woman change the way they think and educated men on women’s sexual pleasure and behaviour. However, it was the unequal power that held them back from making lasting changes. The critiques of sexuality and sexual repression made by radical feminists were examples how large the male dominance of women was. The third and fourth wave of feminism further challenged sexism, sexuality and put greater emphasis on femininity (Munro, 2013). The feminist movements, sexual liberalisation, and women's emancipation allowed for a more open and positive attitude towards female sexuality and the perceptions of sexuality as essential to a woman’s overall wellbeing (Weijts et al., 1993). These discussions around sexuality, sex and equality allowed women to question their views and begun viewing sex in terms of pleasure and enjoyment instead of duty (Wouters, 2004). The feminists battle led to women's sexual desire, pleasure and sexual problems to be taken more seriously, resulting in heightened consciousness of sexuality.

Although it has been a continuous fight for women’s rights, the beliefs and attitudes towards sex have changed drastically. Today explicit sexual content is presented on television, social media, magazines, movies, and music videos, which have shaped what is deemed appropriate and a normal sexuality (Brown, 2002). Dijkstra and Barelds (2011), reports that 70% of prime time television programs contains sexual content. The internet has also influenced peoples sex lives, with sex being reported as one of the most regularly searched topics on the internet. Sexual content on the internet is rapidly growing and can predict sexual behaviours patterns, leading individuals to become sexually active at a younger age and to adopt more permissive sexual norms (Brown et al., 2006). Thus, these societal developments highlight the fluidity of sexuality. Over time societal, cultural, and religious values can change a women's experience of sex. Therefore, women that are between 20 – 30 years of age mostly experienced relative societal openness about sex and one of the first generations to have easy access to contraception and sexual education. Whereas, older women grew up in a time with more conservative and restricted values around sex (Brown et al., 2006).

Today sexuality has become more what matters to the individual (Dijkstra & Barelds, 2011). Therefore, attitudes towards sexuality have changed and women engage in different sexual behaviours that are regarded as the new norm. For example, sexual content portrays sex as exotic, sexy, attractive, with women in sex scenes having multiple orgasms, numerous bizarre sexual positions and submitting to the male (Strasburger, 2005). The presentation of sex is pleasurable, and the women engaging in sexual activity as vibrant and energetic, suggesting that any pain or discomfort experienced should be manageable. It has created an unrealistic image and idea about what sex is supposed to be like for women, especially women with endometriosis, where sex can look completely different. Media does not show couples spending time on foreplay, uncomfortable or awkward sex, women or men with bloated stomachs, couples with sexual disorders or gynaecological diseases that prevent them from engaging in enjoyable sex or sex at all. For women with endometriosis, painful sexual intercourse, bloated stomachs, flare-ups called 'endo belly', bleeding during or after intercourse and bowel issues are all common symptoms to experience during intercourse (De Graaff et al., 2016). Therefore, this section shows the evolution of sex and the sexualisation of women. The unrealistic ideas around sex puts pressure on women who do experience issues with intercourse that there is something wrong with them which in turn causes feelings of guilt, shame, embarrassment, and unattractiveness. Women with endometriosis not only experience pain during or after sex, but also other unsexy symptoms such as bleeding during sex, bloating, urination, and defecation which further make the women feel that there is something wrong with them. Women already have a lot of pressure on them to fulfil high expectations and the addition of a chronic illness such as endometriosis causes a further interruption in sexual intimacy, sexual relationships, lowered women's self-esteem, and negative psychological consequences.

Throughout female history, women's sexuality has been suppressed and decided by men. The history of female sex and sexuality has illustrated the development of female sex and sexuality to what it is today. It suggests that female sexuality is viewed from a biomedical perspective that women are made to reproduce, and any problems are related to dysfunction. Also, the increased access to media and sexual content online has sexualised women and made them feel inferior and shame if they cannot do the sexual acts that are displayed in the media. Women's sexuality is already impacted, and with the addition of a chronic illness that causes sex to be painful, this could significantly impact women's sexuality further.

What is sexuality?

The term sexuality is understood as to be able to have sex and to reproduce; however, it is much more than this. Within research, sexuality is used interchangeably with several other terms for example, sexual health, sexual problems, sexual dysfunction, and sexual functioning, suggesting that there is a lack of knowledge around the term sexuality (Cleary & Hegarty, 2011). Sexuality is complex and is a fundamental aspect of humanity. It encompasses sex, sexual orientation, reproduction, pleasure, gender roles, gender identities and intimacy (Rao & Nagaraj, 2015). Sexuality can be experienced or expressed in desires, attitudes, thoughts, beliefs, values, behaviours, roles, and relationships. Therefore, sexuality requires a holistic definition. The World Health Organisation’s (WHO) proposed a holistic definition of sexuality which encompasses several dimensions of the concept such as psychological, physical, and social. This proposed holistic definition of sexuality does not often drive research and explains why research focuses on the physical components of sexuality, such as sexual function and dysfunction. Woods (1987), utilising WHO’s definition of sexual health, proposed a definition of sexuality that is multidimensional and incorporates three key concepts: sexual function, sexual self-concept, and sexual relationships. Cleary and Hegarty (2011), used Woods framework to understand sexuality in women with gynaecological cancer. They found that the three key concepts proposed by Woods could each be further divided into dimensions, creating a neo theoretical framework of the changes in women's sexuality after being diagnosed with gynaecological cancer. These three significant concepts and sub-concepts are sexual functions which is a women's ability to give and receive sexual pleasure which can be further divided into concepts of the sexual response cycle such as sexual desire, sexual arousal, and orgasm. Secondly, sexual self-concept relates to the image that a woman has of herself and the evaluation of the women’s own capability in feminine roles. This can be further divided into the concepts of body image, self-esteem, and sexual self-schema. Lastly, sexual relationships are intimate relationships that a woman shares her sexuality with another person. This can be divided further into communication and intimacy among partners. This sexuality definition has not been widely used in research and although, this definition of sexuality has been used in the context of gynaecological cancer and nursing the definition has not been used for women living with endometriosis.

While the definition proposed by Woods (1987) and then expanded on by Cleary and Hegarty (2011) is useful, the limitation of this definition for women living with endometriosis is that there is no mention of pain. Therefore, I will be using parts of Cleary and Hegarty's holistic definition of sexuality with the addition of the component of pain. This research utilises a holistic definition of sexuality to show that there is more to sexuality than sexual function. As well as to explore in-depth the impact painful intercourse has had on women with endometriosis sexuality.

The next section considers the fear-avoidance model as pain experienced by women with endometriosis during and after intercourse can impact their sexuality. I then move on to discussions of the intersectionality of sexuality, identity, and femininity. This section focuses on the complexity of sexuality, and the very biomedical view of sex, rather than the psychological and emotional views of sex and sexuality.

Fear-avoidance model

A high proportion of women with endometriosis experience pain before, during or after intercourse. The pain can occur every time a woman has intercourse, and the pain may last for many hours following sex. This painful and harmful experience of intercourse can lead the woman to develop a negative cognitive schema around future sexual interactions, causing negative psychological consequences and avoidance of sex (Fritzer et al., 2013). The negative cognitive schema and avoidance behaviour is explained via the fear-avoidance model (FAM), that was initially introduced by Lethem et al. (1983). The model explains why some individuals who suffer from a painful injury can recover while others who display pain-related behaviours and cognitions tend to develop chronic pain. The model proposes that people’s coping responses to pain can vary between two extreme spectrums. One spectrum is a confrontation; these people confront their pain, seeing their pain as a problem that needs action taken, allowing them to adapt more positively towards their injury. The other side of the spectrum is avoidance; these people avoid their pain and avoid any activities or experiences that they identify as painful. The avoidance behaviour increases the reinforcement of the discrepancy between pain sensation, pain experiences and behaviours. Over time the FAM has been adjusted to include additional variables that that influence the fear cycle and avoidance behaviours presented in chronic pain such as pain-related anxiety and pain catastrophising (Alappattu & Bishop, 2011). Catastrophising is a negative maladaptive cognitive style used by individuals. Pain-related catastrophising is where individuals focus on the sensation of pain, which causes them to exaggerate the threat of pain, resulting in negative self-evaluation towards their ability to deal with the pain (Quartana et al., 2009).

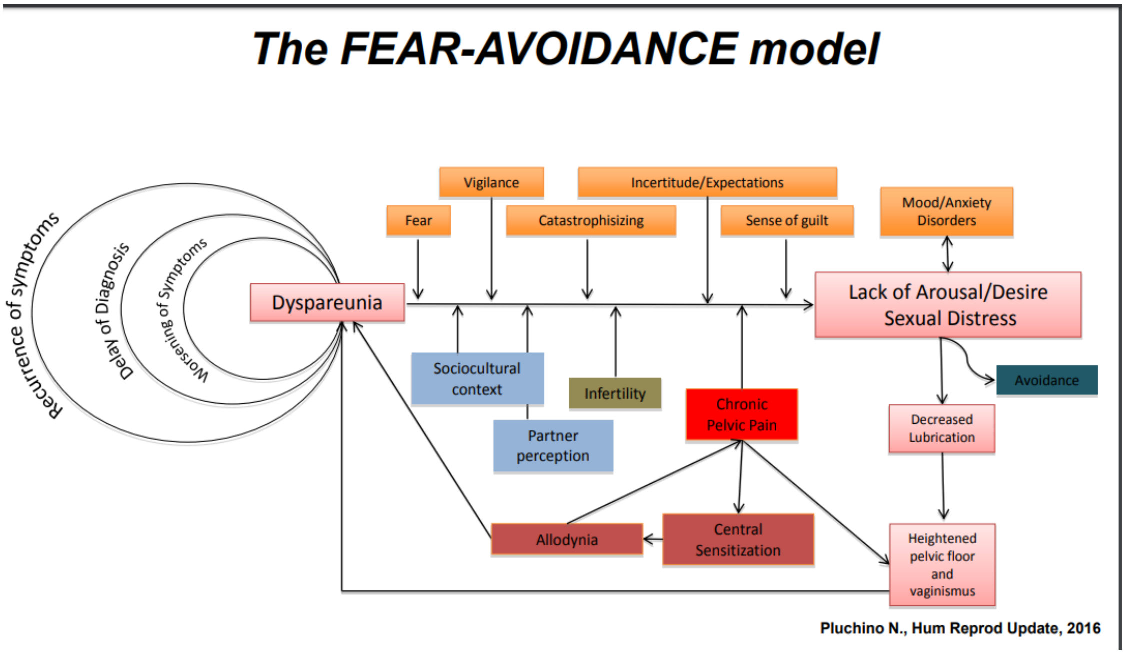
The FAM can be employed to explain how women with endometriosis develop a negative cognitive schema around intercourse and negative coping strategies to deal with the pain. For example, a woman who focuses on the pain sensation of painful sex (e.g., I cannot stop thinking about my experiences of painful sex), then begins to exaggerate the threat of painful sex (e.g., I cannot stop thinking about how much sex hurts). This results in negative cognitions about their ability to handle painful sex (e.g., It is never going to get better and this feels like it is going to go on forever) (Alappattu &

Bishop, 2011). This manifestation itself reduces sexual desire, sexual arousal, and lubrication. Each of these painful experiences sends repeated pain signals to the woman’s brain, that is associated with fear and anxiety, even when there is no physical threat (when not having painful intercourse). Thus, the woman's brain interprets future sexual interactions as dangerous, and the intensity of the pain during intercourse is increased (Elmerstig et al., 2008). Fritzer et al. (2013), research demonstrates that the feelings of fear and threat led to psychological and pelvic tension and therefore, women were unable to relax. Ultimately, catastrophising and the fear of pain can lead to avoidance of sexual intercourse, impacting woman's sexual intimacy with their partner.

Furthermore, Pluchino et al. (2016), adapted the fear-avoidance model to endometriosis patients (Figure 1). This model suggests that women with endometriosis experience of sexual pain can induce a fear and avoidance reaction which leads to decreased sexual desire, arousal, and distress in the women. The experience of sexual pain has biopsychosocial variables which play an essential part in the fear and avoidance model. The variables commonly found in qualitative studies include fear, guilt, catastrophising, fear, expectations and mental health problems lead to avoidance of sexual intercourse and can escalate into a sexual dysfunction or sexual distress. The sociocultural context and the women's partners view on the pain with intercourse are also important factors that contribute to sexual distress, decrease in sexual desire, sexual arousal, and increased avoidance. This can cause a lack of lubrication, increased chronic pelvic pain and pain with intercourse.

Figure 1

The Fear and Avoidance Model Adapted for Women with Endometriosis.



Note. From "Sexual function in endometriosis patients and their partners: effect of the disease and consequences of treatment," by N. Pluchino, J. M. Wenger, P. Petignat, R. Tal, M. Bolmont, H. S. Taylor and F. Bianchi-Demicheli, 2016, *Human Reproduction Update*, *22*(6), 762-774. (doi:10.1093/humupd/dmw031). Copyright by Oxford University Press. Reproduced with permission of author.

This model does have some value when considering why women with endometriosis might not want to have intercourse or avoid it after they have had painful experiences. Nevertheless, that is only part of the story as pain is only one factor. I will not be testing this model using statistics but rather I will be talking to the women about their experiences with painful intercourse and if they use the fear or avoidance narratives around their sexual experiences. It is crucial to consider the lived experiences of the women and the impact this has had on their sexuality and femininity.

Impact painful intercourse has on women's sexual lives

Female sexuality is compromised for women living with endometriosis in many ways, including the ability to have pleasurable sex. Tripoli et al. (2011), reported that 40% of women living with endometriosis and chronic pelvic pain were sexually unsatisfied and had less frequent sexual activity. Vercellini et al. (2011) reported that women with endometriosis experiences of painful intercourse may cause them to develop a negative cognitive schema around intercourse. Thus, women become unrelaxed during their next sexual interaction, making it more challenging to achieve an orgasm. This is supported by Pluchino et al. (2016), who reported that the anticipation and fear of recurring pain during intercourse negatively affects a women's sexual arousal, sexual desire, lubrication and heightened pelvic pain, making their next sexual encounter an unpleasant experience. This fearful reaction also causes emotional elaboration, including frustration and anxiety before, during or after sexual intercourse, feelings of guilt, distress, and decreased sexual motivation. Supporting this, Evangelista et al. (2014) found that ultimately women with endometriosis were more likely to avoid sexual intercourse due to the anticipation of pain. This avoidance of sexual intercourse led to a reduction in the women's sexual desire, self-esteem, and contributes to a lower quality of life and relationships.

Furthermore, Di Donato et al.'s (2014) quantitative study used the Sexual Health Outcomes in Women Questionnaire (SHOW-Q) questionnaire which contains four domains including satisfaction with sex, orgasm frequency, sexual desire and pelvic problem interference with sex. Their results suggest that women with deep infiltrating endometriosis experienced an impairment in all sexual function domains compared to healthy women. Conversely, Evangelista et al. (2014) study used the Female Sexual

Function Index (FSFI) to investigate the different accepts of a women's sexual life and pelvic problems interferences with sex. It was reported that 70% of women living with endometriosis had sexual dysfunction, while 60% of the healthy women also had sexual dysfunction. The results showed that there was little to no difference between the total scores on the FSFI in both groups. However, the results did report that women who lived with endometriosis experienced more pain during intercourse compared to healthy women.

Both qualitative and quantitative research has highlighted that the experience of sex is influenced by endometriosis for many women. What is interesting is that very few studies have considered the journeyed nature of endometriosis and have not asked about experiences of painful intercourse across the women’s lives. Additionally, there is a lack of research that considers if women having painful intercourse for the sake of their relationship refers to this as a sacrifice or fulfilling feminine expectations.

The impact painful intercourse has on sexual relationships

Sexual intimacy is an essential aspect of intimate relationships and humanity. A woman that is unable to participate in sexual activity or intercourse in a fulfilling way has a profound effect on her self-esteem, intimate relationships, and wellbeing. Moradi et al. (2014) study reported that most women with endometriosis who were in a relationship or married reported pain during or after intercourse negatively impacted their sexual relationships and there was a decreased in the couples episodes of sexual intercourse. Many women also mentioned they fail to reach an orgasm which led to frustration from both parties and put a strain on the relationship. Jones et al. (2004) found that the consequences of painful sex and avoidance were that many women described themselves as a ‘bad person’ because they are unable to enjoy sex and the effects this has on their partner. This is supported by Elmerstig et al. (2008), who reported that women with endometriosis experienced feelings such guilt and worthlessness towards their partner, their bodies and themselves. Some of the women believed that there was something wrong with them for not being able to have normal intercourse, with some blaming themselves by suggesting that they may have done something to their body for it not to be working correctly. Additionally, feelings of inadequacy were reported as women discussed how their sexual lives were drastically different from the images and videos that are portrayed on television, movies, and social media (Jones et al., 2004).

Painful intercourse is not the only sexual intimacy act that is different within relationships due to endometriosis, but also oral sex and intimacy. When experiencing painful intercourse, couples focus on the pain instead of enjoyment, causing a lowered sexual desire. Elmerstig et al. (2008) study reported that women abstained from initiating any sexual contact with their partners because they feared this would lead to sex. Whereas, the women would prefer ether oral sex or petting with no intercourse. This apprehension resulted in the women with endometriosis avoiding making any sexual contact with their partners, further impacting their sexuality and relationships. Furthermore, Denny and Mann (2007) reported that when women were explicitly asked how endometriosis has impacted their relationships, numerous women discussed how the lack of sexual intimacy causes arguments and tensions within their relationships. It was found that younger women who were in less established relationships felt that the reduced sexual activity and intercourse would jeopardise their relationships. In contrast, older women often discussed other qualities in their relationships and alternative sexual intimate acts than penetrative sex.

Interestingly, a recent study by Schneider et al. (2020) found that the impact of painful intercourse for adolescence and young women was distressing, and negatively impacted their self-image and overall wellbeing. The results suggest that for younger women, painful sexual intercourse was deemed as a more significant burden compared to other endometriosis related symptoms. Furthermore, five women in Denny and Mann (2007) study reported that their relationships had broken up because of painful sex and the avoidance of sex. Supporting this Hummelshoj et al. (2014) found that the lack of sexual intercourse led to significant psychological distress and contributed to relationship issues such as infidelity, breakups, and divorce. For example, it was reported in two separate studies that 50% and 56% of women confirmed that endometriosis had affected their relationships, with 10% and 8% of cases resulting in a split respectively. Moradi et al. (2014), explained that the reasoning for relationship breakdown was due to the women not having a understanding and supportive partner. Several women in this study suggested that their arguments within their relationships were due to the lack of understanding by their partners and was a major factor to why they broke up. The negative impact endometriosis has on a marital sexual relationships, led some women to become anxious about beginning a new relationship while a few had chosen to remain single. Conversely, Denny and Mann (2007) found that many women described their partners as supportive in their study. Men or partners may not always be aware of their partner's pain during or after sex, as some women might pretend not to experience it. For example, Hämmerli et al. (2018) study found that the number of women who reported painful intercourse was different to their males partners answers regarding pain interfering with sexual intercourse. This behaviour makes it even more difficult for women to discuss the pain they experience openly. It is vital for couples who deal with endometriosis to be able to communicate openly about how to adapt their sexuality to their needs.

Coping strategies

Coping strategies can act as a mediator factor that impacts on pain behaviours. Thus, women's coping strategies for painful intercourse can be a significant contributor to their experience of pain. Folkman et al. (1986) developed a coping strategies model which proposes individuals use two different types of coping strategies to deal with stress: emotion-focused strategies and problem-focused strategies. Emotion-focused coping strategies are where an individual regulates their adverse emotional reactions to the stress instead of addressing the stress. For example, avoidance, withdrawal and suppressing negative emotions about the stress, which negatively impact psychological wellbeing. Alternatively, problem-focused coping strategies are where an individual identifies the cause of the stress and uses problem-solving and social support to reduce the stress resulting in healthier psychological wellbeing. Stress is associated with chronic pain, for example, increased stress can contribute to the incidence and severity of a chronic pain condition (Jensen et al., 1991). Also, the consequences of chronic pain, such as loss of income and marital difficulties, may be viewed as significant stressors. This coping model has been consistent with the chronic pain literature. For example, González-Echevarría et al. (2019) found that younger women with endometriosis who use emotion-focus coping strategies such as social withdrawal and avoidance have a higher risk of developing depressive symptoms and have a lower quality of life compared to those who use problem-focused coping strategies. Supporting this Kraaimaat and Evers (2003) found that people with chronic pain who use emotion-focused strategies were associated with lower quality of health, intensified pain and increase in psychological distress.

The chronic pain literature and research categorise the coping strategies into two dimensions: active and passive (Jensen et al. 1991). The coping strategies for endometriosis can be conceptualised into three categories; (1) active-cognitive where an individual looks at the positive side of their pain, for example, self-statements such as 'I can deal with this pain; (2) active-behaviour where an individual uses problem-solving and social support, for example increasing or decreasing specific activities such as resting, relaxing, mindfulness or using heat or ice before or after having intercourse and; (3) passive strategies where the individual avoids, withdraws or ignores the pain, for example, avoiding all sexual contact and intimacy (Turner et al., 2000). It has been evident that active-cognitive, active- behaviour and problem-focused coping strategies are the most effective strategies in dealing with endometriosis-related pain such as painful intercourse. It is also suggested that coping strategies are individualised depending on the women's situation and the severity of pain. For example, Di Donato et al. (2014) study found that some women used active-behaviour coping strategies such as finding more comfortable sexual positions to reduce the impact of penetration on scarred tissue. Whereas other women continued despite the pain due to their want of becoming pregnant outweighed their experience of pain or because they felt that sexual intimacy was important in their relationship.

Additionally, the fear-avoidance model has shown that catastrophising and anxiety is an essential factor in developing and maintaining pain during or after sex, by impairing sexual arousal. Shafaei (2016) explains that women with endometriosis who fear painful intercourse are more likely to have passive coping strategies and evaluate intercourse as threatening, which then interferes with their information processing senses. Therefore, the woman is concentrating on the threatening stimuli and has less available cognitive resources to concentrate on her sexual arousal. This lack of sexual arousal leads to vaginal dryness and heighten pelvic floor muscles that are associated with painful intercourse. This results in a women's pain intensifying during intercourse due to the increasing tension of pelvic muscles and distraction from concentrating on the threatening stimuli.

Regardless of how women cope with endometriosis and experiences of painful sex, there is still a dearth of research that privileges women's experiences as women living with endometriosis and women living with painful intercourse. Furthermore, there is a lack of research surrounding what it means to be a woman and what coping with painful intercourse means for their identity as women and their sexuality. Until medical professionals start to accept these voices and listen to women and addresses treatment options from a holistic approach, then the dominant discourses of ‘normal painful periods’ will not be challenged. It is the intersection of the impact on life, mental and emotional impact on all areas of their lives, including sex (or lack of sex) that needs exploring.

Intersectionality of sexuality, identity, and femininity

Women’s health is subject to inequalities as it focuses on the female as a reproductive body, a housewife, and often positions women as hysterical and sicker than men. Feminists have challenged the gendered assumptions behind these views (Munro, 2013). However, women with endometriosis still face considerable hurdles to be taken seriously, to get a diagnosis and treatment should take a holistic approach rather than focusing primarily on the biological body (Pluchino et al., 2016). Living with endometriosis impacts on all aspects of women's lives is ignored. While pain during and after sex might be a symptom that doctors take seriously – it only goes as far as exploring biomedical reasons for this, and there is currently a lack of treatment options to help reduce pain with intercourse. Therefore, women with endometriosis are living with painful intercourse during their most sexually active years when they are developing their sexuality. Sexuality is complex and consists of many dimensions, including psychological, socio-economic, biological, and spiritual. Sexuality is who we are as a woman and what matters to us individually (Rao & Nagaraj, 2015). There is limited literature surrounding women living with endometriosis experiences of painful intercourse and the impact this has on their sexuality and femininity. Pain with intercourse is a common experience for women with endometriosis and usually begins with their first sexual encounter, thus during the time of the women's development of their sexuality. The developmental of sexuality is an important time for women to work out what they like, do not like, how to navigate sexual relationships, who they are as a woman, what femininity means to them and their roles as a woman. This is already a difficult period, but with the addition of a chronic illness that causes painful intercourse, this is even more challenging. As covered, the impact of painful intercourse for women is particularly significant regarding sexual function, but research has not covered the impact this has on the women themselves and their sexuality.

Chapter Three

Methodology

My research takes a critical realist ontological and a social constructionist epistemological stance. These philosophical positions explain my understanding of endometriosis - the realist ontological perspective supports the physical features of endometriosis and social constructionist perspective is concerned with how individuals make meaning of these physical features from endometriosis. This chapter will begin by discussing these philosophical positions, the assumptions surrounding critical realists and social constructionism, and the way that social interactions, social processes, language and power matter to experiences in the world. I will then discuss how a feminism theoretical perspective drives my research to capture women's experiences of endometriosis. I will then present some principles of the narrative research approach and argue how this approach is appropriate to explore women's experiences of endometriosis and painful intercourse. I then will discuss the compatibility of structure narrative analysis as a methodology before outlining my analytic procedure. I will also discuss reflexivity and ethical considerations.

Critical realist ontology

I hold a critical realist ontological perspective. Critical realism has the belief that our perceptions do not represent reality, and although they are often volatile and changeable, they do reference the real world in some way. Our perceptions are not independent of the real world, instead they are created exclusively through our symbolic systems such as language (Dean et al., 2005). Critical realists do acknowledge that both worlds exist, an external world independently of human consciousness and a social world that consists of social influenced knowledge about reality. Both of these worlds consist of real objects and structures that have causal powers. These objects and structures can be difficult to see directly but we can see them through the effects they may cause and as such, they are responsible for the things we experience, for example, pleasure and pain (Burr, 2015). The critical realism position has been described as a 'top-down' view, which means that we see reality producing our knowledge and descriptions of the world (Gorski, 2013).

Social constructionist epistemology

Social constructionism challenges how knowledge is gained in mainstream psychology. It critiques the notion that knowledge is gained and derived from generating and testing of hypotheses and observation (Burr, 2015). Instead, it proposes that society constructs knowledge through the description, explanation, and language within its world rather than creating it. Hence, social constructionism focuses on the social processes, interactions and how people understand life events, and how they describe and explain the world they live in. Social constructionists deny that a person's knowledge is a direct perception of reality but rather as a culture and society we construct our versions of reality from social processes, interactions and between us (Burr, 2015). Social constructionism allows us to challenge and critique our views on the world, by considering other perceptions and not attempting to shape truths about objective reality (Andrews, 2012). Constructionists understand the world by the social artefact and social constructs made through social interchange rather than through the forces of nature. However, these functional relationships can differ from one culture to another, as well as change throughout history. Perspectives of people are established by social processes, which can also change through social interchange allowing the interpretation, increased attention and abandonment of these social artefacts and views as social relationships evolve (Andrews, 2012). These understanding of social artefacts are facilitated by language; therefore, language is a key factor in shaping reality.

Using my critical realism and social constructionism perspectives, I will explain my understanding of endometriosis. Endometriosis is a physical disease that can be observed; for example, during laparoscopic surgery the surgeon can see the endometrial-like tissue growing on organs outside the women’s uterus. Endometriosis occurs independently of whether people observe it or not; thus, it is ontologically objective. Endometriosis is also a term that describes bodily disturbances that are frequently experienced by women with endometrial-like tissue growing on their organs outside the uterus. Thus, it is a social constructionism perspective as the physical symptoms of endometriosis are socially agreed upon by a group of people. People construct these bodily disturbances and symptoms through language, in which shared meanings and understandings are developed of the set of symptoms. Endometriosis as a physical condition is objective, but the meaning attached to endometriosis is socially constructed and thus subjective. Therefore, endometriosis is socially understood as a set of symptoms or bodily disturbances, such as chronic pelvic pain during a woman's monthly cycle or painful sexual intercourse, that exists with endometrial cells growing outside a woman's uterus. Endometriosis would not live without its physical features, but the objective features can occur without subjective elements. Although I have a social constructionist view, I acknowledge that reality does exist independently to whether I see it or not.

Feminism theoretical perspective

To capture endometriosis and the gendered nature of this disease, this research is driven by a feminist framework. Feminism research prioritise women's experiences, and these experiences are objective to an investigation. It attempts to view the world from a women's point of view and the researcher holds an activist position in efforts to improve women's lives (Seibold, 2000). A critical element to the feminist framework is the view that the patriarchy is a fundamental principle to how society is organised. Feminist researchers challenge the views and opinions on women to transform the socially constructed and hierarchical ideological of patriarchy (Kiguwa, 2019). Gender is an organising principle which holds limitations such as limiting what people can and want to be in different contexts. Women with endometriosis face these views and constraints frequently. As a result, these women experience diagnostic delay, (Ballard et al., 2006) normalisation of period pain by medical professionals (Staal et al., 2016), the medicalisation of period pain and sexual intercourse (Shohat, 1992) and historically the suppression of female sexuality (Baumeister & Twenge, 2002). The normalisation and medicalisation of period pain and painful intercourse are derived from patriarchy views and power to suppress female sexuality. I will be prioritising women living with endometriosis experiences and giving these women voices to uncover how these women navigate endometriosis, chronic pelvic pain, sexual intercourse, and the consequences this pain has on them as women. These women are the experts in their own lives, and it is my role as the researcher to advocate for these women by interpreting and telling their stories in the most accurate way possible (Seibold, 2000).

Retelling these stories is an effective way of inviting heteronormative society to look at what practices and cultures are being taken for granted (Hesse-Biber, 2006).

Narrative research approach

Narrative research derives from the combination of theoretical and practical processes from several academic traditions (Smith, 2016). Narrative research first emerged from several contemporary movements; the first movement was found in the humanist tradition within western sociology and psychology. This tradition consisted of a person-centred approach where storytellers and listeners are treated as unified and singular. Humanist researchers predominant focus was on case studies, biographies, and personal accounts. Secondly, a narrative emerged in association with postmodern ontology which emphasised how several subjects played a role in the construction of narratives. However, these researchers were more concerned with the meanings behind the stories and how social conditions and power relations shaped a person's narrative (Smith, 2016). These contemporary movements were called the 'narrative turn' as human sciences moved away from the positivist modes of inquiry and towards a narrative theory (Davis, 2002). This led to a cross-disciplinary movement where narrative analysis is now considered a fundamental concept of social and psychological processes that are located across many disciplines. This is due to its ability to be able to account for the structure, context of stories and cultural context in which stories are told (Avdi, & Georgaca, 2007).

Narrative research explores the role of storytelling by people to understand social life and identity in various ways (Stephens & Breheny, 2013). It recognises that the stories told by people are significant and are worth investigating closely. Narrative embraces people's stories and can reveal actual events and experiences people have endured and how these people may reflect and strengthen social identities. This is because people make sense of their personal experiences through telling stories, and thus peoples narrative accounts give meaning to these experiences. Narratives are not independent and do not express an individual's reality. Instead, they aid in constructing the reality within relationships between the storyteller and their external world (Esin, 2011). Narratives are created from social interactions between people, and through the repetition of stories, these storylines become internalised. The more frequent we are exposed and subjected to stories, the more we engage in them, and they become integrated into our normality. In our relationships and social interactions, we engage in these storylines to make meaning about our unique experiences. Thus, storytelling is powerful in helping us make our experiences coherent and meaningful. However, they were not definitive as past and lived experiences also contribute to our interpretations of experiences.

A feminist framework drives this research; yet, there is no definitive method for feminist research. Particular features illustrate research processes as feminist. Feminist methodologies consist of more reciprocal and interpersonal relationships between the researcher and the individual who lives, and experience constitutes the focuses of the research (DeAnne & Jeanne, 2004). Additionally, feminist methodologies are more concern with validity rather than objectivity. Also reliability because feminist researchers work towards the common goal of freeing women from oppression (Kiguwa, 2019). These features exist within the narrative research approach and give value for feminist research by critically engaging in women's lived experiences.

The rationale of narrative analysis

The rationale to why I chose narrative analysis for this research is that stories are a useful resource for communicating a person's experience, the emotions they felt and meanings that they attach within relationships and culture to events, behaviours, actions, and embodiment. Specifically, the narrative analysis focuses on one specific genre of discourse, which recognises people’s narratives as a way of understanding, exploring, and making sense of their realities over a period (Esin, 2011). In contrast, other qualitative research methods are more concerned with all genres of talk and text. Compared to other qualitative methods, narrative analysis is cautious of over-coding the data set. Over-coding occurs when there are a variety of codes that have been assigned to break down the story into smaller stories and chunks to allow the analysis to be more manageable (Smith, 2016). Narrative analysis is aware of this over-coding and aims to keep peoples stories intact to preserve and examine in-depth and detailed stories. This type of analysis can provide a rich understanding of women's experiences and emotions. I am not claiming that the women's stories are precisely transparent or mimic their personal experience, emotion and meaning. Instead, I recognise that the women's stories are available within social relations and culture shape what becomes the women's experience, emotion and meaning. Therefore, a narrative analysis will allow me to capture the women's diverse and unique experience by focusing on how, why and what they felt during their experience enabling me to make meaning of the women's narratives.

Structural narrative analysis

My data analysis has been informed by the structural narrative approach, which was developed by Labov and Waletzky (1997). This approach focuses on the formation of the narrative and how different elements in the structure-function in the personal experience narratives. This can include an examination of the linguistic phenomena used, the story's overall sequential composition, and the resources used to organise and structure the stories. Structural narrative approach was built on the assumption that people's stories of experience comprise of narrative clauses. The narrative clauses are believed to have a start, middle and an end and additional structures can be found in more fully developed narrative clauses. Thus, a six-part model was developed by Labov to analysis the structure of narratives: abstract (A) is the summary or point of the story, orientation (O) setting in which the events are told including time, place, characters and the situation, complicating action (CA) this is the event sequence or turning point of the story, result (R) is the outcome of the plot, Evaluation (E) is the narrators perspective on the events in which the narrator may comment on the meaning and communicates the emotion of the narrative and, Coda (C) is the ending of the story where the narrator links the account to the present. Not every person's story includes every element, and each component can occur in various sequences.

Procedure

The procedure consisted of two interviews and the creation of a timeline. I recruited the participants from social media advertisements, which consisted of a recruitment poster that was posted on the Endometriosis Association New Zealand Facebook page with the permission of the Facebook group administrators. The advertisements (Appendix A) invited women living with endometriosis who have experienced or currently experiencing painful sexual intercourse to contact me if they were interested in taking part in the study. The participants that were interested in participating in the study contacted me via email. I replied to the participants with a set of questions regarding the inclusion criteria to see if the participants were suitable. I emailed the 10 participants that fit within the inclusion criteria and were able to participate in an information pack. The information pack included an information sheet (Appendix B) on the research, consent form (Appendix C) confidentiality agreement (Appendix D) and transcript release form (Appendix E).

Inclusion criteria included the following:

- Participants must be over the age of 18 years of age.
- Participants must have an official diagnosis of endometriosis by a gynaecologist from laparoscopy surgery. Justification for this is laparoscopy is the only way to receive an official diagnosis of endometriosis.
- Participants must have an official diagnosis of endometriosis for at least one year. Justification is that enough time must have passed for women to have healed from laparoscopy surgery, so symptoms are not mistaken from post-surgery recovery pain.
- Participants can have any stage of endometriosis (stage 1- 4). Justification is that the stage is not associated with the severity of symptoms of the severity of the disease.
- Participants must currently be experiencing or have experienced painful sexual intercourse because of endometriosis.
- Participants must reside in New Zealand.
- Participants of any ethnicity are invited to participate; however, I conducted the interviews in English.

Upon receiving the signed consent form, I contacted the participants via a phone call to introduce myself, discuss the research aims, and allow the participants to ask questions about the study. During this phone call, I arranged a time and place that was mutually agreed upon to hold an interview, and I scheduled two interviews. The reasoning for two interviews was to build rapport due to the sensitive nature of the topic and to allow the women to tell me their endometriosis story and their painful intercourse story. The first interview focused on the women's journey's to diagnosis and getting background on painful menstruation and I focused the second interview on the more sensitive topic of painful intercourse. Once the initial contact period was over, the participants underwent the first interview. A summary table of the participants can be found at the beginning of the finding's sections. Due to the current global circumstances of the widespread of COVID-19, I had conducted an alternative plan to face-to-face interviews in case New Zealand or Auckland went back into lockdown. I told the participants that in the case that New Zealand did go back into lockdown, which meant we could not go ahead with face-to-face interviews, then I would have conducted the interviews over zoom. I made sure all the women had access to a laptop, computer, or mobile phone where they could download the zoom app, and I could carry out the interviews as planned via zoom. For the timeline process, I would have written out the timeline while the women spoke about their experiences via zoom. We were fortunate that we did not have to result in this alternative, and I conducted the interviews face-to-face.

At the arranged time, I visited the women in the setting of their choice for their first interview. I focused the first interview on the women's journey of endometriosis, as I deemed it was essential to allow the women to tell their story of gaining a diagnosis of endometriosis and their experiences. These questions were just a guideline (Appendix G) as, during the timeline process, the participants naturally answered these questions when they were discussing and plotting their timelines. I started the interview with collecting the participants demographics, personal information and explaining the interview process of making a timeline of the women's journey together (Appendix F). With the participants, permission, I tape-recorded all interviews, and I was the only one that could view the participant's information and was stored in a secure location. Each participant, with my help, created a visual timeline on a plain A3 sheet of paper. The participants plotted their age horizontally in the middle of the page, from the earliest age of symptoms of endometriosis experienced to their current age. This axis provided the participants an area to begin to frame a visual and descriptive representation of their journey of endometriosis and experiences of painful intercourse. The timeline allowed a way for the participants to construct their talk. The women were encouraged to focus on times when endometriosis was of concern, leaving the time frame of the timeline up to the women. The timelines ranged from age 12 to 36 years and included the women's journey to get a diagnosis, life events, surgery, symptoms, pregnancies and earliest memories of period pain and painful intercourse.

I constructed the timelines collectively with the participants. I showed the participants an example of the timeline of my endometriosis journey. As well as my experiences with painful intercourse to give the participants an idea of what I was looking for. Initially with the first interview, I wrote on the timelines; however, what I wrote was discussed and decided by the participants. Each of the data points (e.g., age) the participants discussed endometriosis and painful intercourse with me which then I plotted the information on the timeline. When each data point was plotted, this allowed the participants to talk about their journey and experiences of endometriosis and painful intercourse at a particular age. This did mean that plotting and discussions would jump backwards and forwards on the timeline. While this process seemed chaotic, it was controlled by the participant's storytelling as the data points progressed. The timeline, therefore, alleviated the need for an interview schedule of questions. The value of the timelines process was that it allowed the participants and I the opportunity to get to know each other and develop rapport and a connection. As I have endometriosis, I shared and exchanged stories with the participants creating an opportunity for further in-depth discussion (Bravington & King, 2019). Additionally, the physicality of creating a timeline together forced us to sit close together as we plotted on the timeline (Bridger, 2013). Thus, the timeline became a bridge between two strangers.

After the first interview and plotting the participant's journey of endometriosis the timelines were taken home by the participants which allowed them to change or add any extra details that they felt that they missed or forgot to put onto their timelines. Sheridan et al. (2011), recommended in their research for the participants to leave the timeline in a prominent place at home, for example, their dining room table. Therefore, I also asked the participants to leave their timelines in an area at home that was visual and suitable for them as this allowed the timeline to become the focus of further commenting and questioning. This allowed the participants to become the researchers of their own lives.

One week after the first interview, the second interview was conducted. I prepared some questions to take with me (Appendix H). During the second interview, we went over the participant's timelines to see if they had made any changes or added any extra detail to them. Once the discussion of any alterations the participants had made to their timelines, I discussed the intention of the second interview, which was taking a closer look at the participant's experiences of painful sexual intercourse that were discussed in the first interview. The first data point on the original participant timelines that mentioned their first experience of painful intercourse became the starting point of the second interview. I asked the participants about their first experience of painful sexual intercourse, which led on to open-ended questions from the interview schedule (Appendix E). There was a range of questions that gathered a more in-depth look into the participants experiences of painful intercourse and the impact this has had on their sense of femininity and sexuality. The questions were open-ended to allow the participants to share as much detail as they wanted about their experiences and how these experiences have affected them. The interview schedule was more of a guide as it became very conversation based. Throughout the interview, I ask questions such as "how did this experience make you feel?" or "how did that experience affect you?". Such questions encouraged further storytelling by the participants. The interview schedule allowed me to make sure that I had covered every aspect of the participant's experiences.

On completion of the second interview, I gave each participant an essential oil blend to be used on their abdominal area to alleviate endometriosis pain to say thank you for their time and participation. I then took the timelines for analysis. Once I collected the data, I listened to the recordings of the interviews and fully transcribed word for word, including as much punctuation to make the text make sense. I then returned the transcripts to the participants to change, edit and comment where they felt were appropriate. The participants did not change or add anything to their transcripts. The participants all gave positive feedback regarding the interviews. The timelines feedback was very positive as the women were able to see their journeys of endometriosis and how far they have come. The participants also found it rewarding reading their transcripts and were very glad they were a part of a study that will help women like themselves. The participants also mentioned that the interviews, timeline and reading the transcripts were therapeutic. This gave me a sense of joy receiving such positive feedback, and I felt honoured that I got the opportunity to sit down and listen to these women's stories and build connections with them.

Reflexivity

As I am taking a feminist and qualitative approach to this research; thus, I must take a reflexive position to recognise and interrogate my role within the study. Reflexivity is practicing self-awareness throughout the research process, which helps make the practice and construction of knowledge visible within the research to produce accurate analyses of the research (Kiguwa, 2019). Reflexivity requires me to be critical and aware of how my own identity, opinions, and interests and how these could affect different stages in my research. By questioning my interpretations and knowledge allows me to produce better and less distorted research accounts (Pillow, 2003).

My role as the researcher and stance on this research is that I am an insider (Wigginton & Setchell, 2016). I have been diagnosed with endometriosis, and I know the impact this disease has on my relationships, social life, work-life, family, and mental health. I had a diagnostic delay of 7 years, with many of those years misdiagnosed with Polycystic Ovary Syndrome and Irritable Bowel Syndrome. I have suffered from severe pain during my periods since a young age, but due to the stigma around women and period pain, I thought it was normal. It was not until I told my doctor about my experience of painful intercourse that the doctor suggested any investigation of endometriosis. After receiving an official diagnosis, I started to realise how common endometriosis was. Majority of the women I began to speak to knew somebody who had endometriosis or had it themselves. The more people I talked to, I started to realise that many women like myself go through many years without a diagnosis and that this disease can be intensely deliberating. Not only do women have to manage the severe pain that comes with this disease, but the impact it has on women's mental health and overall wellbeing is horrendous. I also understand the embarrassment and guilt that comes from experiencing painful intercourse. With how many women that have endometriosis in New Zealand, I knew that I was not alone with experiencing painful intercourse. Therefore, I wanted to shine a light on this unspoken symptom of endometriosis.

Throughout my endometriosis journey I have learnt how to manage my pain. I have an excellent support system that has helped me cope with this disease and can happily say that I now experience minimal discomfort. As an insider, I can emphasise with other women who struggle with endometriosis-related pain, especially painful intercourse (Wigginton & Setchell, 2016). From my own experience of endometriosis, I believe that I have gained a lot of strength, knowledge and understanding of endometriosis and painful intercourse. I acknowledge this disease is significantly individualised, and everyone copes differently. Still, as I have the condition myself, it creates a bridge between the women participating in my research and myself. I strive to address the issues of injustice for women living with endometriosis, bring about the discussion of painful intercourse and give the women voices so their stories can be heard. I am very passionate and motivated to address this topic as I have seen first-hand what many women go through living with an invisible illness.

Insider status comes with both positive and negative aspects (Lumsden et al., 2019). The positive aspects are that my own journey of endometriosis allows me to bring a level of knowledge and understanding of the impacts painful intercourse can have on a woman and her relationship. This knowledge and understanding also allows me to be empathic towards the women participating in the research. However, I do acknowledge that being an insider does have negative aspects, and I need to be aware of my own biases, particularly during the interview and analytic processes. For example, talking to a woman about her experiences with painful intercourse I could assume that her experience was like mine and that she felt less of a woman for not being able to have intercourse without it hurting. I could seek confirmatory statements to support this idea. I was aware of this potential bias and thus, listened to each woman's story well, keeping in mind that other people construct and perceive their experiences differently to myself and may not share the same responses to myself.

Ethics

I made a full ethics application through Massey Northern committee due to the sensitive nature of my topic and the potential for distress, and the ethics committee approved the application. Ref number NOR 20/18. The specific areas that were covered by the full ethics application were related to obtaining informed consent, recruitment, the potential harm to participants, and cultural competency.

I recruited the participants through the Endometriosis Association New Zealand Facebook page with permission from the admins of the page. The Endometriosis

Association admin was able to assist with my recruitment by allowing me to post on the Facebook page my recruitment poster. I also posted the recruitment poster on my personal Facebook page, which got shared by my friends to their Facebook pages. Once the participants had reached out to me, and I had the final participants, I sent them an information pack, including an information sheet, informed consent form, transcript realise form. I discussed with each participant the recruitments of the research and got each participant to sign the documents.

One ethical issue that was of concern was the potential for the participants to experience discomfort or embarrassment. This was because they were reporting on personal experiences relating to sex and endometriosis, which may be distressing or challenging to discuss. To alleviate any discomfort or embarrassment to the participants, I gave all the participants a list of support services, including an endometriosis helpline to contact if they felt distressed during the interview process. I allowed them to skip any questions that they did not want to answer due to being too personal or too distressing to answer. I have the disease myself and disclosed with the participants; therefore, this created a bridge between the women participating in my research and myself. I was able to empathise with the women and understand their journeys with endometriosis which built rapport between myself and the participants. This was highlighted during the interviews when the women would refer to me going through the same experience as them, commenting things such as 'you know what I mean', 'you know the feeling' and 'omg yes'. Also, because the interviews were on sex which can be embarrassing to talk about, I made sure I discussed my own experience with painful sex, so the women did not feel embarrassed or shy to talk about sex. By sharing my experience, the women were then opened to sharing their stories and resulted in numerous laughs during the interviews. Also, another benefit of this research was that the interview process was deemed as therapeutic by the participants. This was because the participants said the interviews allowed them to discuss their feelings, emotions, and experiences to a person outside their usual routine. Additionally, to alleviate distress for me as a researcher and as a woman who has endometriosis, I made sure I took some time after each interview to process what I had heard and not to let it affect myself mentally or emotionally. I had a support system put in place in case I needed additional support. During the interviews, I had no feelings of distress; it was more feelings of joy and honour for being able to share these women stories and to conduct research for the endometriosis community.

Another ethical issue that was considered was cultural competency. It is not known in New Zealand the number of Māori and Pasifika women with endometriosis, but there was a potential to have women of different cultures participate. I needed to consider the Tiriti o Waitangi principles in my research to promote equality and partnership. Thus all Māori women had the right to be invited to participate, I respected all Māori women's cultures, and any cultural traditions upheld. All the women in the research were anonymous, and I stored all identifiable information securely. I had a cultural consultation with the cultural liaison at Massey University, where we had an in-depth discussion and made a plan of approach to the interviews with different cultural groups, particularly Māori in adherence with the Tiriti o Waitangi. This included showing respect to the participants by taking my shoes off, bringing kai to share, introducing myself with a pepeha and asking the participant if they would like to open with a karakia. I had two women in my study who identified as Māori; therefore, I made sure to contact both of these participants to see if there were any cultural traditions they would like me to adhere throughout the interview process. They both responded that I did not need to do this. I held the interviews at my own home, and I made sure to offer the participants a beverage and some biscuits before the interviews. Additionally, I also had women from other cultural groups. I contacted them before the interviews to ask if there were any cultural traditions they would like me to uphold. They also responded that I did not need to do this. All the women were appreciative that I acknowledged their culture and adhered to the Tiriti o Waitangi.

Analytical process

The narrative analysis does not have an exact, concise way of analysing the data; therefore, I used parts of the structural narrative analysis methodology as well as formulating my own form of analysis to interpret and present my data. During the interviews with the participants, I began my process of analysis as I was already developing ideas and finding similarities and differences among them. On completion of all the interviews, I relistened to the interviews numerous times and transcribed them onto a word document. I transcribed each participants transcript, and then I relistened to the participants first interview with each participants timeline in front of me. Familiarising myself with the data allowed me to explore and paint a picture of the woman's past, present and future self. The timeline gave me a chance to reflect and think about each woman's journey of endometriosis and the experiences they had endured. The timeline added richness to my data and gave me another type of story than if I did not use them (Ledesma et al., 2019). Building a narrative analysis required me to pay attention to the transcript as a set. I particularly paid attention to the similarities and the differences in the woman's stories and timelines. I focused on whether the participants told similar stories or used similar narratives about endometriosis and painful intercourse as well as, on a microlevel, what were they doing to help me understand their experiences. While I was relistening to the first interviews, I was making notes on the transcripts of ideas, similarities, differences, and narrative points that came to mind. I also began using the Labov and Waletzky (1997) structural narrative analysis method to explore the different elements in the women's experience narratives. This included the use of the overall story composition and how the women structured and organised their stories. Thus, I used the six-part model to distinguish the abstract, orientation, complicating action, result, evolution, and coda from the women's narratives. Each woman presented with a different structure, and not all of them included every element of the six-part model. However, there were similarities among the women's overall narratives.

I managed to write a narrative summary from each woman's account after using structural narrative analysis. These summaries included the women's journey with endometriosis and painful intercourse from beginning to the present day. Each story had no endpoint as endometriosis is unpredictable and a lifetime diagnosis. From this, I developed a basic understanding of each woman's story and journey. These stories were descriptive, but they required explanation and interpretation from me. The summaries are not presented in the final analysis (Appendix I) but, these stories were a fundamental part of the analytical process. This was because by creating the timelines together, I was able to develop a rapport with the participants and make a connection.

Once I had familiarised myself with the first interviews, I then began relistening to the second interviews and reading the transcripts. Again, I paid attention to the similarities and differences in the woman's stories. I focused on the use of the same or different narratives and how the women explained their journeys to me. Throughout this process, I had my research objectives written on a piece of paper. After every transcript, I referred to the research objectives and focused on what the women were trying to tell me about these objectives. This was useful as the interviews were an in-depth and immense amount of detail surrounding their journeys, relationships, work, emotional wellbeing, physical and mental wellbeing. Therefore, referring to my topics of painful intercourse, femininity, and sexuality made sure I was focusing on the women's narratives around these topics. As I read through the second interviews, I made notes on the transcripts of ideas, similarities, differences, and possible narrative points that came to mind. I colour coded my notes for particular narrative points. For example, I used the colour pink when the women discussed their sexuality; I used the colour blue for when the women discussed their emotions, and I used green for when the women spoke about painful intercourse. Therefore, when I was rereading the transcripts, I would be able to pick out individual narratives, e.g., painful intercourse that the participants discussed.

Once I had colour coded all my notes, I then began transferring all the similar colours from all the transcripts onto a word document. For example, I had the colour green in one section which related to the women's narratives about painful intercourse. This made it clear for me to see what all the different narratives about a similar topic, and thus I could reflect on these narratives. This also allowed me to analysis the narratives as a set and understood what the women were trying to convey to me individually and as a group. Once I completed this with all my notes on specific word documents, I again went back and forth between the transcripts, recordings and my notes beginning to make sense of what the women were trying to convey to me and the meaning behind the narratives. While going through this process, it came apparent to me that there were different stages of the women's endometriosis and painful intercourse stories. For example, stage was around the narrative of pain, including the experience of pain, normalisation of pain and then the turning point to which was the point in time women realised that something was wrong with them. This then led to stage two, which was around the narrative, who am I as a woman with endometriosis? This included avoidance of intercourse and the impact painful intercourse had on the women's sexual function, sexual relationships, and femininity. Then stage three was the impact painful intercourse had on them as a woman and their sexuality and what does this all mean. As the narrative points started to become more visible, I began to gather the quotes from my word documents and put them under the headings of stage one, stage two, and stage three.

Once all the quotes were under the headings, I began going further into the narratives by questioning the perception the women had of themselves and how their social context influenced it. The influence their past and present experiences have had on their interpretation of themselves and their experiences. Analysis narratives at the micro-level required explanation and interpretation from myself on what I believed the women were trying to tell me. From constant data familiarisation and rereading the quotes, I started to form narrative points under each stage. During the process of developing narrative points, it came apparent the complexity of sexuality and women's femininity. It took some time and numerous discussions with my supervisor to understand the real impact the experience of painful intercourse had on the women. Thus, I realised that the women were not going through stages as they could easily flow in and out of stage 2 and stage 3. Therefore, this resulted in the three headings something isn't right, who am I as a woman living with endometriosis and painful intercourse? and what does this mean for their sexuality and them as a woman? This made it clear and easy to follow the different dimensions of sexuality that have been impacted by the experience of painful intercourse and endometriosis. The next chapter four will be on the findings of this research and will go into detail on the narrative points found. It will also link the findings with previous research that has been conducted.

Chapter Four

Findings

This chapter will outline the main findings of the study. The focus of this study was on painful intercourse and the impact this has for these women so the different sections will focus on this aspect of living with endometriosis. The women in the study discussed their journeys with endometriosis and painful intercourse in great depth. In the process of analysing both interviews and completing the timeline with the participants, it became clear that the journey the women faced had similar pivotal points within their narratives. These narrative points are arranged in three sections starting with 'something isn't right' which explores puberty, menstruation, experiences of pain with the realisation that what they were going through was not normal leading to a turning point to the diagnosis. This is followed by 'who am I as a woman living with endometriosis and painful intercourse?' This explores the impact painful intercourse had on the women's sexuality including sexual function, sexual relationships, sense of femininity and feminine roles. The last section is titled 'what does this mean for their sexuality and them as a woman?' Here, I reflect on how the women make sense of their sexuality in the past, present and future.

Ten women participated in the current study and provided written consent to participate. The participants were between the ages of 21 to 35 and all had been diagnosed with endometriosis for over one year. A summary of the participants demographics and characteristics are presented in Table 1.

Table 1

Demographics of Participants

Participants	Age	Ethnicity	Age of Official Diagnosis	Age of first symptom onset	Diagnostic Delay (Years)	Age of first experience of painful sex
Bayley	30	Māori/ European/ Niuean	27	16	+ 11	16
Izzy	35	Pakeha	34	15	+ 19	17
Ash	24	NZ European	21	15	+ 6	17
Kristina	26	Pakeha	24	15	+ 9	18
Jade	26	NZ European	21	16	+ 5	17
Rose	21	Māori/Pakeha	20	16	+ 4	17
Regina	21	Pakeha	20	17	+ 3	20
Becca	22	Fijian	21	16	+ 5	20
Meredith	26	Persian	17	12	+ 5	16
Louise	23	European	21	17	+ 4	18
Average	25.4		22.6	15.5	7.1	17.6

Something Isn't Right?

The normalisation of pain caused all women to suffer in silence for many years. This meant that the women were suffering with painful menstruation and intercourse during their most sexually active years with no treatment or help. This had a significant impact on the development of their sexuality. There was a turning point for all women when they realised what they were going through was not normal and they sought medical help which led to their journey of receiving a diagnosis of endometriosis. This section of the findings will focus in on the narratives of the women prior to diagnosis. I will discuss the women's experiences with pain, both with periods and during sexual intercourse, and the turning point to which they worked out that something isn't right. This point was often only the start of the diagnostic process. The reason for including this analysis is because pain is a dominant factor for women living with endometriosis. I could not discuss their journeys without discussing how the experience of pain and normalisation of pain had impacted the women's sexuality.

Pain

The women in my study presented with individual differences between the ages of their first period, and the timeframe when their pain became unbearable. Nine of the women in the study presented with either irregular periods (light, heavy), discomfort and/or pain with their first menstruation, while one woman had a regular and relatively pain-free period initially. The women in this study described their pain in very emotive terms but the pain was framed as the result of a physical problem but led to physical and mental distress, impacting on all aspects of their lives. What is notable is that the women in this study learned very early on that their periods are associated with pain and that severe pain was normalised. At times the pain was so severe that they passed out, vomited, experienced hot and cold sweats, were unable to attend school, stopped participating in activities e.g., ballet, swimming, walking, and their bodies went numb and into shock. The impact of this pain is shown in the excerpts from Izzy, and Kristina.

> *"I got my period when I was 12. Because I was so young, it was pretty normal, but I know by the time I was 15 or 16 I was missing days off school and heating up a hot water bottle to be so hot to put straight on the skin of my stomach. So yeah, the pain of the heat overtook the cramps, and I would like scream into a pillow." (Izzy)*
>
> *"I'd have days off school where I just I couldn't, I couldn't do it. You're shredding and it hurts you." (Kristina)*

Louise and Ash discussed that the pain was so agonising that it stopped them participating in sporting activities that they once loved to do. Louise's pain got so severe that she had to get a lift pass at school. She now has a disability card as an adult and still finds it difficult to walk far. This shows how debilitating this disease can be.

> *"I used to be so sporty like through school. I did water polo, netball, swimming, cross country like everything. I think it was honestly around like the time of my miscarriage I couldn't do it anymore. And now it's like the thought of doing that kind of intense activity again makes my stomach hurt because I can't do it. I miss it and I think like a part of me is missing." (Ash)*
>
> *"I used to walk everywhere, I had to stop that. I had to get a lift pass at school because I couldn't walk up the stairs." (Louise)*

Getting your first period can symbolise a transition to womanhood and be a time to celebrate a new time in a woman's life (Brantelid et al., 2014). But for these women it meant time off school, giving up activities they loved, and dealing with chronic pain. These narratives illustrate the dominance of pain for the participants when living with endometriosis. Often the solution was to use a biomedical model of pelvic pain and give very young girls contraceptive pills, but the side effects were often worse than the pain.

> *“I stopped the pill and I got really sick. I started vomiting, I'd get really hot and cold flushes and hot sweats. I’d end up waking up at 3am in the night like and I would end up with a couple of days off school because I couldn't function. I don't know if you get like hot and cold sweats but you get really clammy and faint and you just want to lay on the tiles. So, my parents saw that and were like oh actually she is quite bad.” (Jade)*

These experiences of menstrual pain were compounded with the women’s first sexual encounter. All the women expressed that they had experienced painful intercourse with eight of them still currently experiencing painful intercourse. The women’s descriptions on what sexual intercourse felt like for them is shown in the following excerpts.

> *“But sometimes they have gone in and I felt like my guts were going to come out of my mouth. It's just been so painful for me, and they're like gone in and come out and I have crawled along the bed away from them and was like don't try that again (laughs). It's actually makes my stomach sore thinking about it.” (Ash)*
>
> *“When I was 16 it had felt like someone had grab a sledgehammer and smacked it against my uterus. It was complete agony. He had to pull out and I could hardly move.” (Bayley)*
>
> *“Yea it feels like an uppercut to the uterus. If it hits the wrong spot it is tears before you even realize that it actually hurts, but the, the uppercut kind of feeling of it just being like, almost like a bruised feeling.” (Kristina)*
>
> *“I'll have sex and then maybe like 20 minutes later it starts to feels like contractions (laughs). It's like it's crampy and it's sometimes stabby like little needles like sharp pain.” (Regina)*

“It wasn't a stinging pain, I would say it is kind of sharp. But really, kind of deep and like, almost like dule. To the point where I would have to like go to the couch and crouch over and be hyperventilating for a good half an hour because of the pain. Like an uppercut to the uterus like that is basically what it is like the whole.” (Rose)

These narratives are extremely alarming as many of the women in the study have been suffering with this pain for many years and prior to diagnosis many of them thought pelvic pain during menstruation and sex was normal. The normalisation of pain will be discussed further in the next section. The vivid descriptions and metaphors of violence such as uppercut or sledgehammer show how strongly the women want to convey their pain experiences. Metaphors are used by people who experience illness as they are unable to communicate their experience through description alone (Shinebourne & Smith, 2010). These metaphors allow the women to articulate emotions that they have been unable to express and thus creates meaningful representations of their experiences. Huntington and Gilmour (2005) found that pain is the most discussed subject and is the biggest concern for women living with endometriosis and that was also the case for the women in this study.

Normalisation of pelvic pain

“And it would be kind of the heaviest day and it was just put down to, you know being a woman.” (Kristina)

All 10 of the women believed it was normal to experience pain with menstruation and the first time they had sexual intercourse. All 10 women throughout their lives were repeatedly told by medical professionals, parents, and society that pain with menstruation is just a normal part of being a woman and thus, believed them. These attitudes lead the women to self-doubt and diagnostic delays.

Ghai et al. (2020) and Ballard et al. (2006) have illustrated the dominant discourse surrounding periods link pelvic pain and periods. However this research has shown that family groups and other women contribute to misinformation. For example, the following three excerpts show that the women's parents thought they were exaggerating when they said they were experiencing pain with menstruation.

> *"So, first period 13, and I don't think I've ever had a period that isn't painful, and they used to floor me and then my dad would say get off the floor stop being stupid (laughs). I think also for your mum to turn around and go periods are meant to be a bit painful but you're probably just being a drama queen like, I got that a lot as a kid." (Kristina)*
>
> *"So, the whole like bad period thing was never anything that my mum ever took to be anything of importance, so I never spoke to a doctor about it until I was 22." (Izzy)*
>
> *"No no because I was just kind of under the impression that having a period is a painful experience. I don't know whether I just got that from, like, my mum or just friends or media. It's just you know, painful. I was like, I don't want to make like a big deal out of this. If this is just what it's supposed to be like." (Regina)*

The importance of family in how women learn about menstruation is clear in this study. Also, this research illustrated the problems with communicating pain experiences to others. Two women in the study had a family history of endometriosis and had been exposed to painful menstruation throughout their childhood which further normalised the idea that menstruation is associated with pain rather than leading the women to get help faster. Rose's aunty has both endometriosis and adenomyosis and her mother has suspected endometriosis. Rose says, *"The family has been quite open about talking about it."* Female family members help the understanding that pain is not normal however Rose still had a diagnostic delay. A family history was not helpful for Meredith either as she was grouped into a familial group. Meredith mother and sister both experienced pain with periods and intercourse due to endometriosis. Her doctor told her she was like her mother and sister, so the pain was normal for their family. Therefore, when Meredith experienced pain with intercourse she believed that this was what her family must deal with. Meredith's mother also did not discuss sex with her beyond saying she did not enjoy sex. Meredith's mother and family are Persian so cultural aspects may have influenced the expectations or what is appropriate to discuss in the home. Even though Meredith and Rose both had family history of endometriosis they both still experienced diagnostic delay for five and four years. Contrasting to other research this research has shown a family history of endometriosis does not cause the women to seek medical attention sooner or receive a diagnosis sooner but seemingly further normalises pelvic pain for women.

All 10 women believed that experiencing pain with intercourse was normal and did not seek medical advice after their first painful sexual experience. The following excerpts from three women demonstrate the process of realising painful intercourse was not normal.

> *"I guess it's like more when sex started to be more painful. I think more 17 when I had my first long term proper relationship where I was having sex all the time kind of thing. Because it's more than just like a random pick up. But I spent my*

> *whole life thinking that was normal and like the whole just like to suck it up." (Izzy)*

> *"I think initially. Like when I was first was with my first boyfriend, I lost my virginity. I thought it was normal, because like I never had sex before I was like, why would I be abnormal this must be normal." (Ash)*

> *"I started noticing painful sex and I was kind of like is this normal or is this not normal, it wasn't all the time, it was just sometimes really uncomfortable. Then it started that I would have sex and would start bleeding. I started to have like really bad bleeding, and it was so embarrassing, I felt so embarrassed." (Jade)*

All the women discussed the lack of education about sex and how this contributed to diagnostic delays of endometriosis and their acceptance of pain as a part of their life. Kristina explained that if she was educated about painful intercourse, then she would have realised that the pain she was experiencing was not normal and would have sought medical advice sooner.

> *"I think maybe even in sex education being like, you know, it might hurt first time, but you shouldn't be uncomfortable or in pain afterwards. God put that together with other symptoms. You'd figure it out so much quicker." (Kristina)*

Supporting this Louise explained that the topic of sex during sex education at high school was rushed over and the teachers did not go into detail about.

> *"Like during school you don't get taught anything about sex and it is always quite negative. There's no like sex positivity that you are exposed to when you're younger." (Louise)*

Also, informal discussions with friends reinforced the normalisation of pain with intercourse. There are two narratives the women used. Firstly, that sex for the first time will hurt and secondly, good sex may lead to discomfort the next day. Both narratives were used to explain why medical advice for painful intercourse was not sought sooner and how pelvic pain is normalised for young women. Kristina got the belief that intercourse is painful from informal discussions with friends as her friends would joke about not being able to walk the next day after having intercourse. Therefore, she assumed that her not being able to walk the next day and being in pain meant that she had good sex the night before.

The narratives illustrate a lack of information and open discussions, even in families, about painful menstruation and intercourse. This is concerning as women will typically get their first period while living with family and getting sex education at high school. Clearly, there is a need to encourage more discussions within families, challenge the dominant discourses of pelvic pain and encourage schools and parents to engage with the new sex education programmes in New Zealand. This might help fix the first challenge women with endometriosis face – distinguishing whether the pain they are experiencing is 'normal' or 'abnormal and getting a diagnosis (Ballard et al., 2006; Hudelist et al., 2012; Denny, 2004a; Denny, 2004b). This research highlights the contribution of poor information and normalisation of pain for young women by families, peers, and educational institutes. These women are left suffering in silence for many years believing that the level of pain they were experiencing was normal. For many of the woman it was not until they had been experiencing both pain with menstruation and intercourse for years that they started to question that something wasn’t right. I described this as ‘the turning point’.

The turning point

Constructing the visual timelines of the women’s journeys allowed me to see how their symptoms manifested over time and led to each person’s ‘turning point’. This was the point when each woman came to the realisation that the pain, they were experiencing was not normal and started questioning what was happening with their bodies.

> *“I just like, got so hot and like, thought I was going to pass out and I was in so much pain. And I had to come back home from uni. I was like, I can't do this anymore. But that's when I was like, okay, something's not right.” (Regina)*
>
> *“And then I think I was 22. When I had back pain and, like, so like period cramps that just went all the way around to my back and then actually went into the base of my skull and I couldn't move. That was the point that I was like okay, that's not normal, like I've dealt with pain before and that was just incredible.” (Kristina)*
>
> *“But, at 17 is when I became like very aware of like this is really painful. And it's like not normal and doesn't feel quite normal, because I can't get out of bed.” (Becca)*

This research found that it was the combination of painful intercourse and menstruation that led to the turning point of something isn’t right. All the women in this study suffered for many years with various symptoms until they reached this point. All the women's journeys to diagnosis were filled with multiple doctors’ visits, specialist appointments, dieticians, and hormonal treatments. All were misdiagnosed, not taken seriously, and all faced difficulty receiving an official diagnosis of endometriosis clearly shown in the average length of time to diagnosis of 7.5 years (Table 1). Delays and poor advice from family members, peers and school all contributed to the confusion of what the women thought was acceptable or normal levels of pain. This is supported by Ghai et al. (2020) who reports that diagnostic delays for endometriosis are median of 8 years in the United Kingdom with the normalisation of pain and poor advice from medical professionals as major contributing factors to this delay. The next section discusses how living with endometriosis and their experiences with painful sex impact women's identity, sexuality, and femininity.

Who am I as a Woman Living with Endometriosis and Painful Intercourse?

This section starts with discussing the lack of knowledge around the term sexuality. It is important to include the women’s definitions of sexuality to see what it means to them and how they believed pain with intercourse has impacted it. The term sexuality is very complex and many of the women were unaware the true impact painful intercourse had on their sexuality. There were similarities and difference among the women’s experiences and impacts of sexuality. Then I focus on the impact pain with intercourse had on the different dimensions of women’s sexuality. These dimensions are set out under four narratives points including: sexual function, sexual relationships, fear and anxiety towards future sexual interactions and impact on their sense of femininity.

Sexuality

Firstly, I will focus on the women's narratives around their sexuality and identities. In literature and in lay understandings the definition of sexuality lacks consensus (Cleary & Hegarty, 2011). This was reflected in the participants narratives when I asked them what sexuality meant to them. Five of the women responded that it meant their feelings towards sex and a person’s sexual orientation.

> *"Sexuality like two things come to mind, where it's like, you know, your attraction towards somebody or sex in general, or what gender you're attracted to. But then there also comes sexuality and like your personal sexuality, like, how you feel about sex, like how you think about sex and how you interact with sexual interactions." (Becca)*

In contrast, four of the women viewed sexuality much more than just sexual orientation and included that it was their ability to have sex, their self-confidence and self-esteem, comfortability with who they were as a woman and their true authentic self. For example, Kristina and Izzy explained that sexuality is who you are and what matters to you. However, Kristina did acknowledge that initially when she hears the term sexuality she automatically thinks of a person's sexual orientation. Bayley went further to explain that sexuality is your authentic self and that by accepting our vulnerabilities such as endometriosis we can become more comfortable with ourselves and she says "*Sexuality to me would be staying true to your authentic self, would be a big one. Learning to accept, embrace and be okay with your vulnerability.* Rose also has a positive view on sexuality as she said *"It's almost kind of self-confidence as well and knowing who you are. I don't really class sexuality as like attraction to other people, all the time, for me it's more about like myself and how I am feeling."*

In complete contrast to the other participants Louise expressed that sexuality equalled terror but her narrative also illustrates the uncertainty of what sexuality is. This was due to her experiences of painful intercourse which has caused her to be unable to have intercourse for 5 years with her partner.

> *"I don't even know what sexuality means to me. I try to block all of that out. I don't even know I feel like sexuality is like being comfortable with like sex and sex*

> *things that you do and like, what you want to do as well not just like being open to all sex and everything. But yeah, I don't know like I have a really hard time, so I used to think that I was quite a sexual person. Now I think that I probably am not. I'm definitely not now! But I mean like me in general, like if I was normal and all this hadn't have happened. So, sexuality to me means terror and fear." (Louise)*

The women's narrative shows the lack of consensus round the term sexuality. Half of the women only viewed sexuality as sex or a person's sexual orientation. Whereas the other half viewed sexuality as who they are as a woman and what matters to them. Research surrounding the issue of sexuality in endometriosis patients has focused predominantly on aspects of sexual functioning and does not encompass a holistic approach to sexuality (Denny, 2004b). The complexities of sexuality need to be considered for women with endometriosis as sexuality is not universally positive. In addition, without understanding the term sexuality then women are unable to recognise when something such as pain with intercourse is impacting their sexuality. This research illustrates that many women did not believe painful intercourse has impacted their sexuality significantly. However, the more in-depth the interviews went the more the women revealed how pain with intercourse had truly impacted what it means to be a woman. Therefore, the next sections explore the wider impacts pain with intercourse has had on the women's sexuality in four areas: sexual function, sexual relationships, fear and anxiety towards future sexual interactions and sense of femininity.

Sexual Function

Sexual function is the ability that a woman can give and receive sexual pleasure and can be affected by medical conditions (Pluchino et al., 2016). It is an essential aspect of sexual health and a women's sexuality. There is a lack of recognition and analysis of sexual function in the endometriosis literature (Di Donato et al., 2014). Pain during and/or after intercourse is a major factor that affects sexual functioning (Cox et al., 2003; De Graaff et al., 2016; Fritzer et al., 2013; Evangelista et al., 2014; Denny 2009 and Di Donato et al., 2014). All 10 women in this study suffering from endometriosis reported some issue with an aspect of sexual functioning. Therefore, it was important I explored the impact pain with intercourse had on the women's sexual function and in turn the impact this has on their sexuality. Sexual function can be further divided into the sexual response cycle concepts such as sexual desire, sexual arousal, and orgasm. For the women in this study the pain during and/or after intercourse was often at every sexual encounter and thus, affected the three stages of their sexual response cycle. This section in on the women experiences with sexual desire, arousal, and orgasm.

Sexual desire

Sexual desire is the subjective sensations and thoughts of wanting to engage in sexual activities (Peplau, 2003). Sexual desire is a significant part of the sexual cycle response leading to intercourse (Peplau, 2003). The findings show all the women could or had sexual desire which contradicts previous research by other authors such as Hämmerli et al. (2018) and Evangelista et al. (2014). This research shows the complexities of the narratives around sexual desire and that they illustrate fear, frustration and annoyance that they are unable to have pain-free intercourse.

The women had different strategies to deal with sexual desire. Jade had difficulty desiring sexual intercourse with her partner as she experiences pain with every sexual encounter. She explained that for her to build up desire or willingness to have sex with her partner they would stay at separate houses for a few days.

> *"Probably don't as much* (desire sex) *there's like the odd occasion and this is going to sound really strange but sometimes me and my partner stay away from each other for I will go and stay somewhere for like a week just so that we can kind of build-up that desire. It kind of helps a little bit." (Jade)*

Whereas Louise had completely no sexual desire with her partner as she was completely unable to have intercourse due to the pain. She has not had intercourse in five years which has led her to not desire sexual intercourse at all. But her narrative is hopeful that she may experience desire in the future.

> *"I look forward to a time when I look forward to sex. I so want to feel like I want to do it. But at the moment I definitely do not." (Louise)*

Rose expressed that she has more sexual desire now than she used to; however, she requires the right timing for her to be able to desire intercourse. Rose seems to be more accepting of her diagnosis and attributes this to her higher sexual desire compared to the past. Some of the other women expressed that they do desire sexual activity but feel frustrated when they cannot have pain-free sex. For example, Ash expressed that she loves sex but due to endometriosis and painful intercourse she is not always able to have intercourse when she would like to. This leaves her frustrated and annoyed at herself and her body.

> *"Yeah, like I do think as a person like I love sex. I do like 100% and that's why I think this is so hard for me because I'm like I just want to rip your clothes off, and then I'm like, but this situation's not letting me, so I get really angry." (Ash)*

The same was for Becca who desired sexual interactions more than she was able to have them which resulted in her desiring intercourse even more.

> *"I think so definitely, I mean, I feel like everyone does, in some way and I feel like It's a big part of like my sexual identity. I desire it more than I do it because I can't have it as much, I desire it more." (Becca)*

These findings suggest that pain with intercourse can impair women with endometriosis sexual desire. What is important to note was nine of the women felt desire and wanted sex and the tenth women hoped that she might feel desire in the future. Sexual desire and wanting sex were clearly tied to their identity as women but for three women in the study pain with intercourse was decreasing their sexual desire. Di Donato et al. (2014) supports my findings and reports that painful intercourse for women with endometriosis leads to decreased sexual desire and arousal. However, this research has shown that desire when separated from arousal is not necessarily decreased. What is clear across this and other research is that pain and fear of painful sex impacts on a women's sexuality.

Sexual arousal

Sexual arousal is the physiological and genital changes that occur in response to sexual stimuli, such as vaginal lubrication (Basson, 2002). Pain with intercourse can impair a women's sexual arousal response because they process sexual stimuli with minimal simultaneous awareness of sexual emotions (Basson, 2002). Five of the women in this study reported issues with getting aroused and the other five did not. Difficulties revolved around fear of pain during intercourse. The coping strategies for decreased sexual arousal varied between the women.

This is demonstrated by five women in the study who have decreased sexual arousal due to their experiences of pain with intercourse. For example, Jade explained

> *"Yea. It does take a bit of time. It does take him a while to relax me because he will touch me and I'm like AHHH and then, he has to say relax, it does take a bit of time. That's why like spontaneity doesn't happen because it actually takes time to relax me." (Jade)*

Women with endometriosis and pain with intercourse can have other types of concurrent pain diagnosis such as vulvodynia (unexplained pain around the vulva) and vaginismus (muscles spasms in the pelvic floor muscles) (Shum, 2018). Vulvodynia can make intercourse more unbearable and vaginismus making it nearly impossible to have sexual intercourse (Shum, 2018). Both Jade and Regina experience vulvodynia which contributes to their fear of arousal and intercourse. Jade reacts to sexual stimuli such as her partner touching her or initiating sexual intimacy with negative sexual emotions. These negative sexual emotions stem from her past experiences with pain with intercourse and are associated with anxiety and fear. Research has shown anxiety can contribute to increased tension and tightness of pelvic muscles (Pluchino et al., 2016). Jade uses her partners words and time to try and decrease the physical symptoms. This is similar for Regina who subconsciously views sexual stimuli as negative and her body responds by producing pains around her vulva. The narratives of the body being separate from her emotions are shown here.

> *"It's as if my body knows that it's about to have sex and it's like, No. Do you know what I mean? It's like little needle pains, or like stabbing pains. It's just so strange and the only thing I can put it down to is that maybe when I am getting aroused my hormones are going up, and my body is literally like no and sensors that."* (Regina)

Louise has been told by medical professionals that she may has vaginismus because of endometriosis which is contributing to her fear of pain during sex and therefore her arousal. Louise said *"Now I would have a hard time getting aroused because I am terrified and don't want to do anything."* Kristina explained that she had issues getting aroused compared to the past.

> *"Occasionally aroused. Oh, this is the issue arousal Yes. Way more with the toy but even with a toy sometimes not wet, like there is always lube in my cupboard. This is why we don't use condoms because they just cause so much friction but with lube, more lube than less friction. But yea I have definitely noticed that over the years I haven't been able to get as wet as what I use to be able too." (Kristina)*

These findings suggest arousal was talked about by the women as a very physical function of their body in comparison to sexual desire which was mental and cognitive aspect of intercourse. Half of the women in the study had difficulty becoming sexually aroused and the other half of the women in the study were able to get sexually aroused physically but the impact was very individualised. The emotional impact of their past experiences of painful intercourse caused fear about sexual intercourse impacting the physical aspect of arousal such as lubrication. The narratives revealed that the women talked of their bodies as separate from them with physical problems. This is supported by De Graaff et al. (2016) which reports that anticipation and fear of pain may decrease sexual arousal and lubrication. However, this does not reveal the entire picture.

Orgasm

The orgasmic stage is where a woman experiences contraction of the vagina and uterus which indicates the peak of sexual response (Meston et al., 2004) There are multiple ways for women to orgasm but in this study, I am referring to vaginal orgasms.

Vaginal orgasms are internal orgasms which occur because of stimulation along the legs of the woman's clitoris and it is not uncommon for it to be difficult for women without endometriosis to orgasm with penetrative sex (Meston et al., 2004). Herbenick et al. (2018) found that 18.4% of women will orgasm with penetration alone. With the addition of endometriosis and painful intercourse this can make it more challenging to achieve an orgasm (Montanari et al., 2013). Five of the women in the study indicated that they found it difficult to orgasm from penetration alone. This is partly due to pain with penetration and painful cramps following orgasms. Becca explained that penetration is painful for her most of the time and therefore she is more concerned of not being in pain than being relaxed to be able to orgasm.

> *“Um, again depends if it's just penetration, like no. Cause majority of the time it hurts. Yeah, and I'm trying to focus on like not being in pain. I'm trying to think of like, the best way to do it.” (Becca)*

Similarly, Jade’s past experiences of reaching orgasm and then having cramping straight afterwards has caused her to associate orgasm with pain. These negative views towards orgasms have made it more difficult for her to become aroused and to orgasm.

> *“That’s kind of a problem for me, not as often. I feel like sometimes I got to the point where I've orgasmed, I would be in pain afterwards so it started becoming like my body would be scared to do that. Like for ages he was like why aren't you orgasming, and I put it down to that because for a period it would cramp and be pain afterwards.” (Jade)*

Contradicting these narratives, two women in the study discussed how orgasms can help with their pain from cramps. The following two excerpts from Meredith and Izzy indicate that orgasms for them can help relieve pain.

> *"But I also find that orgasms are one of the best cures from pain. It's like something that I will do If I'm in a heap of pain on purpose." (Izzy)*
>
> *"It really depends. Depends on how much pain I am in; it depends on whether we've had enough foreplay. And, if I get a cramp during it, he normally tries to help me finish because sometimes helps with pain. But sometimes it doesn't." (Meredith)*

The narratives above show that half of the women in the study found it difficult to orgasm. The reason I included this section is because during my discussions with the women many of them had the belief that it is difficult for women to orgasm regardless if they have endometriosis or not. Literature does support this by reporting that orgasmic problems are the second most frequently reported sexual problem in women (Levin, 2004). Contradicting this the media portrays orgasms as effortless and easy for all women (Levin, 2004). For women with endometriosis there is already difficulty achieving orgasms but the addition of pain from endometriosis and cramps from orgasming can contribute to more difficulties. Problems achieving orgasm have become normalised and thus the women did not see that orgasmic problems could have been associated with endometriosis rather than putting it down to a problem that many women have. Thus normalisation of orgasmic problems has contributed to diagnostic delay for women with endometriosis and has consequently impacted their sexuality negatively by giving up on orgasms because they believe it is normal for women to have difficulty orgasming.

In summary this section focuses on the physical, mental, and willingness to have sexual intercourse as a woman. The dominant discourse around intercourse is sexual function and thus, demonstrating the medicalisation of intercourse (Melis et al., 2015).

As a society we do not talk about the physicality, mental and emotional aspect of sexual function but instead focus on the functionality and biology of sex (De Graaff et al., 2016). This is because historically women's sexuality and sex has been repressed and prevented women from expressing their sexuality fully (Young et al., 2019). Additionally, due to the lack of discussion around sex there is limited research on sexual function for women who have a medical condition that causes them to have painful intercourse and the impact this has on the women's sexuality. Much of the research is quantitative thus reporting statistics that women who experience painful intercourse have lowered sexual desire, arousal, and less orgasms (Evangelista et al., 2014). In contrast to this my findings suggest that women with endometriosis who experience pain with intercourse physically and mentally can desire sex, get aroused and orgasm. Some women even use orgasms to help with cramping from endometriosis symptoms. More importantly it was the emotional impact from past experiences and anticipation and fear of pain that prevented women from having intercourse rather than difficulties with their sexual function. Pluchino's et al. (2016) fear and avoidance model for endometriosis patients (Figure 1) groups lack of sexual arousal and sexual desire together however this research has shown that women's lack of desire does not always cause avoidance, lack of lubrication and increased pelvic pain. This is because sexual desire is a cognitive aspect of the sexual response cycle rather than a physical component.

Sexual Relationships

Sexual relationships are interpersonal relationships which involve physical or emotional intimacy and sharing one's sexuality with another (Moradi, 2014). Moradi (2014), suggests that women suffering with endometriosis who experienced pain during and/or after intercourse negatively impacts the women's sexual relationships. My findings support this and have demonstrated that painful intercourse can cause problems in communicating partners feelings, avoidance of intimacy and anxiety towards dating. This section is important to include as negative impacts on sexual relationships such as avoidance of intercourse and poor communication can impact sexuality.

Communication

Communication is essential to making a relationship work, however discussions on sexual issues and sexuality can be difficult and embarrassing for women to bring up to their partners. In this study six of the women were in a relationship and four were single. All the women had experienced the difficulty of communicating with their current or past partners that intercourse was painful. The narratives they used to help explain communication issues were linked to a sense of guilt and being *"more needy"* (Regina) compared to women who do not have endometriosis. This was because they felt embarrassment, guilt, and that they were a burden and need more support, patience and understanding compared to women that do not have endometriosis.

Ash reflected that at times she has had sex with her partner but did not enjoy it but she did not say anything to her partner and says "*And then you're left at the end of it just feeling like defeated and just like something's wrong with you and you get really upset."* The use of the word defeated illustrates the level of unhappiness she is feeling. This could have been from her inability to communicate with her partner honestly or because she has been beaten by endometriosis.

Jade was recently diagnosed with vulvodynia which causes intercourse to be painful and she had not discussed this with her partner.

> *"More recently, I feel like everything's like, yeah, piling down and so like I've probably struggled a bit more in terms of being really up front, and forthcoming with my boyfriend and even my friends. Yeah, so for example like my more recently I got a diagnosis like I told him about one thing but not about the other because it like a little bit of an embarrassing thing to talk about…"*
>
> *"…I just don't want him to think there is another thing wrong with me and that I'm just like forever broken." (Jade)*

Like Ash, Jade also expresses a sense of not wanting to add her problems to her relationship which shows a disconnect between her body and her relationship. Her body is not doing what it is supposed to do as a woman and thus it is embarrassing to talk about within her relationship. Therefore, avoiding communicating her problems is to keep some normality in her relationship and prevent playing the 'poor me' or 'sick' role. Jade also reflects that she has not always been as open as she could be. This could be because she believes as a woman, she should be open but by not doing so she is positioning herself as less of a woman because she is not being upfront with her partner. Additionally, the use of 'piling down' as a metaphor illustrates the weight and burden her health issues play on her and her relationship.

Another reason that women were anxious to communicate with their partners about painful intercourse was out of fear of rejection or that their partner would leave them. Ash shared that she was anxious to communicate with her partner that intercourse was too painful sometimes and to ask him to stop as she felt guilty, she would not be fulfilling her partners expectations of her to please him and would result in him cheating or leaving her. This was fuelled by a past relationship where her partner left her because of her diagnosis. Thus, like the fear of painful intercourse, there is the fear of being alone or that a partner would use endometriosis as an excuse to leave.

> *"Well, I feel like you're supposed to please your man, like I always say, men need sex and woman want sex so sometimes you feel like if I can't give him this, he's going to cheat on me or he's going to leave me." (Ash)*

Similarly, Becca struggled to communicate with ex-partners about painful intercourse as she had thoughts that they may leave. Becca said "*Yeah, like in past relationships it made me feel a little bit less desired, but that was just in my head. It wasn't the case it was in my head. I felt like, oh, because it's like this every time we try and have sex that you're not going to want me as much."* Thus, Becca knew that it was her creating this scenario in her own head about her partner leaving however, this is problematic when pulling on the dominant narrative that an intimate relationship with a man has to include intercourse or they will leave. Similarly, Louise also pulls on this dominant narrative and expressed that if she never reaches a time where she is able to have intercourse or sexual intimacy within her relationship then her partner would leave her.

> *"Because initially I thought that like if I didn't get to a point where we could have sex, even any kind of sex not just intercourse. I thought that he would either leave me, or resent me, and you know I wouldn't blame him. It sounds really harsh to say it but like your only live once and that's kind of a shit way to be." (Louise)*

What is also interesting is that Louise said she would not blame him if he would leave. Thus, this illustrates the dominant narrative that women believe they must have intercourse in a relationship for it to work. The expectations of what it means to be a woman in a relationship are clearly tied to the women's inability or ability to have intercourse. Living with endometriosis means there is no easy option for these women and that they either must risk rejection or have a relationship without penetrative sex.

These narratives suggest that if a woman is made to feel that she cannot fulfil her role as a good partner within a relationship then this leads to feelings of worthlessness, hopelessness, and embarrassment (Denny, 2004a). My research shows that the dominant narrative around relationships is that they must involve penetrative sex or the woman fears rejection. This view and beliefs towards intercourse and sexual relationships have a negative impact on their sexuality. Feminine roles and expectations of women will be discussed further in the findings sections impact on their sense of femininity under feminine roles.

Another factor that contributed to poor communication between the women and their partners is due to the lack of discussion in society on how to manage painful intercourse within a relationship. Therefore, seeing your partner in pain during intercourse caused both parties in the relationship to stop initiating sexual intercourse. It did cause some of the women’s partners to have a lower desire for sexual interactions as they did not want to see their partner in pain or hurt them. This contributed to feelings of worthlessness and rejection from both sides of the relationship and ultimately, led to four relationship break ups. This is similar findings to previous studies such as Moradi (2014) and Hummelshoj (2014) that found painful intercourse led to lack of intercourse and resulted in relationship distress, infidelity, relationship breakdown and divorce. For example, Rose retracted from sexual activity with her ex-partner and thus was a contributing factor to their breakup.

> *“You know, I think also because maybe I wasn't as open about talking about it then. The other person took it the wrong way, thinking it was their fault and all*

> *that. So, Yeah, in some ways it's kind of did lead to us splitting, along with other factors yeah." (Rose)*

Meredith's ex-partner became inpatient after her laparoscopy surgery that she was unable to have intercourse until she recovered. Her ex-partner asked the surgeon in front of her after her surgery when they would be able to have intercourse and proceeded to put an alarm on his phone for 6 weeks until they could have intercourse again. Nevertheless, to say Meredith was not impressed and resulted in their relationship breaking up.

> *"Then one of my other ex's was that and I was like, bye bye. When we first started dating he was like I fully understand, no problem, we'll take it slow, let me know, and at one point, he just ended up having like a temper tantrum and I was like, Fuck off. There's the door, see you later? Don't even bother coming back. Like you cannot treat me like that. You know no one can treat me like that. I'll treat myself like that, but you don't get to treat me like that." (Meredith)*

Meredith believed that this was unacceptable behaviour in a relationship and that she should not have to put up with a partner that evolved their relationship around sex. Meredith said "*he just started getting impatient. Then he's like, come on and I was like bye*" which displays a different narrative around intimate relationships. Meredith may believe that intimate relationships should not be solely based on intercourse or she may have had enough of her partners poor communication and impatience and decided to leave him as she knew she deserved better.

When talking with the women some of them had similar experiences where painful intercourse was one of the reasons their past relationships ended. All the women said that it was the men's fault for the breakup as the men could not handle them as women with endometriosis. From these past relationships some of the women have learnt to be open and to adjust their communication styles for future relationships. Five women in the study discussed that they had learnt new communication styles for future relationships. Jade learnt from her past relationship that it was important that she had open and honest communication with her current partner about her experiences of painful intercourse. This was to prevent the relationship from breaking down as well as to make sure that her current partner was going to be supportive and not in the relationship just for sex. It is positive that the women learnt new ways to communicate with their existing or new partners their needs and sexual needs with living with endometriosis because it allowed them to feel that they were taking control of their lives and accepting the diagnosis.

> *"My partner and I have really good communication and when we got together I kind of pre warned him because a past relationship it was a massive issue and actually caused the breakdown of the relationship. So, I was really up front from the beginning and was like Hey, it's not going to be a smooth ride with me just so you know so. He is starting to realize now it is actually a lot worse than he probably thought." (Jade)*

Similarly, Izzy learnt how and when to communicate to her current partner as sexual issues can be an intimate and embarrassing topic to discuss for both of them. Izzy seemingly is protecting her partner from the truth as she does not discuss all her endometriosis related issues to him but she is also protecting herself from possible rejection or feeling like the 'needy one' in the relationship.

> *"Yes, with my partner. But it has to be done at the right time and the right way." (Izzy)*

The findings suggest the importance of good communication within a relationship when a woman experiences painful intercourse. This has caused relationships to have poor communication and led to break ups. As a society we do not talk about sexual issues openly, and thus it is difficult for people to openly discuss sexual issues within a relationship (Weijts et al., 1993). We are not taught how or when to communicate such issues to others or made to feel comfortable to be able to discuss them. Therefore, the women have had no role models or guidance on how to cope with sexual issues within a relationship or how to communicate about them. Not being able to communicate about sexual issues or sexual needs within a relationship can cause a decrease in sexual satisfaction and women to feel hopeless, a burden, frustrated and rejected (Fritzer et al., 2013). But for women with endometriosis, communication becomes even more important due to expectations of how much intercourse they can have and having harder conversations sooner. Van Niekerk's et al. (2020) study highlights the importance of empathy in relationship satisfaction for women with endometriosis. The worry evolved around relationships from women with endometriosis never really goes away. This is because there is no real information for women with endometriosis on how to communicate that intercourse is painful. Therefore, this sense of worry and fear has caused the women to have negative views and attitudes towards sex and sexual relationships which ultimately impacts the women's sexuality. Therefore, poor communication about painful intercourse can impact the women's sense of self and her sexuality.

Intimacy

Intimacy is a vital aspect of a relationship and ones view on their sexuality. When a person's sexual activity decreases so does their sexual intimacy within the relationship.

A decrease of sexual activity can be due to the lack of physical contact which contributes to dissatisfaction within the relationship. Intimacy is more than just sexual intercourse but also includes communicating feelings to each other and intimate actions (Young et al., 2017). In literature the term sexual intimacy is used interchangeable with sexual intercourse thus I believed it was important to ask the women their understanding of the term. Three women in the study when asked what sexual intimacy means to them, responded that it meant sexual intercourse. Whereas the other seven women viewed sexual intimacy as intercourse and other intimate actions such as kissing and cuddling. Thus, this shows that the definition of sexual intimacy was known to most of the women in the study this may be because women with endometriosis focus and enjoy sexual intimate acts within relationships than penetrative intercourse.

Three women in the study enjoyed sexual intimacy. For example, Regina explained that the communication between herself and her partner was very open that when she was having a bad pain day that she would communicate with her partner that she was only able to engage in a limited amount of sexual intimacy. Her partner was understanding and thus, changed direction to intimacy such as cuddling instead of intercourse.

> *"Like everything leading up to it and then I'll just be like, ah, I don't think it's going to go well tonight, I'm sorry I'm too sore and then he will be like that's alright." (Regina)*

Similarly, Bayley explained that due to the unpredictability of endometriosis intercourse can sometimes be pain-free while other times it can be excruciating. The importance of a good relationship or 'connection' is what Bayley contributes to successful intimacy.

> *"Knowing each other's boundaries but there should be a mixture in regard to how you interact. To me it's important you have that intimacy and that level of intimacy and emotional connect. But there will be times when you won't want to go for hours. But I believe if the connection is sincere, honest and real you should get a good balance." (Bayley)*

Seven of the women in the study said that painful intercourse reduced their sexual intimacy with their partner which resulted in avoidance. For example, Becca explained that painful intercourse would affect sexual intimacy which would lead her to avoiding intercourse and sexual intimacy with her partner.

> *"Yeah, definitely does, I feel like I'll be open to it and then I may have one experience that's like worse than the other and I'll be like, no I can't, I can't do it and I'll probably not do it for like a long time. We'll just stop just because it's so off putting." (Becca)*

Becca limited sexual intimacy with her partner out of fear that it would lead to sex and another bad experience. Consequently, lack of sexual intimacy and connection made Becca feel that something was missing from her relationship saying, "*sexual intimacy brings you closer"*. Similarly, Izzy also described that when she is unable to be intimate or have sexual intimacy with her partner that she feels there is a gap within her relationship. At the beginning of Rose's diagnosis sexual intimacy turned into a burden as each time she had intercourse and intimacy it was unpleasant and not enjoyable. However now, for Rose she explained that her experience of endometriosis and painful intercourse caused sexual intimacy to be less of a vital component of her relationships. Thus, she rejects the dominant narrative that relationships must have intercourse and intimacy to work.

Louise had strong narratives around intercourse, intimacy, and herself a woman. Louise associated sexual intimacy with terror. At the beginning of Louise’s relationship, she was able to enjoy sexual intimacy but over time when it started to become more painful, she slowly became more and more terrified of sexual intimacy. This excerpt shows how over time Louise experiences of pain has decreased the sexual intimacy with her partner.

> *“Very much so, completely. But not at the beginning because we went eight months where we were sexually intimate but didn't have penetration. It was very normal like every time we saw each other we wanted to do stuff and we did it like you know when we had time and stuff. And then, even after I had painful sex initially, we still did some stuff, but I would get really tensed. And then over time, it just got to me doing stuff to him, but I didn't want anything for myself. Then it got to a point where I don’t want anything. Some part of me feels like I should just force myself to do it, because I know in other aspects of life where I force myself to do things they are always fine. But this feels like something you don't force yourself because it is just going to get worse. The thought of that now really terrifies me. Even the idea of that really terrifies me.” (Louise)*

Louise’s use of the word terrify shows the intense fear Louise now feels towards any sexual intimacy which shows how significantly damaging endometriosis can be to a woman's sexuality.

In summary the findings suggest that poor communication, fear of rejection and the dominant narrative that intimate relationships must have penetrative sex influence women's views and beliefs about sexual relationships and their own sexuality. Additionally, this research shows that having endometriosis and experiencing painful intercourse can lead to sexual relationship issues such as avoiding sexual intimacy and intercourse due to the pain which resulted in some women feeling that there was something missing in their relationship or led to relationship break ups. Hållstam et al. (2018) suggested that when women with endometriosis were unable to have sexual intercourse they would alternatively turn to sexual intimate acts instead. Whereas in this research only one woman spoke about using alternative methods such as intimate acts than penetration and for some of the women sexual intimacy became less of a vital component of a relationship. However, rejection or the lack of importance for sexual intimacy both influenced the women's views and beliefs about sexual relationships and their own sexuality.

Navigating life with painful intercourse and endometriosis

This section focuses on how the experience of painful intercourse can cause the women to interpret their future sexual interactions as dangerous and the intensity of the pain during intercourse can increase, which relates to the fear and avoidance model and critically evaluate the model (Elmerstig et al., 2008). All 10 women expressed that they felt a sense of fear and anxiety towards future sexual interactions. Feelings of fear led to psychological and physical bodily sensations which caused women to not be able to relax. For example, even just discussing intercourse with Ash she became restless, crossing her legs and holding her stomach. She said *“Yea it is traumatic, like literally the thought of it right now I feel like my vagina is closing and my stomach is pulsing. I'm literally just sitting here in no way sexual or anything we're just having a conversation. And the minute you bring it up I’m like ahh no.”* The word traumatic suggests the detrimental impact of the fear and anxiety felt towards future sexual interactions has on women with endometriosis. Ash physically experienced bodily sensations of her vagina wanting to close when sexual positions or intercourse was mentioned. Due to her experiences of intercourse being traumatic and the fear of future sexual interactions this has resulted in Ash avoiding men altogether.

> *“100% like 100%. I think that's one of the reasons I avoid men because like I just don't want to go there right now. I need to sort myself out first but then I am like I actually have this for life.” (Ash)*

Ash has found this frustrating as she classed herself as a sexual person and enjoyed having sex when it was not painful. Ash believed that she was meant to be in her prime sexual years she said “*Like I am 24. What the hell I am meant to be in my prime.”* Suggesting that endometriosis is taking away from her being able to fulfil her true sexual identity and her narrative pulls on dominant discourses that sex is supposed to be pleasurable and fun for women (Di Donato et al., 2014). This is particularly problematic when sex for women is seen as a way to have children. Ash also discussed that dating when you experience pain with intercourse is very difficult. She questioned when the right time was to tell who she was dating that intercourse is painful because in the past some men have not always been so understanding.

> *“Now being single I’m like is my next partner going to be understanding, is he going to make me feel bad about this, is this going to be awkward, is it going to hurt, if it hurts then it takes the fun out of sex and sex it meant to be fun. We're not just meant to have babies. But it's so hard.” (Ash)*

This shows that Ash experiences have been traumatic, and she is trying to navigate her personal and dating life living with endometriosis. Meredith and Becca were also both single women who discussed that the thought of future sexual interactions with people they were dating gave them anxiety. Meredith explained that in the past when she was dating it had been difficult to tell partners that intercourse is painful and there are times, she may not be able to have intercourse or that she will have to stop. Unfortunately, some of the men she has dated were not understanding.

> *"But yea I wait until like a few dates later when I know it might be leading to something. Then I am like so I have this, and you may need to stop, and they are like oh so does that mean I might not always finish, and I am like yep. I've actually had a guy who turned around and said but why do you keep saying stop. I was like because I am in pain and he said just breathe through it. I'm like you tell me to breathe through the pain I'll cut your fucking balls off and I will tell you to breathe through the pain. That is why I am very strict with who I sleep with." (Meredith)*

Becca also discussed how anxiety provoking dating is when you experience pain with intercourse.

> *"Oh, yeah, if it's like a new partner, or new sexual partner there's a lot more anxiety, with it. I mean there's been times where I haven't quite discussed it with a partner. So, I'm like do I tell them? Is this going to kill the mood and what's going to happen. So there's anxiety behind that as well as he's not going to know why I'm like stopping him, or just I'm going to kill the mood again. But yeah, there's always anxiety." (Becca)*

Like Becca, other women also discussed the narrative of 'killing the mood'. This suggests that the expectations of women to have intercourse and not to have any sexual problems or issues is difficult and daunting for a women with endometriosis. They do not want to be the ones to have to reject or kill the mood when having intercourse by needing to stop.

Endometriosis is an unpredictable disease and the uncertainty of whether there will be pain is ever present.

> *"Yes, it's tough for sure, and especially since I've had the past experiences of it always being painful, like every single time I had sex, fuck I just wanted to die like it was painful. So, it's more of like I'm scared that it will happen now." (Rose)*

Rose indicated due to her past experiences of painful intercourse that now she is scared that it will happen again causing fear towards future sexual interactions. The use of the word 'die' illustrates how severe and damaging her past experiences with pain during intercourse have been. Due to these experiences and the unpredictability of endometriosis she finds dating extremely anxiety provoking as she does not want to experience that level of pain again. This shows that not only on top of living with a chronic illness the anxiety of dating with this illness can be extremely challenging. This revealed the dilemma of when is too soon or the right time for the women to tell their new sexual partner that intercourse can be painful and that they may need to stop during intercourse. In addition to this Bayley discussed that the size of a man's penis can trigger her anxiety and fear towards having intercourse. This is because of an experience where a man with a larger penis size caused intercourse to be extremely painful for her.

> *"But in the past yes especially when thinking about the size of the guy that would trigger anxiety for me. I was like jeepers if this is the average size and I got really bad pain with that then it gets me anxious. I have never been a fan of big size because I got fucked up with an average size so with a big size, I am just like nah I'm out (laughs)." (Bayley)*

Many of the woman are trying to find ways to navigate their new life's living with a chronic illness that causes painful intercourse. There are numerous strategies the women used to cope with the fear and anxiety about future sexual experiences and often the strategies are open to change. Regina, who is in a relationship, explained that she is still learning how to navigate her relationship with painful intercourse. Her coping strategy is to weigh up the pros and cons before she has intercourse to decide if the pain will be worth it or not as she would still like to be intimate with her partner but on her terms but this does not take away the anxiety completely and means Regina has a painful sexual experience.

> *“Um, yeah, I do, because I think my pros outweigh the cons for me. I like having sex too much not too. So, I'll do it. But at the same time, I'm like, is it going to hurt? I don't know, let's just do it, whatever. But, yeah, I definitely like weigh it up and I like make a decision, it's usually just go for it, but there is a little bit anxious.” (Regina)*

It was surprising to hear that all the women were confused and clueless on how to deal or manage with painful intercourse. All the women had limited references and information to cope with painful intercourse and resulted to trial and error to find out ways to manage the pain. This section is important because with limited information on how to manage painful intercourse for women with endometriosis has meant that the women have been engaging in unsafe or harmful sexual activities physically and emotionally for many years which can lead to issues with sexuality. The coping strategies used by the women in the study included avoidance, positional change, self-medicating before sex, placing pillows under their hips during sex or having sex anyway while in pain.

Avoidance

All the women used avoidance of sexual intercourse to cope either due to fear, or not knowing if there were strategies to help reduce pain. Rose explained that when she first started to notice that intercourse was painful, she did not know what was happening and did not know what to do. This is compounded by the fact that intercourse or pain with intercourse is not spoken about within society.

> *"In the beginning I didn't know why It was happening and I didn't really know what to do, either. So, a lot of the time I would avoid doing it." (Rose)*

When Rose received her diagnosis of endometriosis, she then realised why she was experiencing painful intercourse. This led to Rose distancing herself from her ex-partner and would avoid any sexual intimacy and sexual intercourse with them.

> *"Because at a point, it was just so painful that I just wouldn't want to do anything. And yeah, I got to the point where I would distance myself from the person. Because I knew that things like that would lead to sex. But yeah, it wasn't that I didn't want, I didn't want to have pain, either. Cause it hurt like a bitch." (Rose)*

Even with a diagnosis of endometriosis there was still limited information on how to help reduce pain with intercourse. This is because intercourse is not discussed in society and we are not taught on how to deal with painful intercourse.

Nine of the women in the study used avoidance coping strategies to cope with painful intercourse. For example, Becca explained that she would avoid intercourse and situations that have may led to intercourse because she felt guilty if she was to engage in sexual intercourse then experience pain and must tell them to stop.

Jade's narrative pulled on a metaphor 'catch 22' to indicate there is no good option when living with endometriosis and painful intercourse. She then used a colloquial term of ‘psych yourself out’ to indicate that she worried about the pain to a degree that she would avoid intercourse altogether.

> *“I don't want to feel like I'm the stuck in the mud or withholding from them but I think it does definitely cause some issues of not wanting to. I think it's kind of a catch 22 right because you're like, I want to but in my mind I think it's going to hurt and be painful. I don't want to do that and you kind of like, psych yourself out before even doing it and then it is even more painful.” (Jade)*

This shows that Jade focused on the pain sensation of intercourse which resulted in negative views about her ability to handle painful intercourse by thinking that it is never going to get better. These findings are similar to Shafaei (2016), study which found that women with endometriosis that feared painful intercourse were more likely to use passive coping strategies and view intercourse as threatening. This threatening view on intercourse led to interference with the women information processing sense. The women concentrated on the threatening stimulus and had a lack of cognitive resources to cope. Thus this led to heighten pelvic floor muscles that are associated with painful intercourse and vaginal dryness which in turn caused pain with intercourse to increase for the women. However, my findings also suggest that the use of avoidance coping strategy with sexual intercourse and the lack of cognitive resources available to the women contributed to more negative views towards sex and their own sexuality.

Sexual positional change

Another coping strategy used by four women was sexual positional changes during intercourse. This is because certain positions allow for deeper penetration which can cause more pain. Also, women who have endometriosis on their bowels and bladder find some sexual positions to be more painful than others. Thus, the women had to trial and error to work out the sexual positions that were comfortable and enjoyable for them. For example, Meredith over time has learnt what positions are more painful than others and what she likes in the bedroom.

> *"Depends on the pain, depends on the night, depends on how bad it was, depend how the night was going. So, if it's kind of subsides and I'm like, okay, I can handle a little bit more again. If it is too sore deep, then he will just put the tip in and if he needs it deeper then I am like sorry not today. But now since I have grown up and know more about it I am like well we can start here and do this and if that doesn't work then I have back up options. Different positions cause sometimes it works for this position and then other days it doesn't." (Meredith)*

Similarly, Becca, Izzy, and Kristina also have used sexual positional changes to cope with painful intercourse. Becca reflects that the experimentation of the different positions can be 'incredibly painful' but that over time she has learned what is best for her. Izzy changes the angle of her hips and the depth of penetration is also important for her. Kristina uses pillows to change the angle of her hips too and uses lubrication to help her. The type of birth control was also important in terms of structuring times to have intercourse. Kristina has a Mirena in so she does not have a period so she does not have to avoid having intercourse the week before her period and during her period.

Becca also discussed that she has taken pain killers in the past before she had intercourse to reduce the pain. She realised that this was not sustainable as she would not always know when she was going to have intercourse and because it would make her drowsy. These findings are similar to Di Donato et al.'s (2014) study that found that women with endometriosis used active-behaviour coping strategies such as changing their sexual positions to a more comfortable positions where the impact of penetration is reduced. My research highlights that besides avoiding, medication and positional changes women with endometriosis have no other ways of managing pain with intercourse. It is shocking that none of these women have had no help or recommendations from medical professionals or professionals to manage painful intercourse. Thus, highlighting the lack of information and discussion within society around intercourse.

Putting up with painful intercourse

The last way women coped with painful intercourse was by just putting up with it. I was interested why the women would put up with painful intercourse. Five women said they continued having sex despite the pain out of guilt, embarrassment or they did not want to disappoint their partner. For example, Ash had sex despite the pain because she was embarrassed and did not want to ruin the mood.

> *"So, I just change the position and would just try and keep going because for me. I don't know if it's the same pain for everyone. Because mine is like I'm being stabbed in the stomach with like a hot poker. And it feels like everything's getting ripped and I start to feel physically sick and nauseous. So, I keep going. Because I feel bad and embarrassed about it. And I don't want like ruin it, but I'm not okay like the second that it hurts me like I can't enjoy it. Sometimes it feels like it's on fire or something, and it's a really deep as well like it's much deeper than I think it actually is." (Ash)*

Jade discussed that she continued despite the pain as she was hopeless that she would never find a solution and felt bad for not pleasing her partner.

> *"It's hard to explain it. I've gone through so many different types of pain with sex. I think probably more so now is that I'm comfortable so I've kind of got to the*

> *point where I put up with it, I'm like, it's not oh my god stapping knives, get out of me it's like, it's not comfortable, it's not really important to be enjoyable. But I'm not get the hell out of me and I guess it's because I don't want to feel like I'm letting my partner down or I don't want to like kill the mood or the romance. So, it's kind of, Yeah, it's probably being more so for his benefit." (Jade)*

Jade illustrates that sex has now become not important for her to enjoy as she is hopeless of finding a way to manage or cope with the pain during intercourse. Thus, not enjoying intercourse and viewing it as a burden or something she must do to please her partner impacts her sexuality negatively. Similarly, Becca also felt guilty for stopping intercourse if it was painful to continue.

> *"Yeah, just because, many reasons. Either I don't want to disappoint somebody. Or I just want to push through it see if It gets better. But usually, I think it's just because I don't want to disappoint somebody. I think that's the number one reason. Don't disappoint somebody else, because I feel like if I stop and I disappoint them like I disappoint myself as well. I feel like that will make me feel worse. I feel like it's okay if I have satisfied them." (Becca)*

This also highlights the views that Becca holds that women should have intercourse even if it is painful. This was a view held by the other participants as well. Kristina explained that she continued because she felt guilty for stopping intercourse as she did not want her partner to feel rejected and that it was his fault. Additionally narratives around disappointment came up often for many of the women. Disappointment in themselves, their partners and within their relationships. Kristina explained that she continued because she did not want to disappoint her partner. Also, Izzy described that when she was younger, she would continue having intercourse despite the pain because she believed in the patriarchy ideas that we are taught as women that we are supposed to please a man.

> *“I would be least inclined to initiate but until a couple of years ago I would always be that girl that just suck it up. I wouldn’t be the one who stopped it, I bought into all that Patriarchy bullshit.” (Izzy)*

Izzy uses the term patriarchy specifically showing her understanding of the role of men in a sexual relationship and how she took time to build up the courage to be the woman she wanted to be. It seemingly is difficult for women to have an equal partnership with a man when they have endometriosis because of the impact of painful sex on the relationship. Even with a diagnosis of endometriosis there was still limited information on how to help reduce pain with intercourse. This is because sex is not discussed in society and we are not taught on how to deal with painful intercourse (Ghai et al., 2020). When sex is discussed within society it predominantly is around the functionality of sex and biological aspects rather than the emotional, psychological, physical, and spiritual aspects. Instead, the women had to use trial and error which resulted in avoidance, positional change, medication or just putting up with painful intercourse. All these strategies can impact their sexuality and psychological health due to fear, anxiety, guilt, and disappointment. My research highlights that besides avoiding, medication and positional changes women with endometriosis have no other ways of managing pain with intercourse. It is necessary that medical professionals or other professionals start to help these women to manage painful intercourse. Living with endometriosis can be extremely difficult to live with as it impacts on all aspects of these women’s lives.

Fear and avoidance model

The fear and avoidance model indicates that avoidance behaviour can lead to negative psychological consequences, for example increased reinforcement of the inconsistency between pain sensation, pain experiences and behaviours (Fritzer et al., 2013). All women at some point in time experienced fear or anxiety towards future sexual interactions with their partners, or about future relationships and having intercourse with somebody new. The findings suggest that women experience fear and anxiety towards future sexual interactions because of past traumatic experiences of painful intercourse. Some experiences were so traumatic that now even the thought of intercourse can cause negative bodily sensations such as stomach cramping and sensation of the vagina closing. Some of the women's past experiences of intercourse have caused them to catastrophise their pain and be afraid of future sexual interactions. Pain catastrophising has been shown to increased sexual distress in women (Zarbo et al., 2019). However, my research also shows that catastrophizing and the fear of pain led to avoidance of sexual intimacy, which can negatively affect the women's perception of intercourse and their own sexuality. Furthermore, what, and how women discussed their experiences of painful intercourse implies that some or all sexual experiences have been painful and, in some way, traumatic. Subsequently, the whole experience of endometriosis is traumatic.

In summary this section suggests that women with endometriosis are left helplessly to work out how to manage pain with intercourse. The only coping strategies the women came up with were avoidance, medication, positional change or just putting up with the pain. Unfortunately, these coping strategies are not sustainable and most of the women still experience pain with intercourse. I was surprised that many of the women put up with painful intercourse which was due to guilt, embarrassment, societal expectations, and hopelessness. My findings were similar to Di Donato et al. (2014), study which found that women with endometriosis would continue having intercourse despite the pain because sexual intimacy was important in their relationship and because they wished to fall pregnant. However, some women in my study completely avoided intercourse because they feared the pain. Avoidance and continuing despite the pain contributed to feelings of hopelessness, guilt, and that they were less of a woman. Also, my research highlights that the women were not given information on how to manage with painful intercourse and therefore, many of the women have been engaging in unenjoyable sex, view sex as a burden and only an act to please men. These negative attitudes towards sex and engaging in harmful sexual activity can cause the women to further cause harm to themselves physically, emotionally and psychological and to their sexuality. Negative attitudes towards their own sexuality and society’s lack of understanding of the impact of pain with intercourse has on women's sexuality results in the sexual needs of women with endometriosis being ignored.

Impact on their sense of femininity

This section will focus on the impact painful intercourse has had on the women’s feminine roles and sense of femininity. Femininity describes gender identities which are shaped by socio-cultural processes and observations (McCann, 2020). Femininity is embedded in media, news, education and is advertised in a range of environments. Women may engage in many forms of femininity which she adopts consciously, or unconsciously depending on context, expectation of others and life stage (McCann, 2020). Femininity can include a women's feelings about herself and her confidence. Playing the role as a good wife, housekeeper and mother are stereotypical feminine roles which have been defined by society. The feminine role of being a good wife includes pleasing your partner sexually, bearing children and being productive around the house. I was interested to see if the women believed that painful intercourse had impacted their feminine roles and femininity. This is because literature has suggested that women with endometriosis can struggle to fulfil the expected roles of them (Cole et al., 2020).

Feminine roles

> *"I wasn't playing my role properly." (Becca)*

I asked the woman what impact painful intercourse had on their feminine roles. Four women responded that they are unable to fulfil the expected feminine roles of them because of endometriosis. For example, Louise discussed that due to painful intercourse she does not feel like a woman and has no identity as a woman because she is unable to fulfil a main feminine role that other women without endometriosis are able to do.

> *"I don't feel like a woman at all. I don't know if I ever have. But definitely with like not being able to have sex and stuff. I don't have any identity as a woman. I know this is not true, but I feel like it's your one job like biologically your job as a woman is to have sex like and it's just a hole, like, it shouldn't be a problem! like penis not getting hard you can see that's a legitimate problem. This is just a hole, like, all you need to do is like exist and I can't even do that right." (Louise)*

Highlighting that Louise believes that to have an identity as a woman she must be able to have intercourse and reproduce and without these she is not feminine. Kristina was the only participant who mentioned when asked about feminine roles the impact of painful intercourse has on becoming a mother. She illustrated that having a diagnosis of endometriosis impacts a woman's life drastically as she is unable to have pain-free intercourse and may not be able to have children. Endometriosis can lead to infertility thus the implications for women who want to have kids is that they may face years of IVF or having to stop treatment options that stop periods (Bulletti et al. 2010). While only Kristina specifically mentioned children, women with endometriosis are conscious of their timelines of having children. Kristina mentioned the best chance for her to have children is to have them as soon as possible thus putting pressure on her timeline in life. Therefore, Kristina's feminine roles are impacted significantly as she cannot have intercourse let alone try to have intercourse to try to have a baby.

> *"Yep, definitely. When I first found out that it was endo I curled up in a little ball and was like, okay now like now what. I must figure out how to deal with it, then if I can have babies. My partners like what's the rush? and I'm like do I freeze eggs; I've got three years before I'm 30. Then you go into it deeper and you think, okay, so that's getting the Mirena taking out that's going to hurt, getting your period back having your hormones settle back to what they were. And then it's like, oh, well, then I must deal with all that pain that comes with it, because it will but then your meant to have sex while you're sore. And while you're ovulating, and it's like, what. All this shit, so yea I think that my feminine role was definitely impacted." (Kristina)*

What is positive is that six women responded that painful intercourse does not impact their feminine roles significantly. For these women feminine roles were about feeling sexy, accepting their endometriosis but not letting this dictate who they are as women. For example, Regina explains that experiencing painful intercourse does not make her feel less sexy, desirable, and feminine but she accepts that she lives in pain.

Therefore, Regina created a narrative that resists the sick role but says she can be a feminine woman but with endometriosis, it just takes extra effort.

> *"Yeah, obviously it doesn't make you feel sexy, doesn't make you feel like desirable, or, I don't know. The thing is I downplay a lot of my pain because I don't want to be like this sick girl because I don't feel like a sick girl. I live my whole life as I want but I do it in pain." (Regina)*

The impact on feminine roles seems to change for some of the women over time – working on their identity as a woman with endometriosis seemingly takes time and effort. Similarly, the chronic illness literature suggests that when people adopt stoic acceptance and make effort to adapt their life to their chronic illness this allows for better incorporation of their diagnosis into their identity (Wicks et al., 2019). As well as better coping strategies and management of their chronic illness (Wicks et al., 2019). Thus, the women who have put in effort and time to work on their identities as women with endometriosis will be able to cope better with the diagnosis. Bayley discussed that in the past she had let her experiences of pain with intercourse impact her feminine roles and felt she was not fulfilling the expectations on her as a woman. She now understands that it was out of her control and not her fault, thus she did not need to feel that she was not meeting the expectations of a woman. Bayley is seemingly taking control of her life and pulling on a successful narrative, by adjusting her feminine roles within endometriosis and tries to avoid the sick role narrative.

> *"I'm trying to look back then, but my perspectives were different then so trying to come in from today's perspective. I don't think it affected my role regarding being feminine or femininity in general. Because it was something out of my control, it wasn't something I had deliberately done to sabotage myself, that's*

> *my perspective of it. Because I am protective and safeguard over words like masculinity, femininity, vulnerability but it is more because I am trying to work on these things within myself. I am careful I don't say things against my work which is heading in a good place." (Bayley)*

In addition to the internal battle mentioned by the women they also discussed external pressures to fulfil feminine roles including a sexual body. All women in the study had felt pressured to fulfil the role of a sexual woman. This included pressures to fulfil a traditional role of a wife/partner, mother and to constantly please their husband or partner sexually, physically, and emotionally. As well as the pressure from more modern views towards women as being innocent but then sexual, physically slim, beautiful, and well put together, and a sex goddess in the bedroom. These are unrealistic expectations for any woman to fulfil let alone a woman with a chronic illness. These unrealistic expectations further significantly impacted the women's sexuality as they felt they were not good enough. Nine of the women in the study discussed the pressures they face from society by being a woman, but when you add being chronically ill and painful intercourse into this equation the pressure was amplified for these women. For example, Ash discussed the pressures she felt from society to fulfil the feminine role to please a man and to have children.

> *"It makes you feel like you're not a woman sometimes because we are supposed to have sex and please a man. Well, that's like an old-fashioned thing but you know that's what has been drilled into woman. And you're supposed to have babies and stuff and so then going through this and you just get so down on yourself you're like, what is wrong with me and you try to push through it and then you'll end up like almost throwing up because it is so painful. You just feel*

> *like you're less of a woman, and then you're like why would he want to be with me cause I have this wrong with me and it is this whole thing." (Ash)*

Louise and Jade both reflected on why they felt guilty that they were unable to fulfil the expected feminine roles placed on them and they both reported that it was due to the unrealistic expectation society has on women.

> *"But I also don't like how society has both this image that women shouldn't have sex and should be like pure and then an image that they should be really sexual as well. I don't know how you are supposed to choose both." (Louise)*

> *"I just feel like I can't live up to those expectations of what woman should do." (Jade)*

Emphasising the image that society portrays of women to be sexy but not too sexy and the unrealistic expectations placed on women. The external pressure from society, their partners and themselves to fulfil these unrealistic expectations are difficult of women and even more challenging when the women has endometriosis and experiences painful intercourse. This is because pleasing a man and having children evolve around having intercourse. Thus, if a woman with endometriosis is unable to have intercourse it limits the two things that the society's picture of the ideal woman should be able to do; have sex and have children (Cole et al., 2020). Therefore, this makes the woman feel less of a woman and in turn negatively impacts her sexuality. However, most of the women in the study created a successful narrative around having endometriosis and as a woman who experiences painful intercourse. These woman avoided the sick role narrative and instead adopted an identity that was altered to incorporate them as a woman with endometriosis who experiences painful intercourse. Thus, the women's feminine roles were not impacted significantly. Though, the women in the study who took on the sick role narrative their feminine roles were affected negatively.

Femininity

I asked the women the impact painful intercourse had on their sense of femininity. The women understood femininity as their physical attractiveness, feelings about themselves as woman and their self-confidence. Seven women in the study reported that the experience of painful intercourse had negatively affected their sense of femininity. The findings suggest the most common effect on a woman's femininity was that they felt less sexy, feminine, desirable, and lower confidence. The following excerpts illustrate the impact on the women's sense of femininity.

> *"It doesn't make me feel very attractive. Especially when you are bloated and wearing not that nice clothes. Like I won't wear lingerie, or I will look like a baby elephant." (Jade)*
>
> *"Yeah, because you don't feel feminine, at all. Like when you're anxious about it because you feel like when you have sex you should be relaxed and yourself, but you're tense and then it hurts. You just feel so like awful by then you suddenly don't feel sexy or feminine or anything, you are just like a fucking blop that's just lying there in pain asking for a wheat bag." (Ash)*
>
> *"But when I'm puffy It just makes me feel revolting, disgusting, undesirable and like less feminine. I wouldn't want me so why would anybody else?." (Izzy)*

These excerpts illustrate that painful intercourse impacted their femininity around how they felt about their bodies, bodies that were tense and unattractive. The women pulled on metaphors such as 'like a baby elephant' to illustrate how disgusting and bloated they feel. This then leads them to avoiding sex, not only as it is painful but also because they feel unattractive and lacked self-confidence. Jade, Ash, Kristina, and Becca went on to further to discuss that endometriosis and painful intercourse had increased their level of depression, anxiety, and frustration. It also made them put themselves down more as they were unable to fulfil the sexual expectations on them as a woman. Jade and Kristina were prescribed antidepressants to cope. This is common among the endometriosis literature which suggests that women living with endometriosis have a higher risk of developing or worsening their depression and anxiety (Rea et al., 2020).

However, not all women's sense of femininity was impacted negatively. When discussing the impact on their sense of femininity three women have taken time to work on themselves psychologically and emotionally and thus had confidence in who they were as women. For example, Bayley was a very self-aware and an intelligent woman. She had a different perspective of her own femininity after many years on working on herself than when she did when she was younger. She realised that she had no control over her experience of painful intercourse and thus did not allow herself to put herself down as a woman. Instead she questioned why she felt the way she did and realised that a patriarchy society had made her feel that she was less feminine if she was unable to have intercourse. Therefore, she broke away from these beliefs and accepted that experiencing pain with intercourse does not mean she is less of a woman or less feminine. Thus again Bayley illustrates the successful narrative in where she has adopted a stoic acceptance which means she accepts what she cannot control. This has allowed her to incorporate femininity within her identity as a woman with endometriosis and experiences of painful intercourse.

Meredith was also a very strong and confident woman. She knew who she was and did not allow her experiences of painful intercourse to impact her sense of femininity. She has not always been this way and when she was younger her diagnosis and experience of painful intercourse would trigger her depression. Meredith has learnt over the years ways to cope and realised that she has no control of endometriosis, but she can control the way she reacts to it. She tries her best to remain positive and surround herself in a positive environment. Therefore, these coping strategies have prevented endometriosis and painful intercourse to impact her sense of femininity.

> *"I don't think it really has because I can feel like sexy in my outfits and can dress up and all the rest of. Then I'm happy. I am very strong in who I am. If you don't like me fuck off." (Meredith)*

It is interesting that the findings suggest that the women's sense of femininity was affected more than their feminine roles. As these terms can be used interchangeably. Over half of the women indicated that the experience of pain with intercourse had affected their sense of femininity negatively. We can see that the women felt less feminine, sexy and unattractive which also contributed to body dissatisfaction. My research emphasises the importance of finding positive coping strategies to deal with painful intercourse psychologically and emotionally to prevent the women from having a lack of sense of femininity, or feeling that they are incapable as a woman.

Body image

I asked the women in the study whether painful intercourse has altered the way they view their body because a positive body image is important for a person's sexuality. Eight of the women said that their perception of their body image had been affected negatively. Four women discussed that due to painful intercourse they felt that their bodies were betraying them and that they were broken. This was because their bodies were not working how they were supposed to or how the women wanted them too. The body image literature suggests that sociocultural influences the development and maintenance of women's body disturbances (Mills & Fuller-Tyszkiewicz, 2017). Specifically, sociocultural pressures regarding unrealistic expectations on women's appearance which contributes to body dissatisfaction (Mills & Fuller-Tyszkiewicz, 2017). Even though this literature is on fat talk it still has emphasis for women living with a chronic illness such as endometriosis. For example, Ash described how annoyed and frustrated she gets at her body when it does not work.

> *“Yes, I get annoyed at my body. I'm just like, Fuck you. My body doesn’t cooperate. I get mad at my body for endo in general. Every time I am in pain, I can't do things I'm just like, fuck you, but then when I'm trying to have sex it's just like you get so down on yourself and it is awful. You hate your body, no one should hate their body and I feel like especially in today's world.” (Ash)*

Ash illustrates that not only do women with endometriosis have to cope with painful intercourse but also the emotions, feelings and pressure that comes with being a ‘broken’ woman. Becca also felt betrayed from her body when she was unable to have intercourse. She also discussed that she suffered with disconnection between her body and her mental state. This was because her body did not do what it was supposed to do by having intercourse, but she mentally wanted to. This leads to frustration and a sense of betrayal.

> *“I feel like my body's betraying me because the physical doesn't match the mental. So, yeah, definitely, at times, probably more on a bad day but yeah, I feel*

> *like my body's broken. I feel like it's broken or it's just not doing what it's supposed to be doing." (Becca)*

Jade and Regina also described how they viewed their bodies as broken as they were unable to do things that women without endometriosis were able to do.

> *"Yeah, it has changed the way you view your body. I can get really frustrated and kind of, you know, feel broken and let down." (Jade)*
>
> *"I guess I feel quite disconnected from my body sometimes because I'm like why you are hurting me, aren't we on the same game, but that's about it. Yeah, just getting like frustrated sometimes but then remembering there's things I can do to. Like, you know, make myself feel better. So, I'm just going to do those and there's nothing else I can do about it. So just have to accept that." (Regina)*

Jade and Regina both have body dissatisfaction. However, both women during their interviews understood that having endometriosis was not their fault. They both have suffered with depression and feelings of hopelessness thus they were working on trying to not be so hard on themselves as living with a chronic illness is extremely difficult for anyone. Therefore, both these women looked at the positives and what their bodies can achieve such as the ability to conceive children as some women with endometriosis are infertile as a coping mechanism of the feeling of betrayal.

Louise was the only women to discuss how she felt shame towards her body and that she disliked her vagina due to painful intercourse and endometriosis.

> *"I also have problems with shame, like feeling shameful afterwards I don't know why. I have lots of shame about my own body. So other people seeing my body is not my favourite thing."*

> *"But probably like it's more made me aware of my vagina and I dislike my vagina more." (Louise)*

Body image for the women in this study was related to what the body should do and what it should look like. The women used strong language such as 'broken', 'betrayal' and 'shame' to emphasise the hatred they had towards their bodies for not being able to have pain-free intercourse. This language also demonstrates the disconnection from self which is associated with lower comfort with one's own sexuality and sexual activity (Gillen & Markey, 2019). It was disheartening listening to these women's narratives and the sense of hopelessness they projected. The sociocultural pressures of women's body to look and perform a certain way and the internal cognitions towards one's own body contributed to a negative body image for majority of the women. In turn, these perceptions and attitudes have been harmful to the women's sexuality and sense of femininity.

In summary, living with endometriosis and painful intercourse impacts feminine roles, femininity, and body image. Women with endometriosis who experience pain with intercourse are more likely to have negative attitudes and perceptions towards their sense of femininity and body image. The sociocultural pressures and expectations of women are unrealistic (Mills & Fuller-Tyszkiewicz, 2017). For women with endometriosis these expectations are further out of reach. Thus, women are made to feel incapable and broken which contributes to further body dissatisfaction and negative attitudes towards one's own sense of femininity. Although, the women expressed that they felt pressured to fulfil feminine roles many of the women resisted narratives of the sick role and looked through a successful narrative lens. This showed that the women did have positive copings strategies to prevent their feminine roles from being significantly affected by painful intercourse. Also, the women used strong language and narratives to describe their body’s and lack of femininity which emphasised the disconnection some of the women had from themselves as women and their bodies. Thus, highlighting how damaging and traumatic the experience of painful intercourse is on women living with endometriosis and the impact it has on their femininity and body image.

What Does This Mean for Their Sexuality and Them as a Woman?

Throughout the findings we can see that the experience of painful intercourse for women living with endometriosis can impact their sexual function, sexual relationships, sense of femininity and create fear and anxiety towards future sexual interactions. Thus, the impact of these different dimensions has caused changes to the women's attitudes, perceptions, and view on their own sexuality. Sexuality is who we are, what matters to you and how we view ourselves within society (Rao & Nagaraj, 2015). However, sexuality is fluid and changes over time (Rao & Nagaraj, 2015). This section brings the findings together to focus on what sexuality means for the women now and what it means for their sexuality going forward. The women in the study have all been through individual journeys but they all questioned who am I as a woman with endometriosis and as a woman who is unable to have pain-free intercourse? This question had a significant impact on the women's identities and for the future of their sexuality. There were very different viewpoints regarding this question and their sexuality now, a few of these are unpacked below. However, common elements within the women's narratives were the fluidity of sexuality and questioning who they are as women. All women in the study at one point in their journey felt they were broken and incapable as a woman. Izzy and Jade describe how endometriosis and painful intercourse impact on everything that they think about themselves and how both their ex-partners made them feel broken but now they are aware that he did this to them. Regina in contrast feels like the odd one out in society and as a woman. Jade and Regina compare themselves to other women positioning themselves as different to women without endometriosis.

> *"I can't do those things that normal people can. So, yeah, it's just definitely changed the way I think about myself." (Jade)*
>
> *"I guess I see, I see women as like beautiful creatures like so smart. Just beautiful all around like you can literally do anything. Then when I can't do anything. I'm just like, oh I am a shit one." (Regina)*

One woman whose sexuality was impacted the most significantly was Louise. Louise has been seeing a therapist to help her psychologically understand, and cope with endometriosis and painful intercourse. The pain with intercourse was the most severe for Louise and she has not had intercourse for over five years with her partner because of the pain. When discussing the impact painful intercourse has had on her sexuality, she was the only one to discuss it in great detail. I believe this was because many of the women were still unsure what the term sexuality meant and due to the fluidity of one's sexuality. Louise questioned her sexual orientation because she was uncomfortable watching a male penetrate a woman or the thought of that would physically make her vagina clench and she would not find it arousing.

> *"Oh my god, like totally, entirely. I don't have a sexuality anymore. I was worried that I was a lesbian for a while (awkward laugh) not that I am attracted to women. I mean, that's a bit ridiculous but in terms of. Now I'm going to get a little bit TMI terms of like porn I am more attracted to lesbian porn because in*

male to female porn, there's like basically nothing for women. What you see is mostly her either giving a blowjob which I mean, isn't attractive or her getting rammed which just makes my vagina like curl back into me. Because I enjoyed the lesbian porn I was like, am I a lesbian, but I look at actual women, and I am like, no. I've never been attracted to women. When I spoke to (boyfriend) about it and that was very like strange like it was odd for me and him to hear that. Then I also did think I was asexual, but I do like watching porn and stuff. I am still interested in things it's just not with other people and it's entirely because of like pain, fear and pain. It's just hard not to worry about all that stuff. Yeah, so sexuality wise it has affected everything and now I almost felt like I don't have a sexuality." (Louise)

Louise was questioning what was happening to her, what this meant as a woman and what this meant to her sexual identity. The pain she has experienced during intercourse has caused Louise to have negative attitude and view towards her own sexuality and who she is as a woman. Ultimately she does not feel like a woman anymore.

"Yeah, I don't know, I still do feel like I am a female. But I don't feel like I'm a woman, and if I hear somebody use that word about me, I always make me think oh that's weird why would you say that? Whereas I think of other people the same age as me as and I would call them women, but I wouldn't call myself a woman." (Louise)

Thus, Louise has resulted in blocking out any thoughts of her sexuality because for her sexuality means terror and fear.

> *"Yea sexuality is something I don't want to think about. It's like a block in my mind but there's always like little bits in the back of my head that try and come in and I'm kind of like don't want to think about that now. So, sexuality to me means terror and fear." (Louise)*

Louise and Jade also used the term terror in association with painful intercourse. The use of language such as 'terror' is commonly associated with war, hardship and terrorism thus highlighting how damaging the experience of painful intercourse has been on the women's sexuality and the impact it will have on their sexuality in the future.

The benefit of this research was having two interviews and doing the timeline of their endometriosis journey. This was highlighted particularly during Becca's second interview she began to reflect on her endometriosis journey and when she first experienced painful intercourse. As the two interviews progressed and we discussed more deeply about her experiences she realised that experiencing pain during intercourse in her most sexually active years was challenging and it was difficult to develop her sexual identity.

> *"I think it was a lot more difficult in the beginning because when I first had sex, I wasn't in a relationship I was seeing people. I was just trying to find like my sexuality and sexual identity and it was really hard to do that with that going on, because it was like, is this what it was going to be like for me forever. So yeah, it was definitely incredibly hard at the beginning. Knowing how to manage it and trying to figure myself out was hard."(Becca)*

Thus this reflection highlights that the turning point of something isn't right is important for the women's sexual development and the fluidity of sexuality. Sexuality is a developing concept that is complicated by painful menstruation and painful intercourse. Kristina also discussed how her experiences of endometriosis and painful intercourse has led her to believe she is less of a woman and incapable. Kristina reflected on the impact painful intercourse has had on her as a sexual person. Even though there were many aspects of endometriosis and painful intercourse she could not control she could control who she pursed a relationship with. Thus, it was important for Kristina to find a supportive and understanding partner to protect herself and her own sexuality from being damaged further. Kristina reflects back over time on her journey with endometriosis and her sexuality.

> *"Um, it definitely makes you stop and think if it's like, what you actually want. I'm the same as you I'm quite a sexual person and I'm not bothered by one-night stands but rather, going and meeting someone and getting to know them. But having sex with them outside a relationship not bother, but it makes me stop and think should I really be pursuing this person or this thing? Or, you know, whatever it is if it's potentially going to hurt." (Kristina)*

There were three women whose experiences of painful intercourse and endometriosis has led to a positive impact on their sexuality. However, it must be noted that these three women have worked on themselves and have been actively trying to improve their attitudes towards their sexuality. For example, Bayley and Meredith are both two of the older women in this study who were at different stages than the other women with coping and managing with endometriosis psychologically. These women have accepted endometriosis and painful intercourse is out of their control and thus have worked on the things in their lives that they can control. Throughout this acceptance journey they have both become more confident in who they are as woman and actively try to have a positive attitude and perception of their sexuality.

> *"Personally, has it affected my sexuality? I think because I am working on a lot of things and acceptance to do with things with my body I would try and take the good out of the situation and know that it was meant to happen. There were maybe times that if it happened regularly, I admit I would get frustrated because I love to be intimate in that regard. So, dealing with my frustrations if it happened regular would be my main focus point as to what I would work on. But regards to my perception of my sexuality, I don't feel like it has affected me too much because it doesn't change my authentic self or vulnerability it just switched me into a different kind of vulnerability as you're going from getting pleasure, being emotional, love to another element of pain. So, you had this type of vulnerability and now it has shifted you into a different state of vulnerability." (Bayley)*
>
> *"I don't think it has. I still feel feminine still feel pretty when I want to still feel fucking butt ugly when it's a bad day. But I don't think it really has cause I'm pretty confident in me. It stills affects us but not to the point where we're like oh you know what like I'm not worthy, or I'm not sexy or I am not going to put myself down for it." (Meredith)*

Meredith in her narratives is quite forceful using more swear words than Bayley. While both women are happy in their sexuality they are coping with endometriosis quite differently. Meredith is determined to not let endometriosis or painful intercourse control her and resists the illness narrative thus throughout the interviews she tries to convince me that it does not affect her drastically through strong language. Additionally, Rose acknowledged to me that painful intercourse has changed her views towards sex and the spontaneity of sex. She also reflected on her experiences and acknowledged that her experiences have made her who she is, and she has learnt more about herself as a woman and her sexual identity.

> *"It's kind of change my attitude toward sex and in terms of sexuality. I'd say, although it's kind of stopped me becoming okay with the spontaneity of things. It's also made me okay with being more relaxed about sex as well. I've become more relaxed because I'm comfortable with who I am now, so it's kind of changed my whole mindset in a way. Like it's good and bad, because obviously it's painful, but in some ways I've kind of got to know myself as well and I know what works or doesn't." (Rose)*

It is important to note that this does not mean to say the women have mastered coping with endometriosis and painful intercourse as the unpredictability of the disease can set the women back at any time. For example, Meredith discussed with me a time when she was at a family event and family friends asked her when she was going to have children numerous times. However, Meredith has had a hysterectomy and is unable to have children. She said, "*Every time I hear someone says that a woman is useless because she can't have children it automatically just triggers something that I never thought I would end up hearing, every single time someone says that I am like mmm and it brings me down."* Meredith has learnt to accept her diagnosis of endometriosis and looks at the positives of not having children. For example, she said she would not want to pass her genes down to her daughter and watch her suffer and that she will be a great aunty. Therefore, the unpredictability of endometriosis makes it difficult to cope all the time and the fluidity of one's sexuality also suggests that attitudes, perceptions, and views on one's sexuality it consistently changing. However, these women had better coping mechanisms and confidence in themselves which they can pull on when they are triggered to get back into a positive mindset. This gives hope to the other seven women in the study that through personal development and acceptance that they will be able to cope and manage their experiences of endometriosis and painful intercourse more efficiently, which in turn led to more encouraging attitudes and perceptions on their sexuality.

In summary the experiences of pain during intercourse for women with endometriosis can influence their attitudes, perceptions, and views towards their own sexuality. As well as the pressure from societies, female history regarding sex and sexuality, fear, and their partners. Thus, highlighting that sexuality is fluid, complex and needs constant working on to maintain a healthy and positive sexuality. The lack of information regarding sexuality and painful intercourse for women with endometriosis make it challenging for these women to manage and cope with their experiences of painful intercourse. Most of the women in the study now hold negative views, perceptions, and attitudes towards their own sexuality and thus this will impact their sexuality further in the future. This emphasises the sense of hopelessness these women experience and the need to work on one’s own sexuality. Subsequently, a few women in the study have begun the journey of developing more positive attitudes and perceptions towards their sexualities but have expressed the unpredictability of endometriosis and painful intercourse can cause this to be difficult.

Chapter Five

This chapter brings together my findings. It will highlight the complexity of sexuality, new information and contribute knowledge to the available literature on endometriosis in New Zealand. I will conclude by discussing what future research should focus on and possible interventions.

Discussion

This research aimed to find the impact painful sexual intercourse has on women with endometriosis sexuality and their sense of femininity. The analysis revealed a similar journey for the women so three key narrative points were found which had further narrative subpoints. The first was something isn't right with the subthemes of pain, normalisation of pain, and the turning point. The second who am I as a woman living with endometriosis and painful intercourse? Is comprised of sexual function, sexual relationships, fear and anxiety towards future sexual interactions and impact on their sense of femininity. Lastly, what does this mean for their sexuality as them as a woman. These narrative points highlighted the complex way that endometriosis and the experience of painful intercourse can affect female sexuality.

The normalisation of pain with menstruation and intercourse

The normalisation of women's menstrual and pelvic pain illustrates the challenges women with endometriosis face at the beginning of their journey. These include distinguishing whether their pain is normal or not, being misdiagnosed and diagnostic delays. Medical and social discourses surrounding menstrual pain's normalisation have been dominant within the endometriosis literature (Denny, 2004b). Medical professionals have told women who experience menstrual pain that it is part of being a woman, and they are unlucky (Denny, 2004b). Also, educational institutes focus predominately on female anatomy, biology, and reproduction for female sexuality and sexual function (Cameron-Lewis & Allen, 2013). Many of the women in this study reported that during sex education, it was never discussed or taught that intercourse should not be painful. Thus, this research illustrates how family members, friends and educational institutes contribute to the misinformation of pain with menstruation and intercourse. All the women in the study suffered from severe pain for many years before seeking medical attention and receiving an official diagnosis of endometriosis. However, this research found that the first experiences of painful intercourse contributed to a sense that something isn't right and after the pain persisted women began to seek medical attention. All women reached a turning point to realise that the pain they were experiencing was not normal. This emphasised the importance of correct information and adequate education on menstruation and sex to teach women to seek medical attention earlier.

The complexity of sexuality

During the developmental years, teenagers try to work out who they are as women and as sexual beings. The formation of one's sexuality and sexual identity are derived and based on our interpretation of personal experiences (Horley & Clarke, 2016). When the women in this study began experiencing painful intercourse, the average age was 17.6 years of age. These painful intercourse experiences contributed to developing negative attitudes and perceptions of one's sexuality early on. The dominant discourse surrounding sexual intercourse and sexuality is sexual function. Thus, research typically only focuses on the physical and biological aspects of sexual functioning (Melis et al., 2015). Research suggests that women living with endometriosis who experience painful intercourse also experience sexual functioning problems. Evangelista et al. (2014) reported that's women with endometriosis who experience pain with intercourse have lowered sexual desire, arousal and orgasms. However, my research found that women still experienced sexual desire and could become sexually aroused and achieve orgasms and two of the women used orgasms as a method to relieve cramping. It was the build-up of fear and anxiety of having penetrative intercourse and the emotional aspect that prevented the women from having intercourse. My research highlights the complexity of sexuality for women with endometriosis and the importance of a holistic definition of sexuality. It is a combination of multiple dimensions such as sexual function, sexual relationships, fear and anxiety and sense of femininity that can impact a women's sexuality.

Sexual relationships are another dimension that can affect a woman's sexuality. The experience of painful intercourse can cause problems in communication and intimacy. This is supported by Moradi (2014), who reported that decreased sexual intercourse resulted in infidelity, relationship distress and breakups. Women find it difficult to communicate their sexual issues because there is a lack of understanding and discussion around sexual issues, and sex and women are made to feel uncomfortable communicating these issues. My research highlights that poor communication, and the fear of rejection are significant factors contributing to problems in sexual relationships. Also, many of the women in the study held the belief that sexual relationships must have penetrative sex to be a good functioning relationship. These expectations contributed to further fear and anxiety towards sexual intercourse and in turn, contributing to negative perceptions on their sexuality.

The fear and anxiety surrounding sexual intercourse and future sexual interactions played a significant role in the women's negative attitudes and perceptions of their sexuality. Fear and anxiety of sexual intercourse resulted in the women avoiding intercourse and sexual intimacy which contributed to feelings of guilt, embarrassment, and hopelessness. This is similar to Pluchino et al. (2016), who found that women with endometriosis who avoided sexual intercourse experienced increased feelings of guilt, embarrassment, and shame. There is limited information on managing and coping with painful intercourse. My research highlights that the women living with endometriosis and painful intercourse used avoidance, sexual positional change, medication, or they put up with painful sex. The women were using these strategies, particularly having intercourse despite the pain, as there is little else available to them; arguably engaging in harmful sexual behaviour. Interestingly the women did not use this narrative directly but rather suggested something was wrong with them, they were broken and less of a woman as their bodies have betrayed them. They went on to suggest sex was important to maintain relationships, because they want intimacy, and only one woman specifically mentioned sex for the purposes of having children. Two participants also mentioned that sex means terror and intense fear and one used the word traumatic. Thus sexuality is changed for women with endometriosis. It is not a simple matter that sexual functioning is impacted, but rather their sense of femininity and sexuality are shaped by their endometriosis, pain and sexual experiences.

Additionally, the pressures from society on women to look and act in a particular way are unrealistic. These expectations are further out of reach for a woman that lives with a chronic illness such as endometriosis. Women try to fulfil these societal expectations of them as women to have intercourse and reproduce which both can be impacted by endometriosis. De Graaff et al. (2016) illustrates that women with endometriosis are made to feel that they are less of a woman if they cannot fulfil the expected feminine roles. However, the feminine roles for the women in my study were not significantly affected by painful intercourse. The women pulled on successful narratives and avoided taking on the sick role. The research revealed that women did have poor body satisfaction and they compared themselves unfavourably to women without endometriosis which has been shown in other research (reference). This research did show that the women used disconnection narratives such as hating parts of their bodies linked to sex such as their vagina's, desiring sex but not being able to have sex, and referring themselves as not normal. The disconnection between the women's body and themselves as sexual and feminine women is concerning thus, suggests the dominant discourse of powerful women having lots of sex or having sexual freedom are silencing how traumatic the experience of painful intercourse and endometriosis is.

Overall, this research has highlighted how the experience of painful intercourse can impact various dimensions of women with endometriosis sexuality. The experiences of painful intercourse can negatively impact sexual relationships and femininity, which contributes to negative perception, attitudes and views on their sexuality. However, the experience of painful intercourse did not significantly affect women's sexual functioning. This research also highlights the fluidity of sexuality; thus, sexuality can change across a person's life span. This was shown in the research with three women who had sought psychological help and actively worked to change their attitudes towards painful intercourse which has contributed to a more positive perspective on their sexuality. Although, these women have not mastered coping with endometriosis and painful intercourse this shines hope to the other women that with determination and support, they too are able to change their views and perceptions on their sexuality.

The impact painful sexual intercourse has on women with endometriosis sexuality, and their sense of femininity is predominantly negative. This research revealed that sexuality and femininity are intertwined and develop alongside each other, so painful menstruation and painful intercourse contribute to these. The term sexuality is understood to be able to have sex and the ability to reproduce. Within research, sexuality is used interchangeably with several other terms, such as sexual health, sexual problems, sexual dysfunction, and sexual functioning (Cleary & Hegarty, 2011). This lack of consensus about sexuality as reflected in the participant’s narratives suggests a lack of knowledge around the term sexuality both in layman and academic spheres. The definition of sexuality in this research was a fundamental aspect of humanity encompassing sex, sexual orientation, reproduction, pleasure, gender roles, gender identities and intimacy (Rao & Nagaraj, 2015). I used a holistic version of sexuality similar to Cleary and Hegarty (2011), who used Woods (1987) framework to understand sexuality in women with gynaecological cancer. Firstly, sexual function is a women’s ability to give and receive sexual pleasure which can be further divided into concepts of the sexual response cycle such as sexual desire, sexual arousal, and orgasm. Secondly, sexual self-concept relates to the image that a woman has of herself and evaluating one’s competency in feminine roles. Lastly, sexual relationships are intimate relationships that a woman shares her sexuality with another person. This can be divided further into communication and intimacy among partners. This sexuality definition has not been widely used in research and not with women living with endometriosis before. This definition was useful for the women in this study, particularly when considering sexual function as the participants still desired sex, got aroused and could orgasm. The other elements of the framework also applied to the women who had issues with intimacy and problems with communication with partners. Pain (menstruation and sexual intercourse) however was not captured sufficiently in the framework, so I used the fear-avoidance model.

Pluchino et al. (2016), adapted the fear-avoidance model to endometriosis patients. The model suggests that women with endometriosis experience of sexual pain can induce a fear and avoidance reaction, leading to decreased sexual desire, arousal, and distress in women. The experience of sexual pain has biopsychosocial variables including fear, guilt, catastrophising, expectations and mental health problems, leading to avoidance of sexual intercourse and can escalate into a sexual dysfunction or sexual distress. The sociocultural context and the women’s partners’ view on the pain with intercourse are also important factors contributing to sexual distress, decreased sexual desire, sexual arousal, and avoidance. This can cause a lack of lubrication, increased chronic pelvic pain and pain with intercourse. The model was useful for this study because fear based on past experiences and the worry about future sexual experiences contributed to bodily sensations such as tightening abdominal muscles or vagina, nausea, and visible signs of distress. The participants had all experienced some degree of distress, including depression and anxiety. What this model did not capture was that sexual desire, sexual arousal and orgasms were distinct for these women. Thus, in conjunction, the holistic view of sexuality is necessary for women with endometriosis alongside consideration of the fear and avoidance model. But what these models do not address is the full extent of the impact of painful intercourse had on the women’s femininity and what it means to be a woman.

The use of a feminist theoretical perspective in this research challenged the views and opinions on women's sexuality and sexual experiences that have been socially constructed and influenced by the patriarchy. It highlighted the limitations of gender for women with endometriosis such as diagnostic delays, normalisation of period pain and pain with sexual intercourse and historically the suppression of female sexuality. However, when sex is not pleasurable but is viewed as something to be endured to maintain a relationship or avoided due to the pain by women with endometriosis, feminist understandings of sexuality and sexual empowerment are not necessarily that helpful. Suggestions that women control their bodies and their sexuality when they live with an unpredictable largely uncontrollable disease are not beneficial. The women in this study were aware of patriarchal views of women’s bodies, women’s health and female sexuality and resisted, but often this took time and only led to a sense of acceptance of the diagnosis and their gendered limitations rather than success and freedom from the patriarchal views.

Both qualitative and quantitative research has highlighted that the experience of sex is influenced by endometriosis for many women. Interestingly, very few studies have considered the journeyed nature of endometriosis and have not asked about experiences of painful intercourse across the women’s lives. The use of narrative analysis was able to capture these journeys and accounted for the structure, and context of stories and cultural context in which the women's stories were told giving the women a voice to share their experiences. This research has shown that many of the women’s first sexual encounter was paired with pain, thus during the time of women’s development of sexuality. The development of sexuality is a critical time for women to work out what they like, do not like, navigate sexual relationships, who they are as a woman, what femininity means to them and their roles as a woman. This is already a difficult period, but with a chronic illness that causes painful intercourse, this is even more challenging. Additionally, there is a lack of research that considers if women having painful intercourse for the sake of their relationship refers to this as a sacrifice or fulfilling feminine expectations.

Furthermore women with endometriosis experiences of painful intercourse and painful menstruation are often not taken seriously by doctors and are a turning point for women to seek medical attention. However, medical treatment and even a diagnosis of endometriosis only go as far as exploring biomedical reasons for the pain. There is currently a lack of treatment options to help reduce pain with intercourse. This research has also shown that attitudes of young women and sexual education in schools and society are not currently helping women with endometriosis. Instead, it is leading to misunderstandings and normalisation of pain. Despite the challenges that women negotiate as a result of endometriosis, sexuality is clearly a very important part of their lives. The way we perceive, express, identify and view our own sexuality is part of our identity and is deeply related to our sense of wellbeing. It is important for women with endometriosis to have a positive sense of sexuality, however this is challenging when there is a lack of accessibility to support and assistance with sexuality.

Future research

Endometriosis requires more awareness and knowledge; thus, more research within the endometriosis community is required. Future research should focus on exploring women with endometriosis experiences of painful intercourse in menopausal women. There is limited research on endometriosis in these age groups, whether this is because after menopause endometriosis symptoms are speculated to have reduced, or the lack of knowledge and discussion surrounding older women’s sexual experiences and sexuality, or other unknown factors. The prevalence of endometriosis is 5% between 25 and 35 years, and there is a 2.2% prevalence of endometriosis for postmenopausal women (Alio, 2019). The data on postmenopausal endometriosis is limited and confined mainly to case reports. However, it would be valuable to investigate whether postmenopausal women with endometriosis still experience pain with intercourse and then explore what coping strategies they used to deal and manage painful intercourse with being in long-term relationships. Thus, this would give insight into different coping strategies that younger women who are in newer relationships could use to manage pain with intercourse.

Future research could also focus on exploring endometriosis within specific ethnic minority populations and their experiences with painful intercourse. There is a lack of statistical information on women with endometriosis from these populations in New Zealand whether this is due to the lack of accessibility to medical professionals, or cultural practices surrounding menstruation, sex and sexuality or other unknown factors. However, it would be valuable to research the incidence and experience of endometriosis among Māori and Pasifika women in New Zealand. This could provide new data to then be compared with the Pākehā population. This is important because the discourses surrounding endometriosis and women’s bodies are westernised and take a biomedical stance. For example, before colonisation menstruation was empowering for Māori women and was classed as *tapu*; however, western society has cause menstruation to be viewed as dirty and shameful (August, 2005). Additionally, the westernised discourses surrounding endometriosis and women’s bodies do not incorporate the women’s lived experiences or cultural views. Consequently, culture and history can affect illness incidence and how a woman experiences it (Stodart, 2013). Further, some cultures have different attitudes, perceptions, values and practices surrounding sex, thus exploring whether one's culture or cultural practices could be used to manage painful intercourse would be insightful.

Lastly, future research could focus on exploring women with endometriosis sexuality in same-sex relationships as the literature is predominantly from women in heterosexual relationships. There is a limited amount of information regarding endometriosis and same-sex relationships. It would be valuable to research whether the experiences of women's sexuality regarding role expectations, the childbearing, social experience of endometriosis, and intimate relationships differ for women in a same-sex relationship. Additionally, this research highlights the demands for specific interventions targeted at reducing the pain with intercourse. Specific interventions could include viewing painful intercourse at a broader clinical perspective, considering potential psychological and interpersonal consequences. Also, providing psychological support such as a psychologist or sex therapist for women with endometriosis to help manage and cope with painful intercourse. These two interventions could reduce feelings of being an incapable woman, a burden, reduce mental health problems, and increase positive attitudes towards one's sexuality.

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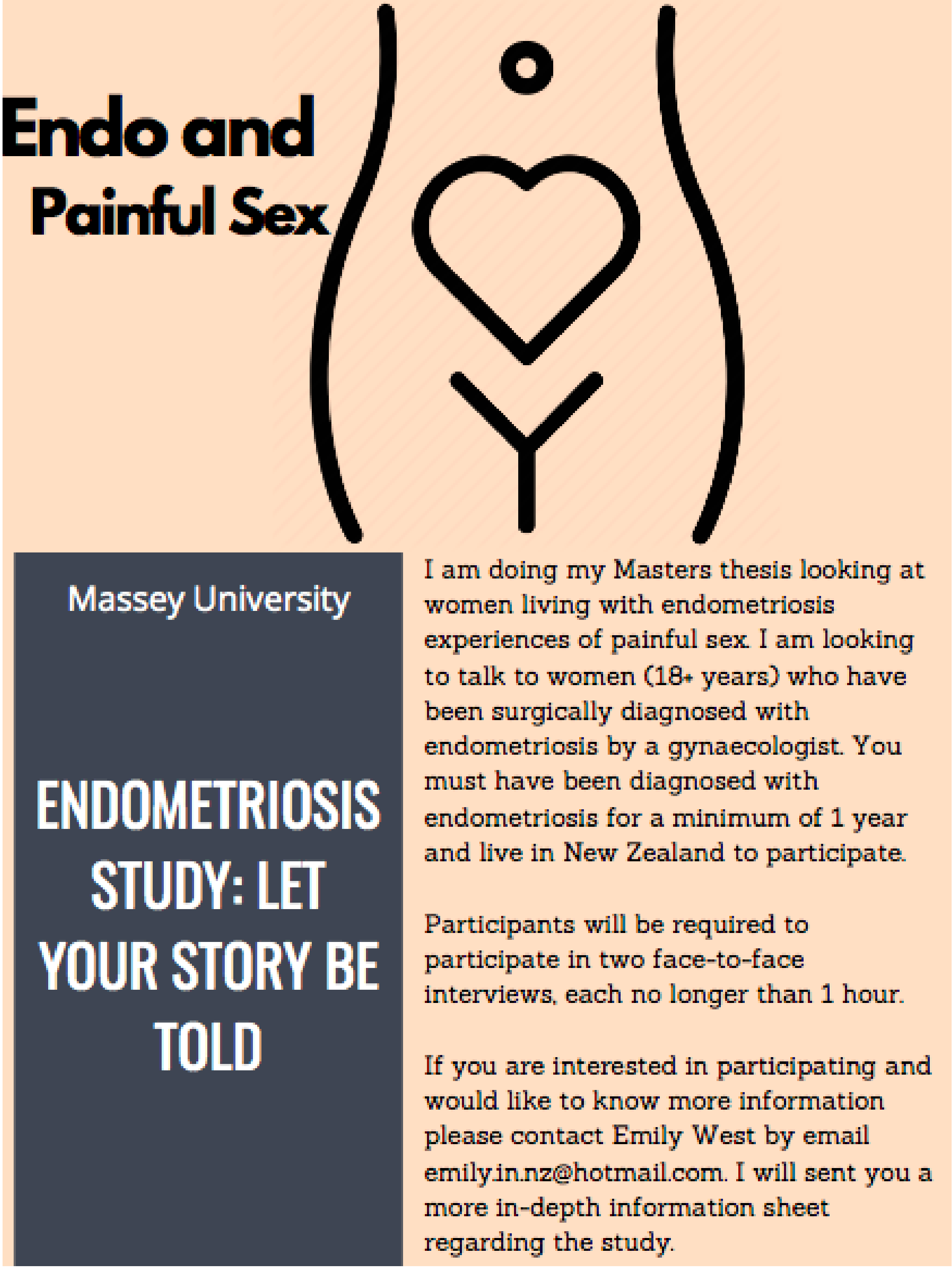
Appendices

Appendix A: Recruitment poster



Endo and Painful Sex

Massey University

ENDOMETRIOSIS STUDY: LET YOUR STORY BE TOLD

I am doing my Masters thesis looking at women living with endometriosis experiences of painful sex. I am looking to talk to women (18+ years) who have been surgically diagnosed with endometriosis by a gynaecologist. You must have been diagnosed with endometriosis for a minimum of 1 year and live in New Zealand to participate.

Participants will be required to participate in two face-to-face interviews, each no longer than 1 hour.

If you are interested in participating and would like to know more information please contact Emily West by email emily.in.nz@hotmail.com. I will sent you a more in-depth information sheet regarding the study.

Appendix B: 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

Women living with endometriosis experiences of painful sex

INFORMATION SHEET

My name is Emily West and as part of my Master of Science Thesis in Psychology I am doing research on women living with endometriosis experiences of painful sex and how this has impacted their sense of femininity and what it means to be a woman.

Project Description

Endometriosis is a common inflammatory disease estimated to effect 120,000 girls and women in New Zealand. The presentation, diagnosis and management of endometriosis is individualized, and it is not well understood even in the medical profession. This research is particularly interested in exploring your experiences of painful sex due to endometriosis and what strategies you use to cope. I am interested in this topic as sexual intimacy is an important part of an intimate relationship, there is little research that considers the impact of painful sex due to endometriosis on sexuality and identity as a woman. Sex is also something that is supposed to be pleasurable and there is little voice given to women for whom sex is painful. I will ask you about your diagnosis journey, current symptoms, and both past and current experiences of painful sex.

You are invited to take part in this study. Whether you decide to take part or not is your choice. If you do not want to take part, you do not have to give a reason. This Information Sheet will help you decide if you want to participate in this study. It outlines why I am doing the study, what involvement is needed from you if you wish to participate, any benefits or risks there may be, and what would happen at the completion of the study. Before you decide you may want to discuss the study with other people such as partners, family, whānau, friends, or health providers.

Who can participate in this project?

Participants will be recruited by utilizing social media and through the Endometriosis support Facebook pages with permission from the Facebook group administrators.

Inclusion criteria

- Women over the age of 18 years of age.

- Have an official diagnosis of endometriosis by a gynaecologist from laparoscopy surgery. Participants can have any stage of endometriosis as the stage is not necessarily associated with the severity of symptoms.
- Have experienced or currently experiencing painful intercourse as a result of endometriosis.
- Have had an official diagnosis of endometriosis for at least 1 year so that enough time has passed for women to have healed from laparoscopy surgery and so symptoms are not mistaken for post-surgery recovery pain.
- Reside in New Zealand and for face-to-face interviews you will need to reside in Auckland.
- Participants of any ethnicity are invited to participate; however, the interviews will be conducted in English.

If you participate what will you be required to do?

If you wish to participate you will be invited to take part in two semi-structured interviews, at a time and place that we mutually agree on. I would prefer to conduct the interviews face-to-face but understand you may like to conduct these via Zoom or Skype. The first interview will focus on your diagnosis journey and we will start to complete a timeline of events. I will leave the timeline with you and then come back at least one week later for the second interview. The purpose of the second interview is to discuss your experiences of painful sex due to endometriosis. The timeline will be created together to help reflect on your journey with endometriosis and painful sex. Each interview should take no longer than one hour.

Due to the challenges of living with endometriosis I know that it may be difficult to discuss your experiences. I do not anticipate harm or discomfort as part of this research however, I do acknowledge that this disease is difficult, and it may be hard for you to discuss some topics. I live with the disease myself and understand the battle of this disease and the effect it can have on your relationships, work and social lives and mental health. You do not have to talk to me about anything that you do not want, you can stop the interview at any time, and you have the right to ask questions. If you would like to withdraw from the study, you can withdraw up to two weeks after the second interview.

Data Management

The interviews will all be recorded on a voice recorder with permission from the interviewees. The data will be stored securely and only the researcher and supervisor will have access to this information. Once the interviews have been transcribed you will be provided with a copy of your transcript, which you may edit and make adjustments if you feel necessary.

After you have read through your transcript a Transcript Release Authority Form will be provided for you to sign if you wish, allowing the researcher to use the information in the transcription for the write-up of the research.

On completion of transcription, the transcripts will be coded for themes and ideas present throughout the interview. To ensure autonomy, all identifying information will be removed from the transcript, the data and the write up of the research. However, there is the possibility that your response may be used in other research publications.

All personal information and data will be stored on a password protected computer and on a Massey University hard drive until the research is complete in February 2021, and then it will be deleted. An anonymous form of your transcript and coding will be stored indefinitely in Massey H drive as the data saved to Massey University's network is backed up, maintained and managed, secure, replicated and protected against viruses.

Participant's Rights

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

- Decline to answer any particular questions
- Withdraw from the study at any time up to two weeks after the second interview
- Ask any questions about the study at any time during participation
- Provide information on the understanding that your name will not be used unless you give permission to the researcher
- Be given access to a summary of the project findings when it is concluded
- Ask for the recorder to be turned off at any time during the interview

Please contact the research or supervisor if you have any questions about the project.
Contact details below:

Researcher:	**Supervisor:**
Emily West	Kathryn McGuigan
Email: emily.in.nz@hotmail.com	K.Mcguigan@massey.ac.nz
Mobile: 0210304988	09 414 0800, ext. 43115

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 20/18. If you have any concerns about the conduct of this research, please contact Dr Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43347, email humanethicsnorth@massey.ac.nz.

Appendix C: Consent form

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I have read, or have had read to me in my first language, and I understand the Information Sheet attached as Appendix I. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I agree/do not agree to the interview being sound recorded.
2. I wish/do not wish to have my recordings returned to me.
3. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

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

Signature: ______________________ Date: ________________

Appendix D: Confidentiality agreement form

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MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Women living with endometriosis experiences of painful sex.

CONFIDENTIALITY AGREEMENT

I .... (Full Name - printed)

agree to keep confidential all information concerning the project ....

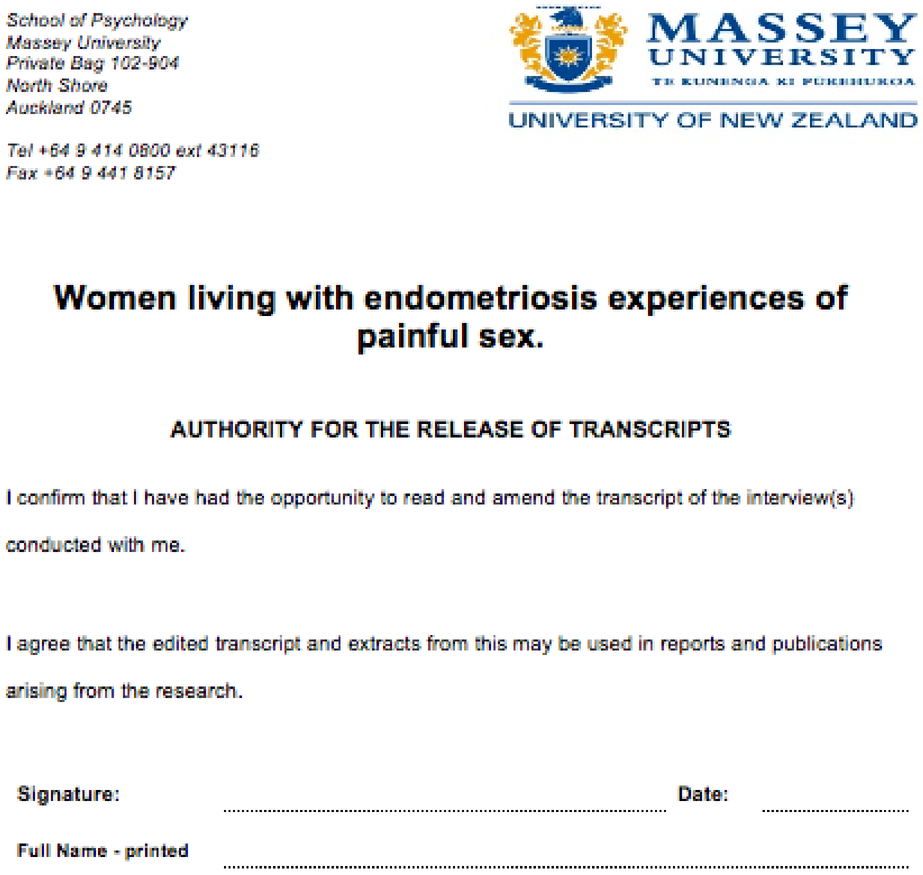
....

.... (Title of Project).

I will not retain or copy any information involving the project.

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

Appendix E: Authority for the release of transcripts form



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Women living with endometriosis experiences of painful sex.

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

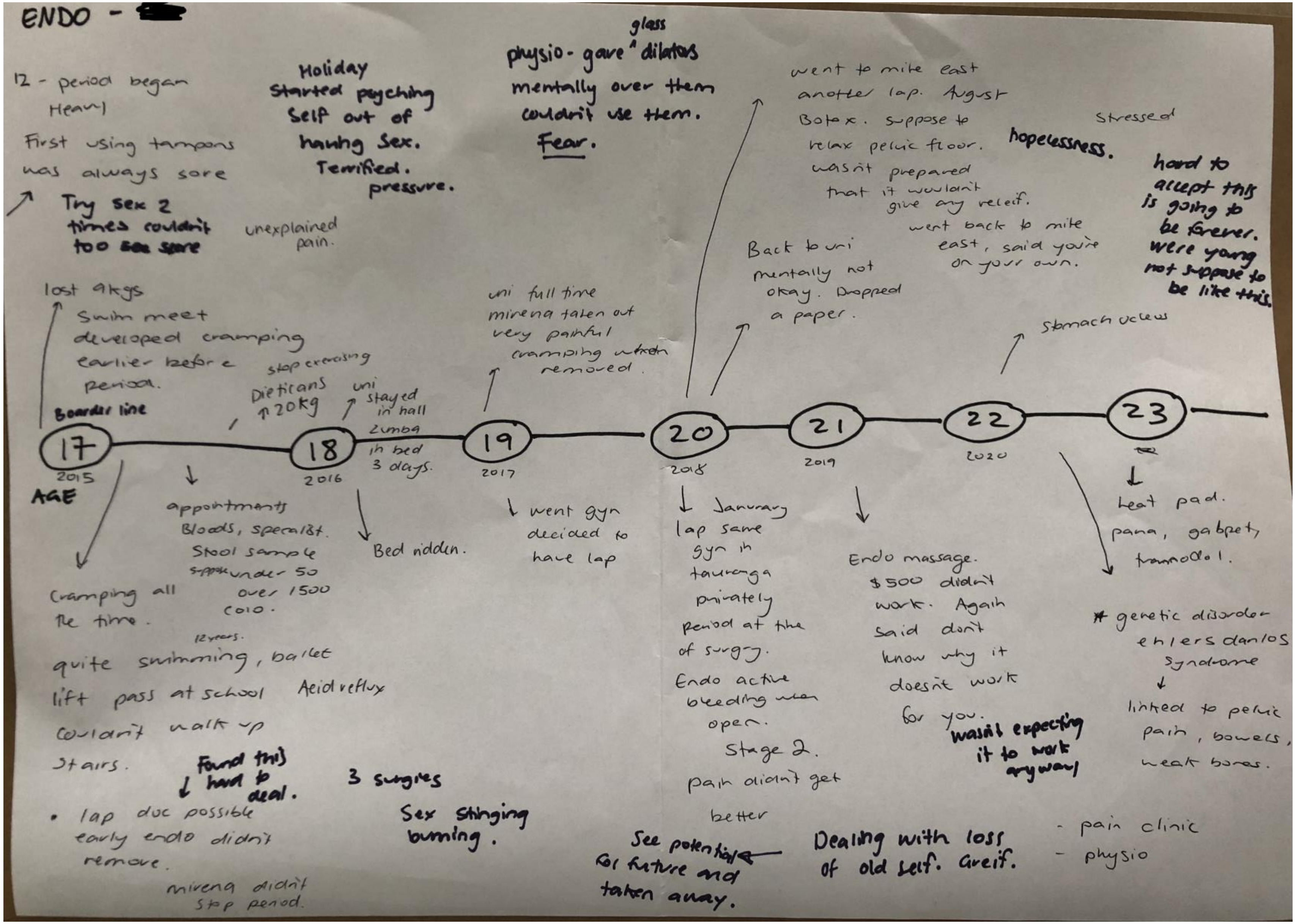
I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

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

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

Full Name - printed ....

Appendix F: Timeline example



Appendix G: Interview schedule for the first interview

Interview one:

Topic: The woman's journey to getting diagnosed and painful sex symptoms

Can you tell me when you first started experiencing symptoms of endometriosis?

Can you describe your symptoms?

What happened when you first started experiencing these symptoms?

How long was it until your doctor mentioned that you could have endometriosis?

What was involved in the investigations for endometriosis that you have had? E.g. ultrasound, specialist appointments

How long did it take to get an official diagnosis?

How long did you live with endometriosis before you received and official diagnosis?

What treatments have you done or currently using for endometriosis symptoms?

How many surgeries have you had for endometriosis?

How did your diagnosis of endometriosis change your gender role? e.g. role you play around the house, work, friends etc

When did you first experience painful intercourse?

Can you tell me what happen when you first started experiencing painful intercourse?

Can you describe the pain?

Have you discussed with your doctor or gynaecologist about painful intercourse?

What suggestions have you had by medical professions to help with painful intercourse?

End interview with an open discussion around the current interview topic, challenges, or any questions the participants have.

Appendix H: Interview schedule for the second interview

Interview two:

Topic: Management of painful intercourse and the consequences

Does sex become more painful at certain times e.g. during ovulation, week or your period etc?

What are your cultural or religious beliefs about sexual intercourse and sexual intimacy?

Are periods discussed within your culture or religion?

Is sex something that is spoken about within your cultural or religion?

Is painful sex something you can discuss with your family and with your partner?

If you are unable to talk to your family or partner about painful sex then who do you discuss it with?

Is sexual intimacy in a relationship important to you?

What does sexual intimacy mean to you?

What does sexuality mean to you?

Did/does painful sex stop you from having sexual intimacy? Sexual intimacy can be kissing, oral sex, dates etc.

Did/does painful sex stop you from having sexual intercourse?

How does or has painful sex affected your relationship/s?

How has painful intercourse affected your sexual partner? E.g. have you ever broken up with a partner due to painful intercourse

In what ways does painful sex affect your feminine roles e.g. wife/partner/get pregnant/just being able to have sex as woman are told they must have sex/babies to be a woman.

In what way does endometriosis or painful sex affect your

How do you feel when you cannot have sex due to the pain?

Do you experience fear or anxiety towards about sex even when you are not having sex? e.g. in the middle of the day or going about normal life activities.

Do you look forward to sex? E.g. sexual desire

During sexual intercourse do you reach orgasm frequently?

Do you have any other conditions that may prevent you from enjoying sex? E.g. depression

Are you able to become aroused or lubricated during foreplay?

Have you been having sex and had to stop due to the pain being too painful?

Have you continued to have sex despite the pain and if so, why is this?

Has painful sex affected your sexuality?

How often do you have sexual intercourse?

Do you need to schedule when to have sex now?

Have your symptoms of painful sex altered the way you see yourself?

Has painful sex altered the way you view your body?

How did you manage painful sex at the beginning?

How do you manage painful sex now?

What does being a woman mean to you?

Has painful sex altered the way you see yourself as a woman?

Has painful sex impacted your sense of femininity?

Sensitive questions:

> **Are you able to have children? If not is this due to the endometriosis**
>
> **How important is it for you to become a mother?**
>
> **If a woman cannot have children how do you believe they are viewed?**
>
> **How do you/or would you view yourself if you cannot conceive?**

Has a medical professional ever said to you that to treat endometriosis you should get pregnant?

What do you wish you knew about endometriosis at the beginning of your journey?

What do you wish you had had during your journey of endometriosis to help you cope?

What else would help you cope and deal with painful intercourse?

What else would help you cope better with endometriosis?

End interview with an open discussion around the current interview topic, challenges, or any questions the participants have.

Appendix I: Summary of participants journey using the timelines

Izzy: Izzy, was a 35-year-old woman in a long term relationship, with one child from a previous relationship. She had been living with endometriosis symptoms for over 20 years without her knowing until her most recent laparoscopy.

Izzy remembers when she was 15 years old and would miss days off school due to excruciating menstrual pain. She would put a hot water bottle straight onto the skin of her stomach and scream into a pillow. Izzy believed it was normal to experience pain with menstruation. She went on hormonal contraception at age 15, but this contributed to suicidal thoughts and depressive symptoms; thus, she discontinued the pill. Izzy never spoke to a doctor about her menstrual pain until she was 22 years old as she assumed menstruation pain was normal. She had a procedure at age 22 where gynaecologist blew up her uterus with CO2 to investigate her pain but was told everything appeared ‘fine’. After this procedure, she got the Mirena inserted, but once again, this affected her mental health drastically and got it removed shortly after.

Izzy became sexually active at age 14 but started to notice pain with sexual intercourse when she was 17. She described the pain after sex as cervix was bruised. She went through most of her sexually active years, thinking that painful sexual intercourse was normal.

While in a relationship when she was younger, Izzy did not use hormonal contraception for five years. She fell pregnant with her only child at the end of those five years and always thought it was odd she did not fall pregnant earlier. Izzy realised how lucky she was to be able to conceive while having endometriosis. It was not until she was admitted to hospital for an emergency D&C procured when she was in her early thirties, was endometriosis suggested. She was given an ultrasound before the procedure at the hospital, and it was the ultrasound technician that said she might have endometriosis and adenomyosis. This was never put on her records, and no further investigation was taken.

When Izzy was 34 when she had enough of living in constant pain and sought medical advice, her doctor referred her to a gynaecologist, who performed a laparoscopy on her shortly after. She was officially diagnosed with endometriosis and adenomyosis during this procedure. However, the specialist told Izzy that he ablated her endometriosis as he said he was unable to excision it or it would cause scar tissue. At the time of diagnosis, Izzy's specialist also told her that a hysterectomy was the only option and gave her littler information about endometriosis. Izzy was unhappy with his dismissive attitude and thought he had appalling bedside manners. After surgery, Izzy's pain became worse and unbearable, causing her to drop hours at work.

Izzy's seemed sad at the fact that she was unlikely to have any more children and that the option had been taken away from her. However, she is looking at other options such as egg freezing and is seeking more information before she has her hysterectomy.

Ash: Ash was a single, 24-year-old woman employed by Chanel. Ash began the interview by telling me that since she can remember, she has always had terrible menstrual pain. It was that bad that she would often pass out and vomit due to the intensity of the pain. She doesn't remember a time when she wasn't in pain during her cycle in her teenage years.

When Ash became sexually active, she noticed that sexual intercourse was painful. She described sex that it felt like being stabbed in the stomach. Often, she would want to vomit after sexual intercourse due to the pain. When she was 17, she had a miscarriage with an unsupportive partner. Now she looks back and believes that endometriosis caused her miscarriage which worries her for when she wants to conceive later on. However, these endometriosis-like symptoms persisted all through her teenage years, and when she was 19, she sought medical advice and told her doctor about her painful menstruation and painful sex. Her doctor thought she might have had cysts and was referred to a gynaecologist. Within months she has a laparoscopy surgery and was officially diagnosed with endometriosis.

Ash found the recovery from the laparoscopy surgery difficult because she went back to work too soon. She had little support from her partner at the time and was in a hostile place. She bled for three months straight after the surgery, and it wasn't just menstrual pain for her anymore; it was constant pain every single day. She is unable to leave the household as she is unable to survive without her painkillers for a short period.

One-time Ash was taken to the hospital during her shift at work as she had awful pain. She was slipping in and out of consciousness, and her body became numb due to the pain. She went back to her specialist to ask why she was still in so much pain in which she responded that her nerve ending was fried from being in pain for so long and that there was not anything she could do. Given the only option to live in pain made Ash extremely upset, and she felt hopeless.

Ash decided to get a second opinion and was referred to another specialist who did an internal examination. The specialist told her that she had adenomyosis and that her only option was to get a hysterectomy or to live in pain. Ash was in shock that this was the only option and that having a family one day may be taken away from her. She was unhappy with how dismissive the specialist was and did not know how to deal with this news.

Now Ash lives in pain most days, is unable to exercise regularly, and it lost on what her options are. After hearing Ashs story, we discussed gynaecologists in New Zealand, and I reassured her that not all gynaecologists were dismissive. I gave Ash the details of the gynaecologist, who is an endometriosis specialist and did my surgery. Ash now dares to seek a third opinion.

Bayley: Bayley was a 30-year-old woman who has a daughter from a previous relationship. Bayley was extraordinarily positive and self-aware.Bayley has always had regular menstruation with minimal to no pain, which is rare for a woman with endometriosis. Thus, endometriosis was never suspected or investigated until later on in her life.

Layal started experiencing painful sex at age 16. She described it as if someone had grabbed a hammer and smacked it against her uterus. She assumed that painful sexual intercourse was normal.

She had her daughter at 21, and a few weeks after giving birth, she got a post-operation infection. She had a few complications over the next few years after having her daughter, and she was referred to have an ultrasound. The ultrasound revealed some abnormalities, and thus, she was referred to a gynaecologist. She mentioned to the gynaecologist that she was experiencing pain during sexual intercourse and other endometriosis like symptoms.

She was then sent for a laparoscopy surgery when she was 27 and received an official diagnosis of endometriosis. The specialist found that Bayley was riddled with endometriosis and had stage 4. Her gynaecologist said she might be able to fall pregnant again by her right fallopian tube, but there is a chance of an epitomic pregnancy. Bayley praised her gynaecologist and mentioned that anyone she dealt with was lovely, informative and supportive.

After surgery, she had a few complications which lead to her having to go back on hormonal contraception. Her menstruation became irregular and caused long periods of bleeding, which was emotionally distressing for her. It took such a negative effect on her she stopped the hormonal contraception shortly after.

Since then, she has been majority asymptomatic and only sometimes has digestive issues. She does get the occasion endo flare. Bayley's positive attitude appears to have helped her to get on with her life and enable her to cope with endometriosis.

Kristina: Kristina was a 26-year-old woman, who ran her own business from the age of 19 but had to give it up as the stress of running a business begun to make her endometriosis symptoms worse. She was in a long-term relationship and was eager to share her story in hopes to help others feel less alone.

Since Kristina could remember, she has always had painful and heavy menstruation. There would only be two to three days a month where she was not in pain. When she was 15 years old, she went on the hormonal contraceptive pill, which contributed to changes in her mood. She went on to discuss that there were times when she was 18 at university when the pain was so intense that it would send her body into shock. She would have to leave her lectures and go home, missing days off university and work. She assumed menstrual pain was normal and did not seek medical advice for it.

Kristina's first time being sexually active was not sore or uncomfortable. Intercourse only started to become painful a few years later on when she was 18 years old. Kristina described sex as an uppercut to the uterus that would send shooting pains all over her body, and afterwards, it felt too bruised. She believed sex was supposed to be that painful.

Kristina sought medical help when she was 19 for the pain she was experiencing and had put her on antidepressants as her doctor told her that the pain "was all in her head". The antidepressants did not help her moods or pain. A few years passed and Kristina fought to get an ultrasound as she knew something was not right. The ultrasound technician could see that her left ovary was stuck to her uterus. Nevertheless, her doctor called and said that no endometriosis was found on the ultrasound and to not worry about it. She was too offended and upset that the doctor did not believe her, and she had to fight to see a gynaecologist. That ended up being the last time she went to the doctors.

After fighting for surgery at age 24, Kristina has a laparoscopy surgery where she was officially diagnosed with endometriosis. Again, her gynaecologist had awful bedside manner, which made Kristina give up on the health care system altogether. The recovery was challenging as well as finding out about this life-changing diagnosis that could affect her chance to have children. Kristina fell into a deep depression and at the same time, she and her partner at the time decided to break up as he could not handle the diagnosis. Kristina's family were also unsure of how to support her, and she felt very alone.

Kristina suffers from severe sciatic nerve pain which travels down her thigh to her knee, chronic back pain and hip pain. She has tried multiple different hormonal contractive, but many of them have given her horrible side effects. Unfortunately, she is unable to live without her pain medication and takes multiple painkillers daily. Kristina found comfort that her story was not uncommon but also made her angry that the healthcare system has let down many women. She was eager and willing to tell her story in the hopes to make others feel less alone and contribute to research in this scare field.

Regina: Regina was a 21-year-old woman who was employed by a fashion label. Regina menstrual cycle was always very irregular, but her menstruation was not painful at the beginning. She was put on a hormonal contraceptive pill when she was 17 years old to regulate her menstruation. Nevertheless, after two days of taking the pill, she passed out in class as it gave her awful migraines and thus discontinued this contraception.

When Regina became sexually active, she experienced no pain at the beginning or nothing that seemed abnormal to her at the time. She was taking a different hormonal contraception pill when she was 18 years old for one year. When she came off this hormonal contraception was when her menstruation became painful. The cramps started to become unbelievably painful, as well as back pain, nausea and hot and cold flushes. She remembers there were times while she was at university where she had to leave to go home as she thought she was going to pass out due to the pain. Regina assumed that pain with menstruation was normal and thus did not discuss this with her doctor.

Regina got into a relationship when she was 19, and it was not until she was 20 that she started to notice that after sexual intercourse, she was experiencing pain and cramps. She described it as little needles and sharp pains throughout her pelvic after sexual intercourse.

The pain started to get worse, and Regina decided to tell her doctor her symptoms. She was referred to a gynaecologist, and within a short period, she had a laparoscopy surgery and was officially diagnosed with endometriosis. Regina felt her gynaecologist was supportive and understanding, which made the process of diagnosis easier.

After surgery, Regina was pain-free for a few months, but unfortunately, her pain returned. During the interviews, Regina was in discussion with her gynaecologist to get her Mirena taken out, which was inserted during her surgery. Regina explained to me that she does not want to keep putting hormones and medication into her body and wants to try and heal it naturally. Regina can-do attitude and positive mindset helped her copes with her endometriosis systems as well as her supportive partner and family.

Rose: Rose was a 21-year-old woman. Rose’s mum and aunt both have endometriosis, and her aunty was unable to have children because of it.

Rose’s menstruation only begun to get painful later when she was 17 years old. Her menstruation started to become heavier and more prolonged and noticed more bowel and bladder issues. She assumed that this was normal and did not seek medical help.

When Rose begun university, she started to get intense menstruation where it got to the point that she passed out a couple of times due to the bleeding and pain at university. After this, Rose knew something was not right and sought medical advice from her doctor, who was supportive and told her about endometriosis. Rose first saw a private gynaecologist, but the price of surgery Rose could not afford. Therefore, she went public and was referred to a gynaecologist. He gynaecologist was quite dismissive, and her attitude towards Rose was like that she did not care. This upset Rose, but she was unable to change gynaecologists as she could not afford too.

Sexually intercourse has always been painful for Rose, but the pain has been increasing. She described the pain sharp, deep, dull pain, and it would get to the point where she would have to crouch over in a ball and hyperventilate for half an hour due to the pain. Rose’s last partner was not supportive of painful intercourse, but her new partner is and has helped her feel less guilty towards it.

Rose was 20 when she has her laparoscopy surgery and officially got diagnosed with endometriosis. After her surgery, her gynaecologist came in to explain what she had found, but Rose was still drowsy from the surgery. The gynaecologist did not remove the endometriosis but just told her that she had it, which Rose was confused as she thought the gynaecologist was going to remove the endometriosis if it was found. Rose felt the discharge process was not well organised, and she left the hospital feeling confused and frustrated.

Rose was still in pain after the surgery as no endometriosis was removed and was referred to the pain clinic team where she is working on managing her pain. She does not want to live in pain and rely on pain medication; thus, she is looking at a holistic approach to coping with her symptoms.

Louise: Louise was a 23-year-old woman who was very self-aware. She was very eager to participate in the study and help women like herself dealing with endometriosis.

Louise began her menstruation when she was 12 years old, but it was not until 17 years old that they became painful. Louise competed in swimming and ballet when she was growing up. However, at the age of 17, her periods became heavier, and she developed cramping. The cramping and pain became so bad that she had to give up swimming, ballet, and she was unable to walk. She had to get a lift pass at school as she could not even walk up the stairs. Thus, she began missing many days off school.

Louise was 18 years old when she started to have intercourse with her boyfriend; it was instantly painful. The pain was a stinging and burning sensation. Louise also mentioned that even putting in tampons for her was extremely painful. The pain became so painful that Louise started to avoid any intercourse with her partner. Again, the doctors were not sure why she was experiencing this pain.

At 18 years old Louise went to the doctors to get answers to what was happening to her. The doctors believed she has inflammatory bowel disease, but surgery showed that she did not. Then she was referred to a gynaecologist who suggested she may have endometriosis. She had a laparoscopy surgery, and the gynaecologist found no endometriosis but said she might have found possible early endometriosis and left it there. She had the Mirena inserted during surgery, but this did not help her pain.

For several years after her first laparoscopy, Louise's pain became worse. During this time, she had multiple blood tests and examinations by doctors, but no one knew what was wrong with her. When Louise began university, her pain was making her bedridden. She had to go down to part-time at university and work. Her pain completely debilitated her.

It was 2018 until Louise saw another gynaecologist under the public system. Louise underwent another laparoscopy surgery and the gynaecologist shad that she has possible early endometriosis again, but it was blistering, bleeding and active. The surgeon did excision some of the endometriosis out but not all of it. After Louise's surgery, she received no relief and thus has been through a journey of different treatment to try and help get her pain under control. She has had botox in her pelvic area, pelvic physio, pain management consultation, endometriosis massage, different pain killers, diet change, and receive third opinions from an endometriosis specialist in New Zealand. The endometriosis specialist is struggling to help Louise still get her pain under control, and thus Louise feels incredibly hopeless.

Sexual intercourse at this stage was non-existent. Louise was diagnosed unofficially with vaginismus and had not had sexual intercourse with her partner for five and a half years. The pain during intercourse was unbearable; she completely avoids it. This has caused problems within hr relationship and on her self-esteem. However, she felt there is pressure for her to have intercourse that now she is unable to relax or even try.

Jade: Jade is a 26-year-old woman who started her period when she was 15. Jade's periods were always very heavy and spent much time going to the nurse's rooms at high school complaining of being in pain. The nurses took Jade to family planning, where she had an appointment with the doctor there who put her on the contraceptive pill.

At 18, Jade started to notice that sex was painful, and she was confused about whether that was normal or not. Then it started that she would have sex and start bleeding, which caused much embarrassment. Went she went to her doctor she was sent to get an ultrasound which came back as nothing was wrong. Things kept escalating in pain for Jade and went to her doctor's numerous times complaining that there was something wrong.

Jades bleeding got worse and was sent for an emergency ultrasound where a mass was found in her uterus. She was rushed to the emergency department to get a d&c hysteroscopy, and the mass was removed. She was put back on the contraceptive pill, but this did nothing for her pain. Jade was dismissed by her doctor's numerous times.

When Jade was 20, she complained again to her doctor that sex was painful, which then she got referred to a gynaecologist. She was put on the waitlist for laparoscopy surgery, and one year later she had the surgery. The gynaecologist told her she had superficial endometriosis and burnt it off rather than excision.

After her first surgery, Jade suffered for years with horrible symptoms and pain. She has treated several different treatment options with nothing that works for her. Thus, when she was 23, she got another laparoscopy surgery with an endometriosis specialist who removed endometriosis by excision. However, after this surgery, Jade still suffers from painful intercourse, painful menstruation, and horrendous symptoms. She is hopeless about what her next option is to try and treat her endometriosis.

Meredith: Meredith got her period when she was 12 years old. Meredith experienced pain straight away with her menstruation and had her first hospital visit when she was 12 years old. Her mother and sister have been diagnosed with endometriosis previously, and thus her family doctor knew straight away that she was the same as her family. She was put on a contraceptive pill when she was 13 years old.

From the age 16, Meredith start experience weight gain, mood changes, became less active, and horrendous pains that she would pass out from and be crippling over in pain. She also missed a whole term of school because of her pain. She also had sex for the first time, which was extremely uncomfortable. When she was 18, she decided to try to have sex again with her boyfriend, and it was excruciating.

After experiencing horrendous symptoms, she was referred to a gynaecologist who performed a laparoscopy surgery, and she was diagnosed with endometriosis. She had the Mirena insert, but this caused more problems of drastic mood changes, social withdrawal, depression, and pain. Meredith has had a horrific experience with medical professionals in the emergency department dismissing her pain and not treating her correctly.

Over eight years, Meredith has now had seven surgeries for her endometriosis with her most recent surgery she had a hysterectomy to remove her uterus from an endometriosis specialist in New Zealand. She could no longer deal with the debilitating pain she was experiencing daily. She also got nerve blockers in her pelvic area to help decrease the pain. Since having a hysterectomy, Meredith's quality of life has increased, and her pain had reduced. However, she still does get pain. She has not had intercourse since her hysterectomy so she cannot comment on whether this has helped reduce pain with intercourse.

Becca: Becca began her menstruation at 11 years old. Her menstruation was irregular, heavy, and sore at the from an early age. Becca believed this was normal for a woman to have pain with menstruation. Becca would miss days off school, became less active, would pass out due to the pain and would always be in the nurse's office during school because of the pain.

Becca complained for years about her pain but did not think anything of it. At age 17, Becca had enough and went to her doctors who told her that nothing was wrong. Due to her living circumstances, she bounced between 20 different doctors to hear the same thing over again that there was nothing wrong with her. She was put on the contraceptive pill at 18, which caused her symptoms to get worse. She started bleeding for months on end and thus went back to the doctor where she was diagnosed with PCOS. She was diagnosed with this for three years.

When Becca was 20, she moved back to Auckland and had to find another doctor. She found a young female doctor who she was sceptical at first as she had a bad experience with doctors. However, her new doctor put her on another contraceptive pill which again worsened her symptoms. It was also during this time that Becca had sex for the first time, which was a harrowing experience. She brought this up with her new doctors, who then referred her to a gynaecologist. At 21, she has the laparoscopy surgery and was diagnosed with endometriosis. She was revealed that she knew what was wrong with her but also anxious as endometriosis is incurable. Becca had the Mirena inserted during her surgery and is the treatment option she is currently using to manage her endometriosis.

The Mirena has not stopped Becca menstruation and still experiences pain with menstruation and sex. She has tried several different treatment options such as diet change, different hormonal treatments, different medication, and pelvic physio, but nothing is helping to manage her pain.