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“I didn’t need to know that!”: The Regulation of Women with Endometriosis

A thesis presented in partial fulfilment of the requirements for the degree of

Master of Science

in

Psychology (Endorsement in Health Psychology)

at Massey University, Wellington, New Zealand.

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2019

ABSTRACT

Endometriosis is a condition that primarily affects women of reproductive age and has the potential to impact upon every facet of women's lives. The relevance of gender to endometriosis is frequently acknowledged within the literature, although only a small number of studies have taken a gendered and critical stance to the topic. Using online illness narratives in the form of blog posts, this study uses a feminist post-structuralist perspective to explore how women construct their endometriosis experiences, drawing upon discourses that regulate the female body. This study found that women are regulated by discourses of *Ideal Femininity*, which encompasses discursive constructions of 'silencing', 'sacrifice', and a 'disordered body'. Discourses of *Legitimation* involves the construction of an 'open body' and 'dismissal'. These findings suggest that women with endometriosis have limited control over their bodies due to the negative and dominant representations of the female body. Therefore, representations of the female body should be considered when positioning endometriosis as an individual and pathologised issue for women. It is imperative that we challenge discourses that position women as responsible for their condition by way of being female and where endometriosis is constructed as a reproductive disorder; this could go some way to address the unjust social power relations that govern women's bodies.

ACKNOWLEDGEMENTS

Many thanks to my great supervisor Denise Blake for your constant support and advice.

To my wonderful husband, Martyn and my girls, Charlotte and Amelia, for your never-ending patience and love. And to my mother, Shona for always supporting me, and to my father, Ian, who passed away while I completed this work, and who is always sorely missed.

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CHAPTER ONE: INTRODUCTION

Endometriosis is a complex health condition affecting mainly women of reproductive age and has the potential to cause great distress for those who suffer from it. Life domains negatively impacted by endometriosis include psychological wellbeing, intimate relationships, social and work life, productivity, and education (Gilmour, Huntington, & Wilson, 2008; Moradi, Parker, Sneddon, Lopez, & Ellwood, 2014; Rush & Misajon, 2018). A wide range of aetiological theories surround endometriosis, over which there is no consensus. However, it is widely accepted that it requires estrogen to thrive (Bulun, 2009). Women frequently struggle for a timely diagnosis and effective treatment (Hummelshoj, 2017). As there is no definitive cure, current treatments include the surgical removal of the lesions that characterise endometriosis, and pharmaceutical treatments to suppress hormones (Bulun, 2009).

The exact prevalence of endometriosis is also unknown. Literature widely cites that the condition affects approximately up to 10% of women of reproductive age worldwide (Giudice & Kao, 2004; Viganò, Parazzini, Somigliana, & Vercellini, 2004). However, research that proposes these prevalence estimates tend to use participants who are already displaying gynaecological complaints such as pelvic pain or infertility, which places them in a high-risk category for endometriosis (Eisenberg, Weil, Chodick, & Shalev, 2018). Furthermore, estimates may be compromised by the requirement to view lesions via laparoscopic surgery to confirm diagnoses (Vercellini, Viganò, Somigliana, & Fedele, 2014). Ultimately, endometriosis and its aetiology and prevalence are uncertain, diagnoses are commonly delayed, and there is currently no cure, nor treatment that effectively reduces symptoms in all women.

A diverse range of symptoms can signify endometriosis, with acute or chronic pain at a number of different sites often reported as women's primary concern (Moradi et al., 2014). Many of these symptoms, such as fertility issues and painful sexual intercourse, affect aspects of women's lives that are socially constructed as gendered and as defining 'femininity' (Denny, Culley, Papadopoulos, & Apenteng, 2011). Additionally, for some women

symptomology is cyclical and parallel with women's menstrual cycles with excessive or prolonged menstruation reported. Consequently, the experience of endometriosis should be considered within the socio-historical context of the female reproductive body.

It can be argued that a highly gendered cultural construction of endometriosis has emerged that is bound up with representations of a female body (Jones, 2015). I am aware that both social and cultural forces shape experience, but as endometriosis is commonly referred to as a cultural construction within the critical literature, I shall continue to refer to it as such. Descriptions that frequently describe endometriosis within medical discourses are “enigma,” “puzzling,” and “mysterious” (Shohat, 1992, p. 60). Feminist scholars draw comparisons between these portrayals and cultural and political representations of the female body as mysterious compared to the normative standard of the male, (Jones, 2015; Seear, 2014; Shohat, 1992).

A small body of research shows how this gendered cultural construction influences medical beliefs and practices along with women's experiences (Jones, 2015, 2016; Seear, 2009a, 2014; Shohat, 1992; Young, Fisher, & Kirkman, 2018). Jones (2015) has produced an analysis of endometriosis as a cultural construction drawing on hysteria discourses and argues that endometriosis can be considered a new form of this complex and highly gendered diagnosis that highlights the importance of gendered social roles and beliefs. Drawing on a socio-historical reading of medicine and the female body to consider how clinicians construct women with endometriosis, the findings of Young et al. (2018) indicate the construction of women as “reproductive bodies with hysterical tendencies” (p. 1). Shohat's (1992) feminist analysis of endometriosis discourses within medical, self-help and technological writings and practices also demonstrates that endometriosis is frequently constructed to reinforce social roles around reproduction and the heterosexual family, while constructing the female body and behaviour as “disorderly” (p.74). She suggests that medical technologies, while valuable, help to dismiss the voices of women with endometriosis as medical discourse constructs them as passive recipients, with clinicians “cleaning” up their polluted bodies (p. 74).

Additionally, Seear (2009a, 2009b, 2009c, 2009d, 2014) has created a critical body of research around endometriosis. As well as researching the cultural construction of endometriosis, she also explores how women experience endometriosis and endeavours to give them a voice. Sao Bento and Moreira's (2017) interviews with women with endometriosis also take a critical perspective and place interactions between medical personnel and women within a context of symbolic institutional and gendered violence.

Although not taking a critical perspective to endometriosis, other studies do acknowledge the relevance of the association between menstruation and endometriosis and the way in which the highly gendered symptoms of endometriosis influence experience (See Denny, 2009; Manderson, Warren, & Markovic, 2008). Recommendations include more education for clinicians and for them to be more trusting of women's subjective experiences as well as greater awareness around endometriosis for lay people (Cox, Henderson, Andersen, Cagliarini, & Ski, 2003; Cox, Ski, Wood, & Sheahan, 2003; Denny, 2009). In particular, educating young women to differentiate between what is and is not a 'normal' level of menstrual pain is suggested (Manderson et al., 2008; Markovic, Manderson, & Warren, 2008).

In contrast to the research determining endometriosis as a cultural construction and placing experiences within a wider sociocultural context, several studies, including the work of Bullo (2018); Cox, Henderson, Wood, and Cagliarini (2003); Facchin, Barbara, et al. (2017) and Facchin et al. (2016), locate women's experiences and distress within an individual context.

Recommendations in these studies include that women take control of their illness by gaining knowledge and/or seek psychological help for endometriosis symptoms.

Considering the distress endometriosis can cause women, there is value in these recommendations. However, it is useful to consider them within context as they draw attention to several issues that impact upon women. Historical medical discourse has perpetuated associations between the female psyche and reproductive organs that result in women's unexplained illnesses being attributed to their 'deviant' behaviour or 'nature' (Showalter, 1985). As will be shown, this persisting legacy is illustrated in endometriosis experiences where

women report being told that their symptoms are psychological in origin, and therefore illegitimate. In addition, such approaches place endometriosis as an individual problem in which women are responsible for their own health and distress, even when it is widely acknowledged that there is no single, effective cure. These approaches overlook the social power relations that construct women's experiences of endometriosis.

With a limited number of studies that consider endometriosis from a critical gendered perspective, this work seeks to add to this small body of literature. By this, I mean to locate the experience of endometriosis within a context of gender and power, with a view to unpacking how the female body with endometriosis is regulated. I initially discuss how cultural representations position the female body as polluted, inferior, and abject. Next, endometriosis is presented as a highly gendered cultural construction. I examine the symptoms, biological underpinnings, and theoretical constructions of endometriosis to demonstrate that female reproductive organs and processes continue to be framed as the cause of distress, thereby reinforcing cultural notions of women as pathologised. Menstruation and hormonal discourses, two issues with which endometriosis is bound, provide examples of the use of reproductive processes as justification to regulate the female reproductive body. Then the construction of endometriosis as a threat to medical and social order and the implications of this construction and the legacy of the typical endometriosis patient profile are examined. Following this, I review the current literature with a focus on the lived experience of endometriosis. Finally, the research rationale is outlined, and the structure of the remaining chapters is presented.

The Female Body and the 'Need' for Regulation

It is important to consider discourses surrounding and defining the female body when exploring the endometriosis experience. This is because the possible symptoms of endometriosis are heavily linked to female bodily aspects that are constructed as defining femininity, such as menstruation, fertility and sex (Denny et al., 2011). These discourses also impose the expectation of particular social roles, self-surveillance, and consequently women blaming, which has implications for how women perceive their bodies and experiences of 'self'.

Discourses about the female body also influence medical practice (Lupton, 2012) This section defines these discourses in a general sense to provide context for later discussion on how representations of the female body impact on women's endometriosis experiences.

Feminist theorists argue that the female body has been historically and culturally pathologised, and consequently positioned as inferior, due to its representation as different to the male body (Ussher, 2006). This is grounded in the concept of the male body being the 'norm' while the female body is "othered" (De Beauvoir, 1949/1989, p. xxii). Gendered oppositional binaries position males more positively whereas females are more negative. For example, "reason/emotion" and "order/chaos" signify that the male/man is more in control and rational than the female/woman counterpart (Bayer & Malone, 1996, p. 667). Representations through art, literature, religious and medical discourses frequently reinforce these binaries through constructing woman as weak and unstable, or conversely dangerous or mysterious (Lupton, 2012; Ussher, 2006).

Any difference between the male and female bodies, and any inferred inferiority, is largely constructed through women's unique reproductive capabilities. One of the principle differences is what Shildrick (1997) labels women's "leakiness" where reproductive processes involve the uncontrollable leaking of bodily fluids, such as menstrual blood or breast milk (p.16). The female body is pathologised as different from the male body, which does not 'leak' in such an uncontrollable way as women. Ussher (2006) asserts that these leaking reproductive processes represent an excess of femininity, which contributes to the construction of women as "the monstrous feminine" (p.1), a term borrowed from Creed's (1993) analysis of females as monstrous in film. Creed explains that she coined that phrase in order to highlight the "importance of gender in the construction of her monstrosity" (p. 3).

Both Ussher (2006) and Creed (1993) draw on Kristeva's (1982) theory of abjection to illustrate this 'monstrosity' of the female body. Ussher argues that the female reproductive body is positioned as "abject," using Kristeva's definition of the term as something "that which we most dread" (p. 6). Abjection, according to Kristeva, is "what disturbs identity, system, order" and

“what does not respect borders, positions, rules” (p. 4). In this respect, the female body’s reproductive processes are more than different; they render the body as dangerous and polluting because of its difference and sexuality, while also as weak due to its supposed debilitating aspects such as menstruation and reproduction (Creed, 1993; Ussher, 2006). Ultimately, these representations construct the female body as disordered and a threat to the social and moral order. The female body requires regulation (Ussher, 2006).

Ussher (2006) suggests a regulatory measure is the requirement that women’s ‘excessive femininity’ is concealed and that women self-surveil to ensure this happens. According to Foucault’s (1975/1995) theory of power, self-surveillance and self-policing are performed when the self enacts disciplinary measures through an external gaze sitting in judgement. This coerces how one acts and is thus internalised (Ussher, 2006). In this sense, the endometriosis body could find it harder to ‘hide’ the menstrual and other bodily processes that render it leaky and inferior.

The defining of women by their reproductive processes has implications for women’s so-called ‘nature’. Shildrick (1997) theorises that women are more embodied than men due to their reproductive and biological processes, and therefore are less able to transcend from the body to the mind, as men have been presumed to do. For instance, Shildrick argues that women are unable to overcome passion and irrationality, which reinforces gendered binaries. These arguments are bound in notions of Cartesian Dualism, where the body and the mind are separate, and the mind is viewed as superior. Shildrick surmises “bodies could interfere with moral thought instructing the mind, rather than the other way round, as is the case with men” (p. 26).

The presumed association between women’s reproductive processes and the mind has historically been embedded in medical discourses. Illnesses of the womb and other reproductive organs were considered responsible for the deviant behaviour of women, without consideration of genuine reasons of distress (Ussher, 2006). The idea that the uterus controlled women’s behaviour manifested through various constructions of hysteria, a diagnosis referring to all women’s unknown maladies, which justified the regulation of women. For example, Roman physician Galen built on Ancient Greek assumptions that

gynaecological ailments were connected to the mind and emotions (Nezhat, Nezhat, & Nezhat, 2012). He argued that women who were not sexually active became mad due to lack of fulfilment. In the middle ages, however, ‘hysterical’ symptoms were often attributed to demonic possession and witchcraft, supporting the constructions of particular women with immorality and sin (Nezhat et al., 2012; Tuana, 1993). Ussher (1989) argues that these accusations were methods of controlling women who did not behave in socially sanctioned ways.

In the 19th century, medical and psychiatric treatments for hysteria attempted to “manage women’s minds by regulating their bodies” (Showalter, 1985, p. 75). Treatments included clitoridectomy to limit women’s sexuality without impinging on their ability to reproduce, or placing leeches around women’s genitals (Showalter, 1985). Women who required these treatments were those who deviated from social norms by desiring a divorce, not engaging in sex with their husbands, or wanting to have a career instead of childbearing (Showalter, 1985).

The negative representation of women as inferior to men constructs a socio-cultural context in which women and their bodies require regulation. The historical association between women and her reproductive processes and the regulation of female bodies has particular meaning for the cultural construction of endometriosis. In this sense, discourses about the female body matter to experiences of menstruation, fertility and sex, processes of self-surveillance and of a self. It also has implications for medical practice.

Endometriosis: A Gendered Cultural Construction

I now turn to discuss the construction of endometriosis. Here, I argue that the symptoms, biology, and theory surrounding endometriosis construct it as a highly gendered condition, grounded in traditional social roles and based in the supposed failure of women’s reproductive processes. By the term ‘social roles’ I mean the gender-specific cultural practices in which women are designated as mothers and wives. An exploration of endometriosis as a cultural construction, therefore, is one in which traditional social roles form the foundation.

Symptoms

Hummelshoj (2017) labels endometriosis as a “disease of many illnesses” (p. 779). This is because it can be characterised by many different symptoms, and woman’s experiences of endometriosis are not necessarily uniform.

Endometriosis symptoms can include infertility, chronic fatigue, diarrhoea, incontinence, constipation, and prolonged or excessive menstruation, but the most common and disrupting symptom is that of pain. Pelvic pain, leg pain, dyspareunia (pain during sex), dyschezia (pain during defecation), dysuria (painful urination), and dysmenorrhoea (pain during menstruation) are some of the common pain sites that cause great distress as well as disruption to women’s lives (Gupta, Harlev, & Agarwal, 2015).

Many of the reported symptoms place endometriosis within the socially constructed processes of reproduction and femininity. Symptoms, for some women, frequently coincide with cyclical patterns of menstruation, and as noted above, symptoms include excessive or prolonged menstruation.

Additionally, problematic infertility symptoms position endometriosis as not only a failure of reproduction but within constructions of women’s femininity whereby women’s traditional social role is to reproduce. Furthermore, due to pain being seen as connected to childbirth and menstruation, women are frequently expected to suffer pain as part of being female (Bendelow, 1993).

Associations between women’s symptoms of endometriosis and their reproductive processes have a historical basis. While researching historical texts, Nezhat et al. (2012) discovered that references to endometriosis-like symptoms have long been recorded. They found that a lack of motherhood and sexual intercourse emerged in texts and images from classical and late antiquity as the apparent cause of symptoms such as pelvic and abdominal pain, fainting, and vomiting. For instance, in Ancient Greece, the uterus was considered animalistic and “hungry for motherhood” which eventually developed into the notion of the ‘wandering womb’ (Nezhat et al., 2012, p. 2). This womb was conceptualised as roaming the body looking for its baby, and was blamed for women’s pain symptoms thus signalling the significance of women’s reproductive capabilities within women’s experiences. The supposed

cure for this pain was, consequently, marriage and motherhood (Nezhat et al., 2012).

In the same way, hysteria, in its various historical forms, is especially relevant. Nezhat et al. (2012) have compiled evidence to suggest many historical writings on hysteria referred to symptoms similar to endometriosis. While Jones (2015), on the other hand, argues that endometriosis could be considered the new 'hysteria' due to all symptoms being attributed to women's uterus and endometriosis treatment frequently involving the suppression of women's disorderly bodies through hormonal treatments or encouraging them to reproduce. It is argued that historically by attributing women's ailments to a lack of reproduction, it justified the repression of women in Ancient Greece and confined them to traditional social roles (Allison & Roberts, 1994). These beliefs continue to impact on the biological and theoretical underpinnings of endometriosis.

The Biological Underpinning of Endometriosis

Medical discourse continues to position endometriosis as a gendered illness through biomedical beliefs that associate the uterus as the cause of women's distress. Jones (2015) argues that current medical discourse is reminiscent of the theory of the 'wandering womb' I previously discussed, only now it is understood as the endometrial lining that is roaming the female body and causing problematic physical symptoms. Endometriosis causes tissue, *similar* to the lining of the uterus, which is known as the 'endometrium', to grow outside the uterine cavity. Known as ectopic endometrium, this tissue (found outside the uterus) responds to hormonal changes and bleeds during menstruation. However, unlike eutopic endometrium (located inside the uterus), the ectopic tissue has no way of escaping (Denny & Mann, 2007b). This induces a chronic inflammatory environment, resulting in lesions, scarring and adhesions (Denny & Mann, 2007b; Vercellini et al., 2014). These lesions are most commonly located within the pelvic cavity, including the ovaries, fallopian tubes and the pouch of douglas (the area between the rectum and the uterus), the bladder and the bowel (Denny & Mann, 2007b). Although rarer, it has also been discovered within the brain, neck, and chest.

According to Jones (2015), there are arguments as to why there are flaws in the persisting association between endometriosis and the uterus, which influences how endometriosis is culturally constructed. Firstly, endometriosis lesions are not specifically found within the uterus but outside of it, although this can include the surface of the uterus. Secondly, the endometrium tissue is *similar* to but certainly not identical to the endometrium lining of the uterus as there are molecular differences between the eutopic endometrium, and the ectopic endometrium (Bulun, 2009). Finally, although endometriosis affects mainly women of reproductive age, it has also been found in menopausal women, women without uteruses, premenarcheal girls, female foetuses and men (Marsh & Laufer, 2005; Rei, Williams, & Feloney, 2018; Signorile et al., 2010; Streuli, Gaitzsch, Wenger, & Petignat, 2017).

Theories Constructing Endometriosis

Although a large body of work attests to the wide range of aetiologies underpinning endometriosis, there is no consensus about the biological mechanisms. While the theories shown here give examples as to the implications that medical beliefs have on the experience of women, this work does not attempt to unpack each of the biological theories but contextualise the way in which medical theories matter to the diagnosis, treatment and experiences of endometriosis. As with social discourses that will be shown to produce experiences of endometriosis, medical theories also draw from and collaborate with ideas of endometriosis as a failure of women's reproductive systems.

The most widely accepted biomedical theory for the pathogenesis of endometriosis is Sampson's Retrograde Menstruation Theory, or Menstruation Reflux Theory. This theory proposes that menstrual blood flows back into the fallopian tubes, allowing ectopic endometrium to implant and grow within the pelvic cavity. This tissue forms cysts and lesions which cause a chronic inflammatory reaction in response to hormonal change, thus resulting in the formation of scar tissue, adhesions and pain (Denny & Mann, 2007b). Nulliparous women (not given birth), and those with short and heavy menstrual cycles are also more likely to be diagnosed, a factor which Viganò et al. (2004) argue supports the reflux menstruation theory. This theory helps to fortify

social roles where women are biologically destiny to reproduce and too much menstruation over a woman's life span results in endometriosis.

However, this theory is contested. Gupta et al. (2015) point out that it fails to explain why endometriosis is found in not only non-menstruating females, but in males as well. It has also been established that most women suffer retrograde menstruation, where menstrual blood travels back to the fallopian tubes, to some degree but do not develop endometriosis. Consequently, there is also a belief that some women experience immune dysregulation. Normally, the immune system would detect and expel excess menstrual tissue and endometrial cells; however, this does not necessarily occur for women with endometriosis (Denny & Mann, 2007a). Therefore, it is assumed that they have an immune surveillance dysregulation, which allows the endometrial tissue to implant outside the uterus. Another, less widely accepted perspective, agrees with the immune surveillance dysregulation theory not disposing of ectopic endometrium as it should, however, Evers (1994) further believes that all women potentially have endometriosis but not all display symptoms.

The consequences of these theories are that the immune dysregulation theory argues that women with endometriosis themselves are disordered, while Evers' (1994) theory that all women have mild endometriosis, but not all develop problematic symptoms, implies that *all* women are disordered, according to Seear (2014). These theories represent the way in which women are constructed through biological, social, cultural, and political discourses that continue to position women as mothers, disordered if they do not reproduce, and overall inferior to the male norm.

Menstruation and Hormones

Thus far, it has been established that menstruation dominates much theory surrounding endometriosis and that there is an estrogen element affecting endometriosis's growth. Now, the discussion integrates concepts of the female body requiring regulation with menstruation as an example of how their reproductive processes define women. This is important because endometriosis is associated with negative representations of menstruation. Additionally, it

highlights how hormones also justify discourses that require women to be controlled

Menstruation is pathologised through cultural construction, and in this way, the bodily fluid of menstruation becomes “a highly meaningful and anxiety provoking fluid” (Lupton, 2012, p. 146). According to Martin (1987), menstruation is positioned as a failure of femininity or a “production failure” because women should be either pregnant or breastfeeding, and to menstruate means that they have failed in the first instance (p. 115).

Menstruation discourses use bleeding as evidence of uncleanness, pollution, and that women’s bodies are weak. For example, cultural myths surrounding the reason for menstruation include the punishment of women for being sinful and therefore meant to suffer pain, or female bodies having a design error compared to men, as well as the above-mentioned failure to reproduce (Laws, 1990).

Consequently, a culture of silence and shame surrounds menstruation. This is reproduced through menstruation euphemisms frequently used by women including names that promote secrecy. Male terms used to discuss menstruation tend to be more derogatory and therefore promote shame and stigma (Laws, 1990). Furthermore, menstrual blood leaves through the area of the body which is associated with sexuality, leading to further necessity of concealment so the female body can be considered a sexual object (Bramwell, 2001; Roberts, 2004). These examples demonstrate how the cultural construction of menstruation regulates women through the necessity of concealment, which women internalise and then self-police their own bodies and behaviour to ensure secrecy.

Not only have reproductive processes such as menstruation served to define women by representing a pathologised body, but hormones are also bound up with representations of women lacking control through female conditions such as premenstrual syndrome (PMS) (Shildrick, 1997). PMS is a constructed disorder, characterised by irrationality and anger among other symptoms that women suffer prior to menstruation and such behaviour is blamed on hormones (Chrisler & Caplan, 2002). That premenstrual women can experience

symptoms as portrayed by PMS is not disputed here. However, that symptoms position women as inferior through inference of mental instability is problematic. For example, studies have shown that when premenstrual symptoms are not pathologised or treated as abnormal, women experience fewer mood complaints (Chrisler & Caplan, 2002; Ussher & Perz, 2013).

That female hormones are used to construct women as out of control and therefore in need of regulation is of relevance to endometriosis because endometriosis is largely accepted as an estrogen-dependent condition, meaning that it requires the estrogen hormone for the endometriosis tissue to grow. Estrogen is found in both women and men, although it is largely associated with women and is thought of as a female hormone. Shohat (1992) contends that hormone treatments for endometriosis focus “on the suppression of the disorderly body” reinforcing endometriosis as a ‘female’ illness due to its association with a ‘female’ hormone (p.74). Furthermore, Jones (2015) draws comparisons between hysteria discourse in which women’s uncontrollable behaviour was associated with their bodies, and today’s representations of endometriosis as a female hormonal disorder in which “erratic behaviour seems even more intrinsic because it is hard-coded in the very makeup of women (p. 1100). This infers that all women are disordered.

This section has established how reproductive processes and hormones justify regulating women due to their supposed inferiority and irrationality. The next section discusses the construction of endometriosis as a threat and the implications of this. It also highlights how traditional social roles both produce and reproduce knowledge surrounding endometriosis.

Endometriosis: A Threat to Medical and Social Order

Prior discussion has demonstrated the construction of the female body as a threat to social order because of its deviation from the male norm. Bodies experiencing endometriosis are also threatening as they are not contained “within medically and socially defined boundaries” (Jones, 2015, p. 1090). Discussion on the construction of endometriosis as based on too much menstruation has established aetiology as presenting endometriosis as a threat to social order through women not adhering to expected social roles of

motherhood. Here, I outline how endometriosis is also constructed as a ‘threat’ to medical order, the implications of this, and how self-help literature and medical practice function to reinforce and restore order.

In respect to medical boundaries, endometriosis and its treatment are bound up within representations of the female body and is consequently a reminder of the failure of medicine and its inability to control women (Jones, 2015; Shohat, 1992). As previously illustrated, the association with reproductive processes dominates many beliefs about endometriosis. The pathologisation of these processes has justified controlling the female body through the medicalisation of pregnancy, menopause and as discussed prior, menstruation through the construction of PMS (Martin, 1987). However, unlike menstruation and pregnancy, the lack of definitive cure or cause of endometriosis makes women with endometriosis difficult to control medically.

Consequently, Jones (2015) asserts medical discourse has taken a female body that does not remain within medical boundaries and placed responsibility for the condition on the women who suffer from it rather than acknowledging the limitations of medicine. Seear (2014) and Shohat (1992) illustrate how conceptualisations of endometriosis as this so-called mysterious disease echo representations of the mysterious woman who is unknowable. It is the condition itself that is near impossible to decipher and is beyond the scope of mortal clinicians to untangle (Jones, 2016; Seear, 2014). Here, it is women’s ‘nature’ that is to blame. This can manifest in the inference that women’s pain and other symptoms are psychological when clinicians are unable to locate an organic cause to women’s distress. An occurrence that Whelan (1997) suggests transpires when clinicians do not wish to admit their own “inadequacies as diagnosticians” (p.56).

The Self-Care Punishment

A further consequence of endometriosis as a threat to medical order is the assumption that women should be able to manage their illness through lifestyle change. Women report clinicians recommending self-care methods and recall incidences of then feeling blamed by the clinician for not doing enough if symptoms persist (Seear, 2009b). The overarching theme is that women are

supposed to control their ‘unruly’ bodies and again here, it is not the clinician that is inadequate but the woman.

Jones (2016) criticises this self-care discourse for perpetuating that one needs “perseverance, effort and informed decision making” to overcome endometriosis (p. 567). This reproduces a discourse of ‘healthism’ in that women are responsible for their health and wellbeing and negates wider social, cultural and political forces that provide the context for the experience of endometriosis (Seear, 2009d, 2014).

Some frame this self-care as empowerment. Researchers report findings of women with endometriosis feeling empowered through joining online and real-life support groups and expanding their knowledge base around endometriosis (Cox, Henderson, Wood, et al., 2003; Emad, 2006). Although, in contrast, Seear (2014) questions the concept of empowerment and women being in control of their bodies, when women are actually forced to take action in response to lack of proper medical care.

It can be difficult for women to meet self-care obligations as self-care recommendations overlook accessibility difficulties. Endometriosis management methods include special diets such a wheat and dairy free, organic food to avoid dioxins, exercise as well as acupuncture and herbal options (Huntington & Gilmour, 2005; Seear, 2009d) But these alternative treatments may be a privileged issue as financial and practical constraints play a key role in why some women resist the discourse that tells them to be responsible for their health (Seear, 2009b). Exercise classes, special diets and organic foods can be expensive (Seear, 2009b). Furthermore, women with endometriosis often suffer from chronic fatigue, not to mention debilitating pain that would make exercising impossible. Additionally, some women report feeling overwhelmed with coming to terms with a large amount of often confusing medical resources about what to eat or do (Seear, 2009b).

The inability of some women to comply with the advice and ‘take charge’ of their own health has further implications. Seear (2009b) points out that this pressure, framed as empowerment, serves as a moralising discourse for women

to be responsible for controlling their illness. Failure to meet this expectation can result in self-blame and guilt for women not managing their endometriosis.

Restoring Social Order

As discussed previously, biological underpinnings place endometriosis as a failure of reproduction, and therefore women not meeting their social role obligations and following the required social order. Endometriosis self-help literature reproduces this expectation of taking up traditional social roles. Analyses of endometriosis self-help literature by Seear (2009c) and Jones (2015) illustrate that not only are women positioned as responsible for their own health and controlling their bodies, they are also constructed as being responsible for the care of others. For example, they are supposedly responsible for their children developing endometriosis also if they do not follow certain, sanctioned guidelines (Seear, 2009c).

Additionally, Jones (2016) provides examples from the literature of how women are responsible for their partner's sexual fulfilment even when they are suffering the pain of dyspareunia. If women fail to have an interest in sex (due to the pain) then it is her responsibility to seek out therapeutic help to cope with it (Phillips & Motta, 2000, cited in Jones, 2016). In this sense, the sexualisation of pain argues that women should be more concerned with the effect of endometriosis on the male sexual partner than on themselves. Jones also notes that self-help literature always frames sex as a heterosexual matter, with dyspareunia (painful intercourse) being constructed as a matter of penile penetration.

The Typical Patient Profile

Embedded within medical and social order is the typical endometriosis patient profile. This profile spun the idea of endometriosis as a 'career women's disease' that affects mainly Caucasian, middle-class women who focus on their careers, are aged in their late 30s or 40s and who delayed childbirth (Whelan, 1997). As far back as 1953, Meigs (1953), a gynaecologist, proposed that it was physiologically abnormal for women to have infrequent childbearing and late marriage. He argued that endometriosis was more likely to occur in women who had "postponed the fulfilment of her normal reproductive function" (p. 48).

Seear (2014) suggests Meigs was inferring that women are to blame for their condition due to delaying childbearing and marriage. As with other medical and social contexts discussed in this work, this medical profile further served to position the traditional social roles of motherhood and marriage as the ideal, while also blaming women for their condition as they did not fulfil their reproductive roles. This was perpetuated through both medical literature and popular magazines (Carpan, 2003). For example, Whelan's (1997) research on gynaecological discourse and classification systems asserts that infertility continues to be privileged over women's reports of pain by clinicians.

However, the typical patient profile did not relate to all women, with illness intersecting socio-economic status and ethnicity. Seear (2014) proposes that discourse around endometriosis has served a political agenda for 'desirable' reproduction through the medical belief that endometriosis mainly affects affluent Caucasian women. She cites Meigs (1953) concern about more affluent and educated members of society reproducing less than their poorer, less educated counterparts. The belief that endometriosis affected mainly Caucasian career-women, as mentioned above, had implications for non-Caucasian women's diagnosis and therefore treatment. For instance, African-American women were not thought to be afflicted by endometriosis, and a large percentage were misdiagnosed with pelvic disease when they actually suffered from endometriosis (Carpan, 2003; Nezhat et al., 2012).

Furthermore, non-Caucasian women with undiagnosed endometriosis were also more likely to be misdiagnosed with a sexually transmitted disease, reinforcing notions of the 'other' as 'less than' and immoral. In this respect, the denial of appropriate treatment repressed these women. Shohat (1992) posits that if reproduction is the cure for white women's endometriosis or as she terms, "disorderly conduct" for lack of childbearing, then non-diagnosis of non-Caucasian women has implications for "reinforcement of infertility" (p.68). She argues that hysterectomies as the cure for pelvic inflammatory disease and misdiagnosis for women of colour suffering endometriosis were consequently serving a "hidden demographic agenda" (p. 68).

This typical patient profile also functions to reinforce psychological assumptions about women complaining of endometriosis symptoms. Within

medical discourse, the endometriosis profile positions women as having negative personality characteristics. They are seen as neurotic, aggressive, anxious, perfectionists who over exaggerate pain and do nothing to resolve it (Whelan, 1997). These negative characteristics reproduce the binary relationship between the female body and the mind. Women who do not meet the typical patient profile are repressed through both the denial of appropriate diagnosis and treatment, as well as being blamed for symptoms that are inferred as psychological (Whelan, 1997).

This legacy of reproduction and psychological inference persists into the 21st century. Recent research by Young et al. (2018) describes how clinician's frequently construct women as "reproductive bodies" and as being for the "purposes of heteronormative sex and reproduction" (p. 12). The authors observe that sex is constructed as a matter of penis-vaginal intercourse. The clinicians in the study also make assumptions that reproduction is the woman's main concern even though a number admit that they did not consult with their patients as to whether this assumption was correct.

Furthermore, Young et al. (2018) report that some clinicians view women as having hysterical tendencies, with associations made between endometriosis and psychological wellness. For example, the authors quote one clinician as saying, "do mad people get endo or does endo make you mad? It's probably a bit of both" (p. 13). This occurred particularly if the clinicians found the patient "difficult" (p. 14). That is to say, the women who did not agree with or accept the clinicians' advice or judgement, or were not the "good patient," were constructed as "using endometriosis as an excuse for their own inadequacies" (p. 14).

This section has demonstrated how discourses around the female body influence medical practice with negative implications for women. This is reinforced by the construction of a typical endometriosis patient profile. I now consider the way in which current endometriosis literature represents women's endometriosis experiences.

The Experience of Endometriosis

In this current section, I review the literature specific to the experience of women with endometriosis, drawing on, where appropriate, the previously discussed social and cultural discourses that shape women, in order to show how conceptualisations of the female body negatively construct endometriosis experience. Finally, I outline the research aims and rationale for this study.

The literature presented here focuses on studies that encompass diagnostic delay, broad ‘experiences’ of endometriosis, the way in which women have endured and contested how the condition is constructed, and specific psychological impacts. While many studies (Cox, Henderson, Andersen, et al., 2003; Denny et al., 2011; Whelan, 2007) acknowledge the gendered effects of endometriosis, few privilege this as the central focus of their research specific to women’s experiences, with Seear (2009a, 2014) and Sao Bento and Moreira (2017) being the exception. However, Denny (2009) does consider the gendering of pain and knowledge and how this affects endometriosis experiences. Furthermore, many of the studies on mental wellbeing and quality of life of women with endometriosis draw on samples commonly recruited by tertiary care providers such as specialist centres. As such, the knowledge produced could represent women under specialist care who may suffer from moderate to severe pain and have the ability to access specialist care (De Graaff et al., 2013).

I begin this section by specifically discussing the commonly reported diagnostic delay to highlight the cultural expectations of women, such as menstrual normalisation and menstrual stigma. Next, I examine what happens after diagnosis, focusing on uncertainty around treatment and fertility. I then explore the impact of endometriosis on women’s everyday lives, including employment and social and intimate relationships. Finally, I outline the psychological impact of endometriosis.

The Diagnostic Delay

Women report that it can take years before a diagnosis of endometriosis is reached (Ballard, Lowton, & Wright, 2006; Cox, Henderson, Andersen, et al., 2003; Denny, 2004b). Markovic et al. (2008) attribute this delay to the “social

construction of gender” (p. 354), meaning that it is ultimately bound up within gendered beliefs around women and illness and cultural norms around menstruation.

The normalisation of menstrual pain has a significant impact on women’s experience with seeking (or not seeking) a diagnosis for their symptoms. An inability to identify what constitutes a normal or abnormal menstrual experience contributes to the delay in women seeking medical assistance. Some women did not consider themselves ill, just ‘unlucky’ (Ballard et al., 2006). Women report that they felt it was normal to suffer pain and it was just part of being female (Manderson et al., 2008; Moradi et al., 2014). The expectation of women’s ‘endurance’, a term coined by Markovic et al. (2008), is socially constructed by friends, family, peers and teachers (Cox, Henderson, Wood, et al., 2003; Huntington & Gilmour, 2005; Markovic et al., 2008; Moradi et al., 2014). Examples of the normalisation of menstrual pain include teachers making allowances for students due to their pain but not expressing any concern that it may be abnormal (Markovic et al., 2008) and mothers telling their daughters that they are “stuck with it” or to just “get on with it” (Seear, 2009a, p. 1223). Normalisation is further compounded by others trivialising and dismissing women’s accounts of pain (Seear, 2009a). Furthermore, research by Manderson et al. (2008), demonstrates that women are positioned as weak and treated with disdain when speaking about their pain.

Seear (2009a) explored the normalisation of menstrual pain and secrecy surrounding menstruation, focusing particularly on why other women dismiss women’s endometriosis experiences. Seear argued that women seek to minimise menstruation experiences because of ‘social sanctions’. For example, study participants reported that a culture of concealment was necessary to avoid accusations of malingering to get out of work or sex, and any risk of social scorn or ostracism. This included being challenged about competence for work after disclosure.

Stigmatisation is also dominant in research findings. A recent study by Gupta et al. (2018) on adolescents’ perceptions of endometriosis found that stigma and judgement towards ‘invisible illness’ still persist. Manderson et al. (2008)

explored women's experiences of disdain when attempting to discuss menstrual pain, while Moradi et al. (2014) identified that women did not talk about their endometriosis experiences due to feeling shame. Denny (2009) highlighted experiences of women being positioned as morally weak for not coping with pain, which perpetuated social and familial norms about the expectation of pain in females. These persistent beliefs mean that engaging in an open dialogue around menstruation could be detrimental to women because they could be positioned as weak, and work to reproduce negative constructions of women as 'less than' and 'delicate' (Ballard et al., 2006; Manderson et al., 2008; Seear, 2009a).

The above-mentioned cultural norms surrounding menstruation, menstrual pain and beliefs around women and illness also affects the experiences of women within the health care system once they do seek help for their symptoms. As previously discussed, many women experience obstacles in acquiring an accurate diagnosis and medical treatment while their symptoms, particularly pain are dismissed as psychological (Denny & Mann, 2008). Whelan (2007) refers to this dismissal as a 'delegitimation' of women's experience, where the subjective experience of women is discredited. Gendered beliefs around menstruation persist in clinical settings, with many clinicians dismissing women's pain as merely menstrual pain, echoing social norms that pain is expected in women and therefore they just need to endure it (Denny, 2009; Denny & Mann, 2008; Moradi et al., 2014). Emad (2006) found that women experience their fertility as more important to clinicians than pain complaints.

This reluctance on the part of clinicians to believe that women have a legitimate gynaecological condition persists even when women discuss the possibility of endometriosis themselves (Cox, Ski, et al., 2003; Denny & Mann, 2008). Research by Cox, Henderson, Andersen, et al. (2003) represents how women are told endometriosis 'myths' such as they were too young to have such a 'condition'. Clinicians also resisted making specialist referrals (Cox, Henderson, Wood, et al., 2003). Markovic et al. (2008) exposed how one woman threw a fit on the floor of her clinician's office and refused to leave until she received a referral. She was given one begrudgingly, but the clinician noted that he did not believe in the severity of her symptoms. This interaction

demonstrates how women with endometriosis are framed as ‘difficult’, which is a common description within endometriosis literature.

The inference by clinicians that endometriosis symptoms are psychological in nature is a common occurrence (Denny & Mann, 2008; Facchin, Saita, Barbara, Dridi, & Vercellini, 2017; Huntington & Gilmour, 2005). Women are frequently told that they are depressed and prescribed antidepressants (Markovic et al., 2008). Denny (2004a) recounts how one woman approached her clinician about dyspareunia and was told that it was most likely anxiety. Interestingly, as highlighted earlier, when medical professionals are unable to reach a diagnosis they are more likely to pathologise women with psychological issues, rather than accept any responsibility with diagnostic inadequacies (Whelan, 1997).

Women who experience endometriosis also report frequent misdiagnoses of irritable bowel syndrome, ovarian cysts and cancer which extended the pathway to a correct diagnosis (Denny & Mann, 2008; Huntington & Gilmour, 2005; Moradi et al., 2014). Women report clinicians ordering ultrasounds unsuitable for detecting endometriosis. This leads to further doubt over the genuineness of women’s symptoms and circles back to the construction of pain as psychological (Ballard et al., 2006; Denny, 2004b). Although misdiagnosis could be partly explained by symptoms of endometriosis mimicking other illnesses depending on their location, this also indicates that clinicians are not considering the patterns of symptoms but treating each complaint individually (Huntington & Gilmour, 2005).

Not only do clinicians’ attitudes represent negative constructions of women, but they also continue to support traditional gender roles where women’s duty is to reproduce, as was found in historical reports discussed earlier. Some findings suggest that if a woman seeks help for fertility, her concerns may be taken more seriously than if her main complaint is pain (Markovic et al., 2008; Seear, 2009a). Whelan (1997) concludes that “women with pelvic pain are more likely to be considered psychologically dysfunctional than women who complain of infertility” (p. 57).

Upon Diagnosis

A range of literature also explores women's experiences after receiving a final diagnosis. According to Denny (2004b), women report feeling relief, vindication and in some cases, anger at an earlier inference that complaints were psychological. For some, the identification of a 'valid' illness means they can access knowledge to understand themselves and seek treatment. They can also attend support organisations and make visible what had largely been an invisible illness. Perhaps most importantly, their lived experiences were legitimatised in that they were positioned as 'genuine'. However, there are negative aspects to diagnosis, particularly once women discover that there is no 'cure' and there is no guarantee of successful treatment (Facchin, Barbara, et al., 2017; Moradi et al., 2014).

A diagnosis does not necessarily lead to a reduction in symptoms, which in turn perpetuates mistrust of medical professionals. To illustrate, laparoscopic surgery is considered one of the most effective treatments, but lesions can grow back, resulting in women undergoing several surgeries. Pharmaceutical interventions can also cause further distress because of uncomfortable side effects that lead women to discontinue treatment, or through their own research, reject treatment methods. These pharmaceutical side effects include depression, confusion, memory loss, anxiety, weight gain and loss of bone density (Seear, 2009b; Whelan, 2007). Furthermore, some treatments aspire to mimic the state of menopause, which then affects women's experiences of femininity.

Again informing the significance of gendered expectations within endometriosis, some women report being told that pregnancy could help their symptoms (Emad, 2006; Huntington & Gilmour, 2005; Markovic et al., 2008; Seear, 2009b). This advice seems given indiscriminately, even to young women not in a relationship or in a position to have a child, and does not take into account of infertility because of the condition. However, there is little evidence to support the idea that pregnancy eases symptoms (Leeners, Damaso, Ochsenein-Kölble, & Farquhar, 2018). Such advice ignores the specificity of women's lived experience, in that dyspareunia is a common symptom of endometriosis, meaning intercourse can be painful, while some treatments

diminish libido. Markovic et al. (2008) found, that on being told to start a family, women experience their bodies “independently from their intimate relationships with men” (p. 358), reiterating women’s purpose as a reproductive machine with individual parts (Martin, 1987).

Living with It

In women’s accounts of their experience with endometriosis, pain is frequently at the forefront of discussion and appeared to be the most central concern to women in their experiences of ‘living with it’ (Moradi et al., 2014). According to Emad (2006) women still experienced that their pain was dismissed by clinicians even after diagnosis. Denny (2009), on the other hand, found that women’s pain was a concern to some clinicians although they rarely asked about the quality of the pain or how it affected their lives. In this sense, women’s concerns were still ignored in a clinical setting, just as it were prior to diagnosis, reinforcing the need to frame their experiences in a way that legitimated the pain. According to Whelan (2003), women generally present pain in three forms: the impact on daily life and functionality; the types of medicine taken to control pain and demonstrate pain severity; and the declaration of a high pain threshold.

There is a consensus in the literature that endometriosis has the potential to affect all aspects of women’s lives (De Graaff et al., 2013; Denny, 2004a; Facchin, Barbara, et al., 2017; Rush & Misajon, 2018). Clearly, this affects the economic situation of women with sick days regularly needed although women often do not disclose their endometriosis to employers and colleagues because of stigma and fear of being positioned as inferior or unfit for work (Gilmour et al., 2008; Rush & Misajon, 2018). Such fears were often realised upon disclosure with some women reporting that they felt they were not believed or symptoms were trivialised by peers and colleagues (Denny, 2004a). Women who could not work full time had to find flexible or part-time work so they could manage their symptoms (Denny, 2004a). As well as pain, bowel and bladder issues also limited capability to carry out employment (Rush & Misajon, 2018).

A disruption to social life is also frequent. The physical symptoms of pain and chronic fatigue led to an inability to attend social engagements, eventuating in smaller social circles. Some women expressed concern that with their illness, they no longer felt they belonged within their peer groups (Gilmour et al., 2008; Rush & Misajon, 2018). Conversely, some women reported friends were a great source of support, particularly if they had some understanding of endometriosis (Gilmour et al., 2008).

In this same sense, intimate relationships also suffer. The idea of endometriosis as a gendered illness is particularly relevant considering the implications on sexual intercourse and fertility. For example, dyspareunia, where sexual penetration is painful, places pressure on relationships. Some women continue to have sexual intercourse and put up with the pain for fear of losing their partners, while others manage by adopting sexual positions that lessen the pain or through a desire to become pregnant (Denny, 2004a; Denny & Mann, 2007c). Some women stop engaging in intercourse altogether. Single women report a fear that future partners would reject them because of dyspareunia, and also potential fertility issues (Rush & Misajon, 2018). The impact of endometriosis on women's ability to have satisfying intimate relationships and fulfil established traditional gender roles, such as sexual intercourse and motherhood, has several implications for women's sense of self and psychological wellbeing.

Psychological Impact

Endometriosis has been linked to depression, anxiety and a lesser quality of life. Like other experiences of endometriosis, as previously discussed, there is also a gendered element that contributes to the psychological impact, particularly pain experiences, and its connection to experiences of femininity. A review of the literature by Pope, Sharma, Sharma, and Mazmanian (2015) concludes that poor mental health in women living with endometriosis is most likely a consequence of the pain women experience and accompanying issues. In this same way, Facchin et al. (2015) and Souza et al. (2011) further argue that having endometriosis itself is not an indicator of a poorer quality of life and psychological health, but pain severity impacts on psychological wellbeing. In particular, anxiety and depression have been found in women

who suffer from chronic pelvic pain, which is one of the main pain sites of endometriosis (Facchin, Barbara, et al., 2017; Facchin et al., 2015; Souza et al., 2011).

The gendering of pain affects women's psychological health. Facchin et al. (2015) found that non-menstrual pelvic pain affected psychological health more than dysmenorrhoea. The authors suggest that this may be because menstrual pain is supposedly 'normal' and non-menstrual pelvic pain is not, suggesting that this is a constant reminder to women that their bodies are abnormal. Another interesting finding in the same study is that dyschezia (painful defecation) did not affect psychological health. The authors explain since dyschezia is not genital or pelvic pain, it is not connected to experiences of femininity.

A negative feminine identity and experiences of self featured prominently in many women's accounts. This included negative body image, infertility, and being unable to derive pleasure from their sexuality. These experiences were associated with not feeling like a 'complete' women and feeling inadequate (Moradi et al., 2014). Body image concerns were also exaggerated by bloating from pharmacological treatments, anaemia from excessive menstruation, and scars from surgeries (Facchin, Saita, et al., 2017). Furthermore, women with endometriosis reported a lack of control and feelings of powerlessness over the body. (Moradi et al., 2014; Rush & Misajon, 2018). These are implicated in notions of a feminine identity because, as Chrisler (2008) asserts, self-control is vital to the construction of feminine ideal. She argues that women are expected to control what they eat to achieve the ideal body, and furthermore, are expected to control how they act, especially when premenstrual, with emotions such as anger being repressed for fear they do not meet the expectations of women as soft-spoken and nurturing.

The delegitimation of subjective experiences and knowledge about bodies for women with endometriosis because of gendered health beliefs, also affects psychological health. This not only results in lengthening the time for diagnosis, meaning that women are exposed to prolonged suffering, it also has a detrimental effect on women's mental wellbeing. Here, the delegitimation acts to cause self-doubt about mental capability. Women feel isolated,

worthless and their self-esteem is impacted negatively (Cox, Henderson, Wood, et al., 2003).

Several studies (Facchin et al., 2015; Facchin, Saita, et al., 2017) examining the lived experience of endometriosis recommend that psychological intervention be available for women suffering from endometriosis. While there is value in this, the reliance on psychological intervention has the potential to position the experience of endometriosis as an “individual tragedy” and ignores the context in which distress arises (Jones, 2016, p. 566). For instance, while examining differences between women who were significantly distressed compared to their counterparts, Facchin, Saita, et al. (2017) identified that diagnostic delay, medical interactions of a negative nature and lack of support had a key role in the severity of distress. As the above investigation of the literature has shown, several of these factors are the product of the gendered context which frames the experience of endometriosis. While still suggesting psychological intervention for the individual, Facchin, Barbara, et al. (2017) also call for further exploration of the gendered nature of endometriosis with a focus on cultural and gender norms that influence women’s experiences.

To summarise, the literature provides an overview of the way in which social and cultural contexts matter to the lives of women with endometriosis, and are related to gendered social roles. Although gendered concepts arise through the identified research, some overlook or marginalise how gender impacts on experience. It is necessary to consider a theoretical lens that focuses on the topic of endometriosis through specific recognition of gender.

Research Rationale

According to Ussher (1989), for change to be enacted, it is important to recognise any harm that results from knowledge systems. She suggests that there is value in examining representations of the female body and their influence on women’s experiences. In this instance, I propose that this recognition involves the identification of negative representations of the female reproductive body, how that matters to endometriosis experiences, and how women inhabiting these bodies are regulated.

With this in mind, the purpose of this study is to draw attention to the conceptualisations of the female reproductive body in relation to endometriosis experiences. Therefore, this research aims to:

Locate the experience of endometriosis within constructions that regulate the female body

By locating the construction of women's endometriosis experiences within a gendered context, I hope to highlight how entrenched women's experiences are in existing regimes of knowledge that regulate them.

In this chapter, I have provided a context through which the female body is pathologised, and consequently has a bearing on constructions of women's illnesses. I have positioned endometriosis as inescapable from cultural notions of the female body, through biological and theoretical underpinnings that hold fast to notions of the body as disordered. I have shown how endometriosis has served to justify the repression of women and reinforce their purpose of reproduction and the resulting disordered positioning if they do deviate from traditional social roles. Chapter Two outlines the theoretical assumptions and methodological processes that guide the research. I also provide a case for using blogs as data for researching women's illness experiences. Chapter Three provides the findings from the analysis and Chapter Four entails a discussion comparing these results to the existing literature, my personal reflections and the implications of the analysis.

CHAPTER TWO: THEORY AND METHODOLOGY

The previous section argued for a research rationale that could attend to the way in which the discourses surrounding the female body construct women's experiences of endometriosis. It also argued for an approach to research that enables multiple 'truths' as constructed through socio-cultural and historical contexts that concern gender and power. Consequently, this work draws on feminist post-structuralism as a theoretical lens, as well as positioning theory. This chapter begins with a discussion on the assumptions of feminist post-structuralism and positioning theory and the way that power, subjectivities, discourse and language matter to experiences in the world. I then illustrate the compatibility of Foucauldian Discourse Analysis as a methodology before arguing for the relevance of using a data corpus of online blogs for considering women's illnesses. I also discuss reflexivity before outlining my analytic procedure.

Feminist Post-Structuralism and Positioning Theory

Feminist post-structuralism holds that knowledge and subjectivities are constituted through both language and discourse. Gavey (1989) defines feminist post-structuralism as offering "a theoretical basis for analysing subjectivities of women and men in relation to language, other cultural practices and the material conditions of our lives" (p. 472).

The feminist post-structuralist approach holds several assumptions toward knowledge construction. Knowledge is understood as socially constructed and therefore unstable. It posits that there are multiple meanings rather than a singular truth and that knowledge is never neutral, and thus linked with power (Gavey, 1989). In this sense, there are no facts to be discovered in research. Instead, it enables an identification of the dominant knowledge systems that hold power (Gavey, 1989).

Drawing on Foucault's assumptions that power and knowledge are linked, Burr (1995) illustrates that power is enacted through allowing certain "versions" of 'truth' and, therefore, knowledge is a particular version of events which become accepted as 'truth' (p. 64). By understanding how such power works,

feminist post-structuralism challenges and resists dominant knowledge systems and identifies pathways for change (Gavey, 1989; Weedon, 1987).

Feminist post-structuralism posits that our subjective experiences are partly formed through language. The term ‘subjectivities’ consists of conscious and unconscious thoughts, emotions and feelings (Willig, 2013). How we construct ourselves is dependent on linguistic interactions which make available different constructions (Burr, 1995). Language, as with knowledge, is not fixed in meaning. Meanings can alter depending on historical and cultural context. Consequently, meaning does not begin with the person but instead begins with discourses (Davies & Gannon, 2005).

While there are a number of different definitions of discourse, this research takes a Foucauldian perspective to the concept of discourse in that it refers to “a system of statements which constructs an object” (Parker, 1990, p. 191). There are multiple discourses available to any particular object, and they can construct this object in different ways and each discourse “claims to be the truth” (Burr, p. 49). Discourses shape or control what can be done as they construct what we take as legitimate social practices (Willig, 2013).

Not all discourses are equal in power, and it is the dominant discourses that constitute social practices and construct power relations (Willig, 2013). For example, considering the binary male/female oppositions discussed in Chapter One, dominant historical discourses have framed the male as rational and normal, whereas the female is irrational and unnatural (Davies & Gannon, 2005). As discussed earlier, these dominant negative representations of females have been produced and reproduced via a variety of institutions such as art, religion and medicine.

That meaning is embedded in discourses is of relevance when considering the female body. Feminist post-structuralism enables a view of the body as regulated through dominant discourses. Weedon (1987) argues that it is through dominant discursive constructions that biological differences between men and women are emphasised and these constructions have historically removed women from educational opportunities, forcing them to resist notions of irrationality. Returning to arguments made in Chapter One in which the

framing of the female as irrational is reproduced through the construction of PMS as a legitimate medical condition, it is possible to note instances where supposed knowledge/power becomes a medical 'fact' and has very real material effects for women who display emotion. Discourses such as these have removed women from careers and delegitimised their distress in circumstances. In this example, we can consider the power of medical discourse as having material effects, and it is oppressive power such as this that a feminist post-structuralist approach is concerned with disrupting (Gavey, 1989).

A number of subject positions are made available through discourse, which can be either taken up or resisted by a person. Davies and Harré (1990), in their conceptualisation of positioning theory, define subject positions as "parts" allocated to people through the use of a story that is formed through interaction (p 48). The positioning of people during interactions serves to structure their experience, and therefore has implications for the possibilities of a self-hood and subjective experience.

This work takes the stance that agency is possible within post-structuralism. In this sense people can either take up subject positions or resist them. According to Weedon (1987), the subject within post-structuralism is capable of resistance "produced out of the clash between contradictory subjective positions and practices (p. 125). Davies and Gannon (2005) define agency within post-structuralism as the recognition of regulatory powers that have been established through dominant discourses, and with this reflexivity, we are able to resist or counter positionings. The authors question dominant discourses of femininity, and therefore make available different meanings of gender for women to take up. Positioning allows agency, and in this way, women can resist dominant regimes of knowledge and consequently position themselves in an alternate way.

Methodology

Foucauldian Discourse Analysis

It is through the aforementioned concepts of discourse, language, power and subject positions that Foucauldian Discourse Analysis (FDA) is a methodology

compatible with Feminist post-structuralism and positioning theory (Gavey, 1989). According to Willig (2013), “FDA asks questions about the relationship between discourse and how people think and feel (subjectivity), what they may do (practices) and the material conditions within which such experiences may take place” (p. 130).

FDA has previously been utilised in the analysis of lay accounts of health and illness (Ussher & Perz, 2014). The advantage of using FDA in health and illness research is that by locating experiences within dominant discourses, such as the biomedical, and the subsequent impact it has on their behaviour, it opens up understandings of how people are positioned within these discourses. For example, the experiencing of emotions being pathologised as depression, and the implications this then has on how people behave (Ussher & Perz, 2014).

FDA necessarily takes up Foucault’s theory of knowledge and power, in that it is concerned with language as a site of both power and resistance (Willig, 2013). As outlined above, Foucault recognises power and knowledge are paired together in discourse (McNay, 1992). In this way the power/knowledge nexus posits that knowledge is a “version of a phenomenon” and power is the ability of this phenomenon to achieve things (Burr, 1995, p. 64).

FDA is an appropriate analytical methodology for this research as the purpose is to determine how women with endometriosis are regulated. In this way, an approach that determines how power/knowledge is produced through language has the potential to highlight regulatory practices and dominant discourses. By deconstructing the experiences of women with endometriosis, it is possible to acknowledge the wider context within which power is situated and the implications this has for women. In particular, whether women take up self-policing practices within these discourses or if they recognise how they are regulated within them.

Dominant discourses can be threatened by lesser discourses which can then become the new version of ‘truth’, and Burr (1995) points out that if there was no resistance, there would be no need to restate these discourses continually. Burr states that power in dominant discourses is visible when resistance comes

from another discourse. Therefore, “repression produces its own resistance” (McNay, 1992, p. 39). Consequently, through using FDA to consider how women construct their experiences, the analysis process provides a lens to not only how they are regulated through dominant discourses, but reveals these discourses through resistance. As the women advocate for themselves and other women with endometriosis and display agency, dominant discourses can become visible through the women’s resistance.

Malson (1997) criticises some discourse analytic approaches as being too inflexible. She argues this is due to their concern with the body within the text, rather than the material reality of the body. However, she asserts that a feminist post-structuralist approach is appropriate for analysing women’s bodies due to the Foucauldian idea that discourses are about power, and that discourses have material consequences in terms of regulating the body and determining what is or is not normal. This warning is of particular consequence considering endometriosis where dominant discourses have resulted in the misdiagnosis of women who do not meet ‘desirable’ reproduction criteria through a construction of women as immoral and diagnosed them as suffering from sexually transmitted infections instead.

Blogs as Data

This research explores women experiences with women’s online illness narratives published as blog posts. Blogs can be understood as online diaries (Hookway, 2008). Previous qualitative research has explored online illness narratives with cancer patients, people with junior arthritis, and women with fertility issues among others (Keim-Malpass et al., 2013; Prescott, Gray, Smith, & McDonagh, 2015). At the time of producing this thesis, only one study was located that used endometriosis blogs as data. The topic of the research focused on how women share and gather knowledge online (Neal & McKenzie, 2011).

There are several advantages to using blogs as a medium for data. Of particular value, is that bloggers are writing about issues and events that are of importance and relevance to them (Keim-Malpass et al., 2013; Prescott et al., 2015). As qualitative research often focuses on the feelings, perceptions and experiences of the participant, blogs are a useful data source as researchers

have found that participants tend to blog about what they feel is important in the process of their experience (Keim-Malpass et al., 2013; Prescott et al., 2015). For example, Pitts' (2004) research on women blogging about breast cancer shows that women used internet platforms to "negotiate their definitions of self, identity and situation in the context of gendered illness" (p. 42). This was not only achieved through the text but also through the imagery they chose for their web pages.

It is important to note that online blogs are primarily written with an audience in mind so the content may differ than that of a private diary not meant for public viewing (Hookway, 2008). Although the point can also be argued that there is no guarantee that bloggers understand or intend that what they publish on the internet will be publicly seen.

Secondly, bloggers often (but not always) commit their experiences online in real time, which avoids the reliance on memory in relaying their experiences. This is an advantage when researching illness as the experiences can be recorded within multiple contexts, such as throughout diagnosis, treatment and relapses (Keim-Malpass et al., 2013).

Another advantage of using blogs as data is that they serve as a vehicle for a discussion of sensitive information that participants may be ashamed to speak about during interviews (Elliott, 1997). This may be because of the perceived anonymity some bloggers could feel they have by posting online. This is an important feature in endometriosis research as many of the symptoms affect intimate bodily functions that women may consider embarrassing to speak about face to face or in a group setting.

Also, blogs can be considered inclusive due to the low level of technical competence required (Hookway, 2008). However, this argument does not allow for the well-recorded digital divide that excludes people due to a lack of opportunity to access technology, nor does it allow illiterate women to be included. Another disadvantage is the lack of opportunity to clarify or elaborate further on points made as would be possible within an interview.

Other limitations of using blogs as data are the inability to confirm the authenticity of what they report. For example, there is no way of verifying if

the women indeed have endometriosis. Hookway (2008) however, counters these concerns by comparing blogs to face-to-face interviews or questionnaires, where it can also be difficult to tell if the participant is genuine.

In respect to my sample, I believe each of the women is legitimate in their narratives. Their blogs are, for the most part, extensive bodies of work over a number of years with images of themselves in hospital and with loved ones. Frequently medical images from their laparoscopies were posted to show their lesions. For some, they also posted their full names and partners' names, as well as their locations and often details about their workplaces. Some also posted interviews that they had done on television and radio to promote endometriosis awareness.

Data Collection

The endometriosis blogs were sourced through the Google search engine, using the key term 'endometriosis blogs'. Once several blogs were sourced, others were located through snowballing as many blogs also listed links to their own favourite endometriosis bloggers. Snowballing refers to locating links to other blogs through similar blogs. There are a large number of English language endometriosis blogs freely available online, all with varying degrees of content. In order to determine the suitability of the content, certain criteria were considered.

Firstly, endometriosis needed to be the primary topic for the blog, although throughout the course of their blogging some women were diagnosed with additional conditions, such as adenomyosis, a condition that often accompanies endometriosis and consists of endometrial tissue in the muscle wall of the uterus (Evans & Bush, 2015). These were still considered for inclusion, as it is common for women to suffer from additional conditions besides endometriosis. Secondly, some blogs were excluded because they did not speak about their own experiences and appeared more focused on being information sharing sites. Thirdly, the blogger must have had a sufficient number of quality posts specifically relating to her experience of endometriosis. The determination of what constitutes 'quality' in this respect is due to the richness of content. For example, the blogs chosen were text heavy rather than image laden. I also

considered the extent to which women discussed their experiences and subjectivities about endometriosis.

Ethics

Additional criteria for blog selection also encompassed the ethical considerations surrounding social media posts. In this respect, data collection was guided by Eastham's (2011) Decision Making Framework. This framework acknowledges the debate as to whether content published on the internet is considered in the public domain.

Key ethical points taken from the framework involved considering whether the bloggers intended their work to be read publicly. In this instance, only blogs that were freely available were included, as in no login or registration were required to view the text. I also considered whether the blogger had added links for sharing the blog via social media and email. Additionally, I explored whether pathways were freely available for contacting the blogger or commenting on the blog itself. This including links to Facebook, Instagram or Twitter sites, email addresses, or the Contact Us option on the website, as well as the facility to leave comments on the blog itself. This was important as some commentators suggest that contacting bloggers to request the use of their content could potentially be intrusive if the blogger did not intend for their work to be shared (Wilkinson & Thelwall, 2011).

Only once the above criteria were met did I then attempt to contact the bloggers to request the use their blog content as data for this study. This was done primarily via email, via the Contact Us website option, and Facebook Messenger. An email was prepared outlining my research and the risk that the use of direct quotes could lead to the identification of their work (see Appendix). The email included an assurance that I would protect their privacy to the best of my ability with the above-mentioned exception. As some of the blogs featured blog posts from guests, assurance was also given that this content would not be used without specific permission. Each of the women has been given a pseudonym in order to respect their privacy.

The replies I had back were overwhelmingly supportive and enthusiastic for the research. Many of the women stated that they were happy for their writing

to be used in this way and wanted to help promote knowledge and the issues surrounding endometriosis any way they could.

Endometriosis Bloggers

The final data sample consisted of seven blogs. The word count of the individual blogs ranged from approximately 20,000 to 100,000 words with a total word count of approximately 300,000. The time frame of the blogs ranged from 12 months to a number of years. The purpose of the blogs at commencement was often to help other women with knowledge and through the sharing of experiences. The posts all included deeply personal stories about experiences that affected them significantly. The women were based in the United States, Australia, the United Kingdom, and Aotearoa New Zealand. All were over the age of 20 years or older. Although the health systems between countries varied, many of the experiences described were uniform.

As an Aotearoa New Zealand researcher, I am aware of the importance of ethnicity in research, and it is crucial when performing research to understand that methods can perpetuate social injustice amongst marginalised groups. Unfortunately, due to the anonymity of the blogs, it was not established which ethnicities the women identified with. Nor was socio-economic information available.

Reflexivity

Reflexivity is critical to feminist research because it not only involves the researcher identifying who they are in respect to the research process and how their life experience matters to the research but it also recognises the way in which research affects them in a reciprocal manner (Wilkinson, 1988). Reflexivity can also operate as an incentive for change through the self-awareness of the researcher.

Knowing this, I believe it is important for me to point out that I do not have endometriosis. However, along with many other women, I have long been aware of the negativity and shame associated with menstruation.

Gynaecological complaints such as abnormal smears, for me, have also resulted in adverse encounters with a range medical staff from administration to the doctors and nurses. I have experience of being treated as little more than

a body and made to feel 'less than'. Once a doctor told me unsympathetically that I had either cancer or a sexually transmitted infection before dismissing me with vague mentions of a referral (thankfully it turned out she was wrong and to her credit, she did ring later to apologise for her manner). At the time, I attributed this poor treatment more to my youth than to my gender.

Endometriosis is a topic that I knew very little about until I began this research. I always knew of the condition of 'endometriosis' and I have friends who experience it; however I never discussed it with them past the superficial. In my mind, it was always associated with 'bad periods' or fertility problems. Although this is my experience, I suspect that this represents how little awareness there generally is in regards to the condition.

I am a white, married woman with children. I strive to address issues of injustice for women, and I was motivated to address this topic because the idea of an 'invisible' illness such as endometriosis being so prevalent yet so ignored was mystifying.

Analytic Procedure

To analyse the large content of blog data for this work, I first copied the online blog text into word documents to allow saving of the text and to have the ability to highlight passages. Once this was done, I was able to perform careful readings of the blogs multiple times, and categorise the data into themes relating to the experience of endometriosis which were entered onto an excel spreadsheet. Due to the broad content of the blogs, this enabled the data set to be reduced to a relevant and manageable size. In the representation of the women's experiences, I have corrected occasional errors in spelling and grammar to make the quotations more readable; however, I have taken care to ensure no meaning is altered, nor have I converted American spelling.

The analysis process was guided by Willig's (2013) six-stage approach to Foucauldian Discourse Analysis. This approach entails identification of constructions of the object under study, and the discourses these constructions sit in, as well as the function and implications of those constructions.

The first step in the analysis involved searching the data for references to the discursive object, which in this case were references to the *regulated female*

body experiencing endometriosis. While I identified statements explicit to the discursive construction of the female body, I also followed Willig's (2013) recommendations to identify implicit references of the discursive object. This included experiences that affected the body. It also included experiences constructed around bodily functions such as menstruation, symptoms such as pain, fertility capabilities and concerns, sexual intercourse, surgical experiences and interaction with clinicians for treatment options. This resulted in the identification of a number of different ways in which the experience of the female endometriosis body was constructed.

The second step involved deciphering which wider cultural discourses these constructions of experience sat within. Then I considered the action orientation stage; this third step involved examining what these different constructions of experience were achieving, as in what was their particular function. As the premise of this research was to locate the different ways that regulate women, I considered how these constructions operated in ways that controlled women.

Then step four, the availability of subject positions, was explored to see what positions were made available and if the women took them up or resisted them. Step five required unpacking the implications of these constructions and positions. This involved considering the implications of actions, as in what could be said or done by the availability of these positions.

The final step involved considering the potential impact on subjectivities. As discourses influence "ways-of-being in the world" and how we see that world, they also affect what people think and feel (Willig, 2013, p. 133). In particular, the subject positions that people take up have implications for subjectivities.

My analysis resulted in five discursive constructions related to how women with endometriosis are regulated. I label these as regulation through 'Silencing', 'Sacrifice', and a 'Disordered Body' which sit within wider '*Ideal Femininity*' discourses. The remaining two constructions are regulation through an 'Open Body', and 'Dismissal', which sit within discourses of '*Legitimation*'. It is important to note that the findings are my interpretation of the data and therefore may not be representative of all women with

endometriosis. However, they may add another perspective to the experience of endometriosis in which gender is central.

CHAPTER THREE: ANALYSIS

This analysis resulted in the identification of five main discursive constructions of the experience of endometriosis that operate to regulate women. These constructions sit within the wider discourses of *Ideal Femininity* and *Legitimation*. Due to the variety of meanings in particular passages, several of the quotations are at times abridged and repeated in different sections.

Ideal Femininity Discourses

The regulation of women sits within discourses of *Ideal Femininity* that portray often-unrealistic standards established by traditional social roles, that women are expected to take up. This ideal is of the silent, sacrificial woman who suppresses her irrational nature and conceals her blood and breastmilk, so we will not be reminded that she is a sexual object. She must remain the nurturing ‘carer’ who prioritises motherhood and her partner’s sexual satisfaction over her wellbeing. Self-control is also an indicator of *Ideal Femininity* whereby women are expected to control themselves, physically through maintaining appearance such as by weight loss, and also control their subjectivities through the suppression of emotion (Chrisler, 2008).

Regulated By Silencing

In this section, I explore the way in which the experience of endometriosis is constructed as one of being silenced for the women in this research. Strategies of silence are constructed in three main ways — endometriosis as a condition which is unspoken and shameful, as a condition that merits self-silencing and hiding, and silencing through the suppression of emotion.

Several women frame endometriosis itself as being an issue of silence. In this instance, Anne asks how it is possible that such a prevalent condition is so “unspoken of?”

How is it that a disease that affects 10% of the female population (roughly 1% more of the population is affected by endometriosis than diabetes) be so unspoken of? (Anne)

She then goes on to answer her question, declaring that:

[I]t's something women generally suffer silently. (Anne)

The following constructions give some insight into her question and help to shed light on why this condition is “unspoken.”

Shamed and ‘Grossed’ into Silence

The construction of endometriosis as bound up with embarrassment and shame consequently invites silence. Bonnie outlines the humiliating nature of symptoms that endometriosis can cause:

Endo is embarrassing. Full stop. It involves periods, leaks, problems with going to the toilet, problems with sex, the reproductive organs and pain. It's not something that is easily or, often, willingly spoken about. (Bonnie)

The above excerpt frames the nature of endometriosis symptoms within cultural and social taboos that personal bodily functions are not “easily” or “willingly spoken about.” Comparisons can be drawn between the issues she labels as “embarrassing,” and the constructions of the female reproductive body discussed in Chapter One in which the ‘leakiness’ of women’s reproductive processes have been constructed as a source of shame to be hidden (Shildrick, 1997; Ussher, 2006).

While Bonnie conveys the embarrassment associated with endometriosis, other women specifically construct experiences of feeling silenced when others frame endometriosis as a repugnant condition. Several women experienced negative responses inferring that women should not speak about it. In the following passage, Anne recounts experiences of being discouraged to share:

When you mention endometriosis you get a lot of stunned faces who don't know what on earth you are talking about, and when you explain it further, sometimes you even get a few “ews” and “I didn't need to know that!” (Anne)

Here, endometriosis is characterised with disgust through the response of “ews” after Anne explained the condition. Furthermore, she is blatantly told that others do not “need to know that!” therefore explicitly silencing the endometriosis body.

Self-Silencing and Hiding

Negative reactions such as with the example above can result in women silencing themselves and/or hiding symptoms. Cara wrote the following passage after she came across an online image that had compiled a list of negative retorts women experience when speaking out about their endometriosis:

It's words like this that keep women silent.

Being the loud-mouth that I am, I didn't really think about it. Until I tweeted out that image above and saw a reply to the effect of: "This is why I don't talk about my endometriosis."

Why would you want to when people say things like "No one needs to know this"? It's why I briefly hesitated - and still sometimes do - before beginning this blog. (Cara)

Cara concludes that the effect of such negativity is that women will remain "silent." She considered restraining her own behaviour with her blog because she feared negative responses, a form of self-silencing although she resisted this position and went ahead with vocalising her distress. In this respect, social practices dictate what is acceptable to speak about, and operate to keep women silent. If they breach these expectations, there is the threat of ridicule and condemnation that becomes visible through social media. These comments come when they do speak and are told, "no one needs to know this."

She goes on to say that women minimise their symptoms because of the negative responses of others. In this instance, it is clinicians' reactions inspiring these outcomes:

The women who, like I did, downplay their excruciating pain because they've been told to "suck it up" or that the pain is "all in their heads." Women who are too afraid to advocate for themselves and make their symptoms known because a condescending doctor has told them "nothing" is wrong. (Cara)

She positions women as “afraid” to speak out about the severity of their symptoms because of negative experiences. The result is that they remain silent about the symptoms, by “downplay[ing]” them.

Overlapping with self-silencing, the women themselves also acknowledge occurrences of hiding the symptoms they suffer. In the following excerpt, Ella explains her feelings about disclosing her condition within a professional context:

I have been trying to hide how ill I have been from my boss and colleagues, and have worried that admitting I'm ill would look weak and unprofessional. I know that is ridiculous, but without a diagnosis I didn't have the right words to say what I needed, and with it, I worried that they wouldn't understand and just think I have period pain or something. (Ella)

She is self-silencing through hiding her symptoms out of the fear of being judged as weak. Her experience is located within social sanctions surrounding menstrual pain. This is consistent with other research on reasons women are silent about endometriosis (Seear, 2009a). She also appears to place the validity of her condition and symptoms within the legitimization of a medical diagnosis.

Others construct the experience of self-silencing by recounting instances when they feel that this behaviour is not necessary. Greta describes the relief of being in the company of other women with endometriosis:

I didn't have to hide or pretend for a change and that was lovely. (Greta)

This indicates that Greta self-silences by concealing her symptoms in certain circumstances. This implies there is a fear of judgement from others who do not understand endometriosis, which regulates women's voices.

Suppression of Emotion

It is not just the hiding of symptoms that represents women self-silencing, but also the suppression of emotions. Women are silenced through the expectation

that their emotions should be held in check, even in the face of the distressing adversity they encounter during the endometriosis experience. For example, while Donna's description of hiding her pain is consistent with the experiences mentioned above, she also highlights the suppression of her emotional turmoil:

The word 'Fine' I once heard being described as 'Frustrated, Insecure, Neurotic, Emotional'. Yep, that pretty much sums up how I'm feeling. I want to tell people that some days I feel like I'm all over the place, some days I'm an emotional wreck, I'm fed up and I'm hurting. But most of the time I don't. I just say I'm fine - with a smile. A smile also covers up your worries, your anxieties. On the outside your smile is painted on. On the inside you're stressed to the max, with a million and one questions, all running through your head at once. Worrying about the pain, the medications you need to take, your job because you've had so much time off sick, college work, relationships, the future... (Donna)

Positioning herself through the use of the FINE acronym is significant as it strengthens traditional medical representations of women with endometriosis as “frustrated, insecure, neurotic, emotional” (Whelan, 1997). Hiding behind the smile suggests that she self-silences to hide this “neurotic” woman. The condition affecting her body is adversely interfering with many aspects of her life, yet this excerpt implies showing emotions, such as anxiety and stress, is not an option.

Other women demonstrate that some emotions are negative. For instance, Ella introduces her blog post with the explanation that she initially wanted it to be a positive site. However, she writes that:

When I started this blog, I decided that I didn't want it to be a haven for my trauma and pain. My intention is to make people laugh where I can- I often see the funny side of difficult situations (it's a blessing and a curse), while also staying true to the reality of my life with endometriosis.

That said, this is yet another angry and ranty post, so apologies in advance. (Ella)

That Ella initially did not want to locate her “trauma and pain” in a public blog, infers that the expression of such emotions, particularly anger, are seen as negative, and she needs to justify her current blog and in a sense apologise for any negative “rants.”

This is outlined further in the following excerpt, wherein discussing emotion, Ella goes on to explain her position:

I never knew I could cry so hard or so often as I have this year. These massive tears of anger and grief for what has happened and for what I'm scared my future will be. I'm surprised I haven't dissolved my eyes. This sort of reaction goes against the spirit of how we are traditionally encouraged to cope with illness in our society - by staying positive, fighting hard, and keeping a stiff upper lip. (Ella)

Ella acknowledges that her emotional reactions counter the cultural expectation of coping with illness stoically as portrayed by the use of the idiom “keeping a stiff upper lip.” In a sense, her emotions fail to achieve this by expressions of anger, fear, and grief although she knows she is expected to be positive and “fighting” to “cope with [her] illness.”

Silence and Gender

Many women often mention gender when discussing experiences of silence. Here, Ella continues on the theme of self-silencing; however, in this instance, it is behaviour that she felt should be constrained:

I'm one of those girls that wants to make everyone happy and cause no fuss or drama. There came a point this year when I realised some fuss was very much needed if I am to keep going. (Ella)

That she defines herself by her gender as being “one of those girls” who is responsible for the happiness of others and therefore has historically not upset people by being drama[ti]c or causing a “fuss” is notable for two reasons.

Firstly, the responsibility for happiness at the expense of her feelings positions her in a nurturing and self-sacrificing traditional female role. Secondly, the avoidance of voicing distress in order not to make a fuss as “one of those girls” implies expectations that women should self-silence. For example, studies on the gendering of emotion propose that when a male displays emotion, it is considered socially acceptable as it is brought on by a particular context, whereas if a woman displays emotion, she is just seen as being emotional (Barrett & Bliss-Moreau, 2009). Ella negates this expectation of how to act and acknowledges how she has come to the realisation that she needs to make “some fuss.”

The gendered cultural expectations discussed above are reiterated here. Cara acknowledges the role of gender in expectations of women. Again, I draw on Cara’s experience with an online image that is comprised of negative comments made to women who have discussed their endometriosis. In this example, Cara describes them as “misogyny”:

Maybe a little disgusted that these comments are just thinly veiled misogyny, like the one about taking care of families and not complaining. After all, women should be seen and not heard... (Cara)

She recognises a gendered aspect in the comments that is represented through the social role inference of “taking care of families and not complaining” where women are positioned within a traditional carer role. She sums it up with “women should be seen and not heard.” This play on the proverb compares women to children and indicates women’s lower status in society.

She continues her discussion by comparing men’s health issues with endometriosis:

No one ever tells someone with heart disease or diabetes to stop talking about it. And gosh, I can't turn on the TV without seeing an ad for erectile dysfunction medication further supporting my theory that if endometriosis happened to men, we'd have a cure by now.

*But just because it deals with *gasp* LADY BITS, we should all be very quiet and not let anyone know that women have uteri. (Cara)*

This excerpt highlights Cara's experience of silencing and demonstrates her frustration at the privileging of men's health. She illuminates what she feels is the gendered nature of the illness that renders the female and her distress as inferior. Also acknowledged is the relevance of female reproductive organs. Cara uses, somewhat sarcastically, the term "lady bits" to signify the pathologisation of the female body and frames it as something that is shameful or unspeakable.

In several accounts, emotions are again constructed as unacceptable, but in these cases, gendered binaries are apparent through women positioning themselves as less rational in comparison to men. Here, Cara is about to go into surgery and due to nil-by-mouth is feeling unwell and nervous. The nurses call her husband in to comfort her and Ella recognises his qualities:

My husband has a gift for being a calming presence at all times, which balances out my tendency to blow situations out of proportion and expect the worst to happen. Thank God I married someone level-headed and sane... (Cara)

The statement that her husband is "level-headed and sane" whereas she may "blow situations out of proportion" infers that she is not rational. This also suggests that emotions or reactions of women that defy the social order should be repressed.

Again, in the following excerpt, while dealing with a frustrating medical system, Ella speaks about her partner in the same way:

I was also so glad Mr B was with me, I don't think I could have coped with the mishaps if I was on my own. He is great company in a crisis, he has the calm head that I lack. (Ella)

Clearly, Ella believes she lacks a "calm head," therefore positioning herself as irrational and taking up the gendered binaries. In this regard, the admission that

she is not calm under stressful circumstances infers that she should be, and it is socially sanctioned that she should self-silence her distress.

To summarise, there is an expectation that others view endometriosis as shameful, that women are silenced in respect to their pain and other adverse experiences. Some women internalise this belief, taking on a self-silencing position characterised by the hiding of symptoms and suppression of emotions.

Regulated through Sacrifice

The idea of sacrifice runs through several of the blogs. In this context ‘sacrifice’ refers to women needing to give something up when confronted with choices. This sacrifice must be made in order to gain something else, or alternatively, for the sake of someone else. Primarily, sacrifice is constructed through reference to fertility and sexuality, two constructs that can define notions of femininity.

Several women explicitly describe their experiences as involving sacrifice. For instance, here Ella implores others to share their experiences of sacrifices in regards to treatment:

I'd love to hear your thoughts about any sacrifices you've made to have treatments for your endometriosis or chronic illness. (Ella)

In the following instance, she frames sacrifice as necessary in the hope of getting better:

I started to think about just how much pain, sacrifice and trauma we women with endometriosis have to go through for the mere possibility of feeling any better. (Ella)

In this case, sacrifice is a requirement where women “have” to experience “pain” and “trauma” and give up something as a condition of feeling better.

Alternatively, experiences are constructed whereby sacrifice is seen as necessary to conceive, as infertility is, for some women, a consequence of endometriosis. Here, painlessness is sacrificed for the ability to become pregnant. To illustrate this further, Cara expresses the dilemma she experiences

with taking particular medications and making decisions about her current personal wellbeing versus future children:

It's why my first ob/gyn wanted me to get on Lupron as soon as possible - to temporarily shut down my uterus, stop the endo growth and preserve my fertility for a little bit. I won't get into it in this post, but Lupron is a total mess of a medication that I am not anxious to be put on. But DO Google it, if you'd like to learn about its heinous side effects.... So now, my overall treatment was a question mark. Was I willing to sacrifice my future kids in order to have surgeries and ensure that I could lead a healthier, happier, less painful life? So that I could keep working, traveling and doing the things that I love? So that I could live the way I want to? (Cara)

Surgery is the best option for quality of life but doing so would jeopardise fertility. The other option, Lupron, is a drug that may “preserve” her fertility but otherwise compromise her current quality of life through “heinous” side effects. The options involve her potentially “sacrific[ing]” future children for a “healthier, happier, less painful life.” Choosing to still be able to conceive involves sacrificing living the way she wants to. It can also be seen that choosing her well-being over motherhood is a form of resistance to *Ideal Femininity* discourses.

Ella presents a similar dilemma. In this case, Ella is given a “choice” – her fertility prospects or pain management. She cannot have both:

During my afternoon appointment I was presented with a choice- what is more important to you - pain management or fertility? The recommended course of action would differ significantly depending on what I choose.

If it's pain management, then they'd recommend radical action for me. Possible removing my uterus and/or ovaries, then hormones. If it's fertility then this isn't possible, or obvious reasons. (Ella)

Ella's choice involves sacrificing a pain-free existence for future motherhood. If she wants to be pain-free, her reproductive organs will need to be removed. The contrast here represents as motherhood versus a loss of the organs that frequently define femininity.

This sacrificial mother theme continues with Bonnie who is attempting to conceive:

The 'problem' really is that while we are trying for a baby, my endometriosis and every other ache and pain has had to be put aside because I can't start any new medication and therefore cannot be treated for anything. But then, you know what they say - pregnancy can help endometriosis.
(Bonnie)

Bonnie is willing to "put aside" her endometriosis and the pain that comes with it, by sacrificing medication that eases her symptoms. In this sense, she is sacrificing her wellbeing for the sake of motherhood. Perhaps most troubling is that she quotes the endometriosis adage of "pregnancy can help endometriosis," that the literature confirms is not a definitive treatment but may merely mask the symptoms (See Leeners et al., 2018).

Sacrifice does not just involve motherhood; there are also decisions to make regarding sexual relationships. In the same way, personal wellbeing must be put aside to preserve intimate relationships. One of the side effects of certain pharmaceutical treatment options is a lowered or non-existent libido. Ella describes a decrease in libido after taking the contraceptive pill to help control her symptoms and is concerned for her partner:

He deserves somebody who isn't just going through the motions and pretending to enjoy it when things happen.
(Ella)

Her partner is constructed as deserving of a fully engaged sexual partner, and she feels guilty about the situation even though her partner does not complain. She still has sex with her partner, although she is "just going through the motions." This is an experience for women generally as part of the feminine

ideal. It is a woman's duty to perform sex, and when this does not happen, guilt is evoked.

For Ella, this guilt is based on the belief that her partner is "going without," a sacrifice that he must make:

So lovely man is going without increasingly often - which he seems fine about, but I still feel bad. (Ella)

The above two passages present two dilemmas: guilt for not enjoying sex and guilt for not having it regularly. As is the female imperative, Ella still performs but with little engagement:

We were doing it the other day and I was fully engaged in thinking about replacing the broken screen wash mechanism on my car. (Ella)

To continue to be intimate when not enthusiastic is a sacrifice of her wellbeing for the consideration of her partner. In the next passage, this conflict continues between what she wants as the ideal:

I want to feel like a smoldering goddess, not somebody who would generally rather do a massive mountain of ironing (this actually happened) than be intimate with the love of her life. (Ella)

Ella constructs the feminine ideal as an enthusiastic sexual partner who represents a "smo[u]ltering goddess," but her endometriosis means that she would rather undertake a monotonous task than be intimate.

*But I feel like I can't win. If I stay on the pill, I have no desire to be intimate, and if I come off it I'm too busy lying on the floor in agony begging people to kill me to even think about such things. **Sigh** (Ella)*

Ella draws on the metaphor of 'winning and losing' in her representation of her sexual relationship. For her, the pill interferes with her libido yet going off it means that she experiences "agony." Both ways, a sacrifice is involved, and there is a winner and a loser.

While Ella feels guilt due to her lack of libido, Freya feels guilt for the pain that she feels when sexually intimate:

Sex is a pretty key part to every relationship. Unfortunately, for us, it has been non-existent. One of the symptoms of endometriosis is dyspareunia which is a fancy word for painful sex. After many months of trying and being in pain, I gave in. (Freya)

It is socially accepted that sex is a “key” part of relationships, which is portrayed here. Freya tried for “many months” and endured pain, therefore sacrificing her wellbeing before she “gave in” to the pain and stopped having sex.

Despite this, similar to the others, for Freya persisting with sex also had negative implications. In this case, she describes partly sacrificing her feminine identity in order not to suffer:

But on the other hand, if you find yourself an awesome human you're probably still going to want to bang at some point. Pain with sex can cause me (and others,) lots of anxiety because I feel like I'm letting my partner down (he says I'm not but I still feel guilty. Sometimes I feel like a less of a woman because my body is sabotaging me from being able to do intimate things with my partner. (Freya)

Here, womanhood is intimately connected to sexuality which locates the experience within a sexuality discourse in which sex is a vital part of a relationship and more so a duty. She is, in part, sacrificing her womanhood, by being sabotaged by her body and unable to “do intimate things.”

Notions of sacrifice also assume that it is the woman’s prerogative. In this sense, women must sacrifice; it is what they do. However, Anne resists the position that a pain-free existence must be sacrificed by saying:

The fact that a young woman would think that it is just a woman's lot in life to have pain is ridiculous. If one of your friends told you that they had discovered a lump in their breast, would you tell them that it was normal? No! You

would tell them to go to a doctor to get it checked out. It should be that way with pelvic pain. (Anne)

In this passage, Anne specifically points out a gendered dimension to illness, in which “pelvic pain” is not taken seriously. A woman’s “lot in life” reproduces pain as gendered, where being female equates to often painful reproductive processes such as menstruation and childbirth.

Greta has acted on her pain and elected to seek medical help rather than sacrifice a pain-free existence. However, the advice given here is similar to what Anne reports in the previous quotation, where she is told that she must sacrifice wellbeing and “put up” with pain:

I was then advised that irregular/heavy periods were not a symptom of endo and not very common at all. Ok... let that go also. The next piece of advice she decided to give me was “I need to put up with some pain”...Oh My Gosh... At this point I wanted to slap her. I ‘put up’ with pain every day. I have ‘put up’ with it for years! (Greta)

Greta has suffered from pain for “years” and, according to her clinician, she should continue to endure pain.

A construction of sacrifice is also drawn on when speaking about lifestyle requirements that supposedly lessen the symptoms of endometriosis. In this instance, it is the “endo-diet,” a dietary regime that may manage symptoms, that involves sacrifice:

Some aspects of the endo-diet, or perhaps the movement that surrounds it, do not sit comfortably with me. Here’s why:... It’s super restrictive! Basically, you have to quit all the little things that make life worth living. It sets you up to fail. (Ella)

Sacrificing what makes “life worth living” is promoted as helping to regain some control over symptoms. However, Ella resists this option as it also requires women to self-surveil as a form of control over health, while the “super-restrictive” diet increases the capacity of “failure.” This sacrifice is located here as a form of healthism which Seear (2009c, 2009d) argues often

prevails in endometriosis self-care expectations that advocate illness control, which, when considering the so-called enigmatic nature of endometriosis, is not an easy or assured task.

Although Bonnie does not label it as such, she sacrifices her wellbeing for an attempt at a normal social life:

The pain and lack of energy mean I am house bound for a good 24hrs after any enjoyment. (Bonnie)

With chronic fatigue a frequent symptom, along with pain, Bonnie is unable to ‘function’ after any “enjoy[able]” social event. Once again, to achieve what is considered a quality of life, periods of wellbeing must be sacrificed.

It is clear that sacrifice as part of the endometriosis experience is enacted through beliefs that pain is part of being a woman and something to endure for womanhood. The bloggers represent how comfort must be pushed aside for greater goals, such as reproduction, a ‘healthy’ sex life, making sacrifices of restriction for a slim possibility they may be given relief, and a social life. In many respects, women are positioned as inferior, with their own needs and wellbeing being secondary.

Regulated by a Disordered Body

Feminist perspectives consider the ‘healthy’ female body as already pathologised in contrast to men due to its excessive femininity brought about by reproductive processes that render it weak (Ussher, 2006). In respect to these endometriosis blogs, the body is further pathologised due to the condition exacerbating an already disordered female body. *Ideal Femininity* discourses involve the concealment of reproductive processes whereby women are expected to control their body; however, the following section could represent a failure of this.

The physical pain and limitations of the body regulate the lives of the women and attest to the material importance of the body to feelings of inferiority, thus placing personal worth within the functionality of the body, especially when it seems that body is in control. Bonnie lists the symptoms that limit her life,

particularly after she has overextended herself by trying to live an active and social life.

My chest has been hurting over the last few days as has my shoulder - all because of my diaphragm. And yeah, the wetting. The wetting is there all the time. It never lets up. If I'm not bleeding, I'm wetting. SOMEONE TAKE ME TO THE VETS AND GET ME PUT DOWN!! (Bonnie)

Bonnie finishes her discussion on endometriosis symptoms by drawing on the metaphor of an animal that should be euthanised. She takes up a subject position where she is inferior because of a dysfunctional leaky body, with her life's value being placed within the physical realm, and her "bleeding," "wetting," and intolerable pain rendering her worth as the same as a sick animal. This mimics an ableist discourse, where importance is in a physically able body.

Anne locates the endometriosis experience within the body when speaking about some of the most significant concerns of endometriosis. However, in contrast to the previous passage, she adopts a dualistic construction, whereby the body and self are separate, and the body is to blame, not the self:

When you have to re-assess your dreams because maybe your body just isn't capable of doing those things. For some women this will include the news that they will not be able to have their own biological children. For other women, it will be the realisation that maybe they can't pursue a career that they wanted to because their body cannot handle it. (Anne)

In this respect, it is the "body" and not the woman who is not "capable" of conceiving or cannot "handle" a particular career. Subsequently, though, it places the body in control of experience.

In other posts, the separation between the body and self appears to fold, with the construction of the disordered or broken body intertwined with the self. The body's abject or pathologised nature is visible through terms like "broken," "useless," and "failure," and this pathologisation is then taken into the self.

Here, Bonnie firstly blames her body, but then takes it on that she herself is “useless”:

And now, I'm so disappointed with my body and what it's made me become, that I feel useless. (Bonnie)

In this excerpt, it is the body and not the endometriosis that is to blame. This is then internalised as a feeling of being “useless” because this is what Bonnie’s body invoked. This concept of the disordered body being in control of the self is a frequent occurrence within the blogs.

An extension of this controlling, disordered body is the construction of the body being the “enemy” of the woman and turning against her:

At my worst, I viewed my body as the enemy, as a husk I was trapped in. It felt as though everything I did to help or harm my body didn't matter in the end because it was going to do what it wanted to. After my first surgery, which helped only a little, a long list of medications and countless other doctors and therapies, I was exhausted, defeated and all but completely broken. (Cara)

Again, this sits within a dualistic discourse whereby the body is separate from the self. This passage depicts a construction of the experience of endometriosis as the body fighting or rebelling against her while stealing opportunities of living life fully by imprisoning the self within it. At the same time, she constructs the enemy body as being in control as it was always “going to do what it wanted to.”

The discourse of dualism renders the experiences of a self as separate from a body it struggles to have control over. This includes practical issues such as food that the body can cope with or clothing choices dictated by a swollen stomach known as ‘endo belly’. In this passage, Cara describes this lack of control as:

When you feel like you're being rejected by your own body, it's hard to feel like you have ownership over it. And when so many standards and “rules” are imposed on us as

women, it's even harder to feel like you have any say in what happens to your body at all. (Cara)

While Cara constructs a self that is rejected by its own body, she goes on to speak more broadly about the imposition of social norms, which implies she is aware of broader social and cultural discourses that construct women's bodies in particular ways.

Uterus Gremlins

The pathologised female body is reproduced by referring to reproductive organs as the cause of issues and distress, rather than naming endometriosis as the cause. These are reminiscent of historical beliefs around the female body as discussed in Chapter One, in which the female reproductive organs, namely the womb, were the presumed cause of all women's health issues and were mysterious, at least to the male gaze (Nezhat et al., 2012).

Several women construct the uterus almost as a separate entity, much like in classical constructions of the wandering womb (Nezhat et al., 2012). In this excerpt, the uterus becomes an entity in and of itself separate from the subject:

I also apparently belittle my uterus when it is not being a productive member of the house of [Cara]. (Cara)

This conceptualisation of the uterus as not a "productive member" of the body can be located in a practical sense in that endometriosis can be found on the surface of the uterus, and in the case of adenomyosis, in the walls of the uterus. But this is not always the case as endometriosis is also found in other parts of the body. However, the importance of this is that it frames the uterus as a separate entity. If reproductive organs define femininity and womanhood, then in a way, they are taking up discourses where the female body, due to its capability of reproductive processes such as menstruation and pregnancy, is pathologised, symptomatic or not.

It is interesting that despite the construction of the body as separate and the 'enemy', the women do not use disembodied language. That is to say, they use language that indicates the body parts belong to them. For example, many of the women refer to "my body," "my terrible uterus," and "my ovaries." MacLachlan (2004) points out that often in pain and illness discourses,

definitive articles, such as ‘the’ are used to describe the affected area as a way of distancing the person from the disease and the distress. Even though these women describe themselves as feeling separate from their body, they still appear to claim their body parts. This may be because the reproductive organs are a defining part of their experiences of femininity, and to separate themselves from them may represent a loss of womanhood.

In contrast to the above examples, rather than pathologising the uterus itself, it is constructed as being home to something monstrous instead. Those creatures cause the distress:

So, I'm going to try and be consistent and keep doing the things I'm doing to see if next month I can avoid the uterus gremlins again. (Anne)

Objectification in this way serves as a protective strategy to enable the distance from the condition, according to MacLachlan (2004). Others also pathologise the reproductive processes. This draws comparisons with depictions of endometriosis as repugnant in previous sections within this analysis due to its symptomology:

It's the awkwardness at work when you have to explain your repeated absences to your middle aged male manager who thinks periods are gross. (Anne)

Here, periods are “gross,” or at least Anne is aware that this is the opinion of her manager, which renders their encounter as “awkward.”

Medical professionals often convey this pathologisation of reproductive organs. Cara has adenomyosis, and the following quote depicts the way in which the surgeon negatively constructs the condition. Here, she recounts first being alerted to it, but not by the name of the condition, but rather by the framing of her uterus in a disparaging way:

After I woke from the anesthetic, my surgeon spent a long time detailing the numerous organs my endometriosis had damaged, and then ended her soliloquy with “and you have a lumpy uterus.” No further explanation was provided and

the term 'adenomyosis' itself was not mentioned, which really annoys me. (Cara)

The description of Cara's uterus as "lumpy" without any discussion is annoying for her. In this case, she is not given the benefit of the medical term that defines her "lumpy uterus" or provided with any knowledge of what that means; she is only told that there is something further wrong with her reproductive organs.

This section has highlighted how the construction of endometriosis bodies as disordered produces a lack of control for women over their bodies, with some positioning themselves as useless because of this body. Furthermore, they are aware that in the eyes of others, their bodies (and them) are abnormal. I now shift the discussion to discourses of *Legitimation* where the medical and social orders dictate the type of body the women can experience.

Discourses of Legitimation

The following discursive constructions represent discourses of *Legitimation*. Women's experiences are constructed as regulated through their symptoms, subjectivities, and behaviour requiring legitimation from others. As shown below, the endometriosis body is both physically and socially 'open' to a judgement that is normalised. The construction of 'dismissal' frames the endometriosis experience as one of 'delegitimation'.

Regulated Through an 'Open Body': Sliced and Diced

The concept of an 'open body' has been used to depict the female form that is open for penile penetration, as well as the aforementioned 'leakiness' that defines women. Here, endometriosis bodies are constructed as open in two ways. Firstly, by medical processes such as laparoscopic surgery and medical imaging technology that provide a view of the interior. Secondly, the body is open as a target for social judgement.

In the first context, the participants experience their bodies as open to a medical gaze in the quest for legitimation. By legitimation, I refer to validation given to endometriosis symptoms. Several women construct the medical gaze through surgery as cutting them "open" and being "sliced and diced." In the

following excerpt, Cara comes to terms with the realisation that the prospect of being opened via a “cut” is necessary for her wellbeing:

That's the part that really sucks about endometriosis. You really don't know what's going on, unless you cut someone open. And like I said in an earlier post, that's led me to wonder, “Is this it?” Just a lifetime of surgeries? (Cara)

Cara considers it necessary to “cut someone open” to “know what’s going on” with endometriosis. She accepts that her body will be opened potentially numerous times so she can be treated. This places the power over her condition and any legitimacy or treatment in the hands of clinicians and consequently removes control over her body.

The body constructed as open through diagnostic and surgical processes to a clinical gaze also serves to objectify women, treating them as just a body, separate from emotion and embodiment. On the typically long pathway to diagnosis, as well as surgeries, women are sent for scans to locate the sources of their distress internally. This can be problematic with endometriosis as it will not necessarily be visible depending on the type of scan and the extent and type of endometriosis. Anne reports severe pelvic pain, but the lack of evidence results in the dismissal of her concerns:

That ultrasound came back clear, so the doctor told me to just deal with the pain and sent me on my way. (Endometriosis cannot be ruled out through ultrasound.) (Anne)

This experience sits within biomedical discourse where the clinical gaze and treatment are separate from experiences of subjectivity. Anne’s pain reports are not legitimised through the clinician’s method of an interior gaze, and consequently, he does not view her complaints as legitimate since she was “sent on her way.” This dismissal and delegitimation, in this case, has removed treatment options.

When the clinical gaze does not legitimate the condition, people are left feeling “insane” as Greta describes:

Anyone else go through numerous tests, just to be told everything was clear? Doctors believing that was a good thing? Some people may think this is good news. But to me, it just made me feel insane! Like it was all in my head!
(Greta)

Her symptoms not equating to medical evidence results in a psychological response that is distressing for Greta. The clinicians say it is “good” that nothing has been found, but Greta feels the opposite. If her body, as opened through testing and scans, shows no illness, then it positions her with the blame and experiences of “insanity” are drawn on to make sense of the symptoms.

‘Open’ due to reproductive processes

A female reproductive body is also open to social judgement. In this sense, being open means the endometriosis body is subjected to scrutiny about fertility and motherhood, which is problematic, due to the condition’s association with infertility. Many women state that people pry about when they will conceive or warn them to hurry up as biological clocks are ticking. Cara describes the constant questioning as “tiring” and mimics her experiences of bodily boundaries being breached:

“How is your uterus? Is it healthy enough to be a full-blown, baby-making factory? Will you be carrying on your husband's lineage and producing an heir, as your female species is called to do?!”

But for the millions of women out there who are having difficulties with pregnancy, I'm very tired of people assuming that just because a woman is young, that means she's healthy enough to reproduce. (or, you know, wants to). (Cara)

This excerpt represents the social construction of women as “baby-making factor[ies].” It further strengthens traditional social roles through the idea that a “young” woman is expected to want to reproduce, while the frequent prying produces a public body. Comparisons can be drawn between this type of invasive pre-pregnancy questioning and pregnant bodies being open to the

public. For example, Bailey (2001) found that women described their pregnant bodies as becoming “public property” by which people would touch their bodies without invite and comment upon their body shape (p. 122). Cara draws on the metaphor of “species” to invoke the image of an insect or animal on a table for dissection or study, as objects open to social scrutiny.

Social judgement about women’s reproductive processes occurs around menstruation also. In the following excerpt, Bonnie appears to accept the disclosure of bodily functions, such as her period, is necessary when calling in sick to work. This further opens the body to comment. In discussing work and illness, Bonnie states:

Calling in sick to work was always the worst thing, people would just think you are making it up and that all women have periods so it can't be as bad as I'm making it out to be.
(Bonnie)

The disclosure of her symptoms means others make unsolicited judgements on her. Comments such as “all women have periods” minimise her experience and position her as a liar or at best someone who exaggerates her distress because “it can’t be as bad” as she claims. In effect, her condition and distress are delegitimised by her work colleagues.

The body and its intimate functions are also disclosed to government institutions, with little question of the necessity of such personal details being open to non-medical professionals. For instance, while applying for a sickness benefit with a social welfare department, Bonnie had to provide medical notes about her condition and its interference with her ability to continue in employment. However, she is not successful and describes her experience as delegitimised because of the invisibility of her condition:

It feels like they don't believe a word I'm saying basically because they cannot see 'it' and have no evidence of me bleeding or wetting.... And yes, they have stated that they haven't seen evidence of this... (Bonnie)

Surveillance of the body through institutional practices is normalised here through the submission of medical notes. In a way, this disclosure breaches her

bodily boundaries through the disclosure of intimate functions such as her incontinence that would normally be considered private and not up for discussion. However, it appears that this is not enough and in order to legitimise symptoms, institutions require “evidence” of conditions. This assumption or requirement that the endometriosis body is open to lay people operates to remove power and places it with the institution where women’s explanations and subjectivities are not accepted. In a practical sense, economic security depends on the legitimation of a non-medical organisation, and this is withheld because they must see “it” themselves. Furthermore, she feels positioned as deceitful as they “don’t believe a word” she says.

Bonnie also describes this idea that others, particularly those in a position of power, have a right to know, and judge, the female body. While discussing the difficulties of work and endometriosis in the following excerpt, she explains:

Trying to explain the inner workings of your body to an older, male, boss can be particularly difficult. (Bonnie)

An open body is constructed through the assumption that the “inner workings of your body” must be disclosed, in this case, to an employer. This infers a power imbalance in which the “older, male boss” has the right to be privy to the inner body of the younger, female employee. That this process will be “difficult” represents the discomfort at sharing intimate bodily details with work colleagues.

In summary, this construction of endometriosis as formed around ‘open’ bodies serves to remove power and delegitimize women. This overlaps with *Ideal Femininity*, where positioned as recipients of social judgement, women are considered socially acceptable if they meet various constructions of femininity that reinforce social roles such as motherhood and social sanctions around menstruation. In this respect, the female endometriosis body is under surveillance by society. Furthermore, it makes available the subject position of a deceitful woman if others do not believe her.

Regulated through Dismissal

All the women construct their experiences in some way as being “dismissed” or “belittled” and frequently internalise this. This overlaps with the

construction of silencing somewhat. Unlike silencing, which mainly prevents women from disclosing their symptoms or being met with disgust when they do therefore regulating future behaviour, dismissal occurs when women do disclose but are ignored, disbelieved or contradicted.

Dismissal is invoked by a lack of medical ‘evidence’ such as scans, which then produces self-doubt about knowing their bodies. Greta describes the diagnosis and self-doubt process:

Before I was first diagnosed I had endless appointments with my doctor. I knew something was wrong, but my doctors at first didn't seem to agree. They said it was just IBS (Irritable Bowel Syndrome). To go home and change my diet. I knew it was something more but how could I prove it? All the tests and scans were done. Every single one came back clear. I did start to doubt myself. Was I really in that much pain? (Greta)

This excerpt begins with Greta secure in knowing that “something was wrong” with her body. However, she moves through to self-doubt about her perception of pain. The power held within medical technologies that “came back clear” serves to delegitimise bodily knowledge.

As has been represented throughout this work, women’s knowledge and choices regarding their bodies are often dismissed. In this example, Ella recounts part of a conversation with a clinician in which she feels continually dismissed:

***Ella:** But it doesn't...I am in agony a lot of the time. Sometimes I can't breathe, and the endo on my diaphragm causes severe burning pain in my back, shoulder and neck. It really affects my work and my PhD. I've had to contemplating quitting. It's been awful.*

***GP [General Practitioner]:** OK, you just really need to calm down about this, you'll be fine. It really isn't a problem.*

Ella: Well actually, I've been doing some reading and speaking with other people who have endo, and I want to be referred to a specialist endometriosis centre in London for a second opinion and to work out a way forward to manage my pain.

GP: I really don't think that is necessary. You're just making too big a deal of this.

Ella: I'm not. It is a recommendation in best practice guidelines that all diagnosed cases of endo are referred to one of these specialist centers. And it was recommended in the BMJ (British Medical Journal) in March.

*GP: The BMJ (British Medical Journal) says a lot of things.
(Ella)*

Ella, in response to outlining her symptoms and the distress they cause, is dismissed although she is clearly stating that it is an issue for her. This suggests that the clinician is positioning her as a hysterical female. This is consistent with research in which clinicians construct their endometriosis patients as hysterical (Young et al., 2018). Ella attempts to resist this attempt at being silenced by positioning herself as a well-informed researcher, citing evidence to support her requests, including a highly reputable journal. However, the GP continues to dismiss Ella's claims. This interaction represents a power imbalance between clinician and patient, in which the patient is expected to be passive, and not question the legitimacy of the clinician's knowledge.

It is not only in medical settings that the women experience dismissal. Peers are quick to comment about the legitimacy of their symptoms, as Anne describes:

It's the feeling like you are crazy because your boyfriend says that you can't possibly be in that much pain, and that you should just get over it. (Anne)

That a boyfriend dismisses her subjective experience is distressing for Anne. It also perpetuates the social rule that women should cope and carry on quietly.

Dismissal of Choices and Agency

For women with endometriosis, the ability to make choices about their bodies is compromised. In this experience, Cara is given the option of taking a pharmaceutical treatment that will make her body mimic the effects of menopause, but there are potentially serious side effects. Like the construction of sacrifice discussed earlier, such as giving up being a mother to remove unbearable pain, agency is constrained when the women are presented with limited choices for treatment. In the following excerpt, Cara describes how she elects to try the less invasive option, based on her own research, of physical therapy first:

As I've said before, I really don't like to assume I or someone else knows more than my doctor. But I didn't want to put myself through the hell of menopausal symptoms without at least trying physical therapy first. (Cara)

Initially, Cara acknowledges her clinician's expertise. However, she resists the options as represented by the "but." Cara, as other women demonstrated, has researched other less invasive options and asserts agency by using that knowledge to inform her choice.

However, her attempt at agency appears to be dismissed by her clinician not following through on her request:

I'm beginning to think I'm not getting a call back because I chose not to go on Lupron... (Cara)

Cara frames this as a form of punishment because she "chose not to" follow the clinician's recommendations. This idea of punishment for claiming autonomy over the body can relate back to ideas about women not upsetting the social order by being in positions of power (Chrisler, 2011). Cara is empowering herself through making decisions for her own health and wellbeing, but consequently feels punished for going against the medical expertise which then places her at the mercy of the medical order.

The power imbalance with clinicians is a common theme within the blogs and women find it very difficult to resist. In the next example, Anne had requested a procedure during her scheduled surgery that would help to clarify the

likelihood of any future fertility issues. The surgeon dismisses the request and does not perform the procedure:

This surgeon, however, didn't see the point, and so he made me feel embarrassed about it (pretty much the last thing you want to feel when you haven't eaten or drank in 16 hours or so, and are about to find out whether or not you have a chronic condition through your first surgery) and he ended up not doing it. (Anne)

In this interaction, not only are Anne's choices questioned to the point of making her "embarrassed," but the surgeon elects not to perform the procedure because of his clinical judgement. This example represents a lack of respect for patients' rights to make choices about their body. It also positions the body as a public body, in that those in a position of power (the surgeon in this case) can do as they will.

Dismissal of women's pain complaints also extends to fertility being privileged over pain concerns, thus again positioning the female's body as not her own, but a reproductive vessel to continue the 'lineage' or 'legacy' of the male. In Cara's experience, treatment by a medical professional was advice on getting pregnant immediately. She feels ignored:

That same doctor spoke directly to my husband of four months (not me) when he told me I needed to get pregnant "right away" if I ever wanted to have children. That same doctor shuffled me out of his room without a single pain pill or treatment plan. The doctor who had rolled his eyes when I asked for help with my condition simply left me high and dry. (Cara)

To be told indirectly that future pregnancy could be difficult positions Cara as inconsequential. This demonstrates the way in which a woman's reproductive capabilities are not considered hers solely. Here, experiences of endometriosis suggest that reproductive capabilities are privileged over pain concerns. Not only does this excerpt represent the social order of motherhood, it also

represents the way in which society privileges the male. Cara clearly asserts that all communication was directed at her husband.

To summarise, the repeated dismissal has implications where women struggle to have control over their bodies. In this sense, women are positioned as ‘less than’, with their choices and agency dismissed which, of course, has psychological impacts; their choices over their own bodies are challenged, situating them within traditional social roles in which ownership of a female’s reproductive system is not guaranteed.

Resisting Regulation

Throughout this analysis, resistance is frequently implicitly threaded throughout how women’s endometriosis experiences are constructed as shown in a number of the prior examples. Here, the following examples represent explicit shows of resistance. In returning to feminist post-structuralism that posits that it is through recognition of dominant discourses that women can disrupt oppression, it is important to consider how resistance is shown within women’s construction and the implications of this.

Resistance to being silenced

Women frequently call for resistance to the silencing within which endometriosis is imbricated. Here, Anne asserts that endometriosis should be spoken about:

It's not contagious, and the people who have it did nothing wrong to end up with it. It's debilitating and can wreak havoc on lives, through mental and physical health, particularly because it's something women generally suffer silently. (Anne)

Anne legitimises endometriosis as a condition that warrants being spoken about through stating that it is not contagious and that women are not to blame for “end[ing] up with it.” Furthermore, she warns others of the danger of negative “mental and physical” health if women do keep quiet.

Reminders women need to speak up about the severity of their symptoms are a frequent occurrence within the blogs. In the following example, Greta reflects her own self-doubt, but argues that persistence is needed in order to be heard:

All the tests and scans were done. Every single one came back clear. I did start to doubt myself. Was I really in that much pain? Yes I was, but endo can't be seen physically. Persistence is needed. If you think there is something wrong you need to voice it. (Greta)

It is easy to be silenced when lingering self-doubt is paired with a lacking of a confirmed diagnosis. Greta advocates that women need to “voice” what is wrong with them, as the condition cannot be seen physically.

Similarly, Anne advocates for “speak[ing] up” to spread awareness and understanding about endometriosis:

So, if you have endometriosis, speak up! Tell your family and your friends. When you need to call in sick to work, don't pretend that you are sick for another reason. You have done nothing wrong, there is nothing gross about your disease. There is a reason for your pain, and it has a name. Society needs to know what we go through so that there is better understanding, less people living in pain, more research done, and possibly even a cure! (Anne)

Anne calls for transparency in all areas of life such as work, social and familial relationships. She argues that naming the pain is necessary while lying is not. For Anne and many others resisting misinformation about the condition being “gross” or that somehow women are at fault will continue if it is not spoken about.

Cara also acknowledges the need for a voice and rejects being silenced or suppressed:

I'm tired of being brushed aside and being told I don't have it that bad. Because yes, you're right; there are countless people out there who suffer worse than I do. But my body has rioted against me and robbed me of any control since I

was a child. I have a right to be angry, and I have a right to be tired. (Cara)

Being “brushed aside” and dismissed or diminished by others is a tiring experience. However, like the others, it is Cara who advocates for her “right” to experience anger and fatigue for a body that has fought violently against her.

This is echoed here by Ella, who also reassures others that feelings are acceptable:

It's OK to be VERY angry and sad. (Ella)

Specifically mentioning emotions constructs an expectation that women perceive it is not appropriate to be angry, tired, or sad, or at least to express it. Viewing this through *Ideal Femininity* discourses suggests that women should suppress these negative emotions or outbursts.

Fight the disordered body

While the language used in endometriosis frequently represents the body as disordered, the enemy and out of control, many women position themselves as agentic in regards to fighting against the condition. In this way, women draw on fighting language, determined that endometriosis will not beat them. This infers a battle between mind and body in the plight to regain control. In the following excerpt, Donna describes the urge to resist her body as “broken”:

My body is telling me I need to rest, listen to your body it is broken, yet my mind is telling me don't, don't give in, fight this, you know when you get on with your day you will get through it and feel a sense of accomplishment that you didn't give in. (Donna)

A dualistic discourse represents the battle between the “broken” body and the superior mind. Here Donna is resisting by arguing “don't give in, fight this” and promising herself that she will feel better if she persists. This implies an assumption that it is possible to conquer endometriosis and its symptoms by sheer willpower. However, this also serves to place responsibility on the woman for overcoming a condition that has no clear trajectory or treatment. By being unable to “fight” or get “through it,” there can be no “sense of

accomplishment,” and furthermore, “giv[ing] in” may result in feelings of hopelessness and lack of control.

Refuting Dismissal

Women expect dismissal due to the gendered symptomology of endometriosis as bound with menstruation. In this passage, Ella shares information on how to refute the dismissal or judgement from others:

Frame the narrative in a way that is meaningful for your boss and which does not allow them to potentially dismiss it as a ‘women’s problem.’ For example, it was suggested that you could say something along the lines of “I have an illness which causes internal bleeding, and this causes me a lot of pain and exhaustion. To manage this, I would recommend that we do the following things...” (Ella)

The advice here is to change an explanation of the condition from “women’s problem” to a narrative of “internal bleeding.” This appears to change the dynamic of blood discourses from a traditional menstruation discourse where symptoms are trivialised to the more serious “internal bleeding” that legitimates the symptoms within a medical discourse. The internal bleeding narrative is effectively genderless, withholding intimate information but allowing for the necessary symptoms of “pain” and “exhaustion” to be disclosed. In a sense, this could be viewed as empowering the woman. However, it also reinforces notions that conditions that are typically unique to the female body are not considered legitimate illnesses, and furthermore, that conditions linked to the female reproductive system are shameful.

Reaffirming Choice

Throughout the blogs, women frequently resist the idea that others can make choices over their bodies. Numerous women make frequent declarations in which they state that it is the woman’s body to make choices about. The following example represents how women support each other and reaffirm agency:

Try not to be pushed into any treatments, i.e. hysterectomy or pregnancy, that might rule out your future plans in life. It's your body after all. (Bonnie)

The statement that it is “your body after all” serves as a reminder that it is the woman’s body to make choices about. This excerpt counters the two frequently mentioned treatment options of “hysterectomy or pregnancy” which current literature argues are not definitive cures endometriosis (for example see Leeners et al. 2018; Soliman, Haley, Du, Yang & Wu, 2017). These treatment options are also two life-altering choices. That treatment options are dependent upon the women’s choices contrasts with previously mentioned losses of autonomy where the choice is overridden. The “*your* body” heralds that women take up an agentic position regarding their bodies.

Analytical Summary

The constructions of how women experience endometriosis provide a context where regulation of the female body is situated within two wider discourses. *Ideal Femininity* which encompasses an expectation of silencing, sacrificing, and the restriction of excessive femininity through the construction of a disordered body, and *Legitimation*, where others hold power over women’s bodies through the construction of an open body and through practices that render that body as a target of social judgement and opinion, and is consistently dismissed.

Located within *Ideal Femininity* discourses, the experience of endometriosis appears constructed by shame and disgust around the excessive femininity of this condition. Negative responses from others matter, leaving women silenced despite their best efforts at agency. To control their bodies in a manner consistent with *Ideal Femininity* discourses, women are silenced and should not outwardly express emotion such as anger, fear, or frustration at their situation and as recipients of behaviour that they view as unjust. To do otherwise positions them as irrational females. They are expected to take up a passive and silent subject position.

The regulation of women is also enacted through sacrifice. The sacrificial body means that women are rarely expected to have control or autonomy over their

body. Pain is meant to be endured for merely being a woman who is meant to suffer and her wellbeing sacrificed for potential motherhood. Traditional social role expectations can lead to guilt for choosing a pain-free existence over motherhood or not meeting perceived sexual obligations. In this regard, they are positioned as failures, or otherwise, inferior citizens whose personal wellbeing comes second to other needs.

Also representing *Ideal Femininity*, endometriosis constructs a female body that is already considered pathologised within female body discourses, even more so (Ussher, 1989; Ussher, 2006). As consistent within scholarship on the female body, this disordered body is often internalised and affects experiences of a self (Ussher, 2006). It represents a body that is out of the control of the woman and fails to contain its excessive femininity to achieve the feminine ideal, resulting in feelings of hopelessness and despair.

Women are also positioned as inferior through the constant dismissal of their knowledge and autonomy. *Legitimation* is tied to knowledge and therefore to power. The dismissal of women's knowledge and autonomy appears to be part of a greater social order, where the body is a public entity for others to facilitate, deny medical treatment, or judge. In this way, aetiology is located within disordered psychological functioning or capabilities for motherhood. There are attempts to position women with endometriosis as passive, a recipient of delegitimation or dismissal in medical, workplace, or institutional settings, or as a vessel for reproduction with little regard for context or the implications of this decision. At times, the women become complicit by positioning themselves as passive, through having little other choice, particularly regarding medical practice.

The present findings in this work show that women and their bodies experiencing endometriosis are regulated and constituted within discourses that follow negative representations of women. The woman with endometriosis is positioned as irrational or passive by clinicians, or as deceitful when they are not believed. The women themselves resist these constructions and frequently position themselves as agentic women who can prevail over their conditions, or alternatively position themselves as failures or disordered. This agency is not without difficulty, however, as women's social power and knowledge are

frequently constructed as inferior to others, especially men. The following section discusses the implications of these constructions.

CHAPTER FOUR: DISCUSSION

The purpose of this research was to consider discursive constructions of women's experiences as drawn from discourses that regulate the female body. I define discursive constructions as how the discursive object, *the regulated female body experiencing endometriosis*, is constructed through language and discourse. My analysis of the data resulted in five constructions of women's endometriosis experiences which function to regulate their bodies — 'Silencing', 'Sacrifice', a 'Disordered body', an 'Open body', and finally through 'Dismissal'. The power of these constructions to control women comes from their location within discourses of *Ideal Femininity* and *Legitimation*.

This work has found that discourses concerning gender and the female body play a role within women's experiences of endometriosis. Women's struggle to control what happens to their bodies adds support to existing literature that illustrates women as regulated. As discussed in Chapter One, women's reproductive processes are used as "controlling factors" in women's lives (Ussher, 1989, p. 9). Ussher suggests that these processes define women as weak and therefore inferior. In this sense, power relations and reproductive health are linked, and endometriosis is a prime example. Ultimately, the experiences of endometriosis constructed here sit within discourses about the female reproductive body that constrain and shape women's voices and behaviour, how they view themselves, and how others treat them. At the same time, endometriosis experiences reproduce socially constructed notions of women as weak, irrational, and exemplify historical beliefs about traditional social roles.

These findings also add support to conflicting notions of control around women (Ussher, 2006). In one respect women are expected to control themselves in order to meet *Ideal Femininity* expectations through self-silencing and controlling their bodies; self-control, in particular, has been established as central to femininity (Chrisler, 2008). Yet, as shown in this work, women do not have enough control over choices made about their bodies. In this way, the findings show that the dominant discourses that form regimes of knowledge have "real material effects which have direct bearing on

our lives as women” (Shildrick, 1997, p. 15). Overall, the representations of experience in this study show how women with endometriosis are treated with a lack of respect and this represents a lack of social power.

Comparing the Current Experiences of Endometriosis with Previous Research

There is consistency within endometriosis literature as to a number of the discursive constructions identified in this analysis. Within the literature, women report experiences consistent with those in my analysis, such as being consistently dismissed, their pain normalised and symptoms delegitimised (Cox, Henderson, Andersen, et al., 2003; Denny & Mann, 2008; Markovic et al., 2008).

The silencing of women is also reported in previous studies. Perceived social sanctions surrounding menstruation silence women from speaking out about their experiences (Seear, 2009a). Comparisons can also be drawn between the findings in the present study and Sao Bento and Moreira’s (2017) research which consider women’s endometriosis experiences within healthcare. Their use of a critical lens frames women’s reports of interactions with clinicians as symbolic institutional and gendered violence. They illustrate this through binaries whereby the institution, in this case a clinical setting, is the dominant binary holding authority, and the female patient is dominated and weak. In particular, they found women’s pain complaints are routinely silenced, and this is enacted through not only the trivialisation of pain but also through displays of authority by the clinician. For example, when one woman suggested to her clinician that she may have endometriosis, she reports being told “I am the doctor here ... then shut up your mouth and make up another excuse, because you do not have endometriosis” (p. 3029). Furthermore, the silencing through the suppression of emotion in this work is similar to Seear’s (2014) findings that women control their emotions in ways they deem suitable to their gender, such as with emotional responses equating to irrationality in women, so they feel it is inappropriate to express anger and frustration.

Sacrifice does not appear as prevalent within the literature. Although, Denny and Mann’s (2007b) research on dyspareunia and endometriosis found some

women just endured pain to have sexual relations with their male partners, therefore sacrificing their own wellbeing. In her research on self-care, Seear (2009d) also found that self-sacrifice also was a factor, with women's self-care processes enacted as "self-discipline and sacrifice" due to the restrictive lifestyle changes that they feel compelled to make in order to control their condition (p. 198). Additionally, Seear (2014) found that women with endometriosis internalised constructions of disorder relating to menstruation, reporting feeling out of control and disordered themselves. In my research, the women also internalised the pain and fatigue of their body, taking up 'useless' subject positions.

The 'open body' construction places legitimization of illness and symptoms within the power of others, as well as portraying women as targets of social judgement. Again, this can be considered consistent with Seear's (2009a) findings of menstrual social sanctions, where fear of judgement served to dismiss women's experiences. Similarly, Sao Bento and Moreira (2017) constructed the endometriosis experience within clinical settings as invading the body through examinations, treatment, and judgement over pain levels. The authors argue that symbolic institutional and gendered violence is constructed by the objectification of women's bodies and overriding of their knowledge. Consistent with my findings, women are positioned as passive recipients of social and medical judgement, while being positioned as inferior, with their own needs and subjectivities overlooked.

The findings that represent a body that is open and dismissed is also consistent with Shohat's (1992) reasoning that medical discourses construct medical imaging and surgical views of the interior, enabling the dismissal of women's voices in relation to the knowledge they might have about their own bodies. She asserts that technologies that allow an exploration of the female body also omit the views of the women. Again, here, women are regulated through the objectification of their bodies.

Problems with Power

As is the premise of my research, women with endometriosis are regulated in a number of ways consistent with female body discourses. These findings

suggest that women have little control over many aspects of their bodies within the endometriosis experience, despite frequent attempts at agency and that all participants are incredibly knowledgeable about endometriosis. This latter point about knowledge contradicts recommendations in other literature that women become knowledgeable about their condition for their own wellbeing and label this as empowerment (Bullo, 2018; Cox, Henderson, Wood, et al., 2003; Facchin et al., 2016). The individual concept of empowerment suggests that women can “master their illness in the face of mystery and uncertainty” (Seear, 2009d, p. 197). Seear questions this concept, asserting that to expect women to navigate complicated health information and to take control of their own health issue is healthism

I agree with Seear. We should question whether women taking an active role in seeking treatment for endometriosis is a form of empowerment considering the women in this research suggest that they are forced to be agentic to aid in their own wellbeing. To focus on an empowerment model suggests that there are unrealistic expectations of women that they should be in control of their illness. There is only a certain extent to how women can control their health, considering the lack of knowledge about endometriosis. This empowerment discourse can set women up for failure by giving expectations that they may not be able to meet, resulting in further feelings of loss of control. An example in the endometriosis literature of how this healthism is enacted is found when Cox, Ski, et al. (2003) recommend that “the more women understand, the more responsible they become for their actions and, as such, the physician does not have to ‘take all the blame’” (p. 207).

The experiences detailed within the analysis are these women’s “truths” about life with endometriosis, and much of that perspective on experiences is coming from the external gaze. That is to say, it is other people’s judgement, and the women’s awareness of that judgement, that constructs these experiences. Therefore, these findings suggest that it is social power that women need rather than individual empowerment.

Conceptualising Endometriosis

This research has drawn attention to regulatory practices made acceptable by dominant discourses that impact on women's experiences with endometriosis. As is the objective of feminist post-structuralism, the identification of discourses which constrain women provides pathways for these regulatory practices to be challenged (Gavey, 1989). As such, different ways of conceptualising endometriosis as a condition need to be considered alongside how women are represented.

We should challenge social power relations that contribute to ideas that women are failures for not meeting unrealistic expectations about being in control of their illness. After all, this would involve attempting to resist dominant discourses of control that position women as inferior and passive on the one hand, yet insinuates they have sufficient power on the other to control their body. We need to challenge conceptualisations of women and their reproductive processes as being out of control or unruly.

We should advocate for approaches that resist negative cultural representations of women where they are displayed as uncontrollable, and reproductive processes are shamed (Chrisler, 2008). In time, this may enable multiple definitions of femininity whereby women are not represented so negatively and thus constructed as requiring regulation. By contesting negative representations, I hope that women gain more social power. Ultimately, a focus on changing medical and social order in which women are regulated rather than changing a 'self' would serve women better.

In addition, conceptualising endometriosis as more than a 'reproductive disorder' would have benefit. We must challenge the reproductive centric approach and cultural assumptions that position the female body as a reproductive body foremost. This has implications for pain management and treatment.

However, by attempting to reconceptualise endometriosis as something other than a condition that primarily affects women because of reproductive and other processes that define femininity and womanhood, it highlights another tension. By conceptualising endometriosis away from women's unique and

special reproductive processes, we risk reproducing knowledge of the female body as shameful and something to be hidden. Therefore, the female body experiencing endometriosis needs to be legitimated and not devalued.

Research Reflections

Even though I was aware of women's regulation throughout history and that this treatment continues today, I was surprised at my findings. The women who granted permission to analyse their blogs are, by all accounts, resourceful women. All are literate, have worked in a variety of roles, have demonstrated themselves capable of their own endometriosis research, and at least one of them has post-graduate qualifications in a health field. All appeared to have support from family and friends who, in some cases, were instrumental in advocating for them. They were all capable of constructing literate, entertaining, and insightful bodies of writing and were confident enough to post them online and welcome people into their worlds. By all accounts, these women had tools at their disposal that should assist them in their plight. However, as shown here, they continued to be exposed to adverse situations where they were continually dismissed. This represents how change at an individual level could be futile when wider socio-cultural contexts and social power relations dictate so much.

Of particular value in the research process, is that the use of unsolicited blogs as data provides a representation of women's own voices, without influence from research questions. As these blogs were formed pre-existing this research, the women have formed narratives of experiences that are important to them.

There are issues that should be reflected upon with respect to the sample and how it matters to future research. All participants appeared to identify as heterosexual due to the frequent discussion of male partners; thus, this research is adding to the literature exploring the experience within a heterosexual context, while there is little to no literature on the experiences of members of the LGBTQ community and endometriosis. This is of particular relevance considering those who identify as transgender males can also suffer from the condition. This would be of considerable interest in respect to the gendered aspects surrounding endometriosis.

The ethnicity of the women is also unclear. Considering historical accounts of the non-diagnosis of non-Caucasian women with endometriosis and arguments that medical treatment serves a political agenda, there is value in assessing women of varying ethnicities as a view to whether this type of management continues.

It is also important to consider the cultural specificity of this research. That all of the blog posts were from women residing in Western countries means that other cultures need to be explored in future research. This became noticeable to me as I was writing the analysis section. During this time, I spoke recently with a friend who has suffered from endometriosis for much of her adult life. She now lives in the Middle East and had an emergency hysterectomy, which thus far has granted her relief. She did not have to fund it herself because it was viewed as emergency surgery as her bowel was fused to her uterus. According to her, the medical profession in the Middle East considered it a bowel problem rather than a reproductive issue. Her own gynaecological issues that caused her distress for years did not warrant such quick medical service. As she told me this, it struck me how her story reinforced much of what I found in my research: inferiority is infused with femininity and reproductive organs.

In closing, discourses of *Ideal Femininity* can help set women up to fail because it is assumed that they must remain quiet as they cope with their ‘menstrual’ pain and injustices. This silent body must also be sacrificial, therefore reinforcing social roles and the notion that women are designed to suffer. *Ideal Femininity* also does not allow for the ‘messiness’ of endometriosis, with its excessive menstrual blood, incontinence, painful defecation, urination, and sex. This serves to pathologise an already pathologised female body that is linked to shame. At the same time, the *Legitimation* of this body is a public matter. The shame is open, reinforcing notions of a polluted body. Together, these suggest that the control that women are led to believe that they should have over their bodies is subverted through dominant discourses of the female body.

Unfortunately, it is beyond the scope of this work to suggest what could reduce the physical symptoms in women and relieve their pain and other distressing symptoms. However, by awarding women more social power through positive

representations of the female body, we could hope to reduce many of the negative experiences and subjectivities that cause distress for women with endometriosis. Furthermore, by highlighting how women with endometriosis are regulated, this work adds to previous scholarship in establishing endometriosis as a cultural construction, rather than a solely individual experience where women are to blame for their condition.

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APPENDIX

Recruitment Email

Dear _____,

My name is Tash and I'm a research student from Massey University in Aotearoa New Zealand. Firstly, I want to acknowledge the insightful, honest and important work you have been doing in your blog on endometriosis. I've been reading through your blog and really enjoy the way in which you have been open about your experiences of endometriosis.

The purpose of my research is to explore the social and cultural forces that shape the experience of women with endometriosis through the context of it being a gendered illness, with a particular focus on how conceptualisations of the female body shape experience. Consequently, I'd really like to use the ideas you have included in your blog in my research. Hence this is a courtesy email to ask if you would be okay for me to use parts of your blog in my research.

My research is guided by feminist post-structuralist theory which is an approach that aims to disrupt knowledge and identify strategies for change. I hope that my research will draw attention toward the context in which women experience endometriosis, and contest the biomedical and pathological focus that locates it as an individual issue.

If you are okay with me using your blog, I will not include any web links or any demographics such as age or location that may lead back to you. Nor will I include any contextual information that could lead to your identification.

However, if it is okay, I would use some of the verbatim quotes to support the arguments that you make. However, there is a small risk of a quote being placed in a search engine which could lead directly to your blog.

Your blog will not be included without your permission. I will wait for a response for one month and then omit it from my research if you do not respond.

Thank you for sharing your experiences publicly and for seeking to support more women.

I look forward to hearing from you.

All the best in the future.

Kind Regards,

Tasha Westeneng