The Interpersonal Effects of Endometriosis: An anthropological study of the effect of endometriosis on social relationships

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This thesis is submitted in partial fulfilment of the requirements for the degree of Master of Anthropology (Advanced) in the College of Arts and Social Sciences.

I hereby declare that, except where it is otherwise acknowledged in this text, this thesis represents my own original work.

Signed: 

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All versions of the submitted thesis (regardless of submission type) are identical.

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Abstract

Endometriosis is a chronic, inflammatory condition commonly connected with abdominal pain, fertility complications and fatigue. Endometriosis is a severely under-researched condition including its treatment and potential cures, but significantly regarding the effects of the condition on the sufferer. In this thesis I analyse the effects of endometriosis on interpersonal relationships, and the underlying sociocultural factors that contribute to lived experience of having endometriosis. To develop my analysis, I draw from both the available anthropological and medical literature on endometriosis and my interviews of ten participants with endometriosis. My research findings confirm that having and living with endometriosis has profound effects on interpersonal relationships. These include relationships with romantic/sexual partners, family members, friends, medical professionals and co-workers. While the impact of endometriosis on these social relationships is related to social preconceptions and taboos that create a stigma around endometriosis, I also show, as confirmed by my participants, that there is a slow sociocultural shift towards a more positive attitude regarding endometriosis and the sufferers of endometriosis.

Introduction

"[My husband] said, "If it's something that affects so many people, why isn't it talked about more often?"" – Mary

Endometriosis occurs in one out of nine Australian women according to Endometriosis Australia (2021). This is approximately 830,000 women in Australia, and the number could be higher, who suffer from the condition (Endometriosis Australian 2021). Partially due to this, it has become more common for endometriosis to be referred to as a modern epidemic by media sources and the self-help and medical literature of the past several years (Seear 2014: 6). Endometriosis is a chronic, inflammatory condition commonly connected with abdominal pain, fertility complications and fatigue. It is a severely under-researched condition, including its treatment and potential cures, but more significantly there is very little research on how endometriosis impacts the sufferer of this condition. My interviews of women for this thesis confirm some of the extant observations in the literature that endometriosis affects interpersonal relationships (Endometriosis Australia 2021), particularly those with romantic/sexual partners, family members, friends, medical professionals and co-workers. The impact of endometriosis on social relationships is influenced by social preconceptions and taboos that create a stigma around endometriosis. However, as confirmed by my participants, there is an increasing, albeit slow, sociocultural shift towards a more positive attitude regarding

endometriosis and girls and women who are the predominant group suffering with this condition.

I would also like to note that prior to the 1970s, endometriosis was considered a ‘white woman’s disease’, which has contributed to the difficulty of non-white women being diagnosed in the United States, for example. However, a similar trend in the rise of women suffering with endometriosis related symptoms has also been observed among women with a lower education level in the United States, but who are less likely to get a diagnosis of endometriosis (Barnes 2020: 28-32). There is no similar data available for Australia regarding whether or not minority, Aboriginal women or women from a low socioeconomic class experience similar problems in receiving an endometriosis diagnosis.

To aid in the analysis of my findings regarding women’s experience of being diagnosed with and living with endometriosis, in addition to interviews of women diagnosed and living with endometriosis, my thesis is informed by my research of anthropological and social science literature on endometriosis as well as the medical and public health literature. In my analysis I extensively engage three significant anthropological ethnographies that include: *The Woman in the Body* by Emily Martin (1987); *The Body in Pain* by Elaine Scarry (1985); and *The Elusive Embryo* by Gay Becker (2000). While these three important and critical anthropological works on the social constructions of and influences on women’s bodies do not focus on endometriosis specifically, the observations of women’s medical and social experiences in their

entanglement with illness and biomedicine including the embodiment of pain and bodily suffering in these ethnographies echo many of the key themes that my participants shared regarding their experience of endometriosis. These three significant works are also decades old but the experiences of my participants match some of the key themes and experiences discussed in Martin, Scarry and Becker.

As suggested in the title of her ethnography, Martin focusses on the experience of women regarding menstruation, menopause and other women's physiological processes. She relates these experiences and their articulation by the women to broader social, cultural, medical and economic factors and discourses that shape perception of women and women's own self-perception of bodily experiences. While endometriosis is not mentioned specifically, Martin's analysis provides insight into the conceptualisation of 'feminine' experiences, such as premenstrual syndrome, that speak to how endometriosis and its experience and embodiment by women is understood in society by women's kin relations as well as by some of the women themselves who live with this condition. Scarry, alternatively, in her work examines the lived experience of pain, such as the experience of torture and the relationship between the torturer and tortured. In this thesis, I connect Scarry's analysis to delineate how women with endometriosis perceive and relate to their chronic pain. This is particularly poignant on topics relating to the socio-political context of experiencing pain, as Scarry's work is still relevant to analysing the political aspect of bodily pain (Dawney & Huzar 2019: .

Lastly, Becker's work illustrates the relationship between how romantic partners are affected by fertility issues. I observed similar social formations and the profound impact on the different social relationships of people with endometriosis. The relevance of Becker's work to my analysis is also particularly significant since fertility complications are one of the major symptoms of endometriosis that appear to shape how women and their partners navigate their physical pain and suffering produced by the endometriosis diagnosis. I discuss how the embodiment of this diagnosis influences women's decision-making process as to have or not have a child. Becker discusses how women internalise their beliefs around fertility and motherhood, and I observed similar processes among women I have spoken to with endometriosis and the way they internalise this condition. Before I proceed with outlining my research method and the analysis of my findings, it is first important to situate my personal interest in this topic.

My Involvement with Endometriosis

> *"Endo ruined my life, from my perspective. It- it ruined my mental health. Like, I felt myself shatter into a million pieces." – Claire*

I begin this section with the statement by Claire, one of my participants, because my initial experience of endometriosis was much the same. I am a woman with endometriosis, which has motivated me to conduct this study. Of course, I also recognise the potential biases this can engender in the study of a topic so personally connected to my own experience. As such, I would like to acknowledge that this thesis is in part

autoethnographic but I have remained as focussed on the experiences on my participants and the literature as I was able.

I was tentatively diagnosed with the condition when I was 20 years old, in 2020, and have been trying to manage the condition since then. I lost a job due to my condition and went through a period of unemployment because I was unable to work. I have seen some relationships in my life become strained and others strengthened due to my endometriosis diagnosis. I have had to learn to negotiate and be an ambassador for my health in my workplace, with medical professionals and my friends as well as with my own family. My personal experiences are what sparked this research and were integral to knowing where to start and what to ask.

As I spoke more freely about my condition and experiences, I found several other women of my acquaintance who also suffer from this condition. From what they told me, it became clear they had all made sacrifices, such as neglecting their own health and pushing themselves past their physical and mental capacity. This was done for the sake of other people at the expense of the sufferer's health and wellbeing. All of them had struggled to cope with the interpersonal and intrapersonal – the way they relate to themselves and others – and the repercussions of having a debilitating, multifaceted disease. In this thesis my aim is to address these issues and consider how the invisible suffering of women with endometriosis can be better understood in order for them to obtain appropriate support and care.

Research, Participants & Methodology

"No anatomical talk with [my dad], of any kind." – Emma

Chronic illness does not just affect the afflicted individual, it pervades and impacts the lives of those around them as well, thus impacting the relationship between the person with the chronic illness and others. An example of this would be the stress experienced by family members who take care of someone who is ill (Weaver 2016: 498). In the vernacular, this is usually referred to as 'carer's fatigue'. Influenced by the anthropological literature, this was a basic premise of my research for this thesis and was soon validated by the experiences of endometriosis sufferers who I knew personally as well as those who I met through the QENDO Canberra Facebook group. I received a lot of support and validation of my initial research assumption that endometriosis affects interpersonal relationships. Many of the members of the aforementioned Facebook group volunteered to be a part of my research, to the point where I had to turn down some people because I did not have sufficient time allowed for my Master's thesis research. I acknowledge that this method of recruiting participants may have biased the data collected from participants towards a more negative set of experiences.

My research for this thesis focussed broadly on the effects of endometriosis on interpersonal relationships. The first interview question I asked each participant was to define endometriosis in their own words. While no two participants gave the same definition, the question did

provide a baseline for me to understand their personal experience (i.e., was physical pain or mental health of a greater concern to the participant). I asked my participants about their romantic and sexual relationships, friendships, familial relationships, professional relationships and their interactions with medical professionals. My analysis of the responses to these questions resulted in the identification of themes that I discuss in this thesis.

The primary data informing my analysis in this thesis is from interviews of ten participants who volunteered to be a part of this study. All ten participants were assigned female at birth, self-identify as a woman, and have spent their endometriosis afflicted years in Australia. Two of the women I knew personally, and one of them was referred to me through a mutual acquaintance. The remaining seven women volunteered themselves in response to a post on the QENDO Canberra Facebook group. The participants' ages ranged between 24 and 32 years, with the average age being 27.7 years (see Appendix Table 1 for further information). This age range was chosen as an intersection between modern treatment and levels of awareness, a likely age range for a sufferer to have a diagnosis of endometriosis and a time of autonomy over the participants life where they are becoming more financially independent. Most of the participants have heritage from North Western Europe and are best described as Anglo-Australian. One participant had a mix of Anglo, Asian and Indigenous heritage but was primarily raised in an Anglo-Australian setting. Two participants had

heritage from central Europe (see Appendix Table 2 for further information). All of the participants agreed to have their interviews recorded and their information attached to an assigned pseudonym.

After the participants had read the participant information sheet and signed the consent form, I provided them a preliminary questionnaire to complete prior to their first interview. The questionnaire covered their demographic information, their endometriosis symptoms, the level of interference caused by each symptom, the relationships that were affected and how their relationships were affected. This information is recorded in Appendix Tables 1-4. I chose to use the questionnaire so as to focus the interview on what the participant was most concerned about. All questions were touched upon regardless, but more time was spent during interviews on the participant's unique experience.

A date and time were then agreed upon for the interview, either in person or as a Zoom video call. The interviews were semi-structured, with some questions planned before the interview but ultimately the interviews were more conversational. This was to aid in minimising distress to the participants and to allow the participant to feel comfortable enough to speak their mind or decline to answer a question as they wished. I asked various questions relating to the participant's experience, such as how endometriosis had affected their romantic and sexual relationships, friendships, relationships with family, co-workers and medical professionals. The audio files were then transcribed before being deleted. The transcripts were analysed for thematic similarities which in

turn were analysed in relation to the existing literature I researched for this thesis. Each participant was given access to their interview transcript, as well as a pre-submission copy of this study. I was solely responsible for all research, interviews and transcripts.

All of these parameters were agreed upon by the Australian National University's ethics committee prior to the commencement of data collection. Specific ethical considerations and stipulations included: a consent form and information sheet that fully disclosed the parameters of the study to each participant; a statement in the information sheet and at the beginning of each interview that the participant was free to decline to answer a question, leave the interview/study at any time or take as many breaks during an interview as needed; a debrief at the end of each interview to ensure the participant was not overly distressed and had support if they needed; an agreement that I as the primary researcher would have sole access to raw audio files; an agreement that no participant would be identifiable either in the transcript or the thesis text. All of these stipulations were met within this research and no significant ethical issues arose.

The Interpersonal & the Intrapersonal

"I would not wish endo on my worst enemy." – Bella

First to clarify, by interpersonal I mean the social aspects of life that affect both the individual and those around them. An example of this would be a marriage, where interactions between the couple are

interpersonal where they concern both parties directly. By intrapersonal I am referring to aspects of life that primarily affect a single individual but are often contextual to the greater sociocultural sphere. For example, how a person perceives their marriage, or the idea of marriage, is individual and independent of interactions with other people. However, it can be influenced by how marriage is socially and culturally defined.

Sociocultural teachings and the human mind are the anthropological equivalent of the 'chicken or egg' debate**.** As demonstrated by anthropologists we could argue that social and cultural processes come first, then humans react to them and internalise them. It could also be argued that humans created societies and cultures and imposed our own manufactured version of logic on the world around us through social structures (Perkins Gilman 2011). This debate could realistically take several lifetimes to resolve, if a resolution could ever be reached. What can be agreed upon and is well demonstrated by anthropologists, is that the individual and their sociocultural context are inextricable from one another and both interact with each other (Hirschfeld 1988: 613; Ushioda 2009: 215).

For the purpose of my research for this thesis, such a premise created a conundrum – could the effects of endometriosis on intrapersonal relationships be examined without also reviewing the effect of interpersonal relationships, social teachings and cultural norms on the individual? My conclusion was that both must be examined. As such, in this thesis, based on my findings, the discussion centres around three

main themes in the following three thematic chapters where I engage the findings of my primary research, which are: 1) how sociocultural teachings concerning endometriosis are internalised; 2) how these internalised lessons are exhibited externally; and 3) what is the overall outcome for interpersonal relationships. In Chapter 1, I address how medical dismissal, the legacy of female hysteria and embodiment of the condition by women are all reflected in the lived experiences of women with endometriosis. In Chapter 2, I examine how social expectations and stigma play a part in 'living with endometriosis' in a social world. In Chapter 3, and my final thematic chapter drawing from interview data, I detail how the elements discussed in Chapters 1 and 2 affect romantic, sexual, familial, professional, friendly and medical relationships of women living with endometriosis. Each of the three chapters provide a concluding vignette, formed from a compilation of the participants', with some of my own, experiences of living with endometriosis. The purpose of the vignettes is to provide a more relatable depiction of the emotional and physical experiences of endometriosis. Exhibiting the realities of living with endometriosis in both an analytical and personal way illustrates what endometriosis means to the sufferers and those around them.

What is Endometriosis?

> *"I don't know how to really describe it, but it felt wrong. Like, it felt like something was there that wasn't there before and it was kind of like this 'encompassing mass'." – Amy*

Before I move into my three thematic chapters, I would like to briefly discuss what is understood by endometriosis. There are many common misconceptions around endometriosis, even amongst sufferers of the condition. The Endometriosis Australia website has several infographics dedicated to such misconceptions, such as endometriosis being curable or being a sexually transmitted infection. None of my own participants could provide the same definition when asked to define endometriosis. This was always the first question asked at the beginning of the first interview, to examine the inconsistent understanding of endometriosis, even amongst sufferers, and to create a baseline for discussion of individual experiences. What I introduce next draws largely from the medical literature and is based on my own introduction to the illness which serves as the premise and context for the anthropological interpretations.

Endometriosis (or ‘endo’ in the vernacular) is a disease where tissue similar to the endometrium lining of the uterus grows outside of the uterus. Most commonly this occurs on the reproductive, digestive and urinary systems and even occasionally on the muscles, joints, lungs, brain or skin (OASH 2019; Endometriosis Australia 2021). Like the endometrial tissue lining the uterus, endometriosis lesions respond to hormones and shed or ‘bleed’ during menstruation. This causes inflammation, scarring and adhesions that join usually separate organs together (infocus 2019). Due to the chronic nature of endometriosis, various aspects of life can be affected, including physical capabilities,

ability to attend school or work and fertility (infocus 2019). Endometriosis can affect a person's quality of life regarding relationships, work, school, hobbies, exercise and child care (Endometriosis Australia 2021). It can also, in some rare cases, affect men (Seear 2014: 3). However, it is typically viewed as a woman-centric condition.

Due to a lack of clear-cut understanding of its cause, endometriosis has been called a genetic, immune, environmental and hormonal disorder in the medical literature. Similarly, some believe the first medical documentation of the disease was in 1690 or 1860, while others suggest that 'female hysteria' throughout history was most likely a misdiagnosis of endometriosis (Seear 2014: 3). Some correlation has been drawn between a family history of endometriosis and possible genetic cause, short menstrual cycles, heavy bleeding during menstruation, starting menstruation at a young age, retrograde menstrual flow – the menstrual fluid flowing upwards through the fallopian tubes and into the abdominal cavity – and issues with the immune system and hormones (infocus 2019; OASH 2019). The presence of endometriosis has also been linked with other conditions and medical complications such as: allergies; asthma; chemical sensitivities; autoimmune conditions like multiple sclerosis, lupus, rheumatoid arthritis, Crohn's disease, psoriasis and types of hypothyroidism; chronic fatigue syndrome; fibromyalgia; and some cancers, namely ovarian and breast cancer (OASH 2019; Nothnick 2001: 229). Endometriosis has been associated with some subtypes of ovarian cancer: low-grade; clear cell; and

endometrioid. This is likely connected to the fact that there are molecular and genetic similarities between endometrioid and clear-cell ovarian cancers and endometriosis (Pearce *et al.* 2012: 389-393). Some of the common symptoms of endometriosis are: cramping; bloating; fatigue; nausea; heavy menstruation; bleeding or spotting between periods; lethargy; fertility complications; diarrhea; constipation; and inflammation (Endometriosis Australia 2021; infocus 2019; OASH 2019). However, it is uncommon for one woman to experience every one of these symptoms, as symptoms vary across individuals. It should be noted that the severity of the symptoms does not correspond to extensiveness of lesions (infocus 2019).

The condition typically manifests during adolescence or around puberty but typically it takes 7 to 12 years to receive a medical diagnosis (Endometriosis Australia 2021). To address this problem, studies including medical research increasingly over the past few years have focussed on younger women to identify how endometriosis can be diagnosed earlier (Seear 2014: 8). Diagnosis is usually carried out through a pelvic exam, ultrasounds and/or magnetic resonance imaging (MRI) (OASH 2019). Until recently, the most reliable way to be diagnosed was through laparoscopic surgery and the pathological analysis of lesions (Endometriosis Australia 2021; infocus 2019). More recently, alternative, less invasive procedures are being researched and trialled. There is no cure or means of prevention (Endometriosis Australia 2021) but medical intervention such as hormonal treatments or excision

surgeries can be beneficial (infocus 2019). Common methods of symptom management include painkillers, hormonal treatments, alternative medicines, excision or ablation surgery (OASH 2019), medically induced or natural menopause (infocus 2019) and hysterectomies (Barnes 2020: 28-32). Ultimately, most sufferers manage their symptoms through these means and other lifestyle alterations, but they will have the condition for the remainder of their life. Consequently, endometriosis has a lifetime effect on the sufferer's health, wellbeing and other aspects of their life, including their social and interpersonal interactions.

Endometriosis is biophysically discrete, meaning it has no obvious external signs of bodily trauma. This can lead to an assumption that the symptoms of endometriosis are not as bad as the sufferer describes or 'all in their head', particularly with regards to pain (Graffia 2019: 29-30). People in general are often unaware of endometriosis as a medical condition, which leads to the sufferers, their friends and family attributing the symptoms to 'bad luck' rather than indicative of a pathology (Culley et al. 2013: 631-632). It is also not socially acceptable to exhibit pain, which is typically experienced as an internal, private phenomenon (Scarry 1985: 27). This has created a stigma around endometriosis, the rejection or inclusion from society of an individual or group, based on a negatively-connotated attribute. For endometriosis sufferers, the stigma is usually based around the invisibility and lack of knowledge about the condition and the social categories the condition can place them in

(Graffia 2019: 30-32), such as ‘disabled’, ‘infertile’ or even ‘lazy’. This stigma can come from medical professionals, loved ones or professional relationships, and sufferers can be treated as ‘difficult’ or ‘too much of a hassle’ (Graffia 2019: 30-32). Such stigma and the social repercussions are a topic which can be studied from an anthropological perspective as I elaborate next.

Endometriosis, Anthropology & Medicine

> *“If one person in the family is taking up more resources than somebody else, it can feel really awkward.” – Alex*

While there are many disciplines that shed light on the nature of social relationships, anthropology illustrates the dynamic and intricate ties between social, cultural and personal factors in relationships[1]. The types of relationships I examine in this study are divided into four categories: romantic/sexual; familial and friendship; professional; and medical. Much of the literature on endometriosis has focussed on the effect of a woman having this condition on their romantic and sexual relationships. The primary focus of this literature has been on two major factors, that is fertility complications (Culley *et al.* 2013) and dyspareunia (Graffia 2019) experienced by women due to endometriosis and how these affect the couple. The general conclusion of such studies is that both of these factors can cause problems in, and often lead to the cessation of, a relationship. However, fertility complications and

[1] Stout’s *After Love: Queer Intimacy and Erotic Economies in Post-Soviet Cuba* would be an example of such an ethnography

dyspareunia are not the only problematic symptoms that interfere with romantic relationships. Moreover, not all romantic relationships end due to these symptoms, for romantic relationships can serve as a support to the sufferer of endometriosis (Culley *et al.* 2013: 633). Some of the medical literature has identified the link between endometriosis and pregnancy issues such as miscarriages and problems with conceiving (Young *et al.* 2018; Clancy 2009).

By contrast, there is less research focussed on the effects of endometriosis on relationships with family and friends. What has been identified is the issue of finance, which impacts these relationships due to the age that most sufferers begin to experience symptoms of endometriosis. The condition can impact the sufferer's ability to work, which often results in limited financial independence due to a lack of personal income (Endometriosis Australia 2021; Armour *et al.* 2019). As endometriosis lacks any significant visible indications (Graffia 2019: 29-30), family, friends and the sufferer can dismiss the symptoms as an unfortunate circumstance rather than a pathology (Culley *et al.* 2013). This has contributed to difficulties in gaining a diagnosis of endometriosis, as reflected in the experiences of many of my research participants.

Endometriosis also has an impact on the education experience of women with this condition. However, results of studies are not entirely clear regarding how prevalent endometriosis-related absences and academic failures are (Culley *et al.* 2013). In the work place, the effect of endometriosis is usually manifested in absences and loss of productivity

(Armour *et al.* 2019). It has also been observed in the literature that some women with endometriosis feel uncomfortable discussing their condition with employers or co-workers (Culley *et al.* 2013).

The experience and prevalence of symptom dismissal by medical practioners is a key concern for endometriosis sufferers. In many cases, such dismissal implies female hysteria (Nezhat, Nezhat & Nezhat 2012; Graffia 2019). This is one of the major factors behind extended delays in diagnosis of endometriosis, because symptoms are not diagnosed as a medical pathology (Culley *et al.* 2013). The dismissal of women's endometriosis-related symptoms is a consequence of privileging men's anatomy and excluding discussion of human female biology in the medical literature over the last few centuries (Kupiec 2019). Consequently, what has been observed is that a lack of information from medical practitioners to patients and their kin has led the sufferers of endometriosis to Internet forums to understand and resolve their suffering (Emad 2006). This has also led endometriosis sufferers to doubt the knowledge and competency of medical professionals (Whelan 2007). In the proceeding chapters, I compare these factors to types of relationships and how they interact with one another. All these factors and considerations are taken into account when analysing the lived experiences of the participants.

Chapter Summaries

Chapter 1: Internalisation of the External

How people internalise external sociocultural teachings plays a significant role in how we live. It can affect how we think, behave and respond to others. I begin my discussion with this idea because it is important to understand what implicit and explicit teachings and dominant ideas people receive about endometriosis and also how individuals with endometriosis come to internalise and embody these teachings.

There are different ways that a person with endometriosis can come to make meaning and identify with their version of what is normal in day-to-day life, particularly contextualised within the destructive nature of endometriosis concerning the physical body and the social meaning behind being able-bodied (Scarry 1985: 61). Such manifestations of embodiment of having or living with endometriosis are often the result of medical dismissal, scientific theories around female bodies and reproduction (Martin 1987: 5) and the legacy of female hysteria as a diagnosis (Nezhat, Nezhat & Nezhat 2012: 56). These external processes, and the consequent internalisation of them, can often lead to a lack of a diagnosis of the condition creating a social purgatory, where the person is neither healthy nor sick. It is only after diagnosis that the relief and validation of being unhealthy and physically atypical can be felt (Culley et al. 2013: 632).

Even with a diagnosis of endometriosis, there is still the presence in common vocabulary that the illness and controlling the illness is the

responsibility of the sufferer (Graffia 2019: 30-32). There are also sociocultural pressures that those who suffer with the illness, particularly women, must still fulfil all financial and social obligations that constitute a nurturing, feminine individual (Martin 1987: 131), and this is irrespective of the level of sacrifices the sufferers must make. This is further exemplified by the use of hormonal treatments that may temporarily relieve symptoms of endometriosis, just enough for the sufferer to function; despite the fact that these same hormonal treatments can also cause damage to the women (Culley et al. 2013: 635).

Such internalised social messages, emphasised by consistent societal attitudes and external reminders from doctors, medical literature and even friends, family members and partners, exacerbate an already excruciating condition experienced by the women. For example, Rebecca was told by her GP that she had a low pain tolerance, an external message from the doctor that was internalised by Rebecca, deepening the dismissal of her symptoms.

Moreover, such attitudes contribute to women's feelings of invisibility, loneliness and the attribution of hysteria by others regarding her experience of endometriosis, which in turn can lead some sufferers to seek support from online forums, where they can feel understood. Ella, for example, described the relief she felt in talking about her condition on

such forums, stating that she didn't feel "alone" or "insane" when viewing and engaging these online forums[2].

The sociocultural teachings regarding what it means to have endometriosis also in turn affect how the individual reacts in their interpersonal relationships, or how the sufferer relates to other people. That is why the first thematic chapter of the thesis begins from an intrapersonal perspective – how the sufferer relates to themselves and their endometriosis.

Chapter 2: Becoming Socially Acceptable

In Chapter 2, I discuss how the attitudes and concepts analysed in Chapter 1 influence the sufferer of endometriosis to act in a socially acceptable manner. Failure to act in such a way subjects women to stigma and isolation whereas when they successfully conform to a socially scripted role it leads to acceptance, even if being socially acceptable requires a certain level of subterfuge as I explain in Chapter 2.

Firstly, some experiences and emotions are not socially acceptable, and therefore must be avoided. For the sufferer of endometriosis this mostly boils down to the expression of physical pain and distress. While an automatic reaction to pain may be to yell and scream (Emad 2006) this is not a socially acceptable expression of pain in a public space. Pain in one person causes distress for someone

[2] This ties into Rabinow's concept of biosociality as outlined in *Artificiality and Enlightment: From Sociobiology to Biosociality*

witnessing it because pain cannot be objectified (Scarry 1985: 56). Such reactions to physical distress must then be controlled in order for the sufferer to be socially acceptable, despite the fact this can lead to feelings of invisibility and isolation. Ella put it perfectly when she said:

> "How to (have) endo while being socially acceptable, which is… never talk about it, never be in pain, never show you're in pain."

Secondly, there are social scripts that both healthy and unhealthy individuals follow in interpersonal interactions. While these can serve to fill awkward silence and offer comfort to a person with an acute medical condition, someone with a chronic illness can find such sentiments as 'I hope you feel better soon' to be alienating. Another social script that interferes with endometriosis and building an awareness of the condition are the social taboos around menstruation, specifically the concealment, activity and communication taboos (Griffith 2017: 38). These sociocultural taboos can be seen in the context of fertility complications that can occur due to endometriosis.

Lastly, a person in a Westernised culture is required to be independent. Chronic illness significantly disrupts a sufferer's ability to be physically, emotionally and financially independent. As such, reviewing statistics on income, costs of the disease and the experiences of sufferers can enlighten us as to the acceptability of dependence in Australian culture.

Chapter 3: Negotiating Interpersonal Relationships

By the nature of endometriosis, much like Martin's take on menstruation, pregnancy and menopause, it cannot be separated from the professional and the familiar (Martin 1987: 197), the interpersonal and intrapersonal. Rather than segregated into 'appropriate' environments, as decided by sociocultural processes, endometriosis pervades all aspects of life for the sufferers for one crucial reason – it is a part of life for them. Endometriosis interrupts and prevents normal living (Endometriosis Australia 2021; Culley et al. 2013: 632-633). The sufferer is forced to live in two worlds that defy the existence of the other: a world where they are ruled by the natural processes of their body; and a world where they are required to control their body, or at least give the illusion of control.

In Chapter 3, I discuss how endometriosis sufferers interact within their interpersonal relationships. Dyspareunia – pain during or after penetrative sex – is the most obvious and well-researched symptom that interferes with romantic relationships. This particular kind of pain experienced by women as a consequence of endometriosis can either end (Graffia 2019: 25-26) or strengthen a romantic relationship, depending on the couple. How a woman's embodiment of endometriosis impacts her relationship with family members and friends is minimally researched but it has been observed that her professional space is severely impacted by the condition (Culley et al. 2013: 633-634). She is forced to miss work or school and is often unable to complete work-

related tasks (Culley et al.2013: 633-634) and this is primarily due to symptoms that cause immobility, such as pain and nausea. Medical professionals can also be a means of support by administering treatment and advice. However, they can also lack knowledge about endometriosis, causing sufferers to study the disease independently (Whelan 2007: 962-965). All these interpersonal relationships must be negotiated carefully and attentively by the sufferer of endometriosis in order to preserve her relationships.

Chapter 1: Internalisation of the External

> *"I think it's because… it goes back to me having my first period and being private about that. It's… I think, maybe there's a level of me still being uncomfortable talking about endo because it's got to do with the ovaries and the fallopian tubes. With other women I'm fine!" – Emma*

Chronic illness, including endometriosis, alters a person's perspective about the self and the illness they embody. You can wake up one day with a certain view of yourself and then that view becomes distorted by a diagnosis and a list of inescapable symptoms. How much a person embodies their condition will affect them. The sufferer must learn to contend with their own understanding of their condition, the medical understanding of it and how the people around them comprehend their condition. Any and all of these varying perspectives can become internalised and change how the person views themself,

their endometriosis and their life. Therefore, the initial perspective they must contend with is their own and how they embody their condition which is influenced through external sociocultural attitudes.

Embodiment of & Identification with Chronic Illness

> *"I don't necessarily want to tell someone that I'm about to go on my period, I'm just like "Oh, Aunty Irma's coming to town, and I'm having a week away."" – Amy*

By embodiment, I am referring to the physical, emotional and psychological manifestation of endometriosis and how the sufferer associates these with their sense of self. An example of this is whether a woman views her changed abilities due to endometriosis as a disability. Consequently, she might define herself as 'disabled'. Another would be whether the woman labels herself as 'moody', as a common symptom of endometriosis is irregular or unstable moods.

One of the concepts I explored with each of my participants was how they did or did not identify with their condition. I did not ask them about this directly, but rather my participants revealed themselves with their vocabulary choices and how they spoke about themselves. For example, Alex identified more strongly with disabled people with whom she had become friends with since her symptoms manifested. Similarly, Amy often referred to herself as moody, despite knowing her moods were a consequence of factors relating to her endometriosis, such as pain levels, medication and hormonal changes.

Other responses ranged from having nearly complete embodiment of their condition as if to embrace it as a part of who they are to an almost utter disdain of the endometriosis as some outside force invading their private space and an invader they cannot get rid of. Often women expressed conflicting views on these two spectrums of how they embodied and/or identified with their endometriosis. For example, Bella referred to herself as an ‘endo girl’ but also emphatically stated that she did not let her endometriosis define her.

Before I detail what meaning the women in my research attributed to their experience of having and living with endometriosis, it should be noted that endometriosis in itself does not have a clear medical definition nor a set way of identifying with the condition (Seear 2014: 13), whether relating to the social or personal view of the illness. It is then up to each individual with endometriosis to decide what the condition means to them. What it represents to the individual then has an impact on how they manage their condition and symptoms. I observed many of my participants, regardless of what personal meaning they ascribed to their condition, would agree that endometriosis is a kind of torture. The women I spoke with certainly described their endometriosis-related pain as uncontrollable and repetitious, echoing Scarry’s work on the subject of torture. This comparison may sound extreme but if a second person was inflicting the pain that endometriosis does on a woman’s body, it would most certainly be considered a form of torture. Here my thinking is influenced by Scarry (1985). In the case of repetitious torture, the sufferer

may comprehend how much suffering is in store after a few repeats of the torture (Scarry 1985: 58). It is the same for the chronically ill person with endometriosis. As this experience of torture is closely linked to a woman's hormonal cycles, the pain becomes repetitious, nearly cyclical. However, where the torture victim knows that this will be their fate for a period of time (minutes, hours, days, weeks), the chronically ill person with endometriosis will hold out hope of a cure until they are diagnosed, would have visited multiple doctors in search of relief from the pain, and after several treatments may obtain a short reprieve from the pain.

The sheer destructive nature of the disease then comes into play. As Claire phrased her experience:

"I don't feel like a person anymore. I feel like a patient."

Pain has the capacity to be "world destroying" and teaches that an able body, something many take for granted, is not a given in life (Emad 2006: 200-201). This destruction of a person's identity as an able-bodied person forces the sufferer to confront a new reality as a disabled or limited body. There is also an extreme sense of being out of control, which can in turn cause a sensation of self-fragmenting (Martin 1987: 82) and of no longer being a whole, intact person. Just as the bombing of a city not only destroys the architecture but the human meaning behind those buildings (Scarry 1985: 61), so does endometriosis destroy health and the sufferers meaning behind aspects of their health. An example of this would be the physical damage caused to the reproductive organs

also destroying the value the individual has assigned to those organs. In the case of the reproductive organs being damaged by endometriosis, it destroys the perspective of oneself as a mother (Becker 2000: 29).

What sense of self is not directly obliterated by the disease can be damaged by stigma and social attitudes. Stigmatisation due to chronic illness can cause a person to question their own identity within their social structure, as they no longer fit what is required of them to be of social value (Graffia 2019: 30-32). The more a person is treated, the more they can come to see their bodies and selves as atypical (Becker 2000: 27). While social requirements and attitudes on what is normal and what is deviant will change over time (Becker 2000: 33-34), the current understanding is largely based on productivity and physical capability, attributes which many sufferers of endometriosis simply do not have. The ill are encouraged to be stoic, independent and courageous, to continue to fulfil social expectations (Graffia 2019: 30-32) despite any ability or inability to do so.

It is after these experiences that the previous sense of self is shattered and no longer fits the old model for who the individual was. The sufferer must then find a new way to conceptualise themselves. On the one hand, a person may accept and embrace their identity as an ‘endo girl’, as Bella put it. Some will fight the condition as much as they can, like Mary who seemed proud and pleased with herself for having never taken a day off work due to her endometriosis. The most interesting manifestation I found in several of my participants was a sense that the

endometriosis was a part of them but also not a part of them. Their condition was at one point within the bounds of the self or ‘me’ but also not a part of the self, largely in the sense that they could not control or influence their condition.

Scarry phrased this perfectly when she wrote about pain:

> “Even though it occurs within oneself, it is at once identified as “not oneself,” “not me,” as something so alien that it must right now be gotten rid of.” (1985: 52)

At one point, the individual can feel acted upon by the pain and other symptoms (Scarry 1985: 53). This is similar to how women describe labour and uterine contractions, as something involuntary that they passively experience (Martin 1987: 10). However, it is also something that my participants spoke of as inextricable from themselves, much as they would remove it if they could. ‘The body in pain’ is not ‘the self in pain’ but ‘the-not-me in pain’ (Emad 2006: 200-201).

To elaborate on this, one of my participants, Amy, would refer to her menstrual cycle as ‘Aunty Irma’, a phrase she picked up from a television series. She spoke to me about ‘Aunty Irma’ and described her as a ‘bitch’, thus separating herself from her condition and symptoms, particularly mood swings. However, she would also refer to herself in the same terminology and called herself ‘moody’, even when that emotional instability was a direct result of the endometriosis. In this way, Amy could at one point disassociate from her own symptoms, and in the next

moment she would reclaim those same symptoms as a part of her sense of self. ‘Aunty Irma’, then, for Amy, acts as the vessel that embodies the condition and the symptoms, a personification of endometriosis. This is the most explicit illness narrative provided to me by any of my participants and shows a clear attempt at telling a story to recreate the sense of self (Emad 2006: 201-202).

A less direct example of an illness narrative is Alice’s categorisation of herself as a ‘not healthy person’. Alice described her usual, day-to-day experience as ‘unhealthy’:

> “If you were a healthy person, it’d probably be a lot more noticeable, because you’d feel good every day, most days. But because I feel kind of like, really unwell most days, I don’t notice it as much.”

By internalising this idea that a limited or disabled body cannot belong to a healthy person, Alice formed an identity of herself based on the idea of limitation. In this case, her body is limited, her career prospects are limited, her health is limited, her life is limited. Through this form of embodiment and illness narrative, Alice creates an identity based on what her symptoms allow her to achieve. She, in a sense, creates a life based on her condition, rather than basing her condition around her life. All this arises from medical and social conceptions of what is healthy and what is a chronic illness, and each is located at two ends of a scale, two social

categories constructed as mutually exclusive, rather than ‘chronic illness’ being a condition in life and ‘healthy’ being a temporary adjective.

Medical Dismissal

> *“[The doctor] said, “Some people just have an anxious disposition. And that’s clearly you.”” – Rebecca*

In one way or another, our social conception of women and men and others who do not fit in these demarcated gender categories are informed by medical and scientific theories (Martin 1987: 5). As Martin and other medical anthropologists have shown, medical practitioners and institutions have power over how we conceptualise and understand our bodies. These teachings become internalised and affect how we perceive ourselves and others (Lock & Nguyen 2018: 29). What happens when, according to these sources, the medical view of a lived experience is inaccurate and negative? For endometriosis, this is very much the case as medicine views endometriosis as a highly negative condition but biomedicine has a limited understanding of endometriosis (Seear 2014: 3).

Day (2012) separated the lived experience of endometriosis into three phases: the discovery phase; the questioning phase; and the revelation phase. All of these phases are relevant to the experience of and living with this condition; but these experiences are not necessarily recognised by biomedical practitioners in the treatment of endometriosis. From a medical perspective, living with endometriosis is not relevant until

it can be proven through medical tests, such as ultrasounds and laparoscopies (Rosenberg 2002: 237). Essentially, the experience of the condition is ignored until there is physical evidence of the cause of the experience, namely, in this case, endometriosis lesions. Both Rebecca and Bella had experiences of this when they presented their condition to their doctors. For Rebecca, her fatigue was dismissed as being caused by “doing too much” and Bella’s cyclical symptoms were dismissed as a ‘normal’ period.

The consequence of this dismissal experienced by Rebecca and Bella is that both women had delays in their diagnosis of endometriosis. Statistically, it can take 6.4 years (O’Hara, Rowe & Fisher 2020: 5-6) or 7-12 years in Australia (Endometriosis Australia 2021) to be diagnosed after the point of first seeking medical assistance for symptoms. Globally, this time can be anywhere between 5.5 to 13 years for women to be diagnosed after first seeking medical care (O’Hara, Rowe & Fisher 2020: 5-6). For my participants, it took an average of 12 years from the onset of their first symptom, often in the first few months of their first menstrual cycle, and 10 years from when their symptoms were at their worst (typically in their mid-teens) before they were diagnosed with endometriosis. The gap between seeking medical assistance and diagnosis is usually credited to the normalisation of dysmenorrhea, or period pain in the vernacular (Barnes 2020: 28-32). Like in Bella’s experience, trivialisation of symptoms in general is a common difficulty experienced by endometriosis sufferers (Cox *et al.* 2003: 8).

However, while the normalisation of symptoms is a problem, it is not enough to simply stop there. The processes and social ideas that generated this dismissal must also be questioned. What we know of medicine and human anatomy has historically been based on male anatomy and physiology, which can be particularly detrimental to girls and women (Kupiec 2019: 86-88). The notion that men are the default of our species and that women have the same biological structure dates back to ancient Greece and was not questioned until the late eighteenth century (Martin 1987: 27). The eighteenth century may seem like a long time ago but two millennia of assumptions are not so easily unravelled from social constructs. Due to this, girls' and women's health and all that includes is not typically identified based on research on women's biology/ physiology, rather girls and women are put in the 'not male' category. Reproductive health is a prime example, where women's reproduction or female reproductivity has been turned into a form of 'productivity' rather than a topic of health and wellbeing (Kupiec 2019: 86-88). We can see this reflected in the lack of social engagement about endometriosis, and the near-constant protests and debates in recent years regarding abortions – as recent media outlets have demonstrated and Martin mentioned similar debates from the 80s in *The Woman in the Body*. As my research participants conveyed at various points in my time with them – at times sarcastically – that a woman in pain, who cannot enjoy a sexual relationship to the same extent as others or absents herself from work or school due to her condition must simply live with a poor quality of life.

However, as Martin (1987: 45) suggests, a woman wishing to end the existence of a foetus is deemed to be making a horrific decision in our modern world. In the former case, the reproductive pain or the endometriosis-related pain is just an obstacle to overcome by the woman labourer, and the latter, an abortion, is a cessation of the product of that labour (Martin 1987: 45).

Over the past fifty or so years, women have continued to be underrepresented or absent from sample populations in medical research, despite legislation that has attempted to change this (Kupiec 2019: 86-88). Some reasons for this are budgeting, unique reproductive processes (menstruation, pregnancy and menopause) of women or the assumption that there is not enough medical difference between sexes to justify specifically including women (Kupiec 2019: 86-88). Why then, in the case of a disease like endometriosis that primarily affects girls and women, has there been so little research? Is it because you cannot study a man's body to learn about it? You do not have to control for sexual differences when studying the female sex, nor do you have to narrow down the sample population to the 'at risk white male' (Kupiec 2019: 86-88). Why then are girls and women underrepresented for a disease that primarily affects them? It makes no logical or rational sense because depending on their biological sex, a person may have a higher risk for some diseases, or a lower risk for others (Kupiec 2019: 86-88), such as in the case of endometriosis. The idea that women are essentially men but also not men because of our female-specific organs and levels of

particular hormones serves to further fragment women and their bodies within medical contexts. Women's and girls' bodies are both fragmented and dissected by science and medicine but also ignored and alienated from it because of a perception that 'scientific' is synonymous with 'masculine' (Martin 1987: 21).

Such views are certainly a factor in the normalisation of pathologies like endometriosis. Dismissive attitudes towards the sufferers can often result in the sufferer feeling like their illness and symptoms are their own fault, or that they are overreacting (Graffia 2019: 30-32). The consequence of this is that sufferers can postpone seeking medical assistance due to an assumption that discomfort is simply a normal part of life (Culley et al. 2013: 631-632). Regarding my own participants in the research for this thesis, most of them did not seek medical assistance until years after they had experienced their first symptoms because they were told by other women, most often by their mothers, that their physical pain was normal, even if it was debilitating. This links to the portrayal of female bodies in medical texts as 'passive hosts' and segmented into body parts rather than the body as a whole (Martin 1987: 62). What is often not considered is that 'normal' is relative to the individual. Women with pathologies like endometriosis can come to consider their symptoms as 'normal' because it is their average or average in comparison to other women they know (Manderson, Warren & Markovic 2008: 531-532). This is an example of internalisation of medical perspectives that can be detrimental to personal health.

For example, one of my research participants, Emma, acknowledged that she did not discuss her burgeoning symptoms much with her family, as her mother told her such symptoms were to be expected. If women do not discuss what is normal for themselves, biomedicine dominates the space of women's health, leaving many women to believe it is all in their head. For example, as several of my participants can attest to, if women do not discuss what the expected level of menstrual discomfort is versus what is potentially indicative of endometriosis, many women will ignore their symptoms and dismiss their experience as 'normal'.

Continuity of 'Female Hysteria'

> *"[Impression of doctors] "Oh, it'll pass. You're just really hormonal because you're a teenager. And, you know, you're a teenage girl, so you're hysterical, and you're making it up, and you're not actually sick, and you just don't want to go to school."" – Lizzy*

A common experience conveyed to me by all my participants was the implication by medical professionals, family members or in their workplace, that their physical symptoms are signs of female hysteria. 'Female Hysteria' was once a common medical diagnosis and although doctors are not strictly allowed to use this term anymore, there are other ways to explicitly or implicitly convey that what girls and women are experiencing in their body is 'all in their head', such as pain without a clear cause, deemed to be psychosomatic (Bach, Risoer, Forman & Seibaek 2016: 5-7). This can be viewed as a specific kind of medical

dismissal of women's symptoms and is consistent with the misdiagnosis of human female medical issues as female hysteria that dates back to Ancient Greece (Day 2012).

There is a heavy debate over whether endometriosis is a 'new' disease or if it has always existed. I would agree with Seear (2014) who suggests that endometriosis has existed as a medical condition for centuries if not millennia (Seear 2014: 10-11). This perspective also has documented support. There are descriptions of a disease matching the symptomology of endometriosis that date back more than 4,000 years (Nezhat, Nezhat & Nezhat 2012: 56). There is also evidence that most historical cases from the last several centuries of 'Female Hysteria' were endometriosis but were dismissed due to a lack of external, physical signs of the disease (Nezhat, Nezhat & Nezhat 2012: 56). The evidence for endometriosis being a 'new' disease is limited to the fact that only 20 cases of the disease had been recorded in the 1920s (Seear 2014: 5). Many of the symptoms of endometriosis are dismissed and normalised as overdramatised period pain or psychological distress by the biomedical establishment. This has been the experience for most of my participants and has also been observed in endometriosis literature (Kupiec 2019; Seear 2014; Whelan 2007; and O'Hara, Rowe & Fisher 2020). Moreover, symptoms and bodily experiences such as dyspareunia, are entangled with social taboos that limit communication by the sufferer about it and so they silently suffer, potentially reinforcing

the internalised dismissal of symptoms in the minds of girls and women. I discuss such social taboos that inhibit communication in Chapter 2.

Returning to my point regarding the sufferer as hysterical, it is not uncommon for sufferers to be treated by medical professionals as if the pain is ‘all in their head’, often due to the difficulty of locating the endometriosis tissue in the body (Graffia 2019: 30-32). My research participants often had such experiences that they shared with me. For example, two of the women I interviewed had been sent to psychologists by their doctors. The psychologists were outraged because, in their professional opinion, there was nothing mentally atypical about the women. Alice related an experience to me where she had been taken to the emergency room of a hospital while in her teens and the doctors on duty refused to examine her, despite her mother being there and insisting to the doctor that her daughter Alice be examined. The doctors then gave Alice cookies and milk, stating that it would make her feel better. As Alice shared,

> “…the first time it was so painful. I couldn’t sit down; I couldn’t do anything. I had to lay down in the car for them to take me to the hospital. Um… and… the (male medical professionals) said at the hospital, “You’ll be alright. Cookies and milk will help.” [pause] Even though my mother, my legal guardian was there, they said, “Oh, no, we’re not allowed to examine her because she’s under eighteen.”

Beyond being patronising, the response of the doctors indicates that they did not believe anything was medically wrong with Alice or perhaps that she had menstrual pain and was overreacting to menstrual discomfort. As scholars have observed, pain with no obvious physical cause has often been categorised as psychosomatic (Bach, Risoer, Forman & Seibaek 2016: 5-7). Moreover, as endometriosis has no known cause (Seear 2014: 3), the disease itself is often misunderstood, even after diagnosis.

Similarly, in the 1980s, the medical establishment determined that premenstrual syndrome, or PMS, was a pathology despite it affecting 75 percent of adolescent girls and women (Martin 1987: 113-114). And as Martin (1987: 175) suggests the pathologising of women's reproductive physiology intersects with dominant social perceptions whereby women who are perceived to act against their socially assigned role are often treated as deviant. This is the case even when women's 'deviant' behaviour is caused by some of the most natural biological processes, such as hormones, menstruation and menopause. On the one hand endometriosis seems intangible and presents an unknown to the medical establishment. It is unclear how it is caused, manifests or progresses. On the other hand, it is reduced to female hysteria largely due to a lack of understanding about the condition. As such, no matter the semantics used to characterise the sufferer, she is viewed as socially deviant and 'in need of correction', to be made more acceptable according to social

values, which places her in a kind of social purgatory – not a ‘good girl’ but also not quite a ‘bad girl’.

Un-Diagnosis as Social Purgatory

> *“Given that I kind of thought everything else up until this point was normal (with) everyone else’s periods, how am I to know what’s different or not normal?” – Mary*

A consequence of medical dismissal and endometriosis being viewed in light of the legacy of female hysteria is that being undiagnosed becomes a kind of social purgatory. Returning to the gap in diagnosis, on average a person will suffer symptoms severe enough to seek medical assistance for 6.4 years before they have a diagnosis (O’Hara, Rowe & Fisher 2020: 5-6). This represents six years of trying to explain what one is experiencing, to doctors, family, friends, partners, co-workers and employers. However, the sufferer is attempting to explain their condition without a clear word or name to validate that experience. After finally attaining a diagnosis of endometriosis, symptomatic women often report a sense of experiencing “relief, legitimisation, liberation and empowerment”, as opposed to their previous feelings of “fear and self-doubt” (Rosenberg 2002; Culley et al. 2013: 632). Some experience anger at the delayed diagnosis and a sense of vindication when their persistence pays off (Culley et al. 2013: 632). One of my participants, Claire, described her undiagnosed phase to me:

> “I felt like I was… always working really hard to convince them that there was something wrong.”

Bella referred to her diagnosis as a “credibility check” with her family. Several other participants described the ease at which people would show them sympathy and understanding after they had a single word to explain what was happening to them. In these cases, the diagnosis acted as a “narrative resolution” to the pain which helped in explaining the symptoms to the self but also to others, namely friends, lovers, family, co-workers, employers (Manderson, Warren & Markovic 2008: 531-532).

Victim Blaming & Social Responsibility for Illness

> *“I kind of get into that rabbit hole quite often… It’s like, “Yeah, you know what? Why?? You know? Like, why did this happen? You know, what could I have done to prevent this from happening?” and stuff like that. And then it’s like “Well, can I do something to prevent it from happening in the future?” Or, you know “Have I done as much as I could do?”” – Amy*

As a further consequence of un-diagnosis being a form of social purgatory comes victim blaming and a socially assigned responsibility for the illness upon the sufferer. Half of my participants related experiences that were forms of victim blaming, though the literature on the subject is limited. Claire related an experience where a former co-worker had blamed Claire’s migraines on eating chocolate and explicitly said that if Claire stopped eating chocolate, she would no longer experience

migraines. Lizzy had been told by medical professionals that her symptoms were not indicative of any specific disease but were caused by being obese. Each of these are examples of external social attitudes that the sufferer has control over their symptoms and over their endometriosis. Becker in *The Elusive Embryo* related one of her participant's experiences of feeling "chastised" by medical professionals about her fertility complications (2000: 26). These attitudes can also manifest as internalised thoughts and behaviours. Among my research participants, both Mary and Amy showed a harsh attitude towards themselves, with Mary not letting herself or her endometriosis prevent her from working or socialising and Amy spoke of herself as "inconvenient" and "lazy" due to her endometriosis.

In a more institutional context, as Martin (1987) observed, it was suggested in a study from the 1940s that PMS and menstrual leave had been used as an excuse to be lazy and shirk professional responsibility. The support for this was that women stopped taking sick days for menstrual discomfort after an insurance company refused to cover menstrual leave (Martin 1987: 120). In *The Woman in the Body*, Martin points out that many people, despite how unwell or debilitated they may feel, still attended work due to their financial needs (1987: 120). Another example originating in PMS literature are accounts of women blamed for violence, verbal or physical, enacted by men (Martin 1987: 131). In such narratives, the man's behaviour - shouting at his wife or slapping her for acting outside of a nurturing role - is rationalised as acceptable and

considered a means to reinforce women's 'natural' feminine role (Martin 1987: 131). As Martin writes in *The Woman in the Body*, this is rationalised as:

> "The problems of men in these accounts are caused by outside circumstances and other people (women). The problems of women are caused by their own internal failure, a biological "malfunction"." (Martin 1987: 131)

Such external and institutional social attitudes towards women's physical suffering can lead to women sufferers believing they are responsible for their illness and symptoms, or that they are overreacting to a 'minor' problem (Graffia 2019: 30-32). Such attitudes prevail despite the lack of a cure or means of preventing endometriosis (Endometriosis Australia 2021). While it has been claimed that symptoms can be managed through lifestyle choices such as diet, exercise and alternative medicine (infocus 2019), no person with endometriosis I have ever spoken to, within or outside the bounds of this study, has related any sense of control over their condition. This feeling of being out of control can cause a sensation of fragmentation of the self (Martin 1987: 82). Yet, sufferers of endometriosis, through these societal attitudes, are assigned a social responsibility over their symptoms and how they must cope with them, particularly when it concerns how their condition affects other people.

Sacrifice & Femininity

> *"Because after ten years of being told you're imagining it, and then, not really tending to… treat yourself or do anything to deal with it. Um… it just gets worse, right?" – Claire*

There are several factors to pain, namely duration, control and purpose (Scarry 1985: 35). Endometriosis will last a life time with gradually worsening symptoms and the occasional reprieve via medical intervention. The disease is incontrollable and flare-ups, or the acute worsening of symptoms, are only somewhat avoidable. There is no purpose to the suffering caused by endometriosis, apart from what the individual may ascribe to their suffering. It simply exists as part of the self and separate from the self in tandem.

Returning to my comparison between endometriosis and torture, I draw from Scarry (1985) to point to the similarities in the lack of control experienced by the victim or sufferer of endometriosis and torture. There is some purpose to endure both torture and endometriosis, though this is primarily due to meaning-making of the sufferer. For a torture victim, the purpose to them withstanding the harm to their person may be to protect information. For an endometriosis sufferer, the meaning-making is quite personal for each woman and even then, a woman with endometriosis may not be able to attribute meaning to her pain. Bella perceived her experience of endometriosis and knowledge of her own condition as beneficial to her friends' daughters, as she can explain to them at what point menstrual pain becomes problematic. In contrast, Alice could find

no meaning or benefit in her chronic pain. The duration of pain from endometriosis may be different to that of torture, but it is still determined by an outside force, one being the condition itself and the other being the torturer. This comparison is important to make, as distancing seemingly extreme forms of pain, like torture (Scarry 1985: 60), hinders our ability to engage empathetically with those in pain. Pain itself can be used as a symbol for dying or becoming dead because it is recognised, likely unconsciously, by humans that pain is the tangible aspect of the intangible experience of dying. Both occur simultaneously with a disintegration of consciousness and are body-centric processes (Scarry 1985: 31).

However, acknowledging this can be difficult and cause personal distress for third parties, as I discuss in more detail in Chapter 3. From an intrapersonal perspective – how the individual relates to themselves – the lack of empathy created by a psychosocial need to distance ourselves from those in pain leads to the sufferer feeling abandoned and alone. Essentially, the person in pain can become something like a sacrificial offering so that the larger community does not need to face the more challenging and unsavoury aspects of life. This exists in tandem with a sociocultural conception that femininity and the role of the feminine are intrinsically linked to silent suffering, bearing the burdens that others do not wish to. Women with endometriosis often must choose between different aspects of life and sacrifice one part of their life for another in order to manage their endometriosis. They must sacrifice their

interpersonal expressions of negative emotions, such as anger, because anger and allied emotions, while acknowledged as a natural by-product of pain and hormonal changes, are anathema to the peace-keeping role of women (Martin 1987: 130).

For some of my participants, their conceptualisation of this struggle around sacrifice and femininity manifested as concerns around fertility. Consider that a woman who chooses to have a career and children, must then make sacrifices to try to preserve both aspects of her life, to attempt to be both productive and reproductive (Martin 1987: 100). Endometriosis and the likelihood of fertility complications for sufferers can create an added layer to this. Pregnancy often becomes a concern earlier for people who have endometriosis than for people without endometriosis:

> “Like most women at twenty, when you’re told you have endometriosis you probably have-- start thinking about having a child.” (Bella)

Others may question their own femininity and position as a woman due to internalised ideas that, as Amy put it:

> “As a woman, I should be able to have children.”

More common still among my participants was grief over their ability to choose being sacrificed to their condition. This was not limited to choices around children, but choices in life in general, including subjects like partners, sex, their career, what occupations they could fulfil, promotions,

recreational activities and even what food they could eat. Many of the women I spoke with, at least those who wanted to have children, lamented the fact that if they had a daughter, she would most likely be in a similar situation as they find themselves. They grieved and were concerned for the loss that their future daughters may suffer and placed responsibility on themselves to be the guiding, nurturing hand that helped this hypothetical life to be lived fully. They seemed to be preparing themselves to take on more responsibility and to prepare their daughters for the sacrifice that ultimately comes with being a woman and is often expected of women.

Socially Acceptable Castration

"If it's not super visible, it doesn't exist." – Ella

When speaking about castration in this context of women's suffering caused by endometriosis, I am referring to the use of hysterectomies and birth control as treatments for endometriosis, which create temporary periods of castration to varying degrees of efficiency. At the more permanent end, there are also partial or complete hysterectomies as well as natural or medically induced menopause, which are absolute forms of castration. From oral contraceptives (The Pill) to intrauterine devices (IUDs) and hysterectomies, these methods of hormonal control are used to dampen the symptoms of endometriosis (OASH 2019). Every single participant of my study for this thesis had been on some form of contraceptive to manage her endometriosis symptoms. The most common was different brands of The Pill, with IUDs

used by several participants. Injections and contraceptive implants were also mentioned by a few of the participants.

None of the participants of this study had a hysterectomy or received treatment for medically induced menopause, likely due to their relatively young age and the wish of most of the participants to have biological children at some point in their lives. Hysterectomies are more often performed on women past childbearing age. This may be due to attitudes towards the 'utility' of reproductive organs or that a hysterectomy lowers life expectancy and so it is seen as less of a risk for a woman who is halfway through her lifespan already (Barnes 2020: 28-32). In some affluent social contexts, hysterectomies have been used as a preventative measure against cancer of the reproductive system. However, this has typically been on older individuals, past child-bearing years (Downham Moore *et al.* 2021: 16). One participant, Alice, had requested a hysterectomy from her doctor in her adolescence but the doctor declined. We might speculate that this is due to Alice's age and concerns regarding the risks on her health related to potentially life-long hormonal treatment.

It is understandable that doctors consider the risks before prescribing treatments. However, in the case of endometriosis sufferers, they typically will be put on a form of contraceptive in their adolescence, either for birth control or symptom control, and then they may continue with contraceptive treatments for the remainder of their lives, unless they are actively trying to get pregnant. Like all medication, contraceptives

have side effects and risk factors that can diminish health and wellbeing (Culley et al. 2013: 635). While the reprieve from symptoms can be a relief, it is temporary, as the body will acclimatise to the altered hormonal levels. Many endometriosis sufferers on online forums share their experience of IUDs or oral contraceptives lessening the symptoms for six to twelve months before the symptoms worsen once again. From my own experience and observations, such accounts are prevalent on social media support groups for endometriosis. I suggest that the IUDs and oral contraceptives are a form of socially acceptable castration because it silences the natural biological processes of female bodies (i.e., menstrual cycles) so that women who suffer from endometriosis can be socially acceptable and continue on with their lives. If it is truly about the health of women, would doctors be so willing to prescribe medication that can cause depression, mood swings, high blood pressure and cancer (Gotter 2018)? It is a cruel irony that all of those side effects are also endometriosis-related symptoms that should be avoided. Even as there is a growing literature about the relationship between cancer and endometriosis (Nezhat, Nezhat & Nezhat 2012), the increased risk of cancer for endometriosis patients is seldom mentioned by doctors. Moreover, none of my research participants were warned about an increased risk of any associated medical issues beyond fertility complications, and then only if they were actively trying to fall pregnant.

Even laparoscopies, ablation and excision surgeries, cause scar tissue, which is in fact something caused by endometriosis. The

treatment is then causing what the sufferer wants to avoid for a temporary reprieve. This temporary version of treatment is also an attempt to achieve a desirable outcome on a social level rather than a personal one. It is a form of achieving a goal, that is to function close to normal, rather than focussing on correcting the condition itself. A similar approach can be seen in fertility technology, where the medical priority is the creation of a viable foetus, not the correction of atypical physiology (Becker 2000: 16). This is the medical equivalent of putting a Band-Aid on a broken leg, resulting in the sufferers feeling misunderstood, unacknowledged and isolated.

Forming a Sub-Culture

> *"It's just an unspoken kind of solidarity [between endo sisters]." – Bella*

One of the social manifestations of the feelings of isolation and invisibility experienced by endometriosis sufferers, is the formation of a sub-culture that begins to emerge and is evidenced, primarily, in social media support groups, of which there are global, national and local groups that a person can join. Bella described her experience and the empathetic connections between people sharing a common experience as "an unspoken kind of solidarity". While Ella stated that online forums and support groups helped her to feel less isolated, such social connections can also lead to deepening of friendships between sufferers. Alex disclosed to me that most of her friends are disabled in one way or

another, because they are able to communicate more easily with other disabled individuals rather than with able-bodied individuals.

There are not many opportunities for people with endometriosis to meet in-person, but their shared experience can provide a sense of community, much like what can happen with women connecting with each other, in general (Martin 1987: 4). There is also a shared definition of what is ‘normal’, as a person without endometriosis will have a very different concept of what is ‘normal’ for their body compared to someone with endometriosis (Manderson, Warren & Markovic 2008: 531-532). Shared experiences of women (i.e., menstruation) can be a means of binding them to each other. However, if they are taught to despise the shared phenomenon, they will begin to despise each other, themselves and their femininity (Martin 1987: 111-112). The participants who conveyed a sense of solidarity and belonging to the larger endometriosis community were also those who had come to accept their own physiological state. Hopefully, as menstruation, menopause and associated conditions like endometriosis become more common topics of conversation, there will be less resentment around the disease and more space for empathetic connection with others experiencing the same reality.

Concluding Vignette: Torment

I was thirteen when I first started feeling the pain. It was mild, annoying but ignorable. My mum let me have a few days off over the school year. Those were the days when I’d just curl up and cry, gripping

at my belly in agony. I was grateful for those days but after a year, Mum said I had to go to school anyway. She said that every girl my age had them and they all went to school. Besides, school was important. At least she wrote me a note to sit out of P.E.

It wasn't really bad until Year 10, when I was 15. 'Sweet Sixteen' felt more like 'Torment Teens'. I'd try to walk and nearly faint from the pain. I'd eat a plain piece of toast only to dry heave in the bathroom for ten minutes. When I begged my mum for a day off, she told me it was all part of becoming a woman. The pain in my abdomen, in my head, in my legs, was no longer ignorable. At least it was bearable. The teachers were less compassionate. My P.E. teacher stopped accepting the notes my mum wrote and said that I used period pain as an excuse too much. The nurse at the sickbay would send me away. She had an irritated look on her face whenever she saw me coming.

Sitting for my Year 12 exams was the hardest. I was in excruciating pain the whole time, like someone shoved a knife into my cervix. Like someone had punched me in the gut and left their fist imbedded in my abdomen. I felt like I constantly had to go to the bathroom, either to vomit or pee. My teachers wouldn't allow me any extra time because it was just bad period pain. It wasn't a medical condition. By some miracle or just plain stubbornness, I managed to get one of the highest final exam scores of anyone in my school. I got into the university program I wanted and hoped that maybe – just maybe – things might get better. Afterall, aren't the teenage years meant to be the

worst? Once your hormones settle, isn't the nausea, migraines and pain meant to be lessened?

Within six months of starting university, I was unable to get out of bed. I had to take my classes from home and prayed that I wouldn't fail my courses. I hardly ate when all my former favourite foods would make me sick to my stomach. I went to my GP only to be told to take Neurofen and get some rest. That I was probably just stressed from settling into uni. It took another two visits for the doctor to recommend further action. My GP gave me a referral to a gynaecologist and a gastroenterologist. I visited the latter first, only to be told they probably couldn't help. They mentioned something about menstruation flowing up the fallopian tubes and into my abdomen. They handed me off to the gynaecologist.

The gynaecologist was the first to name the malfunction of my body – endometriosis. She never explained what it was, how it happened or what I could do. She told me to look it up online and scheduled me in for an ultrasound. She also suggested I go on a second kind of birth control.

In sheer desperation, I researched endometriosis. All I found was despair and parts of the Internet where hope goes to die. Chronic. Incurable. Food intolerances. Pain. Untreatable. Infertility. Dyspareunia. Cancer. I typed in key search words over and over, hoping beyond reason to find something, anything, that could help. All I found were impossible or vague attempts at management. Exercise lots but not too

much. Cut out any possible edible allergen. Have a child. Get a hysterectomy. Be on The Pill your whole life. Never have sex.

I was only nineteen. This couldn't be what my future looked like. It couldn't. But it was. I felt like I had made a deal with the devil, one that I couldn't remember. This – endometriosis – was simply my own personal hell.

Chapter 2: Becoming Socially Acceptable

> *"How to (have) endo while being socially acceptable, which is… never talk about it, never be in pain, never show you're in pain."* – *Ella*

A major issue experienced by this study's participants was presenting themselves in a socially acceptable way. As Ella put it, most of the advice she received from medical professionals and laypeople was how to become socially acceptable while having endometriosis. For Mary, this meant changing her sanitary pads every few hours to prevent the blood from showing on her outer clothing. Some of the other women would isolate themselves when they became emotional due to increased pain and hormones. Others would simply "train" themselves, to borrow a term from Lizzy, to act as if they were fine when they are in extreme discomfort. This is what I refer to as modulation of expression.

Modulated Expression

> *"So, when I'm home **alone**, I scream. I'm talking guttural scream. I curse out God, I curse out anyone that I can think of, you know, like people that I don't even know. I curse them out because they might not be living with this, so fuck those people, you know."* – *Amy (emphasis added by me)*

One of the lessons every child will learn regarding being socially acceptable is how to control expressions of emotion, and people develop this skill as they age (Edcraft 2021). This becomes more difficult when

living with a chronic condition, like those experiencing pain associated with endometriosis.

Pain and discomfort have an interesting ability to make the external world fade from comprehension and become less palpable. The body in turn becomes more tangible to the person in pain (Scarry 1985: 30). Scarry details the power of physical pain to extinguish psychological distress (1985: 34). This is often due to the psychological prioritisation of discomfort. While physical pain can often be a threat to survival, such as the pain created by a stab wound, psychological pain and distress is a secondary reaction to a threat to survival, like the fear that would follow being stabbed. However, some of my participants spoke of how their physical pain causes them psychological distress, such as Lizzy's distress around needing to "protect" her fertility from her endometriosis condition. Surviving endometriosis and other chronic illnesses is not simply about physiological survival, you also have to socially function, which a person in acute pain is not required to do. A person in chronic pain who is not dying immediately is still required to function within their sociocultural environment.

However, automatic reactions to pain do not often lend themselves to such requirements to function. Natural reactions to pain include: measuring the pain; screaming, yelling or other verbal expressions of the sensation; cutting the pain out or open, metaphorically or physically; taking medication to mitigate the sensation; and intensifying the sensation (*When Pain Strikes* by Burns, Busby & Sawchuk 1999 in

Emad 2006). For example, Claire related an experience in her young adulthood when she started crying from the pain at work and a customer complained about the fact that she was doing it in view of customers rather than going “out back” where Claire could not be seen. Such reactions by Claire to her experience of pain when exhibited externally become socially unsanctioned. We are socialized from an early age that yelling and screaming from pain is unacceptable in the company of others. Children are taught to ‘use their words’ to describe their discomfort and pain to someone who can help.

Another form of modulated expression is silence or a lack of communication, thus denying the existence of pain or discomfort. For Emma this denial manifested as an attitude of needing to get through the day no matter how much pain she was in. For Amy, her denial was in the form of limiting her verbalisations of pain until reaching her own home and then only when she was alone. A confession, or honesty regarding personal matters, can be socially perceived as a betrayal of the self and of everything that comprises the self, including friends, family, country and cause (Scarry 1985: 29). For example, we can observe that when Australians ask one another “how are you?”, the social convention is a simple affirmative adjective (“good, thanks”) before continuing, regardless of how the person actually is. Failure to respond in the established mode can cause awkwardness as the social script has been deviated from. Therefore, showing signs of illness and pain in public spaces is a betrayal and must be avoided. The very existence of that pain

must be denied. Art such as the famous painting, 'The Scream', illustrates an example of the occurrence of pain and the simultaneous denial of it – the subject of the painting is totally consumed by a sound that cannot be heard by the viewer (Scarry 1985: 52). Once again, pain is denied and erased by silence.

For the endometriosis sufferer, such control and modulation of natural expression is required and necessary to garner sympathy. If a person constantly complains of an illness, even a life-long illness, people will be more likely to ignore them. To paraphrase Alice, people get sick of someone who is sick. For example, O'Hara, Rowe & Fisher looked at a case in a hospital where women with endometriosis had been placed in the oncology ward due to lack of space. The oncology nurses were more sympathetic to the endometriosis patients who they perceived to be "resilient" – that is, those who complained about their pain the least (O'Hara, Rowe & Fisher 2020: 5-6). In this case, nurses, who are the socially perceived epitome of the feminine role, people who are required by their profession to have patience and be nurturing, ignored the suffering of girls and women with endometriosis because they complained too much about their medical condition.

Pain Affecting Relationships

> *"Sometimes it's too painful. You can't concentrate, you can't work. So, people are like, "Oh, you're taking sick leave, you're lazy." Pretty much, I feel so guilty every time I take sick leave, right?" – Claire*

Perhaps we should not think too harshly about the nurses because witnessing another person in pain is difficult and can be taxing. The primary concern for people with endometriosis is the almost constant, debilitating, often untreatable and unmanageable pain. While this pain is vividly real to endometriosis sufferers, hearing about someone else's pain typically feels distant, intangible and unreal (Scarry 1985: 3). Returning to the example of the painting, 'The Scream', anyone who has seen the painting, in person or a copy of it, can understand that the person in the painting is terrified (Scarry 1985: 52). However, very few people would be able to feel the terror of the subject and doing so would likely be very uncomfortable and distressing for them.

Unless pain is accompanied by visible physical symptoms, it will resist any attempt to objectify the experience of pain (Scarry 1985: 56). Pain is simply not translatable into objective terms, nor is it compatible with socially constructed reality. In fact, according to Scarry:

> "To acknowledge the radical subjectivity of pain is to acknowledge the simple and absolute incompatibility of pain and the world. The survival of each depends on its separation from the other. To bring them together, to bring pain into the world by objectifying it in language, is to destroy one of them…" (1985: 50-51)

Humans simply do not comprehend pain that is not their own (Scarry 1985: 3), not in a culture based on the principle that 'seeing is believing'. We can accept gravity, the existence of divine beings and the Big Bang

event but we somehow cannot comprehend the experience of another person in pain. Whether this is because we *cannot* comprehend such experiences or we *choose* to turn a blind eye to what is distressing and inconvenient is debatable. Women wishing men had at least one menstrual cycle in their life so that men could understand what it was like and be more accepting of it (Martin 1987: 102-103) do not usually wish this out of malice. Why would we want people we care about to be in pain, when, as Amy and I agreed, we would not wish such experiences on our worst enemy? The wish of discomfort to another perhaps comes from a desire to be understood and seen, acknowledged and visible.

However, the link created by pain between the sufferer and the witness of this suffering does not flow in a single direction but moves both ways. The witness cannot comprehend the experience of the sufferer but it is also difficult for a person in pain to perceive occurrences outside of themselves. Pain is all-consuming and the sufferer cannot comprehend much beyond their own reality. When the pain is lessened, the sufferer's focus can extend to other people and events external to their own physical form (Scarry 1985: 39), rather than their conscious mind being assaulted by constant messages of pain.

Studies between women with chronic pelvic pain related to endometriosis and chronic pelvic pain not related to endometriosis show similar levels of emotional distress. It is then likely that it is the pain itself that causes the emotional distress, less so than other aspects of endometriosis, such as hormonal dysregulation (Culley et al. 2013: 634).

As several of my participants discussed with me, it is distressing to see someone you care for in physical discomfort, especially when the witness of this pain is helpless and cannot lessen the pain. Amy, Claire, Bella, Lizzy and Mary all spoke about the ways their respective partners were distressed seeing them in pain and clearly concerned for them. Empathy is a common human emotion and connected to it are feelings of helplessness which appear unavoidable and can be one of the greatest ordeals of loving someone with a chronic illness – being unable to help them, comfort them or even know what to say.

Social Scripts for Illness

> *"It's hard to know what to say sometimes, when I'm struggling, because it's only me that can feel it." – Mary*

Social scripts for illness are an important way of navigating interpersonal relationships. For example, when a friend's family member dies, we have socially scripted responses ready for that friend. One such response would be 'I'm sorry for your loss' or other expressions of sympathy. We say these because there is often a silence between the witness and the grieving person that we feel a need to fill. Returning to the nature of pain and how pain and distress typically feel distant to a witness or a third party describing it (Scarry 1985: 3), we are still required to offer some form of pre-programmed sympathetic response, whether we truly feel sorry for the person or not. To do otherwise is to go against socially established norms and can be marked as deviant.

Whether the distress felt is psychological or physical, there are scripts that we follow. When someone is unwell, a common response is “I hope you feel better soon”. Different shops will have various ‘Get Better Soon’ cards. This is a socially acceptable response to physical illness. However, such scripts are more suited towards an acute illness because we expect a recovery in due time where the sufferer then returns to a ‘normal’ state of health. These are not scripts that work for someone enduring a chronic illness. A person with a chronic illness will not ‘get better soon’. Several of my participants commonly described feeling offended or frustrated in response to such well-wishes. Such negative feelings are understandable for an illness like endometriosis which can be described as worse than death (Culley et al. 2013: 632-633). While such ‘get well’ comments are kindly meant, if anything, according to several of my participants, it often makes the sufferer feel ignored and misunderstood.

Claire related an experience of what a male boss said to her after a surgery she had undergone:

“Oh, you’ve had the surgery! It’s done now, so you’re fixed now!”

Claire felt frustrated that her condition was so severely misunderstood by the people around her. Ella was asked during a flare-up why she didn’t just “take the day off”, to which she felt compelled to explain that if she took a day off every time she felt unwell, she would hardly ever leave her

home. Such experiences are common for people with chronic illness, including endometriosis.

Our social scripts for physical illness are built around acute illnesses and do not apply well, if at all, to chronic illness. In the case of those with a chronic illness, after a while people stop wishing the sufferer a recovery of any kind because they do not know how to fill the empty, silent void left by that person's illness. Alice's take on this was that "most people… don't like prolonged illness". I would posit that the distancing of the self from the sufferer is less attributable to a 'dislike' of chronic illness and is more due to the helplessness that arises when one must by necessity face a seemingly able-bodied individual and cannot take their own health for granted. Essentially, because chronic illness, pain and suffering are linked with dying, chronic illness is a constant reminder of our own mortality, especially when it affects people still in their youth. Such suffering is a visceral illustration of the passage of life (Becker 2000: 24-25), one that is taxing and distressing to witness, leading people to avoid watching such a morbid performance of human mortality.

Isolation & Invisibility

"I almost wish I had, like, a-… something more visible." – Emma

As briefly discussed in Chapter 1, many factors can contribute to feelings of invisibility and isolation on the part of the sufferer. These factors can include: how the condition is embodied; interpersonal dismissal of symptoms; a lack of a diagnosis; a sense of responsibility for

the illness; feminine roles; social acceptability of expressions of pain; and social scripts for physical illness. In this section, I summarise these factors and examine the consequences for the sufferer.

Sufferers of endometriosis on the Witsendo forum[3] discuss the feelings of isolation that come with endometriosis, particularly relating to an inability to communicate this with men as it is a 'women's issue' and the lack of external physical symptoms causing communication issues (Emad 2006: 201-202). Such communication issues can cause difficulties within interpersonal relationships, much like any lack of communication can. For example, Emma went so far as to say "I almost wish I had… something more visible" so that other people could understand her condition. Three of my participants would self-impose physical and social isolation on themselves when their symptoms were at their worst, either because they did not know how to explain or want to explain themselves and to avoid feeling isolated by others. On a more positive note, a couple of my participants found that their family members and friends would go out of their way to include them. This did not occur for a majority of the participants, but it was still heartening to hear that some friends and relatives do make the effort so that the sufferer of endometriosis does not feel isolated and invisible. Bella in particular spoke of how her family members were supportive of her taking naps at

[3] An endometriosis specific support forum

family gatherings when she was too fatigued, and friends would agree to have a night in instead of going out.

Another consequence of having to live with endometriosis that I would like to touch on is the impact of the feelings of isolation and invisibility on the mental health of sufferers of endometriosis. Two of my participants had experienced suicidal thoughts in direct relation to their condition, and others had experienced high levels of stress related to their experience of endometriosis. Women with endometriosis have mental and psychological health difficulties at a higher rate than other women without endometriosis (Culley et al. 2013: 632-633), which is likely a part of a syndemic phenomenon. The syndemic concept refers to the connection between two diseases where the two conditions interact to create a greater negative effect than the two could cause separately[4]. Griffith (2017) proposes that this relationship exists between endometriosis, stigma and stress. The stigmas are those around fertility issues, sexual intercourse in heterosexual relationships and menstruation, which will shortly be examined in more detail. Endometriosis can be debilitating, but going through such a condition with the perception that the suffer is alone and taboos in place that restrict communication make such a condition more arduous.

[4] On elaboration of this concept from a medical anthropology perspective see: Singer's *Introduction to Syndemics: A Systems Approach to Public and Community Health* (2009).

Feminine Social Taboos

> *"So, **anything** that had any sexual content, including my reproductive organs, was just sort of this Pandora's Box." – Bella*

Most women throughout the globe will learn one important rule when they learn about menstruation – the first rule of period club is you do not talk about period club. This is referred to as the 'etiquette of menstruation' (Culley et al. 2013: 631-632). Girls in Westernised cultures are usually taught that menstruation is a private occurrence that can be discussed with other girls and women but not with boys and men (Martin 1987: 102). The childhood experiences of most of my participants confirmed this principle, such as being able to discuss menstruation with their mothers, grandmothers and other women close to them but being actively discouraged from speaking of the same topics with their fathers and other men. Sometimes this extended to avoiding having a conversation about menstruation or sex in the presence of a man, whether he was an active participant in the conversation or not. Communicating about menstruation, but also sex, menopause and other topics perceived as female-centric are socially restricted by taboos.

To understand why this is so, it is helpful to examine Western perspectives of menstruation and female anatomy over the past few centuries. In *The Woman in the Body,* Martin explains the process by which menstruation has come to be seen as a pathology and also something abhorrent. From ancient times until the 18th century, menstruation was seen as a natural process of expulsion, or "flushing",

specifically of impurities and toxins. The process itself was seen as a positive event, as it kept the body “pure”. In the 19th century, the process of menstruation came to be viewed as something “impure”, paving the way for evidence of menstruation to be socially regulated (Martin 1987: 31-34). This idea of menstruation, or even the menstrual blood, as being impure is specific to the female reproductive system, not the process of purification via shedding itself. Even though the stomach lining goes through a similar process to the endometrium, menstruation is referred to in terms that denote wastefulness and destruction, while the sloughing of the stomach lining is referred to in terms associated with renewal and maintenance (Martin 1987: 50). This perspective has contributed greatly to the idea that menstruation is a negative phenomenon and a ‘women’s issue’ that should be kept private. In some regards, these attitudes have been useful to women over the centuries. Traditional taboos around menstruating women touching food products because they would spoil could have provided women with time off from domestic duties that they would otherwise have to complete every day (Martin 1987: 98).

Returning to modern ideas, Western cultures typically have three taboos around menstruation that have been carried over from North America: the concealment taboo; the activity taboo; and the communication taboo (Griffith 2017: 38). To simplify: there should be no evidence that a female is menstruating; a female cannot perform certain activities when she menstruates; and menstruation cannot be discussed openly. For my research participants, Mary and Bella, as they grew up

their conversations around menstruation were limited with other women and non-existent with boys and men

Similar taboos occur around the act of sex as well. While Western culture can seem sex-obsessed, it is still a difficult topic to broach as it is considered a private matter, making it difficult to talk about dyspareunia. Consequently, the statistics around the prevalence of dyspareunia are inconsistent. Dyspareunia, or pain during or after penetrative sex, is not uncommon for sufferers of endometriosis, which can cause difficulties with, or even the cessation of, romantic relationships (Graffia 2019: 25-26). Dyspareunia is also not listed as a symptom on the Australian or US government websites about endometriosis.

Several studies in different countries have shown that women at least have a socially indoctrinated belief that sex with a male partner is required of them, despite any pain they experience (Griffith 2017: 38-39), which is another consequence of the lack of discussions around sexual topics. Because women cannot talk about sex or related pain, they often have no idea of how to manage it or how to respond to it. Finally, a childless married woman in pro-natalist Westernised cultures is considered an example of 'failed femininity' and anathema to what is expected in a heterosexual marriage (Griffith 2017: 39).

Fertility

> *"I didn't realise how much I wanted kids until the doctor said it was going to be really, really hard to have kids of my own. And then I*

just had to take the morning off because I just sat in my car [laughing] and cried for thirty minutes. That's before I drove home. Um, and now, it feels…- I feel terrible every time I think it." – Ella

We have far more literature on the relationship between fertility and endometriosis than the effect of endometriosis on any other aspect of women's lives. Consequently, there is a lot of context to cover before examining how fertility complications can affect interpersonal relationships, such as romantic relationships, familial relationships and even friendships.

Medical texts often portray menstruation as a 'failure' of productivity, a manufacturer's inability to meet social demands. This lack of production is horrific and abhorrent (Martin 1987: 45), particularly in countries that have been affected by the industrial revolution that saw children become part of the work force and commodities. Menstruation is also a part of feminine identity and marks a clear transition between girlhood and womanhood (Martin 1987: 101). This perspective creates a situation where anyone, especially women, who cannot produce children will be viewed as having failed at a basic social requirement. Such a situation applies to women with endometriosis.

In the United States, two-thirds of women with endometriosis experience fertility problems (OASH 2019) and fertility difficulties are statistically more common for sufferers than for women without endometriosis (Culley et al. 2013: 633). I am choosing to use the term

‘fertility difficulties’ or ‘fertility complications’ because of the negative finality implied by the term ‘infertility’. Despite these statistics, medical representation of the endometriosis-fertility correlation may be overemphasising the negative. It may not be as difficult for endometriosis sufferers to get pregnant as many believe (Young *et al.* 2018: 437-439). Most medical literature also focusses on difficulty getting pregnant, rather than the possibility of miscarriage. Some hormones can contribute to early foetal loss, such as low oestradiol, high follicular progesterone or high cortisol and inflammation (Clancy 2009:147-148). Other physiological symptoms associated with these hormonal irregularities can increase the risk of losing a foetus, even as far through the pregnancy as the second term and pre-birth phases. Lack of inflammatory response in some situations can also increase risk of miscarriage (Clancy 2009:147-148). Both hormones and inflammatory responses are affected by endometriosis.

Invitro fertilisation (IVF) intervention has become quite common for endometriosis sufferers, while fertility treatments are not as often utilised (Culley et al. 2013: 633). This likely connects with the emphasis in medical literature and practice that is placed on achieving pregnancy in the quickest, most direct way, rather than treating the condition causing fertility problems (Becker 2000: 16). Medical treatments like IVF increase the sense that something is atypical or abnormal about the body (Becker 2000: 27). The medical definition of ‘infertility’ itself – the inability to become pregnant after twelve months of sex without the use of

contraceptives – is a negative one (see the words ‘inability’ and ‘without’) that emphasises that a non-pregnant person is abnormal when a couple have the intent to become pregnant (Becker 2000: 27).

Feminine Identity

> *“Whenever I brought [my fertility concerns] up, they’d just be like, “Oh, why are you thinking about kids? That’s forever away.” And, like, yeah, maybe it is. But… it wasn’t for me. Like, I had to start doing things right then to support my fertility. Like, I couldn’t be, “Oh, well, that’s a problem for twenty-seven-year-old me.” That was a problem for nineteen-year-old me.” – Lizzy*

The first social complication of fertility issues is the impact it has on identity. In the case of endometriosis, it can cause the sufferer to question their own identity and adequacy in feminine roles. It is still a prevalent attitude that people will have children by default and that women will become mothers at some point in their lives (Becker 2000: 29). Fertility complications force women who were taught this to reassess their own idea of what being a woman, mother, wife, partner or daughter means (Becker 2000: 2). For the sufferer, this can also lead to feelings of inadequacy, failure and a loss of self-esteem (Becker 2000: 39). For example, Amy was taught by her family that “as a woman, I should be able to have children”. She expressed a sense of grief over the potential loss of choice she now has over becoming a mother.

This sense of loss, while significant in and of itself, is compounded by the social expectation that women will become mothers. On the opposite side from Amy, Alice expressed a desire to not have children, partially because of her endometriosis but also for other reasons. She seemed minimally affected by the potential fertility issues and was hardly concerned. The women I spoke with who wanted children were concerned and the women who also came from families where having children was expected of them showed even greater levels of distress. This is an instance of how gender ideals and expectations can distort an individual's perception of their own body (Becker 2000: 40). Even if and when a person who has experienced fertility issues has a biological child, the changes to their sense of self will not revert back. Instead, their perception of themselves will remain altered, for better or worse (Becker 2000: 240).

Romance

> *"I can't consistently walk our dog every day. Um, so, while I might physically be able to, um… give birth, I don't know if I'd then be able to care for a kid." – Rebecca*

Next to the relationship with the self, fertility will logically affect the relationship the sufferer has with their romantic partner. It has been considered the sociocultural norm for several decades for heterosexual couples to have biological children in their 'middle years' (Becker 2000: 1). The only thing that has really changed is what age is considered 'middle years' and therefore appropriate to have children,

which has increased over time. In regards to fertility complications, emotional distress is a common conclusion in qualitative research for both the sufferer and their partner (Culley et al. 2013: 634). It is also common that psychological stress experienced by the sufferer that can manifest in worry, depression and feelings of inadequacy, can also impact their partner (Culley et al. 2013: 633). In Claire's case, her own depression caused by her condition led to emotional issues with her husband because he was unable to help her. While empathy is a positive natural quality for humans, taking on the sorrow and distress of others is a downside to empathy. Amy acknowledged that she felt like she would have failed her partner in some way if she could not "give him children". Lizzy had at one point offered a clean break-up and separation to her long-term partner on the chance that she could not have biological children. His response was to bring her information on adopting children the next morning. While fertility issues can distance a couple, it is also important to acknowledge that it is something the couple go through together and can strengthen their bond.

Another issue caused by suspected fertility complications is the woman becoming pregnant before the couple is truly ready to have a child. As Bella put it:

> "Like most women at twenty, when you're told you have endometriosis you probably have- start thinking about having a child."

In Young *et al.*'s study, some women with male partners tried to get pregnant before the age they would have preferred, due to assumed difficulties with becoming pregnant and were unconcerned about avoiding unwanted pregnancy (2018: 437-439). If a person believes they will struggle to have children, they will likely try to move up their own time-frame, either by trying to get pregnant before they are ready or at a younger age than they might have otherwise.

Family & Friends

"It's like jealousy and frustration, but not at the people, at yourself." – *Mary*

Having endometriosis also effects friendships and familial relationships. There is very limited literature on this subject and what exists is quite general, such as the social expectation of women becoming mothers (Becker 2000: 29). However, my research participants did disclose some incidents related to this. For example, the women who were raised in families that believed motherhood is the default for women, expressed to me some key issues they had with their families. Ella shared her experience of being pressured by her parents and other family members to "think of her parents" and give them grandchildren. Amy, with a similar upbringing as Ella's, is now greatly worried about the potential fertility issues that she might have because of her endometriosis. This gave the women a sense of guilt, helplessness and loss of control, either to their condition or to other people's desires.

The emotions experienced and their cause in relation to friendships were quite different to what the women felt regarding their families. Mary expressed feelings of resentment as well, but also of:

"…jealousy and frustration, but not at the people (having children), at yourself".

In relation to their friends, the emotional response was usually described as frustration, guilt, resentment and jealousy. Ella, after being told by her doctor that having biological children would be extremely difficult if not impossible, found herself resenting the fertility of her friends. Such frustration and resentment are likely rooted in the feeling of failure or malfunction of the body to produce children (Martin 1987: 45).

At the same time, however, friends and family can be extremely supportive during the ordeals created by fertility issues. This can range from declaring a friend with fertility issues as an 'aunt' or 'uncle' to their own children, or simply being empathetic to the frustration and distress that the sufferer can feel at a loved one's good fortune. It may not be the same as having a longed-for child but it can mitigate the feeling of loneliness created.

Finances

> *""Do we have enough for groceries and then medicine? Or do we just do groceries and… skip the medicine this week?" Which, not ideal for long-term treatment… [My family and friends] knew I was*

always good to pay [the money I borrowed] back to them. But, still, like, I hated that. Calling up and feeling like I was begging." – Ella

The average annual cost of endometriosis in Australia is estimated as $9.7 billion. Over 65 percent of this amount is related to loss of productivity for sufferers, and the rest relates to direct healthcare costs (Endometriosis Australia 2021). On an individual scale, endometriosis will cost each sufferer an average of $30,000 per year in healthcare and lost productivity (Endometriosis Australia 2021). The annual costs for endometriosis have nearly doubled in the past decade (Armour *et al.* 2019: 7-8), although this could be due to the increase in diagnoses and increased awareness of the disease. To summarise, endometriosis is an expensive condition, both through direct and indirect factors.

By direct factors, I am primarily referring to the cost of treatments and symptom management. Lifestyle changes through diet and exercise can be used by sufferers to help alleviate symptoms, as well as complementary and alternative medicine. Some women use this in tandem with biomedical approaches, while others seek non-biomedical help after negative experiences (Culley et al. 2013: 635). As Ella found out when she moved out of her parents' home, symptom management medication can be expensive in and of itself. Sometimes Ella needed to choose between getting medication by limiting her spending on groceries or going without pain medication so she could afford groceries. During her university studies, Claire often ate a single toasted sandwich per day, partially due to severe nausea but also because she could not afford both

medical intervention and food. She consequently had to discontinue her studies because she could not afford to not work. A lot of alternative medicines are also not covered by health insurance and are consequently more expensive than Western medical treatments.

A person's health is significantly impacted by their socioeconomic standing. Their household income determines what they can eat, how much time they have to exercise and what quality of healthcare they receive (Martin 1987: 6). Considering that most people will start experiencing symptoms of endometriosis in their adolescence, the sufferers must then rely on family members, typically parents, to help support them. Some of the participants, like Emma, Amy, Lizzy and Alice, have been supported financially by their family. Others, like Mary and Rebecca have made a point of not asking for financial assistance, either for equity reasons within the family or by personal choice. One of my participants even took up sex work during a period of unemployment so that she could afford to continue symptom-management treatments, rather than asking her family for assistance. She also sufferers from dyspareunia, which would have caused her pain with her work.

All of my participants showed varying levels of distaste towards asking for financial assistance from their family. This was typically described in one of three ways: refusal to seek financial assistance; only seeking financial assistance in desperate times and repaying any money borrowed when they could; or guilt over needing financial assistance. It would seem to make sense that a person would seek assistance and

support from the people who love them in times of need. However, my participants' responses do not support this. I would posit that the common distaste of seeking financial assistance stems from a cultural value of independence. This socialised requirement for individuality, independence and responsibility for one's own actions ties to neoliberal individualisation[5]. Seeking financial support indicates a lack of competence, ability and strength. It is essentially perceived as a weakness or failure.

Reproductive technologies, which many endometriosis sufferers will utilise at some point, are expensive (Becker 2000: 15). Bella and her partner were able to afford IVF to have their baby and consider themselves lucky to have been in that situation. Other common medical procedures like laparoscopies are very expensive and put people at the mercy of insurance companies. As Lizzy found out, insurance companies can claim a laparoscopic surgery to locate and remove endometriosis as a 'luxury' and force sufferers to pay the full amount out of pocket. Lizzy was fortunate that her parents helped her pay for the surgery, as, being twenty-two at the time, it would have "taken a big chunk of [her] life savings".

More indirectly, endometriosis causes a loss in income due to reduced productivity. It has been acknowledged intermittently over the past century that menstruation can be debilitating on its own. Hence the

[5] Jim McGuigan's *The Neoliberal Self* (2014) explains this concept on pages 232-239

use of ‘menstrual leave’ at different points in time (Martin 1987: 120). Lost productivity typically accounts for over 80 percent of total costs in endometriosis sufferers (Armour *et al.* 2019: 7-8). Chronic illnesses in general can cause social stigma due to how disruptive they can be to productivity. In societies and economic systems that value people based on their productivity, people with chronic illnesses that inhibit their capabilities will always lose. This can lead to sufferers of chronic illnesses, especially invisible ones, to act as if they are not sick, potentially risking their health (Graffia 2019: 30-32). Inhibited productivity and an inability to be in the workplace becomes more frequent and impacts overall costs of the disease as the pain level increases (Armour *et al.* 2019: 7-8). For example, Rebecca is unable to work normal fulltime hours at her place of employment due to her condition. She has also had to decrease her hours within the last twelve months as her symptoms worsened. Sufferers who are unable to attend work regularly due to endometriosis can miss out on promotions and even have employment terminated or resign due to stress (Armour *et al.* 2019: 7-8). Alex, Amy and Alice have all experienced periods of unemployment due to their illness and the endometriosis interfering with their reliability. All of these factors add to one another, causing the sufferer to have fewer financial resources, requiring them to seek alternative means of supporting themselves and hindering their ability to be independent.

Concluding Vignette: Floodgates

“So, how have you been?” the psychologist asked me.

I shrugged and gave a polite smile.

“Oh, you know,” I replied casually. “The pain’s been pretty bad but I haven’t taken a day off work or uni in months. So, I guess it’s all good.”

The – I suppose, *my* – psychologist nodded, one eyebrow subtly lifting.

This was the social script we always followed. She would ask, I would answer. It wasn’t the truth but it was a pretty enough lie. Afterall, I didn’t really need a psychologist. She just helped a bit.

My GP had recommended I see a psychologist, that maybe the pain I experienced was psychosomatic. The psychologist in front of me had agreed after three months that I was psychologically healthy but I thought having someone to talk to might help. Afterall, it’s not every day you find out you have a debilitating disease that you’ll never be rid of. If I wasn’t stressed already, that helpful prognosis definitely did the trick.

I guess I could have told my psychologist how badly I wanted to scream. How I could feel the sound rattling around in my ribcage, like a chained dragon, ready to burst out and rain hellfire on anyone in its path. I could tell her how angry I felt at my mum and my friends for telling me this was normal. How that anger felt like a demon trying to claw its way out of me. Maybe I should tell her how alone I feel? How I cried until my eyes stung whenever I had to cancel on my friends. Maybe she could help with how those ice-cold tears threatened to drown me.

But, no. That's not how things worked. I'd tried that before. I had opened up to some people. Some gave unhelpful, unsolicited advice. *Have you tried massage therapy? Maybe if you lost a bit of weight, you'd feel better. Oh, once you have a baby, you'll be fine! I heard yoga is great for endo!*

Other people were sympathetic and compassionate. They would try their best to understand and help me. Close friends would change plans last minute so we could stay home rather than go out to dinner. My partner would get me a heat pack after we had sex and rub my belly until I fell asleep. My cat would snuggle up and nap on my lap when I couldn't get out of bed. That might have been because of the heated blanket, though.

I couldn't make the words come out. I couldn't say how afraid I was, for my body, for my health, for my future. I didn't know the words for how I felt. My feelings were as destructive as water and my mouth was the floodgate. If I opened it too wide, everything would flow out. So, I kept it shut and talked about mundane, little things. That was safe. The chaos inside my body was not safe. It was a battlefield.

Chapter 3: Negotiating Interpersonal Relationships

> *"I think for [my partner], there's a little bit of… I'd almost say the word guilt, but not quite guilt. Um, particularly because I do get that pain after sex. Like, I think it kills him a little bit." – Lizzy*

This final chapter draws from my interview data addressing how the internalised and embodied experiences of women with endometriosis, as discussed in Chapter 1, and the social processes in their day to day lives, as discussed in Chapter 2, are both related to the way the sufferer navigates their interpersonal relationships. As the needs of women with endometriosis are different to people without the same experiences and condition, what the women want and require from their family, friends, partners, doctors and in their professional spaces must be negotiated. If the other party is not willing to compromise, or the woman with endometriosis is not able to verbalise her needs, her relationships and quality of life will suffer as a consequence.

Interrupted Quality of Life

> *"[Managing endometriosis is] definitely a daily activity. A little part-time job that none of us wanted." – Alex*

A significant concern vocalised by my participants was their interrupted quality of life. Such interruptions to 'normal' living standards came in many forms like being unable to work fulltime or having to rely on a partner to fulfil the domestic responsibilities. Alex referred to "endo" as an "unwanted part-time job" that she had to handle on top of her

existing responsibilities. In light of the fact that endometriosis affects quality of life regarding relationships, work, school, hobbies, exercise and child care (Endometriosis Australia 2021), it is unsurprising that women would view the experience of living with endometriosis as laborious. Depending on which study you read, approximately 16 to 61 percent of women sufferers experience difficulties with mobility, self-care and/or daily activities. Sleep, exercise and vitality are other common areas of difficulty. Between 23 to 71 percent of women with endometriosis have difficulty with household tasks (i.e., childcare, grocery shopping, cooking, cleaning) (Culley et al. 2013: 632-633). While it may not seem significant, mobility and being able-bodied are factors that are generally taken for granted. When these are no longer available to a person, all areas of their life can suffer including the fact it can erode one's self-esteem.

Westernised countries are also known to have a culture that prizes productivity and capitalises on the transition of human ability into labour, as Martin (1987) observed in her ethnography regarding ideas about productivity and motherhood. Despite the evident high amount of time and labour associated with motherhood, Martin noted this work is not necessarily deemed productive in the capitalist ideology of what constitutes work. In the capitalist conception of work, human bodies became analogous with machines (Martin 1987: 54). The expectation to function this way is then internalised by people and this is no less true among the kin of women with endometriosis. A person who struggles to be mobile cannot produce labour to acquire the required income for their

minimal quality of life. Moreover, the sufferers of endometriosis are not able to do the essential domestic work without significant challenge and reliance on others. Borrowing terms from Martin in *The Woman in the Body,* institutions focus on “quality control of life” rather than “quality of life” itself (Martin 1987: 148). The body must be controlled and tamed into a functional cog in the industrial machine that is society. Minimal support is offered when this is not physically possible. From my own observations and in the opinion of some of my research participants, some of these problems could be mitigated through earlier intervention or even by teaching adolescent girls how to maintain the health of their bodies and what is medically atypical. However, instead of learning from a young age how to maintain their health, adolescent girls are discouraged by the medical dismissal of their bodily pain and suffering when they seek help. This also results in the danger of a delayed diagnosis (Barnes 2020: 28-32).

It is clearly illogical to use a machine for a decade without maintaining it only to dispose of it when it inevitably breaks down. When we purchase cars, we do not use them for years on end, without taking them to a mechanic, and still expect them to work perfectly for a decade or more. Instead, regular maintenance and using the machine for what it is capable of can ensure the machine can be at its peak efficiency for longer and more valuable to the owner. The same can be said for human bodies, that the more we take care and maintain our bodies, the more protected our bodies will be from natural deterioration.

Natural versus Control

> *"To be honest, I've actually never tried to conceive naturally, because I was always told that I would… need support." – Bella*

This need for control and mastery over the natural reactions of the body is echoed both in how endometriosis is discussed and treated. Much of Scarry's (1985) analysis of the experience of "body in pain" speaks to how women with endometriosis articulated their experience of pain. For example, when a person is in pain, they can feel acted upon from the inside and outside, destroyed and damaged internally and externally all at once (Scarry 1985: 53). A key manifestation of the external element is reduced mobility, while an internal manifestation is the scarring caused by endometriosis. Pain caused by torture is produced, displayed and then translated into power (Scarry 1985: 28). However, when the pain originates inside the body, it is not displayed but controlled which is translated into a kind of power on the part of the sufferer. This could be seen in the way my participants spoke with pride about how they could ignore their symptoms and control their own external indicators. Lizzy talked about this as "training" herself to behave in a certain way so that she appeared healthy.

But it may also be the case that the relationship women have with their endometriosis pain is shaped by a dominant social belief that women are more emotional and therefore less in control of their bodies. As Martin (1987:171) noted, we are implicitly taught that the rational outranks the emotional. This can be observed in semantics and proverbs

(i.e., ‘mind over matter’ where the mind represents the logical, rational part of humans and the ‘matter’ aspect refers to our immediate emotional reaction). North American women experiencing menopause have been typically perceived as out of control and overly emotional, even if the menopausal woman is simply exhausted from fulfilling the socially ascribed role of the feminine (Martin 1987: 175; Lock 1994). Such preconceptions have been used to rationalise that the proper place of woman is in the home, rather than in the work force to justify stratified gender roles (Martin 1987: 17). Because endometriosis is considered a female or woman centred disorder, these stereotypes about women and their reaction to pain are evident in the way women with endometriosis and the associated suffering is socially perceived and medically managed. A woman with endometriosis is dismissed medically as hysterical because she cannot regulate, control and master her own ‘baseness’. Alex was told by a doctor that she was a “stressed out little lady”. Similarly, the manifestations of the disease were attributed to a lack of emotional regulation for Lizzy and Ella, as they were both sent for assessment by a psychologist. However, people with endometriosis show far more ‘mind over matter’ because they can ignore much of their own physical pain and continue on with their lives, despite the internal destruction that doing so can cause. Lizzy and Ella both related instances of experiencing this. For Lizzy, she continued through her day despite a severely enflamed appendix because she thought it was “just period pain”. Ella, while still an adolescent, continued to function and walk on a

broken leg because she had experienced worse pain with endometriosis. This is all because women are expected to live in two worlds at once: the first world being ruled by their hormonal cycles, which is used to dismiss them; the second world being that of industry and production (Martin 1987: 198) that is designed to diminish them to less than a man, even men within their own family unit.

Talking with Partners

> *"What [my husband and I] found most of all is that our relationship got stronger for it. Because we went through it together." – Claire*

As previously stated in Chapter 2, confession, or honesty, can be socially perceived as a betrayal of the self and of everything that comprises the self, like friends, family, country and cause (Scarry 1985: 29). In this case, talking to a partner about pain or other symptoms can be awkward, particularly with a partner of the opposite sex. If a person is having issues with their relationship, they may seek outside help, most likely from a friend, their mother, or possibly a sibling. Others may feel it is a breach of privacy and a betrayal of their partner to discuss specifics of their relationship. Sex is definitely one of the most heavily regulated topics in our culture and can severely impact on a romantic and/or sexual relationship.

Dysmenorrhea (painful menstruation), dyspareunia and chronic pelvic pain often persist despite/after surgical, hormonal and pain management treatments (O'Hara, Rowe & Fisher 2020: 5-6).

Dyspareunia and endometriosis also have a syndemic relationship (Griffith 2017: 38), where each influences the other, potentially making both significantly worse than either condition could be separately. Dyspareunia is not the only symptom that endometriosis sufferers have reported as affecting their romantic and sexual relationships. However, dyspareunia is not uncommon for sufferers of endometriosis, which can cause difficulties, or even the cessation, of romantic relationships (Graffia 2019: 25-26). Sometimes the symptoms can lead to difficulties, misunderstandings or even breakups (Culley et al. 2013: 633). As Alice related from previous sexual partners, she felt the need to lie or hide her discomfort because former partners would take her dyspareunia personally. However, romantic relationships can also serve as a support for the sufferer (Culley et al. 2013: 633), such as Claire's husband taking over most of the household responsibilities when Claire was unable to. The dyspareunia can be as debilitating as the abdominal pain, or even worse (Graffia 2019: 25-26) and can last for hours or days after the sex act takes place. Surprisingly, dyspareunia was not listed as a symptom on the Australian or US government websites about endometriosis. This speaks to how little sex is discussed and how regulated the topic is in Westernised cultures.

While there is not a consistent statistic for dyspareunia among endometriosis sufferers, preliminary studies show that it could be as few as 25 percent or as high as all girls and women who have endometriosis. The stage or severity of the endometriosis tissue does not correlate to

the amount of pain experienced during or after sex (Culley et al. 2013: 633). In one study, nearly 70 percent of women with endometriosis experienced pain for hours or even days after having sex (Culley et al. 2013: 633). Within the participants of this study, 7 out of 9 participants who have had sex, about 78 percent of the group, have experienced dyspareunia. The inconsistent statistics around dyspareunia could be related to how few people report the symptom. Some data sets suggest it is fairly common for women to not report dyspareunia to their doctor or other medical professionals, and medical professionals will often not ask their patients even when the patient has been diagnosed with endometriosis. Other data sets indicate that nearly half of endometriosis sufferers present to their doctors when their dyspareunia affects their quality of life (Culley et al. 2013: 633). This is likely also related to social taboos around discussing sex.

Responses to endometriosis-related dyspareunia include stopping sex when the pain becomes too much, changing positions or even enduring the pain out of a desire for an intimate relationship, freedom from the constraints of the condition or to become pregnant. Women who choose to avoid or limit their sexual activity due to dyspareunia often feel guilty or inadequate (Culley et al. 2013: 633). Claire showed some disappointment and mild frustration at her lack of ability to have sex comfortably with her husband. However, she also acknowledged that as a couple they had found other ways to maintain a level of intimacy and open affection in their relationship. Some sufferers

feel frustration at their inability to have sex comfortably, or even betrayed by their bodies at the pain they experience, while others can manage this specific set of symptoms depending on severity and their partner's willingness to cooperate (Graffia 2019: 25-26). Due to the associated pain and discomfort, sex is a topic that needs to be negotiated within a romantic relationship and can either cause the deterioration or strengthening of the relationship.

Dyspareunia is far from the only factor affecting a romantic relationship of women with endometriosis. However, it does exemplify a significant issue that mediates how the couple negotiates the endometriosis in their lives and potential outcomes of that relationship. Other problems for romantic relationships as mentioned by my participants include fertility complications, suspected or known, the division of housework and the lack of mobility. A lack of self-esteem caused by severe bloating, acne or weight-gain (Culley et al. 2013: 634) can also affect the couple, as the partner with endometriosis may feel inferior or undesirable to their partner. Rebecca explained how her sexual relationship with her husband could become strained due to disclosure of information about her body and condition:

> "I can tell he thinks I'm giving too much information and for him I think that's changed his perception of me over time, and- and, um- Also for him, I think it affects his sex drive as well."

Talking with Family & Friends

> *"I will say, "Oh, I'm just having a bad endo day." And [my family will] know exactly what that means. So, it's- it's really inclusive." – Bella*

> *"Some of my friends just don't- well actually, all of them don't really… get it. I don't think any of them get how difficult it's been and I don't think they know what the reality of it looks like." – Rebecca*

Unfortunately, I could find no literature that addresses the interaction between endometriosis and relationships with family members and friends beyond general relationships. Fortunately, my participants had much to say on the matter.

For my participants, family is one of the most important relationships to discuss. Most of the participants learnt about menstruation either directly or indirectly from their immediate family. More often than not, it was their mothers who educated them or provided direction towards other information sources, like books. Daughters will often learn what symptoms to expect with menstruation from their mother's or other female blood-relative's experience. This has a positive and negative side. On the positive side, other women, like Emma's mother, can be more sympathetic to their daughters because of the pain they themselves experience. Rebecca's mother educated herself about endometriosis once her daughter was diagnosed to better sympathise

with Rebecca. On the negative side though, younger women can be perceived as lazy or irresponsible if they cannot function due to pain. For example, Ella's family has a family history of endometriosis but Ella is still told not to use her endometriosis as an "excuse".

Friends are also important as they can be very supportive or they can contribute to feelings of isolation. Claire provided a perfect example of both. Claire has had a friend offer to be a surrogate for her if she is not able to carry a baby to term. This is a strong show of love and support, as surrogacy is a hotly debated topic and pregnancy comes with its own risks and potential complications as well. Alternately, Claire shared her experience of other friends having excluded her from their groups when Claire declined a few invitations to go out during a particularly unhealthy period of time. Claire's friends stopped inviting her out and started new group chats on social media that no longer included Claire. Ultimately, whether a friend or family member is supportive or excludes the sufferer is the result of social understanding. A person who has been taught to sympathise and acknowledge that everyone's capabilities are not the same will be more compassionate. This is the reason Alex was satisfied to have a large group of disabled friends because they could empathise with her. A person who has been taught that everyone functions relatively at the same level is less likely to be understanding and supportive.

Talking in Professional Settings

> *"I'm a high performer, and the [pain medication] was making me a little bit foggy, to the point where they were having performance conversations with me." – Bella*

Another key issue endometriosis sufferers face is trying to navigate their condition within a professional space. Illness interferes with work because an ill person cannot be as productive as a healthy person. Once again, acute illness is socially tolerable because it lasts for a finite amount of time, while chronic illness is infinite and hinders productivity (Graffia 2019: 30-32). Endometriosis is particularly unpredictable. This is part of the stigma around chronic illness because a person with a chronic medical condition is less productive than someone without (Graffia 2019: 30-32).

While little research has been conducted concerning the impact of having endometriosis on the friends and family of sufferers, some research exists regarding endometriosis' effect on employment. On average, it was concluded that 7.41 hours of work per week were missed when symptoms were at their worst, and that annually, 13 percent of work time (19.3 hours) was unattended due to symptoms (Culley et al. 2013: 633-634). About 23 to 66 percent of endometriosis sufferers report limited work capabilities due to symptoms, mostly pain. Among them 65 percent reported they experienced reduced effectiveness when they could attend work with symptoms, and over 80 percent were concerned about a lower quality in their work when symptoms were present (Culley et al. 2013:

633-634). In an example Bella gave, she was performance managed[6] in her workplace because of side effects from a pain medication she was taking so that she could attend work. Inhibited productivity and an inability to be in the workplace becomes more frequent over time as the condition worsens and impacts the overall cost of the disease as the pain level increases. Lost productivity typically accounts for over 80 percent of total costs in endometriosis sufferers (Armour *et al.* 2019: 7-8), significantly affecting both workplace reputation and income.

Women who are unable to attend work regularly due to endometriosis can miss out on promotions and even have employment terminated or resign due to stress (Armour *et al.* 2019: 7-8). They are also less likely to discuss their condition with their employer, especially male employers, despite a need for professional support. Mary acknowledged that her reason for hesitancy in such cases was due to the subject being "embarrassing" to her. A significant reason behind this decision were unpredictable responses (i.e., some employers or managers have been supportive and sympathetic, while others dismissed or trivialised symptoms) (Culley et al. 2013: 633-634).

There is also the impact of endometriosis on education to consider. Several of my participants related experiences in this area. After Alice started experiencing symptoms during high school, she had

[6] Performance management is common in the Australian Public Service, where an employee's professional performance is discussed with a manager to improve work-related performance issues, ranging from attitude to quality of work.

to drop out because she could not attend school on a regular basis. Ella had to start doing half-days during Year 10 because her symptoms would interfere with her completing a whole day. What little research has been conducted on the impact of endometriosis on education is mixed. Some studies claim only a minority of women found their condition interfered with their studies, grades and their ability to complete their education, while other studies concluded the percentage was significant (Culley et al. 2013: 633-634).

Talking with Doctors

> *"You honestly feel like a pinball. You just sort of, like… get pinged around and you're sore and you just… I honestly thought I was crazy." – Bella*

To reiterate a point from Chapter 1, biomedicine's conception of human biology and disease has historically been based on studies and understanding of men's anatomy and physiology that clearly cannot reflect unique aspects of women's biology and reproductive physiology. Moreover, depending on their biological sex, a person may have a higher risk for some diseases, or a lower risk for others (Kupiec 2019: 86-88). This male-centric focus in medicine likely contributed to the limited or complete lack of knowledge that doctors have about endometriosis. Emma related an experience where her doctor asked Emma if the new symptom she was concerned about could be caused by endometriosis. You would typically expect the patient to ask the doctor that question, not the other way around.

Endometriosis is often treated as being a “mechanical concept of fertility” and medical professionals often treat the fertility complications as the primary – even sometimes, the only – concern of endometriosis (Emad 2006: 202-203). This may be why some doctors suggest getting pregnant as a ‘treatment’ for endometriosis (Young *et al.* 2018: 437-439). Misdiagnosis is common, with irritable bowel syndrome and pelvic inflammatory disease being the most common (Culley et al. 2013: 632).

Often little is asked about the pain by doctors, beyond its location in the body and the level of the pain, even though the duration, intensity and impact of the pain are of major concern to patients. Some of the common experiences of endometriosis patients regarding doctors are: anger at lack of effective treatment; and more positive responses to surgeries than drug treatments (Culley et al. 2013: 635). Rebecca discussed a period of time where she did not see doctors about her endometriosis because she expected to be dismissed as she had previously been. Such a reaction is not unheard of. Most endometriosis sufferers have a negative association with treatment so they will often try to reduce any time spent in a hospital by delaying admitting themselves to the emergency room (Martin 1987: 140). Endometriosis sufferers may also go on for months or years where they avoid doctors and do not get treatment.

Nurses working in the oncology unit, where endometriosis patients were sometimes placed for a time after major surgeries, typically found themselves less tolerant and concerned for the endometriosis patients,

as they were ‘not dying’ from their disease, while cancer is considered more likely to kill you. As such, the cancer patients were treated as a higher priority by nurses, as they perceived them as having a greater claim to medical care (Bach, Risoer, Forman & Seibaek 2016: 5-7). This is an interesting attitude to have considering that a secondary condition contributed to by endometriosis is cancer (Nothnick 2001: 229). Some nurses admitted being “suspicious” that there was an ulterior motive behind pain complaints from endometriosis patients (Bach, Risoer, Forman & Seibaek 2016: 5-7). Nurses categorised endometriosis patients into “easy”, “resilient” and “heavy/complex” based on their pain level, likelihood to complain and make demands and whether they trusted medical systems. Some patients, often the ones categorised as “heavy/complex” felt threatened with regards to their physical health, romantic relationship, children and employment (Bach, Risoer, Forman & Seibaek 2016: 5-7). Such mistrust of endometriosis patients by medical practitioners, and vice versa, is likely a significant contributing factor to why so many women with endometriosis rely on self-study to learn about their condition.

Self-Study versus Medical Information

> *“I felt like I was… always working really hard to convince them that there was something wrong.” – Claire*

Sufferers often seek information from online forums for people with endometriosis about treatments, herbs and just to not feel isolated and alone in their experience (Emad 2006: 202-203), as most of my

participants have done themselves. In light of negative experience, sufferers of endometriosis will question the competency of medical professionals, critique the lack of knowledge of their condition in medical discourse and educate themselves and one another in treatment and coping methods (Whelan 2007: 962-965). The near obsession with self-education is a reaction to invalidating or disillusioning experiences and a belief that the sufferer needs to do extensive research to have their opinion taken seriously (Whelan 2007: 962-965).

When talking to doctors, self-education was nearly treated like a weapon by the women I spoke to. Alex referred to the experience as akin to being a lawyer arguing a case in court. Rebecca created a cheat-sheet of medications, treatments and any alternative therapies she has tried, to hand to new doctors. She also consciously chose her words so as not to threaten the doctor's authority with her own education about her endometriosis, preserving the default hierarchy between patient and physician.

> "I used to also prep… a bit of an intro spiel so that I'd make them comfortable to, like- "I- I know just enough about what I think I have but not more than you! So, you're still the expert! Um, and these are the things I think I want from you, but I'll defer to your, you know, like… medical knowledge." All that sort of thing to try and put them at ease."

There is also a problem with finding a definition of endometriosis. As my own research showed, many people who are given a suspected or surgical diagnosis of endometriosis do not receive a definition of the condition from their doctors. All of my participants credited their understanding of the disease to self-study, rather than any explanation from a medical professional. At least one of Seear's (2014) interviewees asked her, the researcher, to explain endometriosis, as the interviewee, known as Wanda, was uncertain about what the condition actually was, despite being treated for approximately a decade. The presence of endometriosis has also been linked with other conditions and medical complications such as: allergies; asthma; chemical sensitivities; autoimmune conditions like multiple sclerosis (MS), lupus, rheumatoid arthritis, Crohn's disease, psoriasis and types of hypothyroidism; chronic fatigue syndrome; fibromyalgia; and some cancers, namely ovarian and breast cancers (OASH 2019; Nothnick 2001: 229). While some of my participants have related conditions, no doctor warned them about the possibility of related illnesses when they were diagnosed, leaving them in the dark as to what to expect or be vigilant for.

Concluding Vignette: Artist

It took me years to learn how to live with my condition. How to let it be a part of my life without consuming it. How to tell my friends I couldn't have a pizza and movie night with them. How to tell my family I couldn't get out of bed, let alone go to the family barbecue on Easter Sunday.

How to explain to my boss that some days I had to work from home. How to let my partner know that maybe I couldn't have children naturally.

I learned to take on the role of ambassador, of diplomat and of warrior. I had to find a way to explain my boundaries, my borders and what I was and was not willing to let happen in my territory. I had to negotiate and compromise where I could. To let the little things go, so the big things stood strong. I had to fight for what I needed and my quality of life, even when I was too broken and bloodied to stand.

Some family members were only in the background of the painting of my life now. They were there but I couldn't make out their faces because they were rarely around. Some friends had walked out of the frame. There was a space where they once stood but other friends had stepped into the foreground so the picture didn't feel so empty. Partners had come in and out of the picture, leaving behind blurred watercolour on their way. I had lost jobs, opportunities and dreams. There were only a few stars in the sky but the ones that remained shined brightly.

There was so much red to my canvas, so much loss, grief and pain. But there was also blue in the calming sky, green in the vitality of the flora, pink in the faces of my loved ones. There was shadow and there was light. It was a life of dismissal and destruction, power and perseverance. I would have painted it differently if I could but I played with the hand I was given.

Concluding Statement

"If one in ten people were born with something as debilitating as endo but it didn't involve a uterus, we'd be talking about it." - Lizzy

Centuries ago, what we now know as obstetrics and gynaecology was the domain of women. Midwives saw to pregnant and labouring women until the invention of forceps, which were created so that men could usurp the role of midwife, traditionally held by women (Martin 1987: 143). Birthing, and feminine health in general, have now become the domain of institutions and men, where once it was the domain of community and women. The role of self-education is a social way of reclaiming the power that was once the sole domain of women in many cultures.

Due to social and cultural attitudes, particularly medical dismissal and the dismissal of symptoms (Cox *et al.* 2003: 8), and the implication of female hysteria by medical professionals (Graffia 2019: 30-32; Day 2021) the way women with endometriosis embody their experience can be detrimental to their intrapersonal and interpersonal relationships. A diagnosis of endometriosis is entangled with stigma and stress in a syndemic manner (Griffith 2017: 38) and a lack of a diagnosis creates a form of social purgatory, due in part to a social emphasis placed on productivity, such as what Martin and Becker discussed in their respective ethnographies. Whether undiagnosed or diagnosed with endometriosis, the sufferer is required to navigate their disease, taking

responsibility for their ability to function on a day-to-day basis. Women living with endometriosis are expected to sacrifice their long-term health for short-term productivity, such as taking hormonal treatments in the form of contraceptive which can damage the person's health later in life (Culley et al. 2013: 635). These intrapersonal aspects of the condition, the aspects that most directly concern the sufferer, are compounded by the interpersonal effects of endometriosis. The sufferer must learn to modulate their expression in order to be socially acceptable and palatable to those around them. Pain experienced by the self or by another is extremely uncomfortable, as it can makes us feel helpless or cause us to face our own fragility and mortality (Scarry 1985). The social scripts we were taught to comfort those in pain are more appropriate to acute pain, rather than chronic. The words of condolence we were taught to fill the awkward silence left by illness and suffering are then no longer applicable, creating an awkwardness between the sufferer and the bystander. This lack of a fitting response can lead to the sufferer feeling isolated, invisible and ignored (Emad 2006: 201-202). This is compounded further by medical dismissal, lack of social understanding and communication difficulties, forming a detrimental cycle. Endometriosis and the social expectations placed on women (i.e., a career, motherhood, sex with a partner) are not always compatible with endometriosis. Thus, the idea of the sufferer's own femininity comes into question, similar to Becker's conclusions regarding women with fertility complications (2000: 2). This particularly effects their sense of self as a

mother, partner, friend and member of a family. Endometriosis also has an impact of finances, both through direct expenses and lowered ability for income production (Endometriosis Australia 2021) This can further strain the relationships the sufferer has with their partner, family and friends, causing the sufferer to be dependent for financial support or sacrificing desires or necessities in favour of health. All these aspects of endometriosis culminate in an interrupted quality of life (Endometriosis Australia 2021; Culley et al. 2013), a socially reinforced need to control the body and the self (Martin 1987), and difficulty navigating romantic, familial, friendship, professional and medical relationships. These relationships become strained under the pressure of endometriosis and the negative affects of endometriosis on these relationships were of extreme concern to my participants and to others I have spoken to with experience of endometriosis, either in a primary or secondary capacity.

There are still some key areas of improvement, both from a medical and anthropological perspective. Medical research has begun to discover genetic commonalities between endometriosis sufferers, as well as genetic commonalities that endometriosis shares with other medical conditions, such as ovarian and breast cancer (Pearce *et al.* 2012: 389-393). However, the process of endometriosis and how the endometrial tissue spreads throughout the body is unknown. There are no endometriosis-specific treatments and few doctors who specialise in the treatment of the condition. From an anthropological or even sociological perspective, very little is known about the experience of the condition. As

previously mentioned, no acknowledgement of the impact of endometriosis on relationships with friends and family exists, except observations about interpersonal relationships in general. The impact of studies, schooling and education is limited. The research regarding the effects on romantic relationships primarily concerns fertility and sex, less so the domestic inequality, financial dependence and responsibility and unequal assignment of shared tasks. These topics were of concern to my participants in their lives and should be researched to inform policy and social understanding of the lived experience of endometriosis.

While it was a small percentage of my participants, some related experiences that show a sociocultural attitude shift in perceptions of girls' and women's health. Bella remarked that while she knew very little about menstruation when she was a girl, her friends' daughters who are not yet teenagers know the ins and outs. I have noticed in my own family and the people around me that slowly, generation by generation, topics of menstruation and the mechanics of sex are becoming more openly discussed. Lizzy herself is quite open about the details of her 'feminine' health and seemed eager and happy to discuss it, despite surface-level conversations being the usual type of communication within her family. Such attitudes and changes in behaviour indicate a subtle reclamation of autonomy and sovereignty over the body through the rejection of assigned social roles (Martin 1987: 200). Even men who were socialised to perceive menstruation and related biological processes as 'gross' are slowly opening their awareness to the concerns of others. Mary related

the perfect example where her husband, one such person, has wondered about the lack of medical intervention and awareness when endometriosis is so prevalent a condition. Such attitude shifts are what we need to uproot and rewrite the sociocultural factors that have prevented endometriosis sufferers from being treated. As Lizzy said:

> “If one in ten people were born with something as debilitating as endo but it didn’t involve a uterus, we’d be talking about it.”

On a related note, Becker wrote in *The Elusive Embryo* that:

> “[People with fertility complications] seeing themselves as not fitting [traditional] ideals, they question the ideals, often for the first time. Inevitably, they find the ideals wanting. Not only do they find that cultural ideals are often narrowly and rigidly defined, but they also observe that those ideals often have little connection to their lives.” (2000: 238)

When a person no longer fits the role that they have believed they were meant to fill, they will question where they fit in the world, as demonstrated by my participants. If they can no longer be a parent, what are they? If they can no longer work in their chosen career, what can they do? The answer is at once simple and confronting – they have to change the way they perceive themselves. In the case of endometriosis, the whole concept of the self is turned on its head and shaken, until the person no longer recognises themselves. A person can then choose to either reshape themselves to fit the culture or rebel and resist what they

previously believed (Becker 2000: 238). People want to fit into the world (Becker 2000: 250). No one wishes to truly be an outcast but if the world has no room for someone, that is how revolutionaries are born, by carving out their own space. If a person is dismissed by their social sphere, told they are hysterical and made to feel at fault for their own misfortune, they can either fragment or resist. They can become invisible, isolated and refuse to acknowledge or express their own experience, or they can form a new social group with others who understand and sympathise with them.

Endometriosis is a multi-faceted disease. It is torturous. It is internal destruction compounded by external denial. The body deteriorates, the mind shatters and the soul fragments. To be socially acceptable in our current world with endometriosis, and no doubt with other chronic illnesses, is to accept defeat and dehumanisation. It is to be a “child of the system” (Bella). It is to live with the knowledge that no one else “really knows the reality of it” (Rebecca). It is to feel an “encompassing mass” within your own body that feels alien (Amy). It is to acknowledge that you do not “have a choice in that anymore” (Ella). It is to know that even your “nice, white-collar job [wouldn’t] pay for the amount of treatment” you need (Alex). It is to feel “frustration… at yourself” for something out of your control (Mary). It is to constantly need to “[relax your] expectations” (Emma). It is to remind other people and yourself that “you’re a human” (Alice). It is “to deal with a loss [you]

haven't even had yet" (Lizzy). It is to contemplate "just stopping [life]" (Claire).

The interpersonal and intrapersonal spheres of human existence are not extricable, as are the individual and their sociocultural context (Hirschfeld 1988: 613; Ushioda 2009: 215). They cannot be separated into parts. If one person is suffering, the people who love them will suffer. If a person cannot fulfil their assigned responsibilities, someone else will have to complete the tasks. There is a necessity to understand the internalised sociocultural teachings that result in our behaviours so the consequent external attitudes we show to ourselves and others can be positive and beneficial. Yes, social roles are necessary for society to function but the continuation of archaic division between men and women and the masculine and feminine roles is detrimental to health, as evidenced by the experience of women living with endometriosis. To run an efficient socio-economic machine, the focus should be placed on the utilisation of an individual's capabilities notwithstanding their limitations, not forcing every person to fit a ready-made role. Our relationships with others can validate us, fragment us, support us and suffocate us. It simply comes down to an individual's choice to question their socialised beliefs or accept them.

Appendix

Table 1: Age at Significant Events

	At Present	*At First Symptoms*	*At 'Peak' Symptoms*	*At Diagnosis*	*Interval Between First Symptom and Diagnosis*	*Interval Between 'Peak' and Diagnosis*
Alex	32	~12-13	16	27	14	11
Alice	24	16	16	17	1	1
Amy	24	15	16	[19]	[4]	[3]
Bella	27	11	14	20-21	10	7
Claire	26	~12-13	15	25	12	10
Ella	30	~12-13	~12-13	24	11	11
Emma	25	12	12?	19	7	7
Lizzy	24	11	12	22	11	10
Mary	32	~13	~17	~30	27	13
Rebecca	33	~13	~16 (& ~30)	32	19	17
Mean	27.7	~13	~15	24 [24]	12 [12]	10 [9]
Median	24	13	16	N/A [19]	11	7, 10, 11

[ ] = Suspected diagnosis/Including suspected diagnosis

Table 2: Sociocultural Context

	Confirmed Diagnosis	*Heritage*	*Socio-Cultural Upbringing Around Menstruation*	*Socio-Cultural Upbringing Around Sex*
Alex	Yes	Anglo-Australian	Open	Open
Alice	Yes	English & Scottish	Open with women but grew up in a female dominated household.	Unavailable parents, used internet for information.
Amy	No	Anglo-Australian	Open yet judgmental, she didn't want to discuss things with her family out of embarrassment.	Sex until marriage for women, open topic for men.
Bella	Yes	Australian	Didn't know what a period was when hers started at age 11.	Was taken to a night course to learn about sex instead of talking about it.
Claire	Yes	Australian	Given a gift from her mum at first period but told that pain was normal; dad wasn't very open when she was a teenager Catholic school – cramping seen as an excuse to get out of PE.	Didn't really talk to parents about it.

Ella	Yes - Ultrasound	Various	Mostly books supplied by mum with some conversation.	Described as 'strict Christian, English' upbringing.
Emma	Yes	English	Views lack of openness as her own preference to not discuss her problems.	Never discussed with dad but topic is becoming more open with mum.
Lizzy	Yes	Australian	Mum, maternal grandmother, partner's mum, open topic of conversation; dad, paternal grandmother, closed topic of conversation.	Tended to talk with older female friends when she was a teen.
Mary	Yes	English & German	Doesn't remember having conversations about it with mum. Sex-ed in school was a video.	Didn't have 'the talk'. Says she probably could have asked her mum questions but didn't.
Rebecca	Yes	Dutch & Dutch Indonesian	Open with her mum. Medical context with her dad.	Open with her mum, not really with dad.
Summary	Yes: 9/10 No: 1/10	Most common is Anglo-Australian		

Table 3: Relationships of Concern

	Romantic/ Sexual	*Familial*	*Friendships*	*Professional*	*Medical Practitioners*
Alex	Yes	Yes	Yes	Yes	Yes
Alice	Yes	Yes	Yes	Yes	Yes
Amy	Yes	Yes	Yes	Yes	Yes
Bella	Yes	Yes	Yes	Yes	Yes
Claire	Yes	Yes	Yes	Yes	Yes
Ella	No	No	Yes	Yes	Yes
Emma	Yes	Yes	Yes	Yes	Yes
Lizzy	Yes	Yes	No	No	Yes
Mary	Yes	No	No	Yes	No
Rebecca	Yes	No	Yes	Yes	Yes
Summary	Yes: 9/10 No: 1/10	Yes: 7/10 No: 3/10	Yes: 8/10 No: 2/10	Yes: 9/10 No: 1/10	Yes: 9/10 No: 1/10

Table 4: Symptoms

	Abdominal Pain	*Spotting*	*Bloating*	*Constipation*	*Cramping*
Alex	3	6	2	3	3
Alice	8	3	5	6	6
Amy	8	8	6	8	8
Bella	7	-----	3	3	7
Claire	7-10	-----	1-3	6	9-10
Ella	7	1	1	-----	7
Emma	9	-----	6	3	9
Lizzy	4	-----	2	3	4
Mary	7	1	3	1	7

Rebecca	3-8	1	2-8	-----	5
Mean	6.7	3.3	3.5	4.1	6.6
	Diarrhea	*Dysmenorrhea*	*Dyspareunia*	*Fatigue*	*Fertility (Concern*
Alex	9	7	3	5	-----
Alice	6	9	9	10	-----
Amy	6	8	9	7	-----
Bella	3	8-9	5	5	Low
Claire	1	9-10	4-6	8	Low
Ella	7	7	-----	3	High
Emma	3	9-10	-----	4	-----
Lizzy	2	5	3	-----	-----
Mary	1	8	-----	-----	High
Rebecca	1-9	5-7	5	1-10	-----
Mean	4.3	7.8	5.6	5.9	Mid
	Heavy Periods	*Inflammation*	*Lethargy*	*Nausea*	
Alex	6	5	5	6	
Alice	-----	5	6	10	
Amy	6	6	7	7	
Bella	-----	6	3	-----	
Claire	7	6-10	7-8	8-9	
Ella	3	-----	3	3	
Emma	-----	4	4	4	
Lizzy	2	-----	-----	4	
Mary	4	2	1	-----	
Rebecca	-----	2	7	-----	
Mean	4.7	4.8	4.8	6.1	

References

Armour, M., Lawson, K., Wood, A., Smith, C. A. & Abbott, J. 2019. The Cost of Illness and Economic Burden of Endometriosis and Chronic Pelvic Pain in Australia: A National Online Survey. *Plos One,* 14(10): 1-12.

Bach, A. M., Risoer, M. B., Forman, A. & Seibaek, L. 2016. Practices and Attitudes Concerning Endometriosis Among Nurses Specialising in Gynaecology. *Global Qualitative Nursing Research,* 3: 1-12.

Barnes, S. A. 2020. Endometriosis: Disparities in Diagnosis and Treatment. *University of South Alabama,* Thesis(May): 1-43.

Becker, G. 2000. *The Elusive Embryo: How Women and Men Approach New Reproductive Technologies.* 1st Ed. Berkley, U.S.A.: University of California Press.

Clancy, K. B. H. 2009. Reproductive Ecology and the Endometrium: Physiology, Variation and New Directions. *Supplement: Yearbook of Physical Anthropology,* 140(S49): 137-154.

Cox, H., Henderson, L., Andersen, N., Cagliarini, G. & Chantal, S. 2003. Focus Group Study of Endometriosis: Struggle, Loss and the Medical Merry-Go-Round. *International Journal of Nursing Practice,* 9(1): 2-9.

Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgarten, M. & Raine-Fenning, N. 2013. The Social and Psychological Impact of

Endometriosis on Women's Lives: A Critical Narrative Review. *Human Reproduction Update,* 19(6): 625-639.

Dawney, L. & Huzar, T. J. 2019. Introduction: The Legacies and Limits of *The Body in Pain*. *Body & Society,* 25(3): 3-21.

Day, A. 2012. "Yeah, But Can It Kill You?": Understanding Endometriosis in the Atlanta Area. *ScholarWorks @ Georgia State University,* Thesis(Autumn): 1-72.

Downham Moore, A., Towghi, F., Ashford, H. R., Dune, T. & Pithavadian, R. 2021. The Global Proliferation of Radical Gynaecological Surgeries: A History of the Present. *History and Anthropology,* [unknown volume and issue]: 1-25.

Edcraft. 2021. *Emotional Self-Regulation for Children.* Edcraft Blog. [last viewed 7 August 2022]. Available from Emotional Regulation for Kids: How to Help Children Control Their Emotions (edcraft.io).

Emad, M. C. 2006. At WITSENDO: Communal Disembodiment Through Storytelling in Women's Experiences with Endometriosis. *Women's Studies International Forum,* 29(2): 197-207.

Endometriosis Australia. 2020. *What is Endometriosis?* Endometriosis Australia. [last accessed 7 August 2021]. Available from Endometriosis Australia | Home.

Gotter, A. 2018. *What are the side effects of birth control pills?* Healthline. [Last viewed 6 August 2022]. Available from Birth Control Side Effects: Risks and Long-Term Safety of the Pill (healthline.com).

Graffia, B. 2019. Endometriosis: The Psychosocial and Emotional Lived Experience of College-Aged Women. *Capstone Projects,* 5(1): 1-40.

Griffith, V. A. S. 2017. *[Chapter 2] The Syndemic of Endometriosis, Stress & Stigma* In *Stigma Syndemics: New Directions in Biosocial Health.* 1st Ed. London, England: Lexington Books.

Hirschfeld, L. A. 1988. On Acquiring Social Categories: Cognitive Development and Anthropological Wisdom. *Man,* 23(4): 611-638.

Infocus. 2019. *Endometriosis in Australia: Prevalence and Hospitalisations.* Australian Government: Australian Institute of Health & Welfare. [last accessed 11 August 2021]. Available from Endometriosis in Australia: prevalence and hospitalisations (full publication;1Aug2019Edition)(AIHW)

Kupiec, K. 2019. Missing from Research: Exposing the Deficit in Knowledge and Research of Endometriosis and Women's Health. *Dissenting Voices,* 8(1): 79-92.

Lock, M. 1994. Menopause in Cultural Context. *Experimental Gerontology,* 29(3-4): 307-317.

Lock, M. M. & Nguyen, V-K. 2018. *An Anthropology of Biomedicine.* 2nd ed. Wiley Online Library: Wiley Blackwell.

Manderson, L., Warren, N. & Markovic, M. 2018. Circuit Breaking: Pathways of Treatment Seeking for Women with Endometriosis in Australia. *Qualitative Health Research,* 18(4): 522-534.

Martin, E. 1987. *The Woman in the Body: A Cultural Analysis of Reproduction.* 1st Ed. Boston, U.S.A.: Beacon Press

Nezhat, C., Nezhat, F. & Nezhat, C. 2012. Endometriosis: Ancient Disease, Ancient Treatments. *Fertility & Sterility,* 98(65): 1-62.

Nothnick, W. B. 2001. Treating Endometriosis as an Autoimmune Disease. *Fertility and Sterility,* 76(2): 223-231.

O'Hara, R., Rowe, H. & Fisher, J. 2020. Managing Endometriosis: A Cross-Sectional Survey of Women in Australia. *Journal of Psychosomatic Obstetrics & Gynaecology,* pp. 1-8.

OASH. 2019. *Endometriosis.* U.S. Department of Health & Human Services: Office on Women's Health. [last accessed 7 August 2012]. Available from Endometriosis | Office on Women's Health (womenshealth.gov).

Pearce, C. L., Templeman, C., Rossing, M. A., Lee, A., Near, A. M., Webb, P. M., Nagle, C. M., Doherty, J. A., Cushing-Haugen, C. L., Wicklund, C. G., Chang-Claude, J., Hein, R., Lurie, G., Wilkens, L. R., Carney, M. E., Goodman, M. T., Moysich, K., Kjaer, S. K., Hogdall, E., Jensen, A., Goode, E. L., Fridley, B. L., Larson, M. C., Schildkraut, J. M., Palmieri, R. T., Cramer, D. W., Terry, C. L., Vitonis, A. F., Titus, L. J.,

Ziogas, A., Brewster, W., Anton-Culver, H., Gentry-Maharaj, A., Ramus, S. J., Anderson, A. R., Brueggmann, D., Fasching, P. A., Gayther, S. A., Huntsman, D. G., Menon, U., Ness, R. B., Pike, M. C., Risch, H., Wu, A. H. & Berchuck, A. 2012. Association Between Endometriosis and Risk of Histological Subtypes of Ovarian Cancer: A Pooled Analysis of Case-Control Studies. *The Lancet Oncology,* 13(4): 385-394.

Perkins Gilman, C. 2011. *The Man-Made World: or, Our Androcentric Culture.* Online ed. Google Books: The Floating Press.

Rabinow, P. 2017. *[Ch. 5] Artificiality and Enlightenment: From Sociobiology to Biosociality* In *The Ethics of Biotechnology.* 1st ed. London, England. Routledge.

Rosenberg, C. E. 2002. The Tyranny of Diagnosis: Specific Entities and Individual Experience. *The Milbank Quarterly,* 80(2): 237-260.

Scarry, E. 1985. *The Body in Pain: The Making and Unmaking of the World.* 1st Ed. Oxford, England: Oxford University Press.

Seear, K. 2014. *The Makings of a Modern Epidemic: Endometriosis, Gender & Politics.* 1st Ed. London, England: Routledge.

Singer, M. 2009. *Introduction to Syndemics: A Systems Approach to Public and Community Health*. San Francisco, United States: Jossey-Bass.

Stout, N. 2014. *After Love: Queer Intimacy and Erotic Economies in Post-Soviet Cuba*. 1st ed. Durham, United States: Duke University Press.

Ushioda, E. 2009. *[Ch. 10] A Person-in-Context Relational View of Emergent Motivation, Self and Identity* In *Motivation, Language Identity and the L2 Self.* 1st ed. Bristol, England: Multilingual Matters.

Weaver, L. J. 2016. Transactions in Suffering: Mothers, Daughters, and Chronic Disease Comorbidities in New Delhi, India. *Medical Anthropology Quarterly: International Journal for the Analysis of Health,* 30(4): 498-514.

Whelan, E. 2007. 'No One Agrees Except for Those of Us Who Have It': Endometriosis Patients as an Epistemological Community. *Sociology of Health & Illness,* 29(7): 957-982.

Young, K., Kirkman, M., Holton, S., Rowe, H. & Fisher, J. 2018. Fertility Experiences in Women Reporting Endometriosis: Findings from the Understanding Fertility Management in Contemporary Australia Survey. *The European Journal of Contraception & Reproductive Health Care,* 23(6): 434-440.