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“Am I ‘Normal’?”: Adolescents’ Awareness and Experiences of Endometriosis and Menstruation

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A thesis submitted in partial fulfilment of the requirements of Birmingham City University for the degree of Doctor of Philosophy.

The Faculty of Health, Education, and Life Sciences

November 2022

Acknowledgements

The completion of this thesis was dependent on the support of so many people. Firstly, I want to express gratitude to my research participants. I want to thank the many schoolgirls who completed my survey, and the teachers/school staff who enabled access, and facilitated data collection. To the adolescents and young women with endometriosis who took part in the interviews, I wish to say a huge thank you. You not only gave up your time, but you shared your personal stories with me, and I hope I have done them justice in writing this thesis. Thank you also to Endometriosis UK, who enabled access to such participants, by promoting my research through your support platforms.

I will forever be indebted to my supervisors, who have supported me at every step of the way. You've had my back through it all, the laughter, and the tears, and I will be eternally grateful that you encouraged me to keep going, especially when I doubted myself.

To my fellow PhD Students, particularly those who resided with me in the 'Attic' for most of the journey. Thank you for supporting me, reading my work, making me laugh, and listening to me rant. I started the journey with you, but you've all graduated now, and seeing your successes have further helped to spur me on. Well done to you all!

I am very lucky to have some amazing friends, who over the last 6 years, have listened to me talk about endometriosis and periods on probably way too regular an occasion. Thank you so much for taking an interest in my research, and for encouraging me along the way. The emotional support you have provided has been invaluable (and so has the wine).

To my family; my parents and brothers, all their other halves, and to my in-laws. Thank you so much for all your support, for cooking for me, cleaning for me, for the childcare, for the encouragement, and for the belief in me. If it takes a village to raise a child… add in a PhD and you have been my city!

And lastly but by no means least, to my little family. Gu, I am so very grateful for the love and support you have provided me throughout this journey, which has been a little longer than we anticipated. The financial support, and your incredible hard work in providing for our family, is something I'll always be appreciative of. At the start of this we were newlyweds, and now we are parents, we got thrown some curveballs along the way, but we got through it together. Thank you!

Which leads me onto Leo, and where do I start. My little miracle in so many ways. You have provided me with many cuddles, unfaltering love, and the determination to make you proud. You have taught me how to be brave, how to be strong, and most importantly, to never give up. So, this one is dedicated to you, my lionheart, my warrior, my scrappy little boy!

Abstract

The majority of those with endometriosis, a common condition affecting an estimated 10% of cisgender women of reproductive age, experience symptom onset during adolescence. However, little research attention has been given to the voices of adolescents and young adults living with the chronic condition. Lack of awareness of endometriosis, menstrual stigmas, and inadequate menstrual health education are considered to contribute to well documented delays in the diagnosis of endometriosis.

To date, this thesis is the first empirical study to explore United Kingdom-based adolescents' awareness, as well as their experiences of, endometriosis. Taking a pragmatic approach, with a feminist lens, two studies were undertaken: a qualitative study (Study 1) exploring the experiences of endometriosis among adolescents/young adults with a diagnosis of endometriosis; and a quantitative study (Study 2) investigating the awareness of endometriosis among adolescent girls, as well as their experiences of and attitudes towards menstruation.

In Study 1, twenty-four participants aged 18-24, recruited from endometriosis support groups and social media, participated in qualitative narrative interviews. Findings showed that the symptoms of endometriosis in adolescence are wide-ranging, and significantly interfere with many aspects of life, including school, sport, social life, and relationships. Adolescents face a long delay in obtaining a diagnosis, which is contributed to by a widespread lack of awareness of endometriosis and frequent dismissals by health professionals. Drawing on Bury's (1982) concept of 'biographical disruption', qualitative findings highlight how adolescents' experiences are significantly shaped by their age and life-stage. This study makes a novel contribution demonstrating how endometriosis in adolescence is experienced as a 'biographical threat', to both their present and imagined life-trajectories. Furthermore, this biographical threat is contextualised by the gendered, contested, and stigmatised nature of endometriosis. Endometriosis, therefore, not only impacts many of the key aspects of adolescent life, but threatens adolescents' lives and self-concepts as teenagers/young women, and their imagined futures as mothers/parents, intimate partners, and careered people.

Study 2 used a cross-sectional survey, with 442 teenage girls aged 15 to 19, recruited from schools in the West Midlands. Findings highlighted that most (94%) adolescent girls experience period pain, which for most of these is moderate to severe; many (23%) miss school due to their periods (most often due to pain); and many do not know whether their periods are regular or typical. Only 8% of girls reported that they thought periods were positive, and there was further evidence of stigma and taboos surrounding menstruation, particularly towards discussing it with males and teachers. Finally, an overwhelming majority (92%) had no knowledge of endometriosis, and most (85%) would like to learn about it given the opportunity. The most popular method of gaining such knowledge was at school (51%).

This research contributes to the evidence base pertaining to adolescent menstruation and endometriosis, and offers support for the need to provide de-stigmatised menstrual health education to all (including education about endometriosis), and to ensure an age-based approach to endometriosis healthcare and support. It also informs future research in this area.

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Abbreviations

Abbreviation	**Full Term**
AMAQ	Adolescent Menstrual Attitudes Questionnaire
AWCI	Adolescents with Chronic Illness
AYA	Adolescents and Young Adults
AYW	Adolescents and Young Women
CPP	Chronic Pelvic Pain
DIE	Deeply Infiltrating Endometriosis
GP	General Practitioner
HRQoL	Health-Related Quality of Life
MHE	Menstrual Health Education
MMAT	Mixed Methods Appraisal Tool
NICE	National Institute for Clinical Excellence
NSAIDs	Nonsteroidal Anti-Inflammatory Drugs
OCP	Oral Contraceptive Pill
OTC	Over the Counter (medications)
PCOS	Polycystic Ovary Syndrome
QoL	Quality of Life
RCT	Randomised Controlled Trial
UK	United Kingdom
USA	United States of America
WWE	Women With Endometriosis

Chapter 1. Introduction

1.1 The Research Context

Endometriosis is classically defined as a chronic gynaecological condition, in which endometrial like tissue is found outside of the uterine cavity, often on the reproductive organs, bowel, and bladder. In response to hormones, these tissue deposits induce a local inflammatory response, which can lead to fibrosis and adhesion formation (Kennedy et al., 2005). Common symptoms include chronic pelvic pain, dysmenorrhoea, dyspareunia (pain during sexual intercourse), fatigue, heavy menstrual bleeding, and infertility. The definition of endometriosis as a gynaecological condition has been recently challenged as outdated, as it does not reflect the true scope of the condition, which often manifests outside of the female reproductive tract (Taylor et al., 2021). Therefore, endometriosis should be considered a systemic disease, rather than one only affecting the pelvis (ibid).

Endometriosis affects approximately 1 in 10 women of reproductive age (Eskenazi and Warner, 1997), although the true prevalence rate is unknown due to delays in diagnosis. The prevalence of endometriosis in adolescents is even more unclear (Saridogan, 2017), however the majority of women with the condition report that their symptoms began during adolescence, even if it was not diagnosed at the time (Greene et al., 2009; Manderson et al., 2008). Endometriosis is common in adolescents who suffer from chronic pelvic pain (CPP), occurring in approximately 62% of those referred for laparoscopy due to their CPP, and increasing to 75% in those whose CPP is resistant to treatment (Janssen et al., 2013).

Research into adolescent endometriosis has had a largely medical focus, with most attention paid to its clinical presentation and response to treatment (Saridogan, 2017). Yet, even according to the most recent endometriosis guidelines, there is limited evidence available on endometriosis in this demographic (ESHRE, 2022). In the past, endometriosis was considered a ‘career women’s disease’, affecting those in their mid to late 30s who delay pregnancy (Sanmiguel, 2000), and only very recently, in 2017, the NICE Guidelines were updated to acknowledge the occurrence in this age group (Kuznetsov et al., 2017). Current evidence on adolescent endometriosis suggests that adolescents’ clinical presentation may be different than adults with endometriosis, they may have a longer wait for a diagnosis, and their endometriosis may be more progressive (ESHRE, 2022). Despite this evidence, very little research has addressed the illness experience of endometriosis in adolescents (Culley et al., 2013; Fedele, 2021; Young et al., 2015).

Adolescence is a critical transitional period in the lifespan, characterised by major biological, cognitive, and psychosocial developments. The occurrence of a chronic condition during adolescence can influence these fragile developmental processes (Suris et al., 2004), and research conducted with adolescents with chronic illnesses has indicated there are disruptions to schooling and peer relationships, as well as a re-thinking of future life plans (Grinyer, 2007; Kirk and Hinton, 2019; Lum et al., 2017; Taylor et al., 2008). The limited available evidence on adolescents' experiences of endometriosis suggests that it too causes disruptions such as these (Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018). In addition, endometriosis is a gendered, stigmatised, and contested condition, and thus, those affected often struggle to receive treatment, a timely diagnosis, and the support of others (Denny and Weckesser, 2019). Such issues exacerbate the emotional and psychological burden already brought on by living with endometriosis (Plotkin, 2004).

The delay in diagnosis is one of the most salient aspects of the literature pertaining to women's experiences of endometriosis (Culley et al., 2013), and improvements to the diagnostic process are considered, by a global consortium of investigators, to be a key research priority (Rogers et al., 2017). In addition to the 'medical level' delay (Ballard et al., 2006), during which adolescents frequently have their symptoms dismissed by GPs, are told they are too young to have endometriosis, or encounter a reluctance in being given diagnostic procedures (Cox et al., 2003a; Denny, 2004b; Denny and Mann, 2008; Markovic et al., 2008), it is common for delays at the patient level. These precede medical level delays, and are defined as a delay in seeking help after symptoms begin (Ballard et al., 2006). Adolescents may have a tendency to normalise irregular symptoms and lack an awareness of endometriosis (Cox et al., 2003c; Denny, 2009; Manderson et al., 2008; Markovic et al., 2008). This results from poor menstrual health education (MHE), which often fails to provide enough information on the embodied experience of menstruation (Brown et al., 2022; Burrows and Johnson, 2005), and the stigmas associated with discussing menstruation with others (Seear, 2009a). When it comes to their menstrual health, adolescents are often therefore left wondering, ***"Am I 'normal'?"***. This may be particularly significant in adolescence, a life-stage in which belonging, and 'fitting in', is of principal importance (Thomson, 2007).

Disparities in women's healthcare, inadequate provision of MHE, and the lack of awareness of endometriosis have all gained traction in the media over recent years. Furthermore, an All-Party Parliamentary Group on Women's Health was set up in 2016 to provide a platform within Westminster to discuss women's health issues, including raising awareness of conditions solely affecting women. As part of their 2017 enquiry into women's health, they recommended MHE within the school curriculum about normal and abnormal menstruation, when to seek help for periods, and education about endometriosis (APPG Women's Health, 2017). They also aim to ensure that women can access the right treatments, in a timely manner. The existing evidence which supports such recommendations comes from research conducted with adults with endometriosis (e.g. Cox et al., 2003c; Manderson et al., 2008; Markovic et al., 2008), and surveys carried about by charitable organisations (Plan International UK, 2018) or commercial parties (Bodyform, 2018; Procter & Gamble, 2018). However, there is still insufficient academic research with adolescents providing such evidence, which may support the implementation of improved MHE, and improved healthcare for adolescents with endometriosis.

1.2 Research Aim and Objectives

The main aims of this research were to explore adolescents' awareness and experiences of endometriosis, and to determine which aspects of menstruation may be associated with 'normal' or 'typical' menstruation. These aims were addressed through the following research objectives:

1. To explore the experiences of adolescents living with endometriosis, and the impact of endometriosis on their lives and identities as adolescents/young adults.
2. To identify adolescents' healthcare, information, and support needs regarding endometriosis.
3. To explore the awareness of endometriosis among a large sample of adolescent girls.
4. To investigate the menstrual experience in a UK sample of adolescent girls, the prevalence of dysmenorrhea, and to provide insight into their perceptions of the typicality of menstrual symptoms.
5. To develop recommendations for schools to educate adolescents, and for clinical health services and support services to support adolescents with endometriosis/suspected endometriosis.

1.3 Research Design

To facilitate the aims and objectives, a pragmatic approach to the research was adopted, with a feminist theoretical lens. It was deemed that the best way to address the research aims was to conduct two separate studies, as the focus was on two different, although inter-related, populations. Therefore, a qualitative study (Study 1) explored the experiences of endometriosis among adolescents/young adults with a diagnosis of endometriosis (n=24), and a quantitative study (Study 2) investigated the awareness of endometriosis among a sample of adolescent girls (n=442), as well as their experiences of and attitudes towards menstruation.

1.4 Thesis Outline

This chapter has described the research context, including an introduction of the research problem, and has outlined the aim and objectives, the research design, and an overview of the thesis. The remainder of the thesis is split into 4 main parts.

The first part of the thesis is labelled ‘Literature Review and Study Methodology’ and is comprised of three chapters. The first chapter in this part (Chapter 2) provides context and background for the major topics within this thesis, including endometriosis, adolescence, and chronic illness in adolescence. It also provides literature reviews on both menstruation in adolescence and women’s experience of endometriosis. Chapter 3 outlines the method of conducting a systematic narrative review of the current qualitative and quantitative literature addressing the experience of endometriosis in adolescents, and the results are discussed. The final chapter in this part (Chapter 4) draws on the two preceding chapters and discusses the gaps in the current literature. The methodology of the thesis is then detailed.

Part 2 of the thesis provides an account of the qualitative study (Study 1) and consists of three chapters. Chapter 5 outlines the study’s research questions and method, including participants, recruitment, data collection, and analysis. It also addresses ethical considerations and a reflective account of the research process. The findings from the qualitative study are presented in Chapter 6. Finally, Chapter 7 discusses these findings, drawing on past literature and theories surrounding chronic illness. The strengths and limitations of the research are also discussed.

The quantitative study (Study 2) is reported in Part 3 of the thesis and includes three chapters. Chapter 8 outlines the research questions, method, and ethical considerations. Chapter 9 reports on the findings from the quantitative study. Finally, Chapter 10 discusses these findings with relation to past literature on menstruation experiences, dysmenorrhea, the ‘typicality’ of periods, and endometriosis awareness. The strengths and limitations of the research are also discussed. *N.B Some of the findings from Study 2 were written up as an article and published in the Journal of Pediatric and Adolescent Gynaecology (see Appendix 24 and Randhawa et al., 2021).*

The final part (Chapter 11) draws upon the findings of the qualitative and quantitative studies to outline the implications of the research for policy and practice, and the recommendations for future research. This final chapter ends with a reflection on the contributions of the thesis, and the benefits of completing two separate but interrelated studies.

Thesis Part One: Literature Review and Study Methodology

Chapter 2. Literature Review: Background and Context

2.1 Introduction

This chapter introduces and describes the key topics of this thesis. Background information on endometriosis is provided, including its definition, symptoms, aetiology, prevalence, diagnostic process, and treatment options. Following this, context and background are provided in light of the focus of this thesis; the experience of endometriosis in adolescents. Firstly, adolescence is discussed, with an exploration into the major developments that take place within this life phase. The experience of living with a chronic illness during adolescence is then discussed. As will become clear, there is little available evidence on the experience of endometriosis in adolescents, and so the literature regarding menstruation in adolescence, and that regarding women's experiences of endometriosis are then reviewed. The former includes a discussion around the stigma and attitudes associated with menstruation, and adolescent's experiences of menstruation. This chapter therefore provides the broad context of the subject area, setting the scene for a more structured search, reported in Chapter 3, which explores literature around endometriosis in adolescence in more depth.

2.2 Endometriosis

Endometriosis is a chronic systemic condition, classified as the presence of endometrial-like tissue outside of the uterine cavity (Kennedy et al., 2005; Taylor et al., 2021). This tissue is commonly found on the pelvic organs (the reproductive organs, bowel, and bladder) and areas of the peritoneum. It can occasionally be located in other areas of the body including the kidneys, lungs, or even the brain (Sourial et al., 2014). In response to oestrogen, these tissue deposits elicit an inflammatory reaction, the result of which can vary in extent from small lesions, to large ovarian endometriomas and extensive fibrosis/adhesion formation (Giudice, 2010). This can cause a marked distortion to both the architecture and functioning of the affected organs, thus resulting in a large variety of symptoms such as pelvic pain, heavy menstrual bleeding, dyspareunia (pain on sexual intercourse), and infertility. It is also common for those with endometriosis to experience bowel and bladder symptoms, including painful urination and bowel movements, and other gastrointestinal problems (diarrhoea, constipation, etc,).

2.2.1 Aetiology of Endometriosis

Endometriosis is often described as enigmatic because its exact cause remains unknown. There are a number of theories attempting to explain the pathogenesis of endometriosis, however none of them have been conclusively confirmed (Sourial et al., 2014). One of the oldest theories proposes that endometriosis is a result of retrograde menstruation; whereby endometrial tissue residues flow backwards through the fallopian tubes and into the peritoneal cavity during menstruation (Sampson, 1927). There is some support for this theory, for example, endometriotic lesions are commonly located in the lowermost portion of the peritoneal cavity (Laufer et al., 2003), which is thought to be due to the accumulation of menstrual waste under the influence of gravity (Burney and Giudice, 2012). However, there also remains much debate around this theory. This backward flow of menstrual waste appears to be a common physiologic event, occurring in up to 90% of menstruating women with patent fallopian tubes (Halme et al., 1984), few of whom have endometriosis. It is also unable to explain why endometriosis is found in pre-pubertal girls, new-borns, or (rarely) males (Sourial et al., 2014). While this theory may account for the displacement of endometrial tissue in extrauterine areas, factors such as a genetic predisposition, oestrogen dependence, progesterone resistance, and immune dysfunction may explain why some women develop endometriotic implants when others do not (Burney and Giudice, 2012).

Some theories propose a non-uterine origin of disease, an example of which is coelomic metaplasia (Burney and Giudice, 2012; Sourial et al., 2014). According to this theory, extrauterine cells, such as peritoneal cells, abnormally transform into endometrial cells. This transformation may occur due to endocrine disrupting chemicals (Burney and Giudice, 2012), or an inductive stimulus such as hormonal or immunological factors (Sourial et al., 2014). This theory would explain how endometriosis is found in pre-pubertal girls. However, oestrogen, which usually propels endometrial growth, is only present in low levels in such girls, and so they may present a different form of endometriosis than is found in those of reproductive age (Sourial et al., 2014).

This is a very brief overview of some of the theories proposed to explain the aetiology of endometriosis (see Sourial et al., 2014 for a review of other theories), however it does illustrate that while each theory explains some aspect of endometriosis, no single theory accounts for all of its varying manifestations, of which there are many (Laufer et al., 2003). As such, “A unifying theory regarding the origin of endometriosis has remained mystifyingly elusive.” (Burney and Giudice, 2012: 2). This means that there is no definitive cure for endometriosis, and so treatment is aimed at managing the condition (Sourial et al., 2014).

2.2.2 Prevalence of Endometriosis

Endometriosis is a condition which predominantly affects women of reproductive age, although it has been found in premenarcheal girls (Laufer, 2000) and post-menopausal women (Haas et al., 2012). Endometriosis is estimated to affect approximately 10% of women of reproductive age (Eskenazi and Warner, 1997), however the exact prevalence is unknown, and estimates vary considerably, between 2.7% (Bernuit et al., 2011) and 28.6% (Parazzini et al., 2020). This variance is likely to be due to differences in both the population under study, and the way that diagnosis is reported (Zannoni et al., 2014). It is a considerable problem in women who have fertility issues; as many as 47% of whom ultimately receive a diagnosis of endometriosis (Meuleman et al., 2009).

The prevalence of endometriosis among adolescents is more difficult to clarify (Saridogan, 2017). Rather than make population estimates, systematic reviews have focussed on the prevalence among those referred for laparoscopy for dysmenorrhoea or chronic pelvic pain (CPP); of whom 62% (Janssen et al., 2013) and 64% have endometriosis (Hirsch et al., 2020). In those whose CPP was resistant to treatment, the prevalence was 75% (Janssen et al., 2013). Although such research suggests a significant incidence of endometriosis among adolescent girls with pelvic pain, the authors do acknowledge several limitations. Most reviewed studies used retrospective data collection methods, which maybe prone to a positive selection bias, and therefore an overestimation of prevalence (Janssen et al., 2013). The criteria for referral for a laparoscopy varies between reviewed studies (Hirsch et al., 2020; Janssen et al., 2013), and often depends on the subjective opinions of GPs and surgeons, and therefore those with the most severe symptoms maybe more likely to be referred (Janssen et al., 2013; Saridogan, 2017). Consequently, these prevalence rates may be exaggerated, as they might only include the most severe cases.

However, a major obstacle in determining the prevalence of endometriosis in adolescents is that many women report that although their symptoms began during adolescence, they did not receive a diagnosis until they were well into adulthood (Greene et al., 2009). Haas et al. (2012) examined the age distribution of women admitted to hospital for surgical treatment of endometriosis in 2005 and 2006 in Germany, and found that the 10-15-, 15-20-, and 20–25-year-old age groups represented just 0.05%, 1.93%, and 6.11% of admissions respectively. This, coupled with the finding that most women (78.37%) were aged between 20-45, indicates that women under 20 are much less likely to be diagnosed with endometriosis. Saridogan (2017) suggests that clinicians, adolescents, or their families might have a higher threshold when agreeing to and performing a laparoscopy in this age group. Indeed, laparoscopies in this demographic often cause embarrassment and anxiety, therefore it may be preferable to delay them until all avenues have been explored (Pandis et al., 2009). Finally, not all those with endometriosis experience symptoms, as it can occur asymptomatically (Dunselman et al., 2014). In such cases, one would be unlikely to present to a clinician. Therefore, reviewing all evidence together, the prevalence of endometriosis in adolescents is likely to be higher than current statistical estimates.

2.2.3 Diagnosing Endometriosis

The gold standard for diagnosing endometriosis is visual inspection achieved during surgical laparoscopy (Kennedy et al., 2005). However, it often takes many years after symptom onset until women have this surgery, as the average delay for a diagnosis of endometriosis in the UK is 7.5 (Endometriosis UK, 2011) to 8 years (Ghai et al., 2020). This long wait is characterised by delays at both the 'patient level', in seeking help for symptoms, and at the 'medical level', in obtaining a referral and subsequent diagnosis of endometriosis (Ballard et al., 2006). This is discussed further in Section 2.7.2 of this chapter.

Before obtaining a laparoscopy, women may undergo several other diagnostic investigations, including transvaginal ultrasounds or magnetic resonance imaging (MRI) scans (Giudice, 2010). However, these methods have a low sensitivity for detecting peritoneal and ovarian adhesions and implants (Brosens et al., 2004). They perform better at detecting and diagnosing ovarian endometrioma, providing the diameter is greater than 2cm (Brosens et al., 2004). If endometriosis is not diagnosed during ultrasound or MRI, women may either be referred for laparoscopy, or given a false-negative result, with no further investigation until they present again (Ballard et al., 2006).

Once laparoscopy confirms endometriosis, information is often provided on the severity of disease; usually assessed using the revised scoring system of the American Society for Reproductive Medicine (Canis et al., 1997). This system classifies disease by stages, ranging from stage I (minimal) to stage IV (severe), based on the extent and location of disease, and the type, appearance and depth of infiltrating lesions (Giudice, 2010). However, correlation is often lacking between the disease stage and the type or severity of pain symptoms experienced (Vercellini et al., 2006). An exception to this is deeply infiltrating endometriosis (DIE), which is defined as nodules that extend >5mm beneath the peritoneum, as the depth of this infiltration is related to symptom severity (Chapron et al., 2003; Kennedy et al., 2005). As pain levels do not always equate with severity of disease, women may feel frustrated or aggrieved if their disease stage minimises their level of suffering (Denny, 2009). Conversely, women who have no symptoms, yet receive a diagnosis of advanced stage disease during investigation for other conditions, can be alarmed (Cox et al., 2003c).

Adolescents are often found to have disease stages I or II (Dun et al., 2015; Gallagher et al., 2017), however there is evidence of stages III and IV (Fong et al., 2017; Hirsch et al., 2020), and of DIE (Audebert et al., 2015). Older adolescents can be more likely to have more advanced stages, which may be an indication that endometriosis is progressive (Fong et al., 2017). Given the potential long term consequences of undiagnosed endometriosis, including impacts on quality of life and future fertility (Fong et al., 2017), addressing diagnostic delays is critical. As such, the exploration of this delay, and the identification of non-invasive diagnostic methods, are often highlighted as research priorities for endometriosis (As-Sanie et al., 2019; Rogers et al., 2017).

Evidence suggests that when symptoms start during adolescence, it may take longer to receive a diagnosis than when symptoms start later (Arruda et al., 2003; Ghai et al., 2020; Greene et al., 2009; Pino et al., 2022). Greene et al. (2009) found that those with adolescent onset (aged ≤19 years) waited an average of three times as long to seek medical attention for their symptoms than those with adult onset (aged ≥20 years), and once medical attention was sought, it took them almost three times as long again to receive a diagnosis. One potential reason for this is that adults may present to clinicians with fertility issues rather than pain, and may therefore be taken more seriously (Arruda et al., 2003). While longer delays in obtaining a diagnosis for those with adolescent onset are consistently found, some research suggests that in those who do receive a diagnosis *during* adolescence, it is received more quickly than for those who obtain a diagnosis during adulthood (DiVasta et al., 2018; Fong et al., 2017). There is yet to be a thorough exploration of why this may occur, however factors such as parental advocacy and health insurance coverage may play a role (DiVasta et al., 2018).

2.2.4 Treatment for Endometriosis

There is no cure for endometriosis and so the aim of treatment is to manage symptoms, through medical and/or surgical means (Sourial et al., 2014). Long-term treatment often involves repeated courses of medical or surgical therapy (or both), as often, pain recurs within 6 to 12 months of treatment completion (Giudice, 2010). Medical therapies usually consist of painkillers and/or hormonal treatment. A range of analgesics and non-steroidal anti-inflammatory drugs (NSAIDs) are commonly used. A Cochrane review indicated that there was no evidence of the effectiveness of NSAIDs for pain relief in women with endometriosis (Brown et al., 2017). In addition, NSAIDs might have significant side effects such as gastric ulceration and disturbance of ovulation, so need to be taken with caution (Kennedy et al., 2005).

Hormone treatments include the oral contraceptive pill (OCP), intrauterine devices (i.e. the coil), and those which induce pseudo-menopause, such as gonadotrophin releasing hormone (GnRH) agonists (Kennedy et al., 2005). A systematic review indicated that these treatments can be effective in reducing endometriosis-associated pain in most women, however up to 19% may experience no pain relief (Becker et al., 2017). In addition, recurrence of pain after cessation of treatment is common, appearing in 17-34% of women (Becker et al., 2017). Hormonal treatments can have many unwanted side-effects, often affecting appearance, and so some women do not feel it is worth enduring these to reduce their pain (Denny, 2009). GnRH agonists have the additional side-effect of causing bone density loss, and therefore their use in adolescents may be limited until after they have completed bone formation (Saridogan, 2017). Treatment with hormonal therapy is not appropriate for those seeking infertility treatment for endometriosis.

Surgical treatment for endometriosis may be used after medical treatment has failed, or as a first line treatment (Giudice, 2010). Laparoscopy is most commonly performed (De Graaff et al., 2013), during which visible diagnosis can be achieved, and areas of endometriosis can be removed via either excision or ablation (Kennedy et al., 2005). Laparoscopic surgery can improve pain outcomes, particularly when compared to diagnostic laparoscopy alone (Jacobson et al., 2009). However, treatment is not permanent, and symptoms often recur. Abbott et al. (2003) found that 36% of their sample of women required further surgery within 5 years of laparoscopy, and Audebert et al. (2015) found that 34% of the adolescents in their study required further surgery within 8 years. In severe cases, some women undergo radical surgical procedures including partial or full hysterectomy, however, even these measures do not always provide a permanent solution (Giudice, 2010). Recurrence of symptoms may be a major concern for adolescents, as it may lead to multiple operations and symptomatic suffering extending over a large proportion of their lives, until they reach menopause (Saridogan, 2017).

2.2.5 Summary

Endometriosis is a chronic condition, affecting approximately 10% of women of reproductive age, with the prevalence among adolescents remaining unclear. Symptoms include pelvic pain, bowel and bladder issues, and infertility, but it can also occur asymptomatically. With no definitive cause, endometriosis cannot be cured, and treatment is therefore aimed at clinical management. It can take many years to obtain a diagnosis, which may be lengthier if symptoms begin during adolescence. Women often experience a number of social and psychological impacts while living with endometriosis (Culley et al., 2013), which are discussed in Section 2.7 of this chapter. However, little is known about the experiences of adolescents who have endometriosis (Culley et al., 2013; Young et al., 2015), which is therefore the focus of this thesis. To provide some context and background to this thesis, focus will now turn to the key concepts of adolescence, adolescents with chronic illness, and menstruation.

2.3 Adolescence

The word adolescence derives from the Latin word *adolescere*, meaning 'to grow up' (Sawyer et al., 2018). Definitions of adolescence differ depending on discipline, and therefore the notion of adolescence is somewhat contested (Dahl, 2004). Most definitions, however, describe adolescence as a 'transitional' period between being a child and being an adult (Dahl, 2004; Holmbeck, 2002; James, 2017; Sawyer et al., 2018; Smetana et al., 2006; among many others), and between being dependent and becoming independent (Kehily, 2007), but there is a lack of clarity about when adolescence begins and ends. This is in part because adolescence begins with biological changes (i.e. puberty), but ends in the attainment of 'adult' social roles, (i.e. home ownership, marriage, etc.: Dahl, 2004). Furthermore, this span of time has gradually been increasing over the last few decades, as the onset of puberty has become earlier, and adult social role transitions are occurring later (Sawyer et al., 2018).

Defining adolescence by age is therefore challenging, but many have attempted. In 1904, G. Stanley Hall published what is considered to be seminal work in the field of adolescence, in which he used the age range 14 to 24 years. However, the World Health Organisation, the United Nations General Assembly and UNICEF define adolescence by the age range 10-19 years (UNICEF, 2011). This definition, which has been in place since the middle of the 20th century, is still widely used, although there has been significant change in the course of adolescent growth and the timing of social role transitions since that time (Sawyer et al., 2018). Therefore, more recently, researchers have suggested that an age range which represents a more contemporary notion of adolescence is 10 to 24 years (Hagell et al., 2013; James, 2017; Sawyer et al., 2018).

These inconsistencies provide further confirmation of the difficulty in defining 'adolescence' and indicate that definitions which are based on age may need to be continually re-visited. It is also important when discussing this transitional stage, to be mindful of the terminology used; the terms 'adolescents', 'teenagers', 'young people', and 'youth' are often used interchangeably. Social constructionists prefer to use the terms young people or youth, and refer to those in this phase as a socially constituted group, who are shaped by the culture and society in which they live (Kehily, 2007). The terms adolescents and teenagers are considered to be more biological, used by those interested in psychology or human development, who discuss this period as a developmental stage (ibid). With the onset of puberty occurring between the ages of 9 and 12 years, and the accomplishment of adult roles delayed until the mid-20s, the period of adolescent development has expanded, and is much larger than just the 'teenage' years alone (Dahl, 2004). Therefore, when discussing this life-stage in developmental terms, the term adolescence may be most appropriate, and is adopted henceforth for the duration of this thesis. However, when referring to the work of other researchers, the terminology they have adopted will be used.

2.4 Adolescent Development

While there may some ambiguity around terminologies and age-based definitions, there is agreement in the conceptualisation of adolescence as a time of major change. Although initiated by biological developments, adolescence also encompasses major social and psychological developments, which occur at a rapid rate, second only to infancy (Holmbeck, 2002). In addition, these developments do not occur independently of one another. For example, changes resulting from puberty can alter physical appearance (i.e. appearing as an adult), which may then effect social encounters (Dahl, 2004). Neither do they occur independently of external events, such as changes at school or home (Petersen et al., 1995). How one negotiates these developments will have repercussions that will last into adulthood (Suris et al., 2004). Some of these aspects of adolescent development, particularly relating to females, will now be discussed in further detail. This will provide context for the thesis, in which the experience of menstruation and endometriosis during this period of adolescent development is of interest.

2.4.1 Biological Development

The key biological change associated with adolescence is puberty; the physical change and sexual maturation occurring during the transition from childhood to adulthood. Puberty spans over a number of years (Dahl, 2004), and is initiated by the release of hormones into the body, which can occur up to 2 years before any observable changes are seen (Hauser-Cram et al., 2014). In females, these observable changes begin between ages 8 and 13 years, with the development of breast buds, also known as 'thelarche'. An average of 2.5 years later, the female will begin her periods, known as 'menarche'. At this point, females have reached full reproductive capacity (Emmanuel and Bokor, 2018).

There can be considerable variation in the onset and timing of puberty. The average age of menarche varies between countries; with recent estimates suggesting it is 12.9 years in the UK (Millenium Cohort Study, 2016), 12.3 years in Australia (Armour et al., 2021a), and 12.25 years in the USA (Biro et al., 2018). Several factors contribute to these variations. High body weight and low socioeconomic status are associated with earlier menarche (Kelly et al., 2017). Differences in menarcheal age have consistently been found between people of different races and ethnicities. Most documented is the earlier age of menarche of Black girls compared to White girls (Anderson et al., 2003; Chumlea et al., 2003; Herman-Giddens et al., 1997). For example, Herman-Giddens et al. (1997) found the average age of menarche in Black girls in the USA was 12.16 years, compared to 12.88 years for White girls. Girls of Asian ethnicity may also be more likely to enter menarche earlier than White girls (Kelly et al., 2017). The terms race and ethnicity are often used interchangeably in social science research, but often both refer to differences in physical (race) and cultural characteristics. However, the link between ethnicity/race and menarche can be over-simplified, as ethnic/racial inequalities, such as material disadvantage and adiposity (obesity), can also be a factor in observed differences (Kelly et al., 2017).

Approximately 9.5% of girls begin to menstruate before the age of 11.2 years (Kelly et al., 2017), and 90% of girls have reached menarche by 13.75 years (Chumlea et al., 2003). Due to the variations in the timing of puberty as illustrated, adolescents may have very different experiences to their peers (Petersen et al., 1995), and therefore may find it difficult to make comparisons with them.

2.4.2 Cognitive Development

During adolescence, there is an increase in the capacity to use abstract reasoning and to think hypothetically, a stage in cognitive development which Piaget terms ‘formal operational thinking’ (Piaget, 1952/1936). Adolescents begin to ‘think about thinking’ (Kuhn and Franklin, 2008). They have more enhanced decision making skills than children, and are better at making logical and reasonable choices (Dahl, 2004). Their learning becomes more specific, and focuses on contexts which relate to potential career choices (Eiser, 1993). Their cognitive capacities have reached adult levels by middle adolescence (Petersen et al., 1995), however, they are more prone to making emotionally influenced decisions, which can lead to erratic and reckless behaviour (Dahl, 2004).

According to Elkind (1967), adolescence is a period of “egocentricism”. Adolescents’ ability to conceptualise their own thought also brings with it the ability to think about other’s thoughts. This may pose problems, however, as adolescents may fail to differentiate between the focus of others’ thoughts, and those which are central to their own thinking. This failure to differentiate is the crux of adolescent "egocentricism" argues Elkind, because the adolescents become convinced that they are the object and concern of others' thoughts. They believe that other people are as preoccupied with their appearance and behaviour as they are. They therefore anticipate others' reactions; that they will be admiring or critical, and this can account for the self-consciousness, which is particularly characteristic of early adolescence. While Elkind (1967) suggests that this 'imaginary audience' starts to dissipate during mid-adolescence, Frankenberger (2000) found evidence that this can carry on into early adulthood.

2.4.3 Psychosocial Development

The increased capacity in abstract thinking allows adolescents to begin thinking more about themselves, their futures, and how they compare to others (Petersen et al., 1995). Adolescence is often conceptualised as a time of identity formation, which is a key part of this life stage according to Erikson's theory of psychosocial development (1968). Adolescent identities can be considered as "the ways in which young people view themselves and make sense of their lives" (Robb, 2007: 109). These identities are negotiated against the social and cultural milieu in which development occurs, and it is therefore not merely an internal process (Erikson, 1968).

There are many aspects of identity including gender, ethnicity, class, and sexuality, among others. Gender is a central aspect of the developing identity; in transitioning towards adulthood, one is becoming a young man or a young woman (Robb, 2007). By considering gender as an aspect of identity, other key aspects of identity, such as sexuality and attitudes towards the body, can also be understood. For example, Aapola et al. (2005) suggest that in comparison to young men, young women's bodies may be subject to a greater extent of objectification. They may therefore feel more pressure to look good, and become concerned with their physical appearance, health, and fitness (ibid). Although, it must be acknowledged that following advances in social media (i.e. Facebook, Instagram, Snapchat, etc.) since this work was authored, concern with physical appearance is also rising amongst young men (Fardouly and Vartanian, 2016). What it means to be a young woman is constantly changing, as it is shaped by historically changing social contexts. However, even if the historical time frame and social context remain constant, constructions of being a young woman can shift, as gender also intersects with social identities such as ethnicity and class (Aapola et al., 2005; Robb, 2007).

While adolescents attempt to grasp these aspects of their identity, they rarely do so in isolation. They are part of their family system, as well as a growing peer network, which may include friendships, groups, and romantic relationships (Hauser-Cram et al., 2014). Interactions with these social groups will help form their morals and values, and will contribute to their developing sense of autonomy (Erikson, 1968). Close relationships with parents continue during adolescence (Petersen et al., 1995), and parents remain a valuable source of support. Support may differ between parents; mothers are often perceived as being the providers of emotional support, and fathers as providing informational and/or material support (Steinberg and Silk, 2002). However, parent-child relationships do transform during adolescence, as more time is spent with peers, and less with parents (Smetana et al., 2006). Adolescents may still seek parental advice over long-term issues (i.e. career choices), but peers will influence their style, opinions, beliefs, and behaviour (Petersen et al., 1995; Smetana et al., 2006).

Peer relationships are considered to be one of the most important aspects of adolescence (Brown and Larson, 2009). Friendships take on new levels of intensity; peers are no longer simply play-mates, but are people who adolescents trust, converse intimately with, and feel understood by (Buhrmester, 1996). These relationships also differ from parental relationships because they enable feelings of equality, and more room for autonomy. Friends become a key source of support during adolescence, which can be more significant than parental support by mid-adolescence (Bokhorst et al., 2010). Friendships can also influence mental health; Ueno (2005) found that a higher number of friends during adolescence was associated with fewer depressive symptoms. This relationship was mediated by a sense of belonging, which in itself is a key aspect of identity development, associated with feelings of security and attachment (Thomson, 2007). Positive friendships can protect the well-being and self-esteem of adolescents during periods of major adjustment or transition (Corsano et al., 2006). Girls in particular seek support from their friends during times of stress, and such support is associated with increased levels of self-esteem (Rueger et al., 2010). However, there can also be a ‘dark side’ of adolescent friendships, including jealousy, bullying, and exclusion (Smetana et al., 2006), which may negatively impact self-esteem.

Self-esteem, or “the extent to which we value or feel positively about the self” (Bowker, 2006: 215), can be vulnerable during adolescence, while attempting to grasp several developmental changes. Low self-esteem in early adolescence can predict depression in both late adolescence and early adulthood (Masselink et al., 2018), and may also be associated with problems such as poor school performance, relationship difficulties, and substance abuse (Hazen et al., 2008). Self-esteem generally increases during adolescence (Erol and Orth, 2011), however there are some gender differences in self-esteem levels, with girls showing poorer self-esteem than boys (Bolognini et al., 1996). The number of domains on which one bases their self-esteem increases from childhood to adolescence (Harter, 1988), and the view of the self therefore becomes more cognitively complex (Bowker, 2006). Some domains which are important to adolescents' self-esteem are physical attractiveness, peer acceptance, academic performance, and athletic competence (Harter and Whitesell, 2001; Petersen et al., 1995).

2.4.3.1 Romantic Relationships

Changing peer relationships lead to the instigation of dating and romantic relationships, which form a significant aspect of an adolescent's social world (Bouchey and Furman, 2003). Romantic relationships begin in early adolescence, but change in duration, frequency, and quality with increasing age, by which time romantic partners show more behaviours indicative of commitment and intensity (Carver et al., 2003). In addition, by older adolescence, those in a relationship might report their partner's support more highly than that of their friends and parents (Seiffge-Krenke, 2003).

As adolescent relationships progress, they become more emotionally and sexually intimate (Meier and Allen, 2009). In addition to social changes such as spending more time together, this is influenced by biological developments, such as the development of secondary sexual characteristics and increased interest in sex (Petersen et al., 1995). Sexual encounters in adolescence are not exclusive to those in a relationship; over half of adolescents have had sexual partners with whom they are not in a relationship or dating (Manning et al., 2006). Relationship experience during adolescence can be associated with subsequent relationships during young adulthood (Meier and Allen, 2009), and the content and quality of adolescent relationships can influence developmental trajectories (Collins, 2003).

2.4.4 Summary

Adolescence is a transitional period, in which rapid biological, cognitive, and psychosocial changes occur. The physical changes associated with puberty are complete by mid-adolescence, however cognitive and psychosocial development can continue into young adulthood. The negotiation of this developmental period will have repercussions extending long into adulthood.

2.5 Adolescents Living with Chronic Illness

The occurrence of a chronic condition during adolescence can have an effect on developmental processes, including identity development, autonomy from parents, peer relationships, and self-esteem (Suris et al., 2004). Furthermore, developmental changes associated with adolescence can themselves impact on the course of disease (Suris et al., 2004). Previous research with adolescents with chronic illness (AWCI) draws on Bury's (1982) concept of 'biographical disruption' to understand how young people navigate a chronic illness alongside these developmental transitions (Bray et al., 2014; Grinyer, 2007; Kirk and Hinton, 2019).

Bury (1982) asserts that chronic illness is a form of 'biographical disruption', which dominates and disrupts a person's life, challenges their 'taken-for-granted' bodily assumptions and behaviours, and leads to the re-thinking of their biography and self-concept. Bury's work was based on research with adults with a diagnosis of rheumatoid arthritis, and there is debate about whether it over-simplifies the diversity of experience associated with chronic illness (Williams, 2000b). Therefore, Williams (2000b) argues the need to build on this theory, with particular focus on the timing and context of an illness. In her research with adolescents with cancer, Grinyer (2007) found that the experience of illness during adolescence and young adulthood poses a distinct effect, which results from fundamentally altered life trajectories at a crucial transitional moment. While reiterating that this does not undermine the experience of illness in other age groups, she summarises that "this is a life stage when independence and identity are fragile, educational milestones are crucial, financial resources are limited, physical appearance is central, and relationships and fertility are thrown into crisis. The disruption of any one of these factors can have an ongoing impact, resulting in a chronic effect." (275: Grinyer, 2007).

A chronic illness during adolescence may challenge movement towards autonomy and independence, and in particular, young people can become increasingly dependent on their parents (Eiser, 1993; Yeo and Sawyer, 2005). Parents can be important allies in managing their disease and treatment (Taylor et al., 2008). They are also a significant source of emotional support, and are often relied upon for practical support (i.e. travel to appointments, financial support: Cartwright et al., 2015; Kyngäs, 2004). However, these relationships can also be put under strain; parents can be restrictive and over-protective, challenging an adolescents desire to be independent (Kyngäs, 2004; McEwan et al., 2004). For some illnesses, these restrictions may be necessary though; McEwan et al. (2004) found that adolescents with epilepsy reported restrictions when it was unsafe to do certain activities on their own, in case they had a seizure. While they knew these restrictions were necessary, they questioned whether they would ever be able to achieve autonomy, describing potential challenges of moving out of home and living alone.

Adolescents can experience challenges seeking medical help. Adolescence represents a unique life-stage for medical treatment (Grinyer, 2007), unless specialist adolescent services are set up, then clinicians may only be used to dealing directly with adults, as either the patients themselves, or the parents responsible for their children's care (Christie and Viner, 2005). This poses issues for AWCI; they can feel that discussion is directed towards their parents rather than themselves, or alternatively clinicians may use complex terminology that they are unable to understand (Jones et al., 2011). In addition, adolescents have indicated a fear of being judged when asking about topics that are important to them (i.e. alcohol consumption: McEwan et al., 2004), or lack of clinician awareness of what factors maybe important to them (Grinyer, 2007). Finally, a strict medical regime can be conflicting with key aspects of adolescent life, such as maintaining peer relations and developing a self-image (Suris et al., 2004).

Spending time with friends, and gaining their acceptance, is a critical part of adolescence, however a chronic illness may jeopardise this (Taylor et al., 2008). Some illnesses can limit the amount of time adolescents spend with their peers, due to lengthy hospital stays, school absences, or restrictions on physical activity. Woodgate (1998) found that adolescents weren't included in certain physical activities due to their illnesses. Adolescents have also reported name-calling, bullying, or feeling isolated due to their illness (Kirk and Hinton, 2019; McEwan et al., 2004; Winger et al., 2014). Disclosing illnesses to friends can be beneficial in eliciting support (McEwan et al., 2004), particularly for girls (Cartwright et al., 2015). However, adolescents have reported that others are unable to understand their illnesses, or to appreciate what it is like to live with them (Cartwright et al., 2015; Winger et al., 2014; Woodgate, 1998). These issues with peer relationships have been associated with feelings of isolation, and beliefs of being different to peers (McEwan et al., 2004; Winger et al., 2014; Woodgate, 1998). Adolescents can therefore seek comfort in talking to those with the same illness, who are able to understand (Cartwright et al., 2015; Coyne et al., 2018; Kirk and Hinton, 2019).

School forms a significant part of adolescent life, which can be affected by a chronic illness. The social aspect of school life may be affected by prolonged or repeated absences or bullying. Winger et al. (2014) interviewed adolescents with chronic fatigue syndrome (a chronic disease in which persistent and unexplained mental and physical fatigue is experienced), who described feeling 'shut out' or forgotten by friends after school absences, and found returning to school to be quite a negative experience. School absences might also impact academic achievement (Suris et al., 2004; Taylor et al., 2008), which, along with restrictions imposed by certain chronic illnesses, can cause additional worry over limited career choices in the future (Cartwright et al., 2015; Woodgate, 1998).

In addition to employment prospects, AWCI may face concerns about other implications of their condition in the future. For example, Cartwright et al. (2015) found that adolescents with juvenile arthritis (inflammatory diseases characterised by pain, swelling and stiffness of the joints) were worried about the long-term impact of medication, such as the side-effects and impacts on their lifestyle. Adolescents may also worry about their condition developing or worsening in the future (Woodgate, 1998). Finally, some chronic illnesses might cause adolescents concern towards personal plans, including relationship prospects and having children (Eiser, 1993). They may worry about finding a partner who will be able to take on their illness, and all the extra 'baggage' that might entail (Coyne et al., 2018). In addition, they may have concerns about their ability to have children (Coyne et al., 2018; Jones et al., 2011), and also potentially passing their illness on to their children (McEwan et al., 2004).

Despite these concerns about their future, AWCI have also displayed tendencies towards acceptance of their condition, and hope for their future, particularly in finding a way of managing their condition (Kirk and Hinton, 2019; McEwan et al., 2004; Winger et al., 2014). Kirk and Hinton (2019) described a 'reconfigured future', in which adolescents' future biography would now need to incorporate the potential effects of their chronic illness. This is somewhat aligned to Bury's (1982) notion of chronic illness as a 'biographical disruption', which threatens everyday life, and causes a re-examination of the expectations and plans for the future that an individual holds. Coyne et al. (2018) found some support for this in young adults with chronic kidney disease (who have received a transplant), some of whom felt the need to fit commitments, such as career plans, around their plans for having children, now that their fertility was threatened.

While there are many recurring themes amongst this literature exploring AWCI, it must be acknowledged that different illnesses will be experienced differently. Some illnesses pose more restrictions than others, some require more medication, or a greater level of hospital care, and some will affect future health in different ways (Eiser, 1993). These factors will all impact on the illness experience, including the level of dependence on parents, impact on peer relationships, and thoughts about the future. In addition, much of the research cited thus far is on chronic illnesses which affect both male and female adolescents, however there is little focus on the effect of gender on the illness experience. There is some evidence that the social constructions of femininities and masculinities might affect how adolescents live with a chronic illness. For example, Williams (2000a) found that girls were more likely to incorporate their illness into their social identity, i.e. by telling people about it, whereas boys made attempts to keep their illness hidden. Furthermore, when searching the literature for adolescents' experiences of chronic illness, there was little research on the experience of gendered illnesses (i.e. those associated with one gender), or those typically occurring within just one gender, such as endometriosis.

In addition, when considering the impact of chronic illness during adolescence, features of Erikson's theory of psychosocial development (Erikson, 1968), such as identity development and the search for independence, are often reflected upon in the literature. These are relevant to the study of chronic illness during adolescence, however, for this thesis, where the focus is adolescent *girls*, it is important to highlight the potential androcentric bias of some of the assumptions of that theory. For example, Sorell and Montgomery (2001) discuss how the idea that identity formation results from obtaining independence from others is a stereotypically masculine notion, whereas women often ground their sense of self and identity in their relationships with others. Therefore, by focusing solely on the experience of illness in females, some findings may differ from those outlined in this section. Furthermore, endometriosis only affects females (except in very rare cases[1]), and so the illness experience might vary due to it being a gendered illness.

Before exploring what is already known about the experience of endometriosis, attention will turn to theories and research concerned with menstruation. This is particularly relevant when considering endometriosis, as painful and heavy periods are symptoms of endometriosis that are commonly experienced. Therefore, the way that society and individuals construe endometriosis is related to the attitudes and associations that they hold for menstruation (Denny and Weckesser, 2019).

2.6 Menstruation

The menstrual cycle is a physiological process, controlled by neuroendocrine mechanisms and regulated by hormones, yet it can also be considered a biopsychosocial phenomenon, as it both affects, and is affected by, a woman's personal context (Chrisler, 2017). Chrisler explains that "[W]omen's behaviour is affected by beliefs and attitudes, which are in turn affected by physiological experiences. Furthermore, women's experiences occur, our beliefs are learned, and our attitudes are formed within a cultural context" (Chrisler, 2017: 193). Therefore, while the menstrual cycle is a biological process which is common *among* women, there is a diversity of experiences of such *between* women, which results from differences in sociocultural influences on attitudes, beliefs, and behaviour (Chrisler, 2017; Newton, 2016). Such influences will affect the female's experience of menstruation, from menarche through to menopause.

Menstruation for most women spans over a large proportion of their lives (Costos et al., 2002), and signifies good health, biological maturity, and the ability to bear children (Chrisler, 2017). Menarche is therefore a significant life event, a 'status passage' (see Newton, 2012) yet it is celebrated by only

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[1] See review by Rei et al. (2018) Detailing the extremely rare circumstance of male endometriosis.

half of the cultures around the world (Paige and Paige, 1981). It often invokes a negative emotional response, despite being regarded as part of 'becoming a woman' (Barrington et al., 2021). Adolescents primarily convey negative discourse towards menstruation, depicting annoyance, embarrassment, shame, and secrecy (Beausang and Razor, 2000; Burrows and Johnson, 2005; Jackson, 2019; Jackson and Falmagne, 2013; Plan International UK, 2018). There isn't a complete absence of positive dialog concerning menarche and menstruation, which can be associated with pride, relief, and 'growing up' (Barrington et al., 2021), however, negativity often dominates. To help unpack the source of such negativity, the following sections will explore the secrecy, stigma, and taboo associated with menstruation, and how these affect the experience of menstruation for adolescents. The final section addresses issues related to adolescents' menstrual health, and the experience of such issues.

2.6.1 Attitudes, Stigma, and Taboo Towards Menstruation

Menstruation is often viewed negatively, and is shrouded in secrecy, stigma, and taboo (Costos et al., 2002; Johnston-Robledo and Chrisler, 2013). Johnston-Robledo and Chrisler (2013) use the concept of stigma proposed by Goffman (1963), to argue that menstruation is a stigmatized condition. According to Goffman (1963), the term stigma is used to refer to a deeply discrediting attribute. The word derives from the Greeks, who would visibly brand criminals and slaves with a mark, to convey their status as an undesirable character; one that should be avoided. Goffman differentiates between three types of stigma; 'abominations of the body' (physical deformities), 'blemishes of individual character' and 'tribal stigma' (i.e. race, religion, social class, etc.). Johnston-Robledo and Chrisler (2013) argue that menstrual blood could be considered a mark which fits into all three categories. The rituals associated with concealing menstruation infer that the blood is aversive, an abomination. A stain caused by the leaking of menstrual blood may therefore be perceived as a flaw in one's character, an inability to hide her menstruating status to others. This further extends to even mere reminders of menstrual blood, such as visible sanitary products. Finally, menstrual blood is indicative of a tribal identity, that of being female, and different to males.

The taboo surrounding menstruation may be partly due to beliefs about menstrual blood; at different times and across cultures, it has been considered both magical and dangerous (Chrisler, 2017; Costos et al., 2002; Douglas, 1966). Notions of menstrual blood being magical stem from a time when the physiology of menstruation was poorly understood, and it was therefore a mystery how women could bleed for 5 days without being weakened or killed (Chrisler, 2017; Douglas, 1966). Menstrual blood been considered dangerous, able to contaminate crops, spoil food, etc. (Costos et al., 2002). Scientists have even attempted to demonstrate that menstrual blood is a toxin (Johnston-Robledo and Chrisler, 2013). Perhaps resulting from these beliefs, many groups have imposed restrictions on women's practices during menstruation, such as not bathing, swimming, washing their hair, engaging in sexual intercourse, or preparing food, and some are required to stay in separate 'menstrual huts' (Bhartiya, 2013). While there is no scientific justification for these restrictions, myths are still evidenced in women's and girls' understandings of, and practices during, menstruation; perhaps because they get passed down through generations (Costos et al., 2002; Koff and Rierdan, 1995a; Uskul, 2004).

The stigma and taboo of menstruation is transmitted and upheld by several sociocultural routes, such as advertisements, educational sources, media, and euphemisms (Johnston-Robledo and Chrisler, 2013). Television adverts convey menstruation as dirty, and something to be kept discreet; sanitary products are marketed to maintain freshness and avoid any embarrassment caused by potential discovery (i.e. 'leaking'). Furthermore, such adverts have historically used blue rather than red liquid to portray menstrual fluids, and words such as menstruation or blood are rarely used (O'Keefe, 2006). Only very recently, in 2017, a UK sanitary product was marketed for the first time using red menstrual blood in the TV advert (see George, 2017). The focus of freshness and concealment subconsciously reinforces menstruation as a 'hygienic crisis', something that is dirty and needs to be controlled (Jackson and Falmagne, 2013). This is also reiterated in the terminology used to describe menstrual products including '*sanitary* towels' and 'feminine *hygiene* products'.

The media adds to the stigmatization of menstruation, often representing it negatively in TV programmes, films, and books (Burgum, 2018). One such example is in Steven King's (1974) book 'Carrie', and the film of the same name by Brian de Palma (1976), in which Carrie's menarche marked the onset of her telekinetic rampage. Mentions of menstruation in film and TV are often used as a way of shaming female characters, or as jibes against a man's masculinity (Burgum, 2018).

A more indirect avenue through which menstrual stigma is conveyed is the silence surrounding menstruation (Johnston-Robledo and Chrisler, 2013). Menstruation is considered a taboo subject, and Laws (1991) proposes the notion of "menstrual etiquette", to encompass the communication and concealment taboos present in British culture. These taboos refer to the idea that menstruation should be kept hidden, and not discussed, particularly with men. Support for the communication taboo comes from the numerous euphemisms used for menstruation; Clue (2016) found that there are over 5000 euphemisms for menstruation used worldwide, spanning many cultures. In her UK based study, Newton (2016) found the most popular examples used by both men and women included "period", "on the rag", "time of the month", "on the blob", "painters and decorators", and "the curse". The use of euphemisms allow people to discuss menstruation more comfortably (Griffith, 2017; Newton, 2016), but simultaneously uphold the stigma surrounding menstruation, as if it were not stigmatised, there would be no need to refer to it by another name (Johnston-Robledo and Chrisler, 2013).

Education and information sources further promote the negativity surrounding menstruation. Many girls learn about menstruation from their mothers, who often encourage notions of silence and concealment, and may also pass on myths and taboos (Beausang and Razor, 2000; Costos et al., 2002). Even if mothers do provide positive messages, they may take their daughters aside to have 'the talk', separate from other family members, which reinforces menstruation as something to be concealed (Kissling, 1996). School is also a key source of education about menstruation, however messages often lack positivity (Beausang and Razor, 2000; Cooper and Koch, 2007). Upon visiting a school during their menstrual education provision, Newton (2016) noted that the topic was introduced as a "messy, sensitive subject", and girls were discouraged from talking about personal experiences. From the start, it was therefore outlined as a topic to be kept secret. Again, the segregation of girls from boys during menstrual education reinforces embarrassment around menstruation (Beausang and Razor, 2000), and strengthens the notion that it should not be discussed in front of males. Educational booklets have also been found to contain much more emphasis on negative aspects of menstruation compared to positive aspects, the only one of which that was mentioned was growing up (Erchull et al., 2002).

2.6.2 Adolescents Experiences of and Attitudes Towards Menstruation

The secrecy, stigma, and taboo surrounding menstruation can have consequences for girls' and women's experience of, and behaviour towards menstruation, and their well-being. Given the cultural representations of menstruation, menarche itself is often approached with some uncertainty (Chrisler, 2017). Unlike other pubertal changes which occur gradually, menarche is a sudden and noticeable event, and therefore women often maintain quite vivid memories of it throughout their lives (Chrisler, 2017). Young women describe mixed reactions towards menarche such as relief, it not being a 'big deal', fear, and embarrassment (Lee, 2008; Newton, 2016). These reactions are affected by the education and messages they receive about menstruation. Many girls describe being unprepared for menarche (Beausang and Razor, 2000; Plan International UK, 2018), particularly when the education they receive is lacking. Those who are less prepared tend to recount more negative feelings (Beausang and Razor, 2000), and those who are more prepared have shown more positive reactions (Marván and Molina-Abolnik, 2012). Newton (2016) found that teenagers associated the onset of menarche with physical maturity or growing up, and thus saw it as a social status changer. Conversely, Jackson and Falmagne (2013) found that some stated it was "weird", and they were too young to feel like a woman at the age of 13 or 14. The timing of menarche can affect reactions to menarche; Marván and Alcalá-

Herrera (2014) found that adolescent girls with early menarche (<11 years) felt scared, worried, and less prepared, and those with late menarche (13+ years) were more likely to feel happy or excited about it. However, UK research suggests that a later onset of menarche may be stigmatising for young women (Newton, 2016).

Negative discourses towards menstruation and menarche have been conveyed by adolescents in qualitative research. Plan International UK (2018) conducted focus groups with young people in the UK and found that the language used when discussing menstruation was overwhelmingly negative. Word such as "annoying" and "inconvenient" were commonplace, and girls expressed fear and embarrassment, particularly over potential "leaking". Many said they felt awkward about talking to men and boys about menstruation. Burrows and Johnson (2005) found that girls (aged 12 – 15) in the UK conveyed shame towards menstrual blood, and their discussion about periods was so negative, researchers asked if there was anything positive about menstruation, to which only one girl responded, albeit in an apologetic way, that it made her feel happy and lively in the middle of her cycle. Such discourses depicting embarrassment, shame, and secrecy about menstruation, have been further highlighted in qualitative research conducted with adolescents/young women in the USA (Beausang and Razor, 2000; Cooper and Koch, 2007; Jackson and Falmagne, 2013; Lee, 2008).

These discourses reflect notions of secrecy, stigma, and taboo about menstruation, as outlined in section 2.6.1. In particular, the societal message of menstruation as something to be hidden has been consistently evidenced in research with adolescent girls, who adopt a variety of methods to maintain concealment of menstruation. Managing menstruation at school forms a significant part of these narratives, and girls have described hiding menstrual products, limiting clothing choices (avoiding wearing white), and refraining from physical activities to conceal menstruation (Burrows and Johnson, 2005; Jackson and Falmagne, 2013; Newton, 2016; Plan International UK, 2018). Girls have expressed anxiety about others at school, particularly boys, finding their pads or discovering they were 'on' (Burrows and Johnson, 2005), and when discovery does occur, i.e., boys finding pads/tampons, they have reported being teased by them (Burrows and Johnson, 2005; Newton, 2016). Occurrences such as these can heighten girls' anxieties around discovery and strengthen their beliefs that menstruation should be concealed.

In addition to concealment, research has also found the tendency for the communication taboo to be upheld by both girls and women. Jackson and Falmagne (2013) found that many young women in their USA sample stated that menstruation was something they would not discuss as girls. If they did, they were often 'commiserating' or receiving support from one another about the negative aspects of menstruation, such as how 'annoying' it is, rather than celebrating it. Cooper and Koch (2007) also found this tendency to only talk about menstruation as a complaint. When menstruation is discussed by adolescent girls, and particularly with males, euphemisms are used as a way to make it less awkward (Newton, 2016).

One of the consequences of the communication taboo is a lack of thorough education or understanding about menstruation. Beausang and Razor (2000) found that the young women in their USA study described the overtone of discomfort when given MHE at school; videos were used rather than it being discussed by teachers, and girls subsequently felt too embarrassed to ask questions. Mothers have also been described to display embarrassment discussing menstruation, the result of which is that they may not provide adequate information or answer their daughter's questions (Beausang and Razor, 2000; Cooper and Koch, 2007). Through such practices, girls may not fully understand about menstruation or what is happening to them at menarche, and may also be unaware about menstrual related medical conditions (Beausang and Razor, 2000; Cooper and Koch, 2007).

The stigma and taboo of menstruation can indirectly impact the health of women and girls. The lack of understanding about menstruation, as well as the lack of awareness about menstrual related conditions, can mean that if problematic symptoms occur, they are not recognised and investigated (Markovic et al., 2008). Furthermore, by not talking to one another about menstruation, women and girls lack the opportunity to compare their experiences with others, and therefore to identify any problems they may be having (Ballard et al., 2006; Markovic et al., 2008). They may also be hesitant or embarrassed to discuss menstruation with doctors, and consequently may not receive treatment or a diagnosis for any menstrual related conditions (Burrows and Johnson, 2005; Seear, 2009a). Finally, the stigma associated with menstruation is often used as a way to market menstrual suppression products (Johnston-Robledo et al., 2006; Mcmillan and Jenkins, 2016), however by artificially controlling the menstrual cycle, menstrual irregularities may be concealed or missed.

Much of the discussion in this section so far has focussed on qualitative research, however several quantitative measures assess people's attitudes towards menstruation. A commonly used measure is the Menstrual Attitudes Questionnaire (MAQ: Brooks-Gunn and Ruble, 1980), which measures menstrual attitudes across many dimensions, including menstruation as bothersome, debilitating, natural, etc. There are different versions of the questionnaire depending on who is completing it (women, men, pre- and post-menarcheal adolescent girls etc.). Adolescent girls completing this measure in the USA have rated menstruation as more debilitating than those older than them (Brooks-Gunn and Ruble, 1980), perhaps the most negative of the attitudes measured (Hoerster et al., 2003). Another measure, designed specifically for adolescents, is the Adolescent Menstrual Attitude Questionnaire (AMAQ: Morse et al., 1993). Using this measure with a sample of 405 Mexican adolescent girls, Marván and Molina-Abolnik (2012) found that negative feelings towards menstruation were most common, followed closely by secrecy, and finally positive feelings.

When searching the literature for adolescents' attitudes towards menstruation, there appeared to be a dearth of recent research in this area in the Global[2] North, particularly quantitative research. Much research has been and continues to be conducted within the Global South. However, attitudes towards menstruation may differ between countries/continents because of different cultural and religious beliefs, as well as societal factors (Bramwell and Zeb, 2006; Hoerster et al., 2003). Attitudes can also vary according to one's own menstrual experiences. Brooks-Gunn and Ruble (1980) found correlations between perceptions of menstruation as "debilitating" and higher symptom scores for pain, negative affect, and concentration. They also found that less severe symptomology was reported by those who denied any effects of menstruation. More recently, Aşcı et al. (2015) found a higher rate of complaints about the severity and symptoms of premenstrual syndrome (PMS) in those with negative menstrual attitudes. In studies like these, it is not possible to tell whether worse menstrual symptoms lead to more negative attitudes, or if the negative attitudes lead to worse perceived symptoms, perhaps because symptoms are given more attention (Chrisler, 2017). It may work both ways; they may both influence each other. Research has however shown that attitudes towards menstruation can change in adolescent girls from pre-menarche to post-menarche (Brooks-Gunn and Ruble, 1982), suggesting that individual experience might play some role. However, menstrual experience does not account fully for menstrual attitudes, as those with no experience of menstruation, i.e. premenarcheal girls and adolescent boys, have displayed well defined negative attitudes (Clarke and Ruble, 1978). This may be due to the messages and socialisation processes surrounding menstruation.

2.6.3 Menstrual Health in Adolescence

This section provides an overview of the patterns of menstruation observed during adolescence (i.e. timing of menarche, regularity of menstruation, menstrual symptoms, etc.) and addresses some of the menstrual health issues that adolescents might encounter. The experience of such issues, as evidenced in qualitative and quantitative research, is also discussed.

The average age of menarche in the UK is 12.9 years, however, the timing of menarche can vary considerably depending on several factors including ethnicity, body weight and socioeconomic status.

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[2] The terms Global North and Global South group countries according to their socio-economic and political characteristics. The Global North incorporates Europe, North America, Australia, and New Zealand. The Global South identifies regions within Latin America, Asia, and Africa.

Approximately 9.5% of girls begin to menstruate before the age of 11.2 years (Kelly et al., 2017), and 90% of girls have reached menarche by 13.75 years (Chumlea et al., 2003). Once menstruation has commenced, it can take adolescents some time to settle into a regular menstrual cycle. During the first year after menarche, it is common for cycles to be irregular, but 80% fall within 21 to 45 days duration, with menstrual bleeding lasting between 2 and 7 days (Slap, 2003). By the third year after menarche, 95% of cycles fall within this range, and an individual's stable cycle length is usually established by the sixth year (Slap, 2003).

It is common for adolescents to report menstrual issues including irregular cycles, amenorrhea, menorrhagia, and dysmenorrhea. The prevalence of irregular cycles amongst adolescents has varied in previous research, with studies reporting a prevalence of 9% (Rigon et al., 2012), 23.1% (Agarwal and Venkat, 2009), and 30.5% (Parker, 2006). Variations may be due to the different age groups surveyed; those in the Rigon et al. (2012) study had a higher average age, and Agarwal and Venkat (2009) found that increasing age was associated with decreased prevalence of cycle irregularity. Adolescents with polycystic ovary syndrome (PCOS), who experience irregular cycles, describe feeling "distressed" and "different" due to the irregularity (Jones et al., 2011). They also stated they find it difficult to know when menstruation might occur, and so must always be prepared (Ibid). Young women in research by Donmall (2013), who experience irregular cycles, described a fear of being 'caught short', prompting some to take the contraceptive pill. They consistently described this symptom as "annoying".

Amenorrhea, or the absence of menstruation, is defined as primary if menses have not commenced by age 16, and secondary if three or more menstrual periods are missed any time after the first period (Slap, 2003). Primary amenorrhea is rare, occurring at a rate of approximately 2%, however this figure rises to 7.3% in those who are elite athletes (Torstveit and Sundgot-Borgen, 2005). Secondary amenorrhea also occurs infrequently, in approximately 4% of the population, and is linked to factors such as athleticism, eating disorders, and hormone imbalance (Popat et al., 2008). Amenorrhea can impact the quality of life (QOL) in adolescents (Azurah et al., 2013; Yang and To, 2006), affect their femininity, and cause worry over the prospect of infertility (Jones et al., 2011).

Menorrhagia, or heavy menstrual bleeding (HMB) has been reported at a prevalence of between 17% (Chan et al., 2009) and 37% (Friberg et al., 2006; Revel-Vilk et al., 2012) in adolescents. HMB is defined as menstrual blood loss of more than 80ml per cycle (Hallberg et al., 1966), however young women find their blood loss difficult to quantify, and may refer to pads/tampons used within 24 hours (Wood et al., 2007). Using a pictorial blood assessment chart (PBAS) Revel-Vilk et al. (2012), found that 36% of their adolescent sample met criteria for HMB, although only 15% thought that they had it. HMB can be a reason for school absence during menses (Parker, 2006), and reduced participation in sporting, social, or other daily activities (Li et al., 2020). Adolescents with HMB report anxiety in managing their bleeding, particularly at school, and may spend significant time in the bathroom (Li et al., 2020). The necessity to change menstrual products in the night may also cause sleep disturbance (Ibid). HMB during adolescence is also associated with anaemia (Revel-Vilk et al., 2012).

Dysmenorrhea, or pain during periods, occurs commonly during adolescence. It is defined as primary dysmenorrhea if pelvic anatomy and ovulatory function are normal, and as secondary if pelvic or hormonal pathology is identified (Slap, 2003). Primary dysmenorrhea can usually be effectively treated using either non-steroidal anti-inflammatory drugs (i.e. ibuprofen, naproxen, Mefenamic acid) or oral contraceptives, however secondary dysmenorrhea may be less responsive to these (Slap, 2003). A high percentage of adolescents report pain during their periods, ranging from 68% in Italy (Zannoni et al., 2014), to 73% in Brazil (Pitangui et al., 2013), to 83.2% in Singapore (Agarwal and Venkat, 2009), and up to 93% in Australia (Armour et al., 2020a; Parker et al., 2010). Wide variation in dysmenorrhea rates among adolescents is likely due to different measures for dysmenorrhea and a failure to distinguish between if primary or secondary dysmenorrhea is measured (De Sanctis et al., 2016). Two recent international meta-analyses found the prevalence of dysmenorrhea in 13-23 year olds was 71.1% (Armour et al., 2019b) and 78.5% (Armour et al., 2019a). There were no studies found on prevalence rates in the UK for inclusion in either meta-analysis.

Studies reporting on these rates of dysmenorrhea often include data on the severity of pain, and how this influences life activities. The proportion of adolescents reporting severe pain varies considerably between studies, for example 11.6% (Agarwal and Venkat, 2009), 20.9% (Parker et al., 2010), and 56% (Rigon et al., 2012), and is likely due to different measures for assessing pain severity. Nevertheless, severe menstrual pain has been associated with increased school absenteeism (Agarwal and Venkat, 2009; Armour et al., 2020a; Parker et al., 2010; Pitangui et al., 2013), greater interference with daily activities (Parker et al., 2010; Pitangui et al., 2013), increased likelihood of seeking medical care (Pitangui et al., 2013), and greater use of analgesics (Agarwal and Venkat, 2009).

Regardless of severity of pain, dysmenorrhea has been consistently cited to affect school attendance for adolescents, and affects school activities, sporting activities, and social participation (Armour et al., 2020a; Armour et al., 2019b; Hillen et al., 1999; Parker et al., 2010). Dysmenorrhea can also impact the quality of life of adolescents (Azurah et al., 2013; Wong, 2018; Yang and To, 2006). These findings have also been reiterated in qualitative research, although such research addressing the experiences of adolescents with dysmenorrhea is lacking (Chen et al., 2018; Li et al., 2020). In addition to impacts on school, social and sporting activities (Allyn et al., 2020; Li et al., 2020), qualitative research has indicated that women and adolescents view their pain as a normal part of being a woman (Chen et al., 2018; Wong et al., 2014), and that healthcare providers, society and employers showed little sympathy and did not consider dysmenorrhea a legitimate health issue (Chen et al., 2018; Li et al., 2020).

It may therefore be unsurprising that despite the high prevalence of problematic menstruation, few adolescents seek medical help for their symptoms. Pitangui et al. (2013) found that 73% of their Brazilian sample of adolescent girls reported dysmenorrhea, but only 13% sought medical help. Similarly, Wong (2011) found dysmenorrhea reported by 76% of Malaysian adolescent girls, and only 14.8% had sought medical help. This may be in part due to adolescents' assumptions of what constitutes 'normal' menstruation; if they believe that period pain is 'normal', they may be unlikely to seek help for it. Armour et al. (2021a) surveyed 13–25-year-olds and found that 92% experienced moderate or greater levels of period pain, causing significant life disruption, yet more than half thought their period was 'normal'.

Given the variations in the timing of menarche, the time taken to establish a regular bleeding pattern, and menstrual pain levels, it is difficult for anyone to ascertain what 'normal menstruation' is during adolescence, let alone for adolescents themselves. Wood et al. (2007) suggest that adolescents may piece together an idea of what they think is 'normal', based on their own experience, that of their friends, and the education they receive about menstruation, which as discussed previously, can be lacking. Given that periods are novel to them, then adolescents do not have a personal frame of reference upon which to assess their symptoms (Slap, 2003), and so even pain that is considered to be 'abnormal' in comparison to others' pain, may still be considered 'normal' for themselves, particularly if it is all they have ever known (Wood et al., 2007). Pain or other bothersome symptoms may then become normalised over time (Armour et al., 2021a). Wood et al. (2007) found that only if period symptoms were extreme, or were unpredictable and inconsistent, did young women perceive them to be 'abnormal'. Armour et al. (2021a) found that as pain became more severe, young women were less likely to consider them 'normal', however it did not translate into help seeking behaviours.

Therefore, even if problematic menstruation is recognised, it may not always be acted on. This may be in part due to widely held beliefs that menstrual symptoms are an integral part of female life, and are therefore something to be endured, even if they are severe (Armour et al., 2021a; Markovic et al., 2008; Wong, 2011). Adolescents may also attempt to self-manage their symptoms before seeking help (Li et al., 2020), however, they have consistently been found to take a sub-therapeutic dose of over the counter medications (Armour et al., 2021a; Armour et al., 2019a; O'Connell et al., 2006), and so this may not always alleviate symptoms.

Another potential factor in delayed help seeking may be that when adolescents do seek help, their pain is often normalised (Li et al., 2020), which may deter or disillusion them (Armour et al., 2021a). Further medical investigation occurs infrequently, as highlighted by Parker et al. (2010) in their study of 1051 Australian adolescent girls. They found that 35% of the sample reported problems with their periods, 25% displayed symptoms suggestive of marked menstrual disturbance (including moderate to severe pain, school absence, and high interference with life activities), and 33% had seen a GP regarding menstruation. However, only 9% had been referred to a specialist for further investigation, and less than 1% (10 girls) had received a clinical diagnosis (i.e. endometriosis or PCOS). This may reflect a reluctance of health professionals to refer or operate on adolescents due to their age, and perhaps a lack of acknowledgement that serious pathology can occur in adolescents (Parker et al., 2010). In addition, adolescents may experience difficulties providing a menstrual history to physicians as they do not have a frame of reference against which to assess their symptoms (Slap, 2003). Therefore, if adolescents do seek help for menstrual symptoms, there may be obstacles on both sides of the encounter.

This section has highlighted the wide variation of menstrual experiences in adolescents, and the issues associated with menstruation they may encounter. Dysmenorrhea occurs most commonly, with many adolescents experiencing moderate to severe levels of ‘period pain’. Comparatively few adolescents seek medical help for their symptoms, but if they do, then investigation for causes of secondary dysmenorrhea, such as endometriosis is rare (Parker et al., 2010). Despite the prevalence of endometriosis (see Section 2.2.2), and the widespread disruption to adolescent life that is caused by symptoms suggestive of endometriosis (i.e. dysmenorrhea, HMB), there is a lack of research into the experience of endometriosis in adolescents (Culley et al., 2013; Young et al., 2015). Chapter 3 of this thesis is a systematic narrative review of what is currently known about how endometriosis is experienced by adolescents. However, more research has been conducted on the experience of women with endometriosis, which is discussed in the following section.

2.7 Women’s Experiences of Endometriosis

The impact of endometriosis on women’s lives has received modest research attention, studied both qualitatively and quantitatively. Qualitative research often uses interviews or focus groups to explore the experience of living with endometriosis, or a particular aspect of it. Quantitative research has assessed the health-related quality of life (HRQoL) of those with endometriosis, their mental wellbeing, and the impact on work productivity, among other factors. By summarising the qualitative and quantitative research together, it enables an understanding of the prevalence of the issues women experience (quantitative), and an exploration of why these occur (qualitative) (Broom and Willis, 2007). This topic has been reviewed more extensively elsewhere (Culley et al., 2013; Young et al., 2015), and therefore only an overview of key findings is provided herein.

2.7.1 Symptoms

Women with endometriosis (WWE) experience a diverse range of symptoms, but most commonly pelvic pain (dysmenorrhea and CPP), dyspareunia (pain associated with sexual intercourse), and infertility (Acién and Velasco, 2013). Pain can also occur in the bowel, bladder, kidneys, legs, and back. WWE have described their pain in qualitative research, often describing it as different to 'normal' period pain, and using terms such as severe, horrendous, crippling, nauseating, debilitating, and paralysing (Denny, 2004a; Grogan et al., 2018; Huntington and Gilmour, 2005; Moradi et al., 2014). Metaphors or similes are often used to describe pain (Bullo, 2019), with notions of being stabbed, knifed, or torn, being common (Denny, 2004a; Drabble et al., 2021; Moradi et al., 2014). Women have described this pain occurring around menstruation, ovulation, and sometimes constantly (Denny, 2004a; Huntington and Gilmour, 2005; Manderson et al., 2008). Women have also reported that their pain has progressed in intensity/duration over time (Drabble et al., 2021; Huntington and Gilmour, 2005).

Another symptom frequently reported by WWE is dyspareunia, and is described as sharp, deep, dragging, and agonising (Denny, 2004a; Drabble et al., 2021; Huntington and Gilmour, 2005; Seear, 2009a). This can occur during sexual intercourse but can continue for hours or days after. Large cross-country studies have found the incidence of dyspareunia to be between 25% (Bernuit et al., 2011) and 47% (De Graaff et al., 2013), but in smaller studies it has been found in as many as 80% of participants (Denny, 2004a). Some women have stated they have not reported this symptom to doctors due to embarrassment (Denny, 2004a; Griffith, 2017). Another common symptom of endometriosis is infertility. Women have reported feeling worried or even depressed about the prospect of infertility or a diagnosis of such, stating it affects their perceived femininity (Jones et al., 2004c).

2.7.2 Delay in the Diagnosis of Endometriosis

The often-considerable time taken to receive a diagnosis of endometriosis has gained much attention and is a prominent feature of women's experience of endometriosis (Culley et al., 2013; Young et al., 2015). Current estimates suggest the diagnostic delay is 7.5 to 8 years in the UK (Endometriosis UK, 2011; Ghai et al., 2020). This delay occurs at two levels; the ‘patient level’, between symptom onset and seeking medical help, and; the ‘medical level’, between seeking medical help and receiving a diagnosis (Ballard et al., 2006). In a large international sample, De Graaff et al. (2013) found the average patient level delay was 2.1 years, and the average medical level delay was 4.6 years. In a recent UK report, the median delays were 1 year at the patient level, and 3 years at the medical level, however this was based on a small sample, all recruited from one tertiary care centre (Ghai et al., 2020).

Several factors are involved at the patient level. Women have described being unable to distinguish between normal and abnormal menstrual symptoms, and even if pain was extreme and disruptive, they often just thought of themselves as being unlucky (Ballard et al., 2006; Denny, 2004b; Moradi et al., 2014). Some WWE have said this was in part because they lacked understanding or awareness of endometriosis (Moradi et al., 2014), and when symptoms are disclosed to others (i.e. friends, family, doctors), they also lack awareness, and therefore often dismiss them as normal menstruation (Denny, 2004b). Embarrassment also prevents women from discussing their symptoms, and they therefore miss the opportunity to compare them with others (Ballard et al., 2006). Denny (2004b) and Seear (2009a) discuss the ‘etiquette of menstruation’ (Laws, 1991), whereby menstruation is considered to be something that is kept hidden, and not mentioned in front of others, particularly males. Mothers and friends may actively encourage this concealment (Seear, 2009a). Feeling unable to discuss or disclose to others, or believing their symptoms are ‘normal, some woman have attempted to tolerate them for many years before seeking help (Markovic et al., 2008), and some have only sought help when experiencing fertility issues (Manderson et al., 2008).

Medical level delays are also multifaceted. Often, these occur in primary care, and women have often reported making multiple visits to their doctor before being referred to secondary care, during which their symptoms were dismissed, normalised, or undermined (Ballard et al., 2006; Denny, 2004b; Grogan et al., 2018; Jones et al., 2004c). Denny and Weckesser (2019) describe the gendered notion of pain; perceptions that women are more likely to report and experience pain, and it is therefore viewed as ‘normal’ for them, and as such, not treated appropriately. Additional delays occur when women undergo a period of ‘hormonal suppression’, whereby doctors attempt to treat the symptoms before referring them for further investigation (Ballard et al., 2006; Denny, 2009). Misdiagnoses and inappropriate secondary care referrals are also common (Denny and Mann, 2008; Moradi et al., 2014).

Without a diagnosis, women have described finding it difficult to explain to others what was wrong, which could create problems in work and social settings (Ballard et al., 2006; Huntington and Gilmour, 2005). The receipt of diagnosis is often described as a relief, it legitimises pain, and provides a label with which women can discuss their experiences (Ballard et al., 2006; Cox et al., 2003c; Facchin et al., 2018; Fernley, 2021). It also provides reassurance, that symptoms are not “in the head” (Cox et al., 2003c; Huntington and Gilmour, 2005; Moradi et al., 2014), and that it was not something more serious (Ballard et al., 2006; Huntington and Gilmour, 2005; Moradi et al., 2014). The diagnosis could be viewed as empowering, allowing women to seek appropriate support (i.e. ‘endo warriors’), and to help advocate for those yet to receive their diagnosis (Fernley, 2021). Diagnosis can also bring about negative feelings including anger and frustration, particularly at not being listened to or believed for so long (Denny and Mann, 2008; Moradi et al., 2014). There is also the realisation that endometriosis has no cure, and thus must be managed indefinitely (Denny, 2009; Moradi et al., 2014). In those who are asymptomatic (i.e. presented for infertility), a diagnosis can be quite confronting (Cox et al., 2003c).

2.7.3 Medical Experience

WWE have discussed positive and negative encounters with medical professionals, but negative encounters are more predominant. They have frequently reported being dismissed by General Practitioners (GPs), who have normalised symptoms or failed to take them seriously, thus delaying referral to secondary care. Women have recounted being told medical myths, such as endometriosis does not affect teenagers (Denny and Mann, 2008), and that having a baby would cure their symptoms (Denny and Mann, 2008; Facchin et al., 2018; Huntington and Gilmour, 2005; Moradi et al., 2014). Some believe that medical professionals lack knowledge of endometriosis (Denny and Mann, 2008; Gilmour et al., 2008; Jones et al., 2004c), or do not provide enough information about it (Cox et al., 2003a). In addition to contributing to diagnostic delays, these negative encounters cause women to question the validity of their own symptoms (Ballard et al., 2006), leave them feeling helpless, and instil a pressure to have children before being ready (Facchin et al., 2018). Positive experiences were described by women who felt they were given enough information, were listened to, and were promptly referred for investigation (Denny and Mann, 2008; Facchin et al., 2018).

In addition to medical encounters, women often report their experiences of treatments for endometriosis. The use of hormonal treatments is common; De Graaff et al. (2013) found that 79% of their international sample had used at least one form of hormonal treatment. These treatments have often been described as ineffective (Moradi et al., 2014), or providing only temporary relief of symptoms, which reoccurred once discontinued (Denny, 2009; Huntington and Gilmour, 2005). In addition, side effects are often reported, such as breakthrough bleeding, moodiness, weight gain, and menopausal changes, which can themselves be the cause of discontinuation (Denny, 2009; Moradi et al., 2014). Some women have expressed concern over the long-term effects of medical treatments, and particularly about becoming tolerant to painkillers (Denny, 2009). Women have typically described more symptom relief from surgery, such as laparoscopy, however this is seldom long-lasting, as symptoms tend to return (Denny, 2004a; 2009; Huntington and Gilmour, 2005; Moradi et al., 2014). Experience of multiple surgeries is therefore common (De Graaff et al., 2013). The ongoing treatment cycle causes despair (Huntington and Gilmour, 2005), and some therefore contemplate more drastic surgery such as a hysterectomy (Huntington and Gilmour, 2005; Moradi et al., 2014). Women may also look for alternate ways to cope with their symptoms, such as diet and exercise (Roomaney and Kagee, 2016).

2.7.4 Life Interference

Research studies assessing QoL in WWE have used generic measures and disease specific measures including the Endometriosis Health Profile 30 (EHP30; Jones et al., 2004b; Jones et al., 2006; Jones et al., 2001), EHP5 (Jones et al., 2004a), and the Stellenbosch Endometriosis QoL measure (SEQOL: Roomaney and Kagee, 2018a). Findings suggest reduced QoL among WWE (see e.g. De Graaff et al., 2013; Facchin et al., 2015; Fourquet et al., 2011). Pain appears to be a significant feature in reduced QoL, as studies have reported a correlation between increasing pain and reduced QoL (Nnoaham et al., 2011; Sepulcri and do Amaral, 2009).

The symptoms of endometriosis interfere with many aspects of women's lives. They are reported to disrupt education, impacting school attendance, productivity, grades, educational attainment, and course completion (Gilmour et al., 2008; Manderson et al., 2008; Moradi et al., 2014). Similar disruptions have been noted in the workplace, effecting both productivity and attendance. Evidence suggests that WWE lose between 7.41 hours (Fourquet et al., 2011) and 10.8 hours (Nnoaham et al., 2011) of work time per week when symptoms are at their worst. Nnoaham et al. (2011) found this was mainly due to reduced productivity, suggesting that women are more likely to go into work than be absent, perhaps due to hesitance in disclosing their condition. This is evidenced in qualitative research, in which women have described difficulties explaining work absences to co-workers, particularly males (Facchin et al., 2018; Gilmour et al., 2008; Jones et al., 2004c), and are worried about being perceived as malingerers, with no observable signs of illness (Gilmour et al., 2008). Women have often reported needing to work part-time or flexible hours due to their symptoms (De Graaff et al., 2013; Gilmour et al., 2008; Grogan et al., 2018), which could hinder employment opportunities, career progression, and household income (Huntington and Gilmour, 2005; Moradi et al., 2014).

Evidence suggests a reduction in attendance at social events due to endometriosis, and WWE have consequently experienced diminished social relationships and isolation (Denny, 2009; Gilmour et al., 2008; Jones et al., 2004c; Moradi et al., 2014). Participation in sport or leisure activities is also reportedly reduced, often due to pain, heavy bleeding, and fatigue (Facchin et al., 2018; Grogan et al., 2018; Moradi et al., 2014), and sometimes bowel/bladder symptoms, which have necessitated quick access to a toilet (Gilmour et al., 2008).

In addition to social relationships, endometriosis can have a marked impact on intimate relationships. De Graaff et al. (2013) found that 50% of their sample reported endometriosis had affected these relationships, and 10% considered it the reason for their divorce. Qualitative research corroborates this, in which the stresses and strains of living with endometriosis are described to cause relationship difficulties and breakdowns (Denny, 2004a; Facchin et al., 2018; Huntington and Gilmour, 2005). Dyspareunia significantly interferes with intimate relationships, with women reporting limiting or avoiding sexual activity (De Graaff et al., 2013; Jones et al., 2004c; Moradi et al., 2014), and subsequent feelings of guilt (Denny and Mann, 2007; Facchin et al., 2018). Infertility can also put a strain on relationships for WWE (Facchin et al., 2018; Jones et al., 2004c; Moradi et al., 2014; Roomaney and Kagee, 2018b). However, despite such strains, partners have also been identified as an important and significant source of support (Denny, 2004a; Facchin et al., 2018).

The interference of endometriosis is further compounded by the unpredictability of symptoms. While some women only experience symptoms at the time of menses, studies have found that between 60% (De Graaff et al., 2013) and 77% (DiVasta et al., 2018) also experience acyclic pelvic pain. This unpredictability has been reported to make it hard for women to make plans, including social events and holidays, and they have therefore described feeling like life is on hold, or is controlled by endometriosis (Denny, 2009; Jones et al., 2004c; Moradi et al., 2014).

Uncertainty also extends into the future, and women have indicated concern that symptoms will return, or worsen, and are unaware of their long-term prognosis (Denny, 2004a; 2009; Jones et al., 2004c; Moradi et al., 2014). Other concerns include possible interference with work, education, and intimate relationships (Moradi et al., 2014), and fears about passing the condition on to daughters (Jones et al., 2004c; Moradi et al., 2014). One of the main concerns, however, relates to fertility; women have expressed worry about both their ability to have children (Denny, 2009; Facchin et al., 2018; Jones et al., 2004c), and the financial costs involved if they need fertility treatment (Moradi et al., 2014). The prospect of infertility can impact HRQOL, and challenge one’s notions of womanhood (Roomaney and Kagee, 2018b). While many express a pessimistic future outlook, some women have shown hope towards their future, particularly if they were pain free when interviewed (Denny, 2004a;

2009). One study also indicated that younger women were more likely to express hope about their future, perhaps because they had not had as many relapses and false hopes as older women (Denny, 2009).

2.7.5 Psychological and Emotional Impact

Endometriosis has been associated with emotional and psychological impacts including depression, anxiety, low self-esteem, low self-confidence, lack of control (powerlessness: Jones et al., 2001), and dissatisfaction with appearance. Quantitative research has reported moderate (Fourquet et al., 2011; Low et al., 1993; Roomaney et al., 2020) to high (Sepulcri and do Amaral, 2009) rates of depression, with discrepancies potentially due to sampling differences, as low socioeconomic status may have contributed to observed high levels (Sepulcri and do Amaral, 2009). Anxiety has also been found to be elevated in WWE (Low et al., 1993; Sepulcri and do Amaral, 2009), as has emotional distress (Fourquet et al., 2011). Increased anxiety, depression, and emotional distress in WWE appears to be particularly prevalent in women with increased pain levels (Facchin et al., 2015; Sepulcri and do Amaral, 2009). Lorencatto et al. (2006) compared depression rates in WWE between those with pelvic pain and those without, and observed rates of 86% and 38% respectively. Roomaney et al. (2020) examined predictors of depression in WWE and identified that physical functioning, feelings about the medical profession, and sexual relationships, were all significant predictors.

Qualitative research further explores the issues that affect women emotionally. Some research has indicated that endometriosis interferes with a woman's female identity. For example, Moradi et al. (2014) found that an inability to have sex, not being the mother they wanted to be able to be, and being infertile, were all factors that could impact women's identity. Infertility has been described to particularly affect one's female identity, as well as having other emotional impacts including distress, anxiety, and lowered self-esteem (Cox et al., 2003a; Facchin et al., 2018; Jones et al., 2004c; Roomaney and Kagee, 2018b). Women have also reported negative impacts on their physical appearance, including spots, bloating, weight gain and surgical scars (Jones et al., 2004c; Moradi et al., 2014) which can affect self-confidence.

The long delay in receiving a diagnosis has also been reported to cause emotional impact. Being dismissed or disbelieved by healthcare professionals impacted self-esteem (Cox et al., 2003a), and had women questioning whether they were going insane (Facchin et al., 2018). The failure of healthcare professionals to legitimise symptoms has also intensified feelings of loneliness (Cox et al., 2003a). Loneliness was described to be further compounded by a lack of support and understanding from those in many settings including work, healthcare, family, intimate partners, and friends (Cox et al., 2003a; Facchin et al., 2018; Jones et al., 2004c). While WWE have sometimes described to feel ‘miserable’, ‘upset’ or ‘moody’, some have indicated significant impairment, including severe depression, panic attacks (Facchin et al., 2018), and even thoughts of suicide (Cox et al., 2003a).

2.8 Chapter Summary

This chapter has provided an overview of topics relevant to this area of study. While there is little known about adolescents’ experiences of endometriosis, there has been some research addressing how other chronic illnesses can affect adolescents, which has highlighted their significant impact, particularly on key developmental tasks such as developing autonomy and maintaining relationships. While such research is useful, it makes little reference to the influence of gender on the experience of chronic illness in adolescence, and there is a dearth of research exploring conditions which only affect females. Research exploring the experience of menstruation during adolescence provides insight, as endometriosis is closely linked to menstruation. This highlights the secretive nature of menstruation, and the embarrassment that adolescents may feel in discussing menstruation. Those that experience problematic menstruation may not seek help for their symptoms, despite the significant disruption they cause to their lives. These issues have also been documented in research exploring the experiences of women with endometriosis. Such research has provided a good understanding of how endometriosis affects women, particularly in terms of the interruption to their lives and the emotional impact of endometriosis. However, the experiences of adolescents may differ, as they are also negotiating the rapid physical, social and emotional development associated with adolescence. The next chapter of this thesis will use a narrative review method to synthesise and summarise the current research pertaining to adolescents’ experiences of endometriosis. This will provide an understanding of what is currently known and will highlight areas for further exploration within this thesis.

Chapter 3. The Experience and Psychosocial Impact of Endometriosis in Adolescents: A Systematic Narrative Review

3.1 Introduction

Research into adolescent endometriosis has had a largely medical focus, with much attention paid to its clinical presentation and response to treatment (Saridogan, 2017); however very little research has specifically addressed the illness experience of endometriosis in this demographic. As highlighted in Section 2.7, research exploring women's experience of endometriosis has indicated that it impacts significantly on their lives. However, those reviewing this evidence base have emphasized the lack of inclusion of adolescents in such research (Culley et al., 2013; Young et al., 2015), which is imperative given that adolescence is a crucial stage for identity development.

Research with WWE has not specifically included adolescent perspectives; however, participants have often recalled the issues they faced as a teenager. These include missing school due to symptoms (Manderson et al., 2008; Markovic et al., 2008), being dismissed by healthcare providers, or being told they were too young to have endometriosis (Cox et al., 2003a; Denny, 2004b; Denny and Mann, 2008; Markovic et al., 2008), and a lack of information and education provision during adolescence (Cox et al., 2003c; Markovic et al., 2008). While providing some insight into adolescents' experiences, these accounts rely on retrospective recall, and therefore may not capture aspects of the experience which might be particularly salient *during* adolescence.

A recent review on the psychosocial impact of endometriosis during adolescence (Fedele, 2021) highlighted the substantial effect of endometriosis on the QoL of adolescents; they struggle with significant pain, impaired physical and social functioning, and impacts on their overall well-being. Although providing some contribution, the review was not conducted systematically, and there were no details on the screening process, eligibility criteria (including age range of adolescents), or participant characteristics of the included studies. Furthermore, only 5 studies were included, they were mainly quantitative studies, and one did not include participants with endometriosis. While quantitative research does give an indication of the prevalence of certain issues, it cannot provide detail on why such issues may occur (Broom and Willis, 2007). Qualitative research enables a thorough and complex understanding of an issue, and how people make sense of their experiences (Bryman, 2016). Synthesising both the qualitative and quantitative research together will provide a more thorough understanding of the issues faced by adolescents with endometriosis, and will highlight areas which need further exploration.

Therefore, to guide further research into adolescents' experiences of endometriosis, a systematic narrative review was undertaken. The aim of the review was to identify and synthesise the existing body of research on the experience and psychosocial impact of endometriosis in adolescents.

3.2 Methods

In order to meet the review aim, a critical narrative synthesis method was used (Popay et al., 2006). Such a method allows for the inclusion of diverse methods and research questions, and therefore enables the synthesis of both qualitative and quantitative research (Culley et al., 2013). Where applicable, the PRISMA principles were also adhered to (Moher et al., 2009).

3.2.1 Search Strategy

Systematic literature searches were conducted in June 2018, and updated in November 2021, on eight health, medical, and social science databases. In addition, a manual search was conducted on one relevant key journal. The databases searched and the search terms used can be seen in Table 3.1. Search terms were derived by reviewing the abstracts and keywords of papers written about women's experiences of endometriosis, as well as the search terms used in similar literature reviews. The final terms used were agreed by the candidate and all members of the supervisory team. The limiters "English Language" and "Humans" were set on the searches.

Table 3.1: Research Databases and Search Terms

Database/Journal	Search Terms
CINAHL Medline Web of Science Pubmed	Endometriosis AND (adolescen* OR teenager* OR "young wom?n" OR "young adults" OR girl*) AND (Qualitative OR "quality of life" OR "lived experience" OR interview OR "focus group" OR "case study" OR "well-being" OR experience* OR social OR socio* OR psycho* OR depression OR anxiety OR distress OR emotion* OR questionnaire OR survey)
PsycINFO PsycARTICLES ASSIA SAGE	Endometriosis AND (adolescen* OR "young wom?n" OR "young adults" OR girl*)
Journal of Paediatric and Adolescent Gynaecology	Endometriosis (in title or abstract)

Finally, a Google Scholar alert was set up to identify any relevant/new articles occurring after the search (up to November 2022), and the Cochrane Library was searched for relevant reviews.

3.2.2 Inclusion and Exclusion Criteria

This review aimed to include the fullest range of methodologies, thus quantitative, qualitative, and mixed method studies were included. To ensure a broad overview of currently available literatures, articles were included regardless of if endometriosis was a major or minor theme of the article. There were no restrictions based on the publication date of the articles.

Studies were included if they reported on the experience of living with endometriosis as an adolescent. Papers reporting on broader topics (i.e. experience/efficacy of endometriosis treatment), were only included if they additionally reported the social and psychological impact of endometriosis in adolescents, including having used Quality of Life (QoL) measures. Papers which investigated 'medical' aspects of endometriosis in adolescents, such as prevalence and clinical features, were excluded, as well as reviews, abstracts, commentaries, and opinion pieces. Only papers reporting on those with surgically confirmed endometriosis were included, as this is accepted as the gold standard for a diagnosis of endometriosis (Kennedy et al., 2005).

For this review, the age range for adolescence was defined as 10 to 24 years. This age range corresponds to contemporary notions of adolescence, and incorporates the time period from puberty to the transition into adult social roles (Hagell et al., 2013; Sawyer et al., 2018). Thus, studies were included in the review if the sample primarily encompassed this age range, if the mean of the sample fell within this age range, or if the sample was identified as 'adolescents' or 'teenagers' with no further specificity. Studies which included adolescents and adults were only included in the review if they presented the results for the adolescent sample separately. Studies that retrospectively asked adult women about their experiences during adolescence were not included. Finally, articles were only included if they were peer reviewed and were reported in English language.

3.2.3 Screening for Studies

The screening process is summarised in Figure 3.1 . The search results were imported into EndNote, which enabled identification and deletion of duplicates. The titles and abstracts of the remaining papers were screened for suitability by the candidate (AR) and a supervisor (AH) independently, and those not immediately meeting the inclusion criteria were excluded. Full text articles for the remaining papers were retrieved and scrutinised according to the inclusion criteria, again by AR and AH independently, and those deemed ineligible were excluded. Finally, the references of all eligible papers were searched to identify any additional suitable papers, but none were found. Any discrepancies regarding the inclusion of papers were resolved through discussion between reviewers.

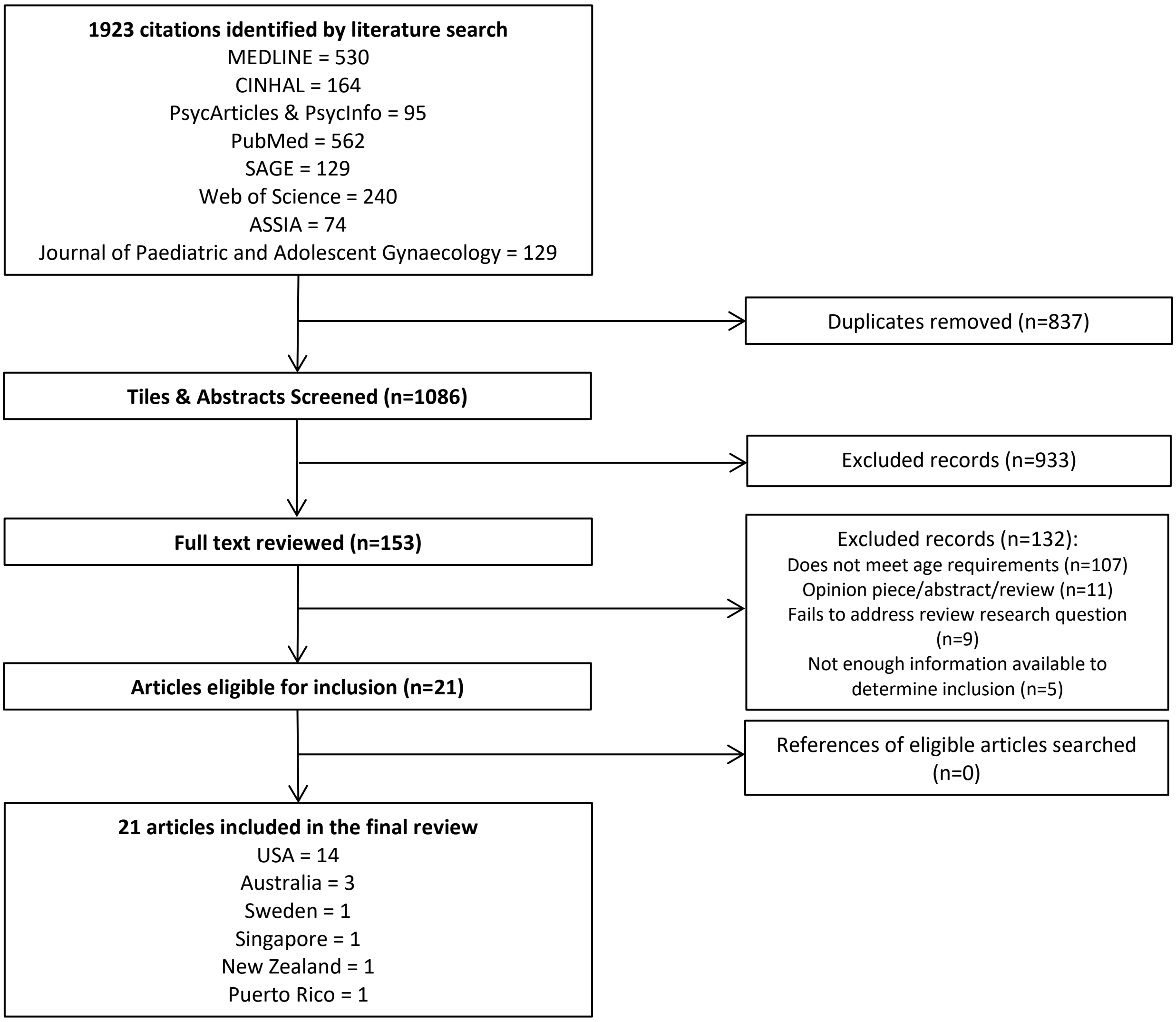

Figure 3.1: Literature Search and Screening Process

3.2.4 Quality Appraisal

The Mixed Methods Appraisal Tool (MMAT: Hong et al., 2018) was used to assess the quality of the articles included in the review. This critical appraisal tool can be used to evaluate the quality of studies in the following categories: qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed-methods studies. A quality criteria checklist is provided for each category. All papers were appraised by two researchers independently (AR all papers, AW qualitative papers, GJ/AH quantitative and mixed-methods papers). Any discrepancies were resolved by bringing in a third appraiser.

3.2.5 Data Extraction

A data extraction form was developed and completed for each paper that met inclusion criteria (See Appendix 1). These recorded details including the authors names, research setting, aims, design, sample characteristics, analysis, key findings, key themes, and limitations.

3.2.6 Analysis

To synthesize the findings from the papers, analysis of the extracted data was conducted according to standard principles of systematic thematic analysis (Braun and Clarke, 2006; 2013). The PhD candidate and one supervisor (AH) independently coded the extracted data and developed a preliminary list of descriptive themes, which identified the main, or recurrent themes/ideas across the papers. These lists were discussed and refined between the candidate and two supervisors (AH & AW) and the final five substantial themes were agreed upon. The extracted data was then reorganised according to these themes.

3.3 Results

The search strategy resulted in 21 papers eligible for inclusion in the review (see Table 3.2); these 21 papers reported on 19 studies, as two published multiple data. All papers were published between 2004 and 2021, and all but one were conducted in high-income countries, with most papers coming from the United States of America (USA). There were no studies conducted within the UK. There were 4 qualitative studies, 14 quantitative studies, and 3 mixed-methods studies. Qualitative studies used mainly semi-structured interviews and quantitative studies used a variety of Health-Related Quality of Life (HRQoL) instruments, psychological assessments, and symptom inventories.

Sample sizes varied from 2 to 16 participants with endometriosis in the qualitative studies, and from 18 to 360 in the quantitative studies (where data is complete). While most papers referred to their sample as ‘adolescents’, there was considerable variability in the age ranges chosen including those aged 10-24 years, 15-21 years, and <20 years, to highlight a few. All papers reported on participants with surgically diagnosed endometriosis, and most participants were recruited through specialist clinics or support organisations. In addition to age, 12 studies reported on participants’ ethnicity, but little other demographic information was provided.

The MMAT was used to appraise the quality of the included articles (See Appendix 2). The qualitative, non-randomised, and quantitative descriptive studies were largely of good quality, supplying much of the information needed to make an accurate judgement (scoring 5-7 out of 7). However, the RCTs and mixed methods studies were deficient in some areas in addressing the quality criteria (scoring 3-5 out of 7). Hong et al. (2018) advise against using studies with low overall methodological quality; however, given the paucity of research on this topic, it was deemed appropriate to use all the existing studies meeting the inclusion/exclusion criteria, taking into account the lack of information regarding methodological quality in some of the papers.

Table 3.2: Paper Characteristics

Type of study	Author (year of publication), Country	Sample Size	Sample age range (years)	Aim	Data collection method	Reference Type
Qualitative	Conboy et al. (2008) USA	7	14-22	To explore the experiences of acupuncture for the treatment of chronic pelvic pain (CPP) in adolescents with endometriosis.	Semi-structured interviews	Journal Article
	Highfield et al. (2006) USA	2	Not stated (described as 'adolescents')	To describe the impact of a course of acupuncture on two adolescents with endometriosis related chronic pelvic pain	Case reports	Journal Article
	Moradi et al. (2014) Australia	13 in the 'teenagers' age group (35 total)	16-24[a] in the 'teenagers' group (17-53 in full study)	To explore the experiences of women with endometriosis and their impact, and whether these differ across three age groups (16-24; 25- 34; and over 35)	Semi-structured focus groups	Journal Article
	Plotkin (2004) USA	16	15-19	To explore the experience of adolescent girls with endometriosis	Semi-structured interviews	Thesis
Quantitative	Ahn et al. (2009) USA	14	13-22	To determine whether electrodermal measures at Japanese acupuncture points are associated with clinical measures in adolescents with endometriosis associated chronic pelvic pain	RCT Author devised questionnaire (baseline); EHP-30; PedsQL; PSS	Journal Article
	DiVasta et al. (2015) USA	51 (at baseline)	15-22	To assess the efficacy of add-back therapy for adolescents and young women treated with GnRH for endometriosis	RCT Author devised questionnaire (at baseline); BDI-II; SF-36; MRS	Journal Article
	DiVasta et al. (2018) USA	295 in 'adolescents at diagnosis' group (402 total)	12-46[b] in 'adolescents at diagnosis' group **(median age 17)**	To determine if there are differences between the symptom presentation of adolescents and those of adults, based on age at diagnosis	Cross-sectional study (within longitudinal cohort study) – Author devised questionnaire; WERFEPHect	Journal Article
	Dun et al. (2015) USA	25	10-21	To describe the experience of adolescents with a diagnosis of endometriosis including symptoms, diagnostic experience, and treatment outcomes	Medical records review	Journal Article

Table 3.2: Paper Characteristics (continued)

Type of study	Author (year of publication), Country	Sample Size	Sample age range (years)	Aim	Data collection method	Reference Type
Quantitative	Estes et al. (2021) USA	72,677 women with endometriosis (matched with 147,251 controls)	18-60[c] (some statistics stratified by age, including an <25 age group)	To compare the incidence of mental health outcomes in women with and without documented endometriosis	Retrospective cohort study - Medical records review	Journal Article
	Fong et al. (2017) Singapore	45	14-25	To describe the clinical profile of adolescents and young women with endometriosis	Medical records review	Journal Article
	Gallagher et al. (2017) USA	50	15-22	To characterise the quality of life in adolescents with endometriosis, being treated with GnRHa plus add-back therapy	Randomised Controlled Trial –Author devised questionnaire; WERFEPHect	Journal Article
	Gallagher et al. (2018) USA	360 with endometriosis (plus 207 controls)	10-24	To determine the impact of endometriosis on quality of life in adolescents and young adults	Cross-sectional study (within longitudinal cohort study) – Author devised questionnaire; SF-36	Journal Article
	González-Echevarría et al. (2019) Puerto Rico	24	13-25	To determine the strategies used by teens and young adult women to cope with endometriosis symptoms, and to assess whether coping strategies may impact their QoL	Cross-sectional study - Author devised questionnaire; BAI; BDI-II; CSI; EHP-5; VAS	Journal Article
	Schneider et al. (2020) USA	151 with endometriosis (plus 287 without)	18-25	To quantify the prevalence of dyspareunia and its impact on the QOL of younger women diagnosed with endometriosis	Longitudinal cohort study – Author devised questionnaire; SF-36	Journal Article
	Roman (2010) New Zealand	20	<20	To describe the effect of laparoscopic excision of endometriosis in an adolescent sample and compare it to an adult sample	Comparative Cohort study Medical records review and Author devised questionnaire; VAS; EQ-5D	Journal Article
	Rowlands et al. (2016) Australia	502 (ever reporting diagnosis of endometriosis, 11,238 total)	18-23	To compare psychological distress levels among women with endometriosis or PCOS compared to women with no history of these conditions	Longitudinal cohort study – Author devised questionnaire; K-10	Journal Article

Table 3.2: Paper Characteristics (continued)

Type of study	Author (year of publication), Country	Sample Size	Sample age range (years)	Aim	Data collection method	Reference Type
Quantitative	Smorgick et al. (2013) USA	138	<24	To describe the prevalence of pain syndromes, mood conditions and asthma in adolescents and young women with endometriosis	Medical records review	Journal Article
	Wayne et al. (2008) USA	18	13-22	To assess the feasibility of an RCT evaluating the use of Japanese-style acupuncture for adolescents with endometriosis	RCT Author devised questionnaire (baseline); EHP-30; PedsQL; PSS	Journal Article
Mixed-methods	Bodén et al. (2013) Sweden	23	18-26	To investigate the support women diagnosed with endometriosis received from the school health care system during their school years and how it affected their quality of life	Author devised questionnaire (open and closed ended questions)	Journal Article
	Rush and Misajon (2018) Australia	148 in 18-25 age group (500 total)	18-63[d]	To explore the subjective wellbeing, health-related quality of life and lived experience of women living with endometriosis	Author devised questionnaire (open and closed ended questions); EHP-30; PWI	Journal Article
	Staccone (2006) USA	9	15-21	To explore the psychological effects of endometriosis on adolescent girls and the psychological side effects of GnRH agonist treatment	Interviews and SF-12	Thesis

Notes

[a] Subsequent thematic analysis for this paper only includes references and quotes specifically identifying the 'teenage' age group, those aged 16-24).

[b] This study was included because the average age of those in the 'adolescent' group was 17 years old.

[c] Subsequent thematic analysis for this paper only includes data specifically referring to the <25 age group

[d] Subsequent thematic analysis for this paper only includes references and quotes specifically identifying the 18-25 age group

BAI – Beck Anxiety Inventory; BDI – Beck Depression Inventory; EHP – Endometriosis Health Profile; EQ-5D – EuroQoL 5D, Health related quality of life measure; MRS – Menopause Rating Scale; PedsQL – Paediatric Quality of Life; PWI – Personal Wellbeing Index; PSS – Perceived Stress Scale; SF12/SF36 – Short Form Health Survey; VAS – Visual Analogue Scale; WERFEPHect - World Endometriosis Research Foundation Endometriosis Phenome and Biobanking Harmonization Project standard clinical questionnaire

3.3.1 Thematic Analysis

The remainder of this section outlines the results of the thematic analysis. The final themes were selected if they were consistent across the studies, or if they represented a meaningful finding about the experience of living with endometriosis as an adolescent. There were five overarching themes. Themes and subthemes are displayed in Table 3.3, as well as which papers each were identified in.

3.3.1.1 Symptoms

Symptoms, and their impact, were frequently described in the reviewed studies. The main symptom discussed was pain, but adolescents also experienced a number of other symptoms of endometriosis, and used a variety of methods to manage them.

Pain

Pain is a significant feature of adolescents' experiences of endometriosis, reported in all 7 qualitative/mixed-methods studies, and in 8 quantitative studies (see Table 3.3). Pain is usually located in the abdominal/pelvic area, and is described as *"sharp"*, *"debilitating"* and *"stabbing"* in qualitative papers. Frequency of pain is reported in quantitative papers; dysmenorrhea is experienced by 64% (Dun et al., 2015) to 99% of adolescents (Smorgick et al., 2013); acyclic pelvic pain is experienced by 20% (Roman, 2010) to 66% of adolescents (DiVasta et al., 2018), and; daily pain is reported by 35% (Smorgick et al., 2013). DiVasta et al. (2018) found that 50% of adolescents began to experience pain from their very first period (as compared to 34% of adults).

In addition to pelvic pain, adolescents experience pain in their backs, down their legs, and in their bowel and/or bladder. Adolescents also report dyspareunia, and rates among those that are sexually active range from 66% (Smorgick et al., 2013) to 79% (Schneider et al., 2020). Those adolescents who experience dyspareunia can have significantly lower QoL scores than those who do not (Schneider et al., 2020). The experience of dyspareunia is discussed in 2 qualitative and 2 mixed-methods papers (Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006), with adolescents stating it makes them feel different to their peers (Plotkin, 2004), and causes concern about future relationships (Rush and Misajon, 2018; Staccone, 2006). Rush and Misajon (2018) found that the impact of dyspareunia was particularly emphasised by their younger age group (18-25 year olds) in comparison to the older participants, as illustrated in this quote from a 22 year old: *"I can't keep a relationship because I can't have sex, if I do it hurts and I'm scared to because I know the pain I'll be in and that makes the pain worse. And not having sex is a deal breaker for most guys my age"* (p.315).

Table 3.3: Themes Identified in the Literature

Main Theme	**Subtheme**	**Articles which identify themes**
Symptoms	Pain	Bodén et al., 2013; Conboy et al., 2008; DiVasta et al., 2018; Dun et al., 2015; Fong et al., 2017; González-Echevarría et al., 2019; Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Roman, 2010; Rowlands et al., 2016; Rush and Misajon, 2018; Schneider et al., 2020; Smorgick et al., 2013; Staccone, 2006
	Other Symptoms	Bodén et al., 2013; Conboy et al., 2008; DiVasta et al., 2018; Dun et al., 2015; Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Roman, 2010; Smorgick et al., 2013; Staccone, 2006
	Symptom Management	Ahn et al., 2009; Conboy et al., 2008; DiVasta et al., 2018; Fong et al., 2017; Gallagher et al., 2018; Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Roman, 2010; Staccone, 2006; Wayne et al., 2008
Time to diagnosis	Time to obtain a diagnosis of endometriosis	Bodén et al., 2013; DiVasta et al., 2018; Dun et al., 2015; Fong et al., 2017; Gallagher et al., 2018; Moradi et al., 2014; Plotkin, 2004; Rowlands et al., 2016; Smorgick et al., 2013; Staccone, 2006
	Factors involved in the Diagnostic Delay	Bodén et al., 2013; Moradi et al., 2014; Plotkin, 2004; Staccone, 2006
Quality of Life and Everyday Experience	School and Work	Bodén et al., 2013; Conboy et al., 2008; DiVasta et al., 2018; Fong et al., 2017; González-Echevarría et al., 2019; Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Smorgick et al., 2013; Staccone, 2006
	Friendships, Social Life, and Dating	DiVasta et al., 2018; Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006
	Sport and Recreational Activities	Bodén et al., 2013; DiVasta et al., 2018; Gallagher et al., 2018; González-Echevarría et al., 2019; Highfield et al., 2006; Plotkin, 2004; Staccone, 2006
	Support	Bodén et al., 2013; Dun et al., 2015; Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006
	Quality of Life	Ahn et al., 2009; DiVasta et al., 2015; Gallagher et al., 2018; Gallagher et al., 2017; González-Echevarría et al., 2019; Roman, 2010; Rush and Misajon, 2018; Schneider et al., 2020; Wayne et al., 2008
Psychological and Emotional Wellbeing	Quantitative Findings: Depression, Anxiety and Psychological Distress	Dun et al., 2015; Estes et al., 2021; Gallagher et al., 2018; Gallagher et al., 2017; González-Echevarría et al., 2019; Rowlands et al., 2016; Smorgick et al., 2013
	Qualitative Findings: Emotional Distress	Bodén et al., 2013; Conboy et al., 2008; Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006
Uncertainty Surrounding Endometriosis and Futures	Lack of Information about Endometriosis and its Cause	Conboy et al., 2008; Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018
	Uncertainty towards the Future	Conboy et al., 2008; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006
	Fertility: Feeling 'Off-time'	Conboy et al., 2008; Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006

Adolescents report that the intensity of their pain can cause nausea and/or vomiting (Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Staccone, 2006). DiVasta et al. (2018) found that 70% of adolescents reported nausea that accompanies pelvic pain. Adolescents feel frustrated when pain treatments are ineffective (Conboy et al., 2008). González-Echevarría et al. (2019) found that 92% of adolescents in their sample reported pain to affect their daily life. Across the studies, pain has been reported to impinge on many aspects of adolescents' lives including school, sport, and socialising (discussed below) and their ability to cope with basic tasks: *"…endometriosis pain makes everyday tasks 10 times harder. I find I need 3 times the energy of my friends just to make it through the day"* (Rush and Misajon, 2018: 313).

Other symptoms

Adolescents commonly experience a range of other symptoms of endometriosis. Abnormal bleeding, including heavy or irregular bleeding is common, noted in 7 papers (Bodén et al., 2013; Dun et al., 2015; Fong et al., 2017; Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Staccone, 2006). Dun et al. (2015) found that heavy bleeding, or 'menorrhagia', occurred in 44% of their sample, and abnormal or irregular bleeding in 60%. Qualitative papers indicate that bleeding can be heavy and prolonged, sometimes described as constant (Staccone, 2006), with girls concerned they would *"bleed to death"* (Plotkin, 2004: 74).

Symptoms associated with the bowel or bladder were also common. They are described in 4 qualitative/mixed-methods papers (Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Staccone, 2006), and include bladder urgency, diarrhoea, painful bowel movements, and painful urination. Dun et al. (2015) found that 56% of their sample suffered from at least one gastrointestinal symptom, and 52% had at least one genitourinary symptom. Papers suggest that between 26% (Smorgick et al., 2013) and 50% (DiVasta et al., 2018) of adolescents experience pain with urination. In addition, DiVasta et al. (2018) found that 53.1% of adolescents experience more frequent bowel movements accompanying period pain. More general symptoms are also widely noted including headaches, nausea, sleep disturbances, dizziness, and abdominal bloating. Adolescents can also suffer from chronic fatigue resulting from their endometriosis, described by one girl as being incongruous for someone her age: *"I'm a teenage girl. I shouldn't have to come home after school and take a nap. That just isn't right."* (Plotkin, 2004: 75).

Symptom Management

Adolescents use a range of different treatments to try to manage their symptoms. Papers suggest that NSAIDs are used by between 27.2% (Gallagher et al., 2018) and 35.6% (Fong et al., 2017) of adolescents, and unspecified OTC painkillers by up to 69.2% (DiVasta et al., 2018). Stronger prescription painkillers are also used, and Smorgick et al. (2013) found that 66% of their sample had used narcotics.

Adolescents are also prescribed hormonal medication such as the contraceptive pill and GnRH agonists. The rate of their use is not clear in most papers, however Smorgick et al. (2013) note that 99% of the young women in their sample used some form of hormonal suppression. DiVasta et al. (2018) found that 37.6% of adolescents stated that they had taken hormonal medication without their pain improving. Qualitative papers report a mixed response to medical treatments, but most discussion centres on the lack of improvement and bothersome side-effects. These side effects can be quite extreme, and while some try to put up with them in an effort to control their pain, others are forced to discontinue their medication (Conboy et al., 2008; Highfield et al., 2006; Moradi et al., 2014; Plotkin, 2004; Staccone, 2006). Some adolescents describe a complex medical regime, whereby a concoction of medications is taken each day to treat all of their symptoms including pain, headaches and chronic fatigue, as well as additional medications to counteract the side effects (Highfield et al., 2006; Plotkin, 2004): *"I am seventeen years old and I have all these medications. None of my friends have a dresser drawer full of medications."* (Plotkin, 2004: 63).

Adolescents also undergo surgical treatment for their endometriosis, most notably a laparoscopy. Roman (2010) found that surgical excision of endometriosis significantly improved dysmenorrhea and pelvic pain symptoms, and had a positive effect on QoL, however 10% of adolescents underwent a second laparoscopy within 2 years due to returning symptoms. Dun et al. (2015) found that 80% of adolescents had resolved or improved pain at 1-year post-laparoscopy, 12% had continued pain and 8% had recurring pain. Surgical treatment is described in qualitative papers to provide an improvement in symptoms, but this is often short lived, with many soon experiencing symptom recurrence (Conboy et al., 2008; Moradi et al., 2014; Plotkin, 2004). Adolescents in the study by Plotkin (2004) describe a treatment cycle of trying hormonal treatments, then surgery, followed by short term relief before symptoms return, and then further hormonal treatments are required, and so on. This can cause frustration, and despite their age, there are reports of completed (Plotkin, 2004) or desired (Moradi et al., 2014) hysterectomy among adolescents.

3.3.1.2 *Time to Diagnosis*

There were 8 papers which discussed findings related to the time it takes adolescents to receive a diagnosis of endometriosis; 2 qualitative, 4 quantitative and 2 mixed-methods (see Table 3.3). These papers discuss both the time to diagnosis, and the various contributing factors, including pain normalisation, lack of awareness of endometriosis, and the receipt of alternative diagnoses.

Time Taken to Receive a Diagnosis of Endometriosis

The time taken to obtain a diagnosis of endometriosis is often referred to on two levels; the patient level, occurring between symptom onset and seeking medical help, and the medical level, between seeking medical help and obtaining a diagnosis (Ballard et al., 2006). Two papers quantified their findings on the former, and suggest that after their symptoms begin, adolescents wait an average of 1 (DiVasta et al., 2018) to 2 years (Bodén et al., 2013) before seeking medical help for their symptoms. Two papers reported findings on the medical level delay, which averaged 10.9 months (Dun et al., 2015) to 4.8 years (Bodén et al., 2013). The majority of papers reported on the total length of time between symptom onset and receipt of a diagnosis, which ranged from an average of 22.8 months (Dun et al., 2015) to 6.87 years (Bodén et al., 2013). However, in addition to the average, some studies also reported the range of time between symptom onset and diagnosis, the lowest of which was 1 month (Dun et al., 2015), and the highest was over 12 years (Bodén et al., 2013). Two papers compared the time to diagnosis between those diagnosed as adolescents and those diagnosed as adults, and found that those diagnosed as adolescents had a shorter diagnostic delay (DiVasta et al., 2018; Moradi et al., 2014).

Factors Involved in the Diagnostic Delay

Insight into the factors involved in the diagnostic delay predominantly come from qualitative or mixed-methods papers (see Table 3.3). One factor is the normalisation of symptoms, which is the tendency to liken them to normal menstruation. Adolescents themselves have described their belief that their symptoms were just normal menstruation, either because menstruation was not often something that was typically discussed (Bodén et al., 2013), or because they just assumed they were unlucky to have painful periods (Moradi et al., 2014). Family has also been noted to normalise symptoms, particularly mothers who have also experienced similar symptoms (Bodén et al., 2013). Medical professionals, such as doctors and school nurses, are more widely reported across the papers to dismiss adolescents' symptoms as being normal period pains, or even suggesting they are all in their heads (Bodén et al., 2013; Moradi et al., 2014; Plotkin, 2004; Staccone, 2006). This has resulted in adolescents feeling frustrated and distressed, and questioning the validity of their own pain (Plotkin, 2004; Staccone, 2006).

Contributing to this normalisation of symptoms is a lack of awareness of endometriosis. Adolescents themselves have reported little awareness of endometriosis prior to their symptom onset or diagnosis (Bodén et al., 2013; Moradi et al., 2014): *"Yeah, I should be aware but it was kept as a secret, I didn't know that this exists."* (Moradi et al., 2014: 6). Adolescents also comment on the ignorance of others surrounding endometriosis. Doctors and school nurses are a source of frustration as they are said to lack sufficient knowledge about endometriosis (Bodén et al., 2013; Conboy et al., 2008; Moradi et al., 2014). Some papers report on medical professionals who believe that adolescents are too young to have endometriosis (Moradi et al., 2014; Plotkin, 2004; Staccone, 2006). This belief delays referrals to secondary care, or results in inappropriate referrals and misdiagnoses (Dun et al., 2015; Moradi et al., 2014). Friends and family are also unaware of endometriosis and are therefore unable to relate or understand. Adolescents want their friends, teachers, and health professionals to be better educated and more knowledgeable about the condition (Bodén et al., 2013; Plotkin, 2004).

Diagnosis itself brings about mixed feelings for adolescents. They have reported partly feeling relieved, at finally receiving a diagnosis and being able to legitimise their pain to others, but also frustration and uncertainty, precipitated by the lack of cure and ongoing nature of endometriosis (Moradi et al., 2014; Plotkin, 2004; Staccone, 2006).

3.3.1.3 Quality of Life and Everyday Experience

There were 18 papers which reported findings relating to the everyday experiences of adolescents with endometriosis, and its impact on QoL (4 qualitative, 11 quantitative, and 3 mixed-methods; See Table 3.3). Everyday experiences include disruptions to school and work, social life and dating, and sport and recreational activities. Also discussed in this theme is the support networks of adolescents.

School and Work

Disruptions to school are widely reported and include school absences and interference with academic performance. Quantitative findings suggest that between 24% (Fong et al., 2017) and 61% (DiVasta et al., 2018) of adolescents with endometriosis experience such disruptions. However, in two of the qualitative papers (Plotkin, 2004; Staccone, 2006) *all* participants report school disruptions, most notably school absences. These absences last anywhere from a couple of days each month, to weeks or even months at a time. Upon returning to school, adolescents struggle to catch up with the work they have missed (Plotkin, 2004; Staccone, 2006). When in attendance, adolescents report poor focus and productivity because of their symptoms (Moradi et al., 2014; Plotkin, 2004). Explaining school absences to friends or teachers can be difficult due to both a lack of physical sign of illness, and others' lack of understanding about endometriosis (Plotkin, 2004).

Endometriosis can also have a long-term bearing on education; causing adolescents to drop out of school altogether (Moradi et al., 2014; Plotkin, 2004; Staccone, 2006), or turn to home-schooling (Plotkin, 2004; Staccone, 2006). Future educational plans sometimes need to be re-evaluated; with long-established university dreams having to be changed, deferred, or dropped completely (Moradi et al., 2014; Plotkin, 2004; Staccone, 2006). This demographic mostly emphasised the impact of endometriosis on school and education, but some papers also indicate that there can be disruptions to work as well (Conboy et al., 2008; DiVasta et al., 2018; Fong et al., 2017; Plotkin, 2004; Rush and Misajon, 2018).

Friendships, Social Life and Dating

Only one quantitative study reported on the impact of endometriosis on social activities (DiVasta et al., 2018), in which 89.7% of adolescents indicated that pelvic pain interfered with social activities, with 64.1% indicating moderate to extreme interference. These rates were slightly higher than for adults in the study (ibid). Social impact is a more predominant theme in qualitative/mixed-methods research, reported in five papers. Both Moradi et al. (2014) and Rush and Misajon (2018) found that social life was a prominently highlighted impact of endometriosis for adolescents, as compared to older participants. Social interference is sometimes described as being due to school absences, and missing out on the social aspects of school, like spending time with friends (Plotkin, 2004). In addition, attendance at social events is often limited (Highfield et al., 2006; Plotkin, 2004; Staccone, 2006), and negative mood states, such as anger or irritability, make socialising less desirable (Moradi et al., 2014; Staccone, 2006), as highlighted in this quote: *"Just because yeah, it's stressful and you're angry and I guess that's the point where it can affect your relationships with people more seriously"* (Moradi et al., 2014: 8). Others' lack of awareness of endometriosis can intensify feelings of isolation and can also put a strain on relationships (Plotkin, 2004; Staccone, 2006). Although not widely discussed, some adolescents report that endometriosis makes dating very difficult, particularly when partners do not understand (Rush and Misajon, 2018; Staccone, 2006).

Sport and Recreational Activities

Two quantitative papers reported the impact of endometriosis on exercise; Gallagher et al. (2018) found that 47.5% of adolescents avoid exercise due to pain or heavy blood flow associated with menstruation, and DiVasta et al. (2018) found that 69.3% of adolescents note moderate to extreme interference with exercise due to pelvic pain. González-Echevarría et al. (2019) found that all but one of their sample reported difficulty walking. Qualitative research describes how adolescents often have to give up or reduce extracurricular activities, sports, and hobbies, usually as a result of pain (Bodén et al., 2013; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006), and as one described: *"It just* ***takes*** *one thing after another."* (Staccone, 2006: 93).

Support

To manage the day-to-day aspects of living with endometriosis, adolescents draw on various sources of support. They identify their mothers as their key source of support (Plotkin, 2004; Staccone, 2006), who not only provide practical and emotional support, but they also advocate for their daughters in seeking medical help and referrals (Plotkin, 2004). This is reinforced by Dun et al. (2015), who found that mothers were the primary referral source for adolescents to the tertiary care clinic. Family also provide financial support for this age group (Moradi et al., 2014). Additional support is provided by others with endometriosis via online support groups, who are able to understand their experiences, and answer questions about endometriosis (Plotkin, 2004). This is somewhat in contrast to friends, whose support is limited due to their lack of understanding about endometriosis (Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006).

Quality of Life

There were 9 quantitative/mixed methods papers (see Table 3.3) which used measures of QoL, including general QoL measures (i.e. SF-36, EQ5D, PedsQL) and endometriosis specific measures (EHP-30, EHP-5). Five of these papers measured QoL as part of their research into treatment efficacy (Ahn et al., 2009; DiVasta et al., 2015; Gallagher et al., 2017; Roman, 2010; Wayne et al., 2008). All papers indicate reduced QoL among adolescents with endometriosis, when compared to controls or normative data. Rush and Misajon (2018) found that their youngest group of participants (aged 18-25) had consistently poorer QoL compared to their older participant groups. Gallagher et al. (2018)

explored some of the factors that may affect QoL, and found that more severe pelvic pain, a longer diagnostic delay, and an earlier age at menarche are associated with poorer QoL. Schneider et al. (2020) researched adolescents with endometriosis and compared those who experience dyspareunia and those who do not, and found those who do had significantly lower QoL scores. In assessing the impact of coping strategies on QoL, González-Echevarría et al. (2019) found that maladaptive coping strategies, such as auto criticism and social withdrawal, were associated with poorer QoL, and adaptive coping strategies, such as social support and cognitive restructuring, were associated with better QoL.

3.3.1.4 Psychological and Emotional Wellbeing

There were 11 papers that offered findings relating to the impact of endometriosis on psychological or emotional wellbeing; 5 quantitative, 3 qualitative and 3 mixed-methods papers (see Table 3.3). Findings from the qualitative and quantitative work are discussed separately.

Quantitative Findings: Depression, Anxiety and Psychological Distress

Most of the quantitative papers report on depression and anxiety within their samples. Rates of depression vary between studies, which may be due to variations in the way it was measured or reported (i.e. self-report Vs medical records screening). For example, Dun et al. (2015) found that only 4% of their sample had depressive symptoms, Gallagher et al. (2018) found that 16.4% of their sample report depression requiring medication/therapy, and Smorgick et al. (2013) found that approximately 42% of their sample have a diagnosis of depression. Two studies measured depressive symptoms (using the Beck Depression Inventory), which found that between 26% (Gallagher et al., 2017) and 54% (González-Echevarría et al., 2019) of adolescents have scores indicative of a mild or greater level of depression. Two studies report on diagnosed/medicated anxiety among their adolescent sample, with close agreement of rates, of approximately 23% (Smorgick et al., 2013) and 25.6% (Gallagher et al., 2018). However, using the Beck Anxiety Inventory (BAI), González-Echevarría et al. (2019) found that approximately 79% of adolescents in their sample had scores indicative of at least mild anxiety (although their sample size was small). In addition, Smorgick et al. (2013) found that 48% of adolescents have one or more mood disorders (depression and/or anxiety).

While rates of depression and anxiety among adolescent with endometriosis vary, it does appear that levels of psychological distress are higher in adolescents with endometriosis than in controls. For example, Gallagher et al. (2018) found significantly higher levels of both anxiety and depression in adolescents with endometriosis than in controls of the same age. Rowlands et al. (2016) noted similar results, however they used a measure of overall psychological distress. Their results indicate a significantly higher odds of having moderate to severe psychological distress in those with a diagnosis of endometriosis compared to those with no lifetime diagnosis of endometriosis. Rowlands et al. (2016) additionally found that those with a recent diagnosis of endometriosis were more likely to have higher psychological distress in the year prior to their diagnosis. Finally, in comparison with older participants with endometriosis, Estes et al. (2021) found that hazard ratios indicated significantly higher risk of anxiety, depression, and self-directed violence in those aged under 25 with endometriosis.

Qualitative Findings: Emotional Distress

Adolescents in qualitative research describe emotional distress associated with endometriosis, including feeling stressed, emotional, miserable, depressed and even suicidal (Conboy et al., 2008; Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006). Some of these emotions are in response to pain, but other factors also play a role. The failure of others to acknowledge pain or symptoms has been reported to make adolescents feel distressed, and question whether they are going ‘crazy’ (Plotkin, 2004; Staccone, 2006). They also experience social isolation and loneliness, either because of their symptoms, or again due to not being believed by others (Plotkin, 2004; Staccone, 2006). Some adolescents report additional emotional distress due to their medication, including mood swings, depression, and in the worst case a suicide attempt (Conboy et al., 2008; Moradi et al., 2014; Plotkin, 2004; Staccone, 2006). Medication can also alter physical appearance and body image, and one study reported on the effect of hormonal medications, which can stop periods, and reduce breast size, thus causing a loss of feminine identity (Staccone, 2006).

3.3.1.5 Uncertainty Surrounding Endometriosis and Futures

This theme represents findings which have come exclusively from qualitative research (3 qualitative studies, 2 mixed-methods study: see Table 3.3).

Lack of Information about Endometriosis and its Cause

The lack of awareness of endometriosis promotes feelings of uncertainty in adolescents. Owing to their lack of knowledge, health professionals are often unable to provide appropriate information to adolescents, leaving them feeling confused and having to seek information elsewhere, such as on the internet (Moradi et al., 2014; Plotkin, 2004). A lack of understanding of what is wrong, particularly in the period before diagnosis, generates further uncertainty, and makes it difficult to explain pain or absences to others (Plotkin, 2004; Staccone, 2006). The enigmatic nature of endometriosis, and thus lack of concrete medical explanation, causes frustration in adolescents and often leaves them searching for a cause (Conboy et al., 2008; Plotkin, 2004).

Uncertainty towards the Future

There are many aspects of life with endometriosis that cause adolescents to feel uncertainty towards their future. The lack of curative treatment, and the high rate of symptom reoccurrence following surgery, can leave them fearing continued pain and additional surgeries (Conboy et al., 2008; Plotkin, 2004). Some also have concerns over future relationships, and being able to find an understanding partner (Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006). However, despite these concerns, one paper did find that adolescents had a remarkable sense of hope and optimism for the future (Staccone, 2006).

Fertility: Feeling 'Off-time'

As evident in five studies (see Table 3.3), adolescents can describe feeling 'off-time'; often finding themselves confronted with concerns that are incongruent with their life stage. Fears and doubt over their future fertility prospects are consistently recognised in all 5 papers. This is an issue they feel that others their age would not normally have to worry about: *"Most kids my age are concerned where the next party is going to be, and I am concerned if I can ever have children."* (Plotkin, 2004: 62). These fertility fears may prompt adolescents to re-evaluate their futures; either accepting at an early age that they might not have children (Plotkin, 2004), or interrupting the 'typical' life course to have children early (Moradi et al., 2014; Plotkin, 2004).

3.4 Discussion

This review has highlighted that there is a dearth of research addressing the experience and psychosocial impact of endometriosis in adolescents. While 21 papers were eligible for inclusion in this review, very few explicitly aimed to explore the adolescent experience, and many aimed to investigate treatment efficacy. Several studies that were identified by the literature search were excluded, because although they incorporated younger participants in their samples (i.e. those aged 16 and over), they did not stratify results by age, and therefore were unable to offer insight into the experience of endometriosis during this crucial developmental stage.

Despite the limited evidence base, this review does provide insight into the experience and psychosocial impact of endometriosis in adolescents. Using a systematic thematic approach, the literature has been synthesized to form five themes which describe the key aspects of their experience; symptoms, time to diagnosis, QoL and everyday experiences, psychological and emotional wellbeing, and uncertainty surrounding endometriosis and futures.

Some aspects of the adolescent experience of endometriosis are similar to those described by women (see Section 2.7 of previous chapter). However, the theme 'QoL and everyday experiences' shows how endometriosis affects school attendance, social life, dating, and sport – things which are considered to be core aspects of adolescent life. Adolescence is a crucial stage of psychosocial development; a time to acquire an independent identity, gain acceptance from peers, and explore romantic relationships (Christie and Viner, 2005; Erikson, 1968). As such, a chronic illness experienced during this time, and particularly one that limits those key activities of daily adolescent life, can pose a threat to their adolescent identity (Suris et al., 2004).

In addition to summarising past research on adolescents' experiences of endometriosis, this review has highlighted several areas which are yet to be well explored. There was little discussion of support networks, and the impact of such support on the illness experience. When it was discussed, most reference was given to the support provided by mothers (Plotkin, 2004; Staccone, 2006), and therefore further exploration of the role of fathers, siblings, friends, and other connections is needed. Those papers that do discuss support were conducted 15-20 years ago, before the explosion of social media, and so the role of these forms of support for adolescents also warrant further investigation.

Many papers reported adolescents' treatment experience, with particular focus on treatment efficacy and associated side effects. However, there was a lack of enquiry into what adolescents' main concerns were regarding their treatment. Trials investigating surgical treatments for endometriosis are often judged on outcomes associated with dysmenorrhea, dyspareunia, and fertility (Hirsch et al., 2016). While such outcomes might be pertinent for adult women with endometriosis, they may not be the primary concerns of adolescents.

With the exception of the paper by Schneider et al. (2020), dyspareunia was seldom discussed/explored, perhaps because researchers felt it inappropriate to ask younger participants about this. However, it may be an important factor to explore further in adolescents and young women, because their sexual lives are at a formative stage, and so painful sexual encounters at this time might have negative implications for their developing sexual identity and subsequent relationship building (Donaldson and Meana, 2011). In addition, there was no evidence of exploration into pain due to tampon use, which may be a symptom experienced by younger adolescents who are not yet sexually active. Previous research has shown an association between dyspareunia and pain during tampon insertion in adolescents (Landry and Bergeron, 2009), and so further exploration into this as a possible symptom in adolescents with endometriosis is warranted. In the absence of dyspareunia, it could prove to be a symptom worthy of diagnostic investigation in this age group.

3.4.1 Strengths and Limitations

A key strength of this review is the inclusion of studies which looked at the impact of endometriosis in those who were adolescents at the time of the research. This therefore gave them the chance to discuss salient issues, and the data was not affected by potential recall bias. The review also included both qualitative and quantitative research, therefore providing a more thorough exploration of the adolescent experience (Broom and Willis, 2007). However, while there were 21 studies eligible for inclusion in this review, the criteria for inclusion was lenient, and as such case report studies, medical records review studies, and research completed for academic qualifications were all included, which might not usually meet the standards of other reviews. Furthermore, in addressing the quality criteria, the randomised controlled trials and mixed methods studies were deficient in some areas.

There are also some limitations of the studies included in the review. The majority originated in the USA, and therefore the findings may not be applicable to other countries. Little demographic information was given about participants, other than ethnicity, which was reported by 12 out of 21 papers. Except for the paper by Fong et al. (2017), which was conducted in Singapore, in the majority of studies the ethnicity was predominately white/Caucasian, at rates of between 77.8% and 100%. This indicates a lack of ethnic diversity among participants. Finally, most studies failed to provide a definition of “adolescence”, or a rationale for the age range chosen, and they lacked consensus on the age ranges chosen to represent this demographic. These limitations indicate the obvious need for further research in this area.

3.5 Conclusion

This review provides an overview of the current knowledge about adolescents’ experiences of endometriosis, however there is a limited evidence base on which this knowledge can be drawn. This review has revealed that there are several similarities between the adolescent and adult experience, however their main concerns about endometriosis can differ by age (Moradi et al., 2014), and the stage of one’s life can greatly impact on how illness is experienced (Grinyer, 2007). Therefore, it is necessary to build on the research base focusing solely on adolescents, to identify their treatment priorities and clinical needs. This review forms the foundations of such a research base, as it has highlighted what is already known, and which areas require further exploration.

Chapter 4. Literature Review Summary and Thesis Methodology

4.1 Introduction

This chapter will begin by providing a summary of the gaps that have been identified in the literature pertaining to adolescents with endometriosis. Following this will be the rationale, aims, and approach of the research conducted within this thesis.

4.2 Identifying Gaps in Previous Research

Chapters 2 and 3 provide an overview of the research addressing the experience and psychosocial aspects of endometriosis and menstruation, with particular emphasis on the adolescent population. Chapter 3 highlighted that there is limited research specifically focussing on the experience or psychosocial aspects of endometriosis in adolescents, and much of the existing research primarily aimed to explore the experience of treatment for endometriosis. An exception was Plotkin's thesis (2004), however, this was conducted almost 20 years ago, and there have been a number of changes in society over this time. There were several areas which therefore required further exploration:

- There was no previous research conducted with adolescents in the UK.
- There was little exploration into adolescents' support networks, including the role of online/social media support.
- There was little exploration into adolescents' experiences of dyspareunia, and no exploration into pain due to tampon use.
- There was a lack of enquiry into adolescents' main treatment concerns.

The body of research addressing women's experience of endometriosis was found to be better established, and included UK evidence. Although much of this research did not specifically include adolescent perspectives, the women in such research often recalled their experiences as a teenager. While this provides essential insight into the adolescent experience, there remained several reasons as to why research *with* adolescents was still needed.

Firstly, the aim of such research was never to explore the adolescent experience specifically, and references to teenage years were simply a by-product of the research. Secondly, such research would have relied on the retrospective recall of an adult's teenage years, raising potential issues of memory inaccuracy (Leedy and Ormrod, 2010). The issue of 'fading memory', or being unable to accurately remember one's own experience, has been noted in other health research (Miller et al., 2010). In addition, researchers have suggested that people can be subject to a 'fading affect bias', in which unpleasant memories are recalled less accurately than pleasant memories (Walker et al., 2003), potentially because we work harder to dampen the emotional impact of negative events. Therefore, aspects of the experience which might have been salient *during* adolescence, might be given less weight as an adult. Finally, the main concerns of the experience of endometriosis can differ according to one's age group (Moradi et al., 2014), and the stage of one's life can greatly impact on how illness is experienced (Burles and Thomas, 2012). Adolescents themselves therefore needed to be given a voice, to enable them to discuss and raise issues that were important to them at the time.

While there are some aspects of the adolescent and adult experience of endometriosis that may differ, the limited evidence base with adolescents has identified several common findings between the two groups. One of these is the lengthy diagnostic delay. Ballard et al. (2006) discussed potential reasons for this delay, and amongst them is the notion that women or teenagers may delay seeking help as they do not recognise that their periods are atypical. In addition, they often have not heard of endometriosis. In order to address the diagnostic delays caused by this lack of awareness, many researchers have suggested that improving the education around endometriosis and menstrual health is a key priority, which should be addressed in schools (Cox et al., 2003c; Manderson et al., 2008; Markovic et al., 2008). However, much of the research upon which these recommendations are based is qualitative in nature, using small sample sizes that reflect the experiences of only those who have endometriosis. As such, it is not possible to draw conclusions of the awareness amongst the wider adolescent population, whom such education would be targeted at.

To investigate the need for improving education and awareness, it would be useful to draw upon quantitative research, which can provide an indication of the public awareness of endometriosis among a large population of adolescents. Research studies conducted in Italy (Zannoni et al., 2014) and Australia (Armour et al., 2021a; Parker, 2006) have provided some insight into this. Each surveyed adolescents from the public about their menstrual health, and additionally asked if they had ever heard of endometriosis. They found that 18.8% (Zannoni et al., 2014), 23.6% (Parker, 2006), and 64% (Armour et al., 2021a) of the adolescents had heard of endometriosis. The latter paper was conducted most recently, and the higher rate of awareness could reflect growing awareness following efforts of Australian advocacy organisations, and increased media coverage of the annual Endometriosis Awareness Month (Armour et al., 2020b). There are no studies conducted in the UK and therefore we do not know whether adolescents in the UK are aware of endometriosis.

The aforementioned studies provide a useful indication of the awareness of endometriosis among adolescents, however, it should be highlighted that having 'heard of' something is not necessarily synonymous with having any knowledge or awareness of it. Shadbolt et al. (2013) addressed this by asking their participants to also describe endometriosis in their own words, therefore identifying those who could provide an adequate description, indicative of knowledge and awareness. They found that many participants were unable to provide an accurate description. Similar research was needed with a UK sample, given that the health and education systems utilised in the UK differ from those in the countries where previous research has been conducted. By obtaining data on the awareness of endometriosis in adolescents in the UK, it would be possible to find out if there is a need to educate adolescents in this country on this topic.

In addition, while much of the qualitative research on endometriosis experiences indicates delayed help seeking due to lack of understanding about what symptoms of menstruation are 'normal', there is no current picture of what symptoms adolescents in the UK perceive to be normal, as has been studied abroad (Armour et al., 2021a). By obtaining such data, we could have some understanding about what adolescents need to know about menstruation, and their educational needs regarding recognising problematic menstruation. Furthermore, as highlighted in a recent systematic review of the prevalence of dysmenorrhea in adolescents (Armour et al., 2019a), there are no UK studies addressing the prevalence or impact of dysmenorrhea in this age group. Finally, an up to date understanding of their communication patterns and preferences around menstruation would also be beneficial, particularly given that adolescents may miss the opportunity to identify problematic menstruation due to communication taboos (Burrows and Johnson, 2005; Markovic et al., 2008).

4.3 The Research Questions

There were several gaps in the academic understanding of endometriosis and menstruation in adolescents, and as such this provided the rationale for further research. Therefore, to contribute further to the knowledge and understanding in this area, this thesis was guided by the following research questions:

1. What are adolescents' experiences of endometriosis?
2. What are the experiences of menstruation in adolescents? What symptoms do they perceive to be typical, and are they aware of endometriosis?

These research questions stemmed from the same evidence base, and therefore were interrelated, but they addressed slightly different populations. The second question focused on adolescents within the general population, however, the first question focused on a subset of that population; adolescents with endometriosis. Therefore, these questions were addressed by conducting two separate studies; study 1, exploring the experiences of adolescents who have endometriosis, and study 2, identifying the menstrual characteristics and awareness of endometriosis among adolescents. Each of these studies had its own list of objectives:

Objectives Study 1:

- To explore the experiences of adolescents living with endometriosis, and the impact of endometriosis on their lives and identities as adolescents/young adults.
- To explore the impact of experiencing a stigmatised, gendered condition during adolescence, and to contribute to the literature on biographies and chronic illness.

Objectives Study 2:

- To describe the menstrual experience in adolescents and provide insight into their perceptions of the typicality of menstrual symptoms.
- To obtain an understanding of the awareness of endometriosis amongst adolescents in the UK, and an indication of their desire to learn about it.
- To provide data to support the work of organisations such as Endometriosis UK, who advocate for the need to improve education around menstrual health and endometriosis.
- To inform schools and government educational bodies of adolescents' MHE needs.

It was important to ensure that in addition to addressing academic gaps, the research questions and objectives would create knowledge that was of particular concern to the lives of girls and women. Therefore, Endometriosis UK was consulted on their content.

4.4 Methodological Approach

Although this thesis has both a qualitative and a quantitative study, it is not a mixed methods study. One of the key features of a mixed methods study is that the two studies are integrated at some stage of the research process (Bryman, 2006). In this thesis, there is no formal integration of the two studies. They were designed, analysed, and interpreted separately. Therefore, in the chapters that follow, each study has its own Methods, Results, and Discussion. However, the final chapter in the thesis will discuss how the findings of the two studies can inform each other, and will therefore draw together some of the results. In this way, the research is similar to some mixed methods studies, for example, when one uses the findings from a quantitative study to contextualise some of the issues raised in the qualitative data (Stewart and Cole, 2007). A benefit of such a research design is that it can enable the qualitative findings to be broadened or generalised, thus magnifying their strength in terms of validity and interpretive power (Hesse-Biber, 2010; Stewart and Cole, 2007). Therefore, although not using a mixed methods design, the final chapter will integrate some of the findings from each study, which was considered a particularly useful tool for outlining the future recommendations arising from this thesis. The methodological approach for each study, and their justification, will now be described.

4.4.1 Study 1: Qualitative Study

Upon the initiation of this research, there was a lack of current and up to date knowledge about the adolescent experience of endometriosis. As such, this research aimed to address this gap, and a qualitative methodology was considered the most appropriate way of doing so. Previous research addressing women's experiences of endometriosis has used both qualitative and quantitative methodology (Culley et al., 2013), and therefore, there was scope to use either method in this study.

Much of the previous quantitative research on WWE has assessed the psychosocial impact of endometriosis using measures of quality of life (i.e. SF36, EHP-30, EHP-5), pain (i.e. visual analogue scales) and mental wellbeing (i.e. BDI, HADS), as well as additional surveys designed for specific study aims. While quantitative research has been useful in determining, for example, the prevalence of psychosocial impairment in those with endometriosis, it is unable to provide an understanding of why this impairment occurs (Broom and Willis, 2007). Measures of psychosocial impact attempt to quantify a subjective experience, such as pain (Young et al., 2015), and are unable to extract the qualities of illness experience that are often important for individuals (Kleinman and Seeman, 2000). Furthermore, the use of such measures with younger adolescents with endometriosis may not be appropriate, because some measures have not been developed or validated for this population (Gao et al., 2006).

Adolescents with endometriosis represent a population that have received little research attention, and as a result, we have little understanding of their experiences of living with endometriosis. Therefore, further exploration is required. According to Creswell (2007), when a need for exploration arises, such as to hear the voices of an understudied population, then qualitative research is appropriate. Qualitative research provides a thorough and complex understanding of an issue, which cannot always be captured on pre-determined surveys, designed around the findings we may anticipate. Qualitative research not only allows for an exploration of what the experiences are, but also how people make sense of their experiences (Bryman, 2016). This was therefore an appropriate methodology to address the first research question.

4.4.2 Study 2: Quantitative Study

As discussed above, there is a dearth of research, particularly in the UK, which investigates both the menstrual experiences of adolescent girls, and their awareness of endometriosis. This research study was therefore designed to address this, and a quantitative methodological approach was considered most appropriate. Previous research which has collected data on the awareness of endometriosis, conducted in other countries, has made use of quantitative methods (Armour et al., 2021a; Parker, 2006; Shadbolt et al., 2013; Zannoni et al., 2014), and therefore their use in the current study allowed for direct comparisons to be made.

Quantitative research deals with numbers, it enables a certain phenomenon to be quantified, such as how many adolescent girls suffer from painful periods, or the percentage who know about endometriosis. Statistics such as these can be powerful, they make people listen and take note, and the everyday use of statistics in society makes them easy for any audience to understand (Miner-Rubino and Jayaratne, 2007). This is particularly important when research findings are used to promote the need for social change; statistics can often influence public policy and legislation (Miner-Rubino and Jayaratne, 2007). This is a pertinent issue in the field of adolescent endometriosis because researchers and endometriosis organisations, such as Endometriosis UK, advocate for the need to improve the education schoolgirls receive about menstrual wellbeing and endometriosis, with a hope that this will help to decrease diagnostic waiting times. For improvements such as these to be made, it would require the attention and action of education providers and policy makers, and numbers may be more engaging to such people (Hesse-Biber, 2010).

Traditionally, a quantitative approach involves the collection of a larger set of data than a qualitative approach. By obtaining the views of a large sample of adolescents, there is an increased likelihood that it will result in change (Miner-Rubino and Jayaratne, 2007). Qualitative research is useful for exploring an issue, such as the impact on adolescents because of their lack of awareness, but quantitative research can indicate how widespread the issue is. In addition, the use of quantitative methods allows the voices of a wider and more diverse sample of adolescents to be heard (Miner-Rubino and Jayaratne, 2007). This may also produce more objective data than if education recommendations are based solely on research conducted with girls with endometriosis, who are likely to express the need for more education, given the impact it has had on their lives. If girls without endometriosis are also unaware of it, and would like to learn about it, then this provides further evidence for the need to improve their education.

4.5 Philosophical Underpinnings of the Thesis

This thesis took a pragmatic approach to the study of endometriosis in adolescents (Morgan, 2007). A thorough review of past research highlighted the areas which required further exploration, and as such, the research questions were devised. Consideration was then given to the most appropriate methodology to employ to answer these questions, and as described above, this required both a qualitative and a quantitative study.

The use of two research methods by one researcher may contrast with previous traditions, in which social science researchers would often fall into one of two mutually exclusive communities; those doing quantitative research and those doing qualitative research. Each of these work within their own 'paradigm' or 'worldview', defined as "the consensual set of beliefs and practices that guide a field" (Morgan, 2007: 49). Quantitative methods are generally informed by positivism (Teddlie and Tashakkori, 2009), and the belief that reality is concrete, and exists externally to the researcher. This is therefore objectively measurable using numerical data and analysis (Bryman, 2016). In contrast, qualitative researchers are guided by constructivism, or the belief that reality is 'constructed' rather than set in stone. It is only knowable through the conceptual frameworks held by researchers, which are dependent on their own values and cultures, and is therefore not objectively measurable (Bishop, 2015; Broom and Willis, 2007).

While these two paradigms have opposing sets of underlying beliefs, they are similar with respect to how they approach research, in terms of outlining their ontology, epistemology, and methodology, or what Morgan (2014) terms the 'philosophy of knowledge' approach. Ontology refers to beliefs about the nature of reality (i.e. single versus multiple), epistemology is concerned with the nature of knowledge (how we know what we know), and methodology refers to the way that research questions are asked and answered (Teddlie and Tashakkori, 2009). While each of these facets are equally weighted, the research process has a 'top down' orientation, whereby the higher order assumptions, about the nature of reality, pose limits on what can be known, and the methodology that can be used (Morgan, 2007).

Issues therefore arise when researchers choose to use both qualitative and quantitative methods, because according to this 'philosophy of knowledge' approach, the underlying ontologies that are associated with each are in conflict (Morgan, 2007; Teddlie and Tashakkori, 2009). To overcome this issue, many researchers who use both methods take a pragmatic approach, rejecting this ontologically driven 'top down' notion, and instead placing central importance on the research problem at hand (Morgan, 2007).

Pragmatists are concerned with the practical consequences of their research. If the use of two methods of research can help understand real world issues, then this is more important than the potential issue of using research methods with apparent opposing ontological positions. In other words, by taking a pragmatic approach, we are choosing to take a value-orientated approach to research (Johnson and Onwuegbuzie, 2004). The emphasis is placed on using the most appropriate methods to answer the research questions (Teddlie and Tashakkori, 2009). This was therefore the approach taken in this thesis, in which the literature review identified several important gaps relating to real world issues, which are best addressing using different methods of research.

In addition to the philosophical assumptions underpinning research, one can also employ a theoretical lens (Creswell, 2007). The theoretical lens used in the current study was feminism. Feminist perspectives are not constricted to any particular theoretical perspective (Hesse-Biber and Griffin, 2015), and can therefore be used alongside a pragmatic approach (Stewart and Cole, 2007). The key aim of feminist research is creating knowledge which centres on the lives of women (Hesse-Biber, 2010), while also applying the knowledge of such women to advocate for social action and change (Brookes, 2007).

Feminist values can be applied to the conduct of both qualitative and quantitative research. Feminism has long been associated with qualitative methods, such as interviewing, as they allow the voices of women, who are often marginalised, to be heard (Hesse-Biber, 2007). As explained by Miner-Rubino and Jayaratne (2007), some feminists therefore believe that quantitative research reduces people's experience to numbers, and ignores their highly contextualised lives. However, several researchers have acknowledged that quantitative research can be conducted from a feminist perspective (Hesse-Biber, 2010; Miner-Rubino and Jayaratne, 2007; Stewart and Cole, 2007). For example, for quantitative research to align to feminist values, the research questions must stem from an issue that is important to feminists, one that will help to improve the lives of women, and that will achieve social justice (Miner-Rubino and Jayaratne, 2007). The quantitative exploration of such issues can in fact be beneficial. It is important to feminist researchers that suppressed voices are heard, and quantitative methods can allow for a large number of women's opinions to be collected. In addition, the results of quantitative feminist research are portrayed in statistics, which are accessible and effective for the non-feminist public, who may be responsible for initiating social change (Miner-Rubino and Jayaratne, 2007).

The use of a feminist lens in this study was deemed appropriate due to the highly gendered nature of endometriosis. Not only does it concern problems with women's reproductive health, but it is often treated in gendered ways as well (Denny and Weckesser, 2019). Women are more likely to seek treatment for pain than men, but are also more likely to receive inadequate care for it, with their verbal accounts of pain often dismissed (Hoffmann and Tarzian, 2001). This bias may stem from a gendered evaluation of pain; men are perceived to be more stoical when experiencing pain, and are thus believed if they actually do seek help, whereas women are perceived to report pain more often, and are not afraid to seem vulnerable for doing so, and therefore pain is ‘natural’ for women but ‘abnormal’ for men (Bendelow and Williams, 1998). Women’s reports of pain are not viewed as seriously as men’s reports, they are more likely to have their pain discounted as having “emotional” underpinnings, and they often receive less aggressive treatment for it (Hoffmann and Tarzian, 2001). The propensity for healthcare practitioners to dismiss women’s pain has been highlighted in endometriosis research, particularly in reference to the diagnostic delays.

It was therefore appropriate to apply a feminist lens to both studies within this thesis. Utilising a feminist lens in this thesis meant that feminist values were considered during the design, conduct, and interpretation of the research. This included formulating research questions and study objectives that were centred on women’s lives and promoting change, and engaging women in the research design process to ensure the methods were acceptable and relevant. Another aspect of conducting feminist research which was adhered to in this thesis was the process of reflexivity; in which the values and attitudes that were brought to the research process were outlined (Hesse-Biber, 2010).

4.6 Researcher Positionality

A key aspect of the research process, and one which enhances the quality and validity of research (Braun and Clarke, 2013), is reflexivity. In order to be reflective, it is important to explain my identity, positionality, and professional background, which might all have influenced the research process, the questions asked, and the data obtained (Hesse-Biber, 2007). In terms of my personal characteristics, I am a white woman, in her mid-30s, and a non-endometriosis sufferer. This denotes me as both an ‘insider’, as I am a woman, who menstruates (and did so as a teenager), and an ‘outsider’, as I am no longer a teenager, and I do not have endometriosis. The potential impact of my personal characteristics is discussed in further depth within Study 1.

My professional background has been quite varied but is largely research based. I worked for many years in mental health research, working on research studies with adults with bipolar disorder, and young adults experiencing psychosis. Following this, I completed a masters in Health Psychology, a prominent focus of which is the experience of illness. As part of my masters, I completed a qualitative research study exploring the use of online support groups by women with endometriosis (see

Shoebotham and Coulson, 2016). Having completed this work, I was keen to look further into the experience of endometriosis, and so was very eager to take on this PhD when the opportunity arose.

While I came to the thesis with a strong background in psychology, I do not now feel tied to any one discipline. The design of my studies, and the questions asked, were influenced by both my own research background, and by reviewing previous research in the experience of endometriosis (which has been conducted by nurses, sociologists, and psychologists, to name a few). I was also influenced to some extent by my supervisors, who have backgrounds in health psychology, sociology, and anthropology.

4.7 Summary

Having identified the gaps in the literature, a pragmatic approach, with a feminist lens, was taken to the further study of endometriosis in adolescents. This required a qualitative study to explore the experiences of adolescents with endometriosis, and a quantitative study to identify the awareness of endometriosis amongst adolescents, and their experiences of menstruation. These studies were designed and conducted separately, which are outlined in Parts 2 and 3 of this thesis respectively. Part 4 reflects on how some of the findings from these studies can be jointly interpreted, and outlines future recommendations that have arisen from the research.

Thesis Part 2: Qualitative Study

Chapter 5. Study 1: Methods

5.1 Introduction

This chapter describes the methods employed within the qualitative study, including their rationale and justification. It begins with an overview of the aims of the research, followed by a description of the exact methods used. The main aim of this research was to explore the experiences of endometriosis in adolescents, which was addressed by conducting a qualitative study using narrative semi-structured interviews.

5.2 Research Questions and Aims

This research study was guided by the overarching research question: *'What are adolescents' experiences of endometriosis?'* The key aim of this study was to improve knowledge and understanding in this previously understudied research area. This would be achieved by building upon the current evidence surrounding adolescents' experiences of endometriosis, and by exploring key areas of their experience which had received little attention in previous research. These aims were addressed through a larger set of research questions:

1. What is the lived experience of adolescents who have a diagnosis of endometriosis?
2. How do adolescents obtain their diagnosis of endometriosis?
3. What sources of support do adolescents with endometriosis draw upon and/or need?
4. Are there aspects of the adolescent experience of endometriosis that differ to those of adults, or that differ to those of AWCI?

These research questions were explored using a qualitative approach, the rationale for which was discussed in the previous chapter (Chapter 4).

5.3 Qualitative Approach

5.3.1 Semi-structured Narrative Interviews

The qualitative approach used in this study was semi-structured narrative interviews. While interviews and focus groups are both used commonly in health research, owing to their ability for an in-depth exploration of participants' experiences of a phenomenon (Gill et al., 2008), interviews provide a rich understanding of an *individual's* experience rather than the *collective* experience gathered by focus groups (Holloway and Galvin, 2017). In addition, interviews are more appropriate when little is already known on the topic of interest (Gill et al., 2008; Gray, 2004). They allow participants to use their own words and language when describing complex issues, such as their views and experiences. They are therefore a suitable method for research which aims to explore the voices and experiences of those who have been previously ignored or supressed in past research (Byrne, 2012). Interviews are also an appropriate method when researching sensitive topics, which participants might be hesitant to discuss in group settings (Gill et al., 2008).

Interviews were therefore the most suitable qualitative method for this study, which aimed to obtain individual accounts of experience, from a sample who had received little previous attention. The interview method chosen was narrative interviewing, which is an effective method when the research question is broad, such as seeking to understand the complete experience of living with endometriosis as an adolescent, rather than one which focuses on a specific aspect of it (Anderson and Kirkpatrick, 2016). In narrative interviews, people are encouraged to tell their story of their experience, which is a valuable research tool because story telling occurs frequently and naturally in people's lives, and it is a way they make sense of their experience (Anderson and Kirkpatrick, 2016). Narratives are additionally useful when researching chronic illness experience, because they enable people to make sense of the disruptive events which may occur in their lives (Riessman, 1990). A story is usually told along a timeline, from beginning, through middle, to end, and therefore gathers a coherent account of the entirety of one's experience.

The narrative interview method was combined with semi-structured interview techniques, including the use of a topic guide. In a typical narrative interview, the interviewer is required to have a relatively flexible agenda, perhaps with one opening question, following which the participants take control of the direction and content of the interview (Anderson and Kirkpatrick, 2016). While this method enables participants to tell their story, and raise issues which are important to them, it may fail to address topics of interest to the researcher, which have not been explored previously (Anderson and Kirkpatrick, 2016). In addition, the narrative approach may be confusing if more guidance is sought by participants on what to discuss. A topic guide, which consists of key questions and prompts, can help to outline the areas of interest (Gill et al., 2008). Their use still enables a flexible interview approach; the sequencing of questions, and the topics that are covered might not be the same for all participants, as it will depend on the interview process and participants' responses. The guide simply ensures that the data collected from each participant covers the topics of interest (Holloway and Galvin, 2017). This flexible approach also allows for the interview to diverge along unanticipated pathways, and to uncover issues which had not been previously considered (Gray, 2004).

The methods of data collection that were used in this research were face-to-face and telephone interviews. The use of narrative semi-structured interviews necessitated a method which allowed for both verbal communication and synchronicity, and therefore methods such as email and web chat, in which interviewees type their response, were discarded. Face-to-face interviews have the additional benefit of the visual element, in which non-verbal cues, such as facial expressions, gestures and body language, can be viewed and interpreted by the interviewer (Lo Iacono et al., 2016). These non-verbal forms of communication can add to the richness of qualitative data (Hesse-Biber and Griffin, 2013). While these can also be obtained by the use of online video interviews (Lo Iacono et al., 2016), some of these cues might be missed, as poor connection, dropped calls and broken speech/images might all pose a problem. This could affect rapport, and might therefore be particularly difficult when discussing sensitive topics - the addition of a video may further increase nerves (Seitz, 2016). Face to face interviews were therefore preferred for the current research, in which sensitive topics would be discussed.

However, the use of face-to-face interviews alone posed restrictions on recruiting and interviewing those from a wide geographical area, and therefore telephone interviews were also used. This method not only ensures for a more diverse sample, which is advantageous when recruiting historically marginalised communities underrepresented in research, but is also time and cost efficient (Holloway and Galvin, 2017). While telephone interviews do not have the benefits associated with the visual element of other interview methods, their use is associated with a level of anonymity, which can help when relaying experiences of a sensitive nature (Drabble et al., 2016). Furthermore, there are a number of strategies that an interviewer can use, such as active listening, reciprocity, and informal ‘small talk’, which can build a rapport, and produce an effective interview (Drabble et al., 2016).

In summary, this research employed individual interviews with participants, to explore their experiences of living with endometriosis. The approach taken was narrative interviewing, however this was combined with semi-structured interview techniques, to prompt participants if needed, and to explore topics of further interest. Both face-to-face and telephone interviews were used, the choice of which was dictated by both geography and participant’s’ personal preferences.

5.3.2 Timelines

In addition to the semi-structured narrative interview, a drawing technique was employed to act as a research tool, for which participants were asked to create a timeline, or visual representation of their journey with endometriosis. Timelines are a complementary research technique to narrative interviewing, the aim of which is to construct the participant’s own story about their experiences

(Woolhouse, 2017). The telling of a story is usually linear, told in chronological order, and therefore a timeline can help to tell this story (Adriansen, 2012). Timelines, or similar drawing methods, are often used in cross cultural research, or research with children, where participants may struggle to verbally articulate their experiences (Bagnoli, 2009). However, they are more widely being used with other populations, and in research about chronic illness, as their use as a research tool can have many benefits (Guillemin, 2004).

In narrative interviewing, participants are invited to recall and recount their experiences, some of which may have happened many years ago, which can be demanding (Woolhouse, 2017). The drawing of a timeline can help to stimulate participants' memories, allowing for the recall of experiences that may otherwise be forgotten, or temporally misplaced (Bagnoli, 2009; Jackson, 2013; Woolhouse, 2017). Furthermore, by asking participants to produce a timeline, they are given an element of control over the research process, and the content they choose to share, which may be viewed as an empowering experience (Jackson, 2013).

In addition to the benefits for research participants, the use of timelines can also aid the interviewer and the research process. They can be a useful way to open an interview, or to 'break the ice', and they may help to overcome silences throughout the interview (Bagnoli, 2009). By focusing on the process of drawing, participants may find it easier to talk about sensitive issues, as they do not need to maintain eye contact with the interviewer (Adriansen, 2012). A timeline provides a chronological overview of a participant's story, which both researcher and participant can see, and which can therefore guide the researcher through the subsequent narrative interview (Adriansen, 2012; Jackson, 2013).

Finally, the use of timelines can add to the depth, or the richness of the data collected. The visual focus of timelines allows participants to go beyond a purely verbal way of thinking, which most qualitative interviews rely on, and can capture the wider dimensions of individual experience, which may otherwise be missed (Bagnoli, 2009). They can expand our understanding of illness by enabling a more complex exploration of the diverse ways that illness is experienced (Guillemin, 2004). A timeline can also offer a more thorough understanding of how the events experienced during ones story fit into the wider contexts of their lives (Adriansen, 2012).

5.4 Sample Inclusion and Exclusion Criteria

The sample for this research consisted of adolescents and young women (AYW) with a diagnosis of endometriosis, aged 15 to 24 years old, and who had experienced symptom onset between age 10 and 24 years. The rationale for this age range is multifaceted, it included; the identification of common definitions of adolescence; exploring the age ranges used in similar health research, and; conversations with experts in the field.

As discussed in Section 2.3, adolescence has been defined as those aged 10-19 years (UNICEF, 2011) since the middle of the 20th century, however the course of adolescent growth and the timings of role transitions associated with adolescence have changed significantly over that time (Sawyer et al., 2018). Therefore, to align with contemporary patterns of adolescent development, a more inclusive definition, now widely adopted by many researchers, is those aged 10 to 24 years old (Hagell et al., 2013; James, 2017; Sawyer et al., 2018). In health research, using the upper age limit of 24 also allows for the sometimes lengthy transition into both adulthood and adult services (Hagell et al., 2013).

With these definitions in mind, various experts were approached to discuss the proposed age range for this research. These included an endometriosis specialist clinician, endometriosis researchers, and trustees/the CEO of Endometriosis UK. All agreed that while the symptoms of endometriosis often begin at a young age, it may be challenging obtaining a big enough sample if the range of 10 to 19 years was used, particularly given the often-lengthy diagnostic delay. Therefore, recruitment was aimed at those whose symptoms began before the age of 19, but with an extended upper age limit of 24. This would allow for the inclusion of those whose symptoms of endometriosis began during adolescence, even if it was not diagnosed during that time. The upper age limit of 24 also ensured that the data collected reflected the true adolescent experience, from those who were adolescents, or from young adults who were still transitioning into adulthood, whose adolescence is the subject of recent recall.

The lower age limit for participation in this study was 15 years. Although there is evidence to suggest that symptoms of endometriosis might start at a very young age (Laufer, 2000), it is very rare for adolescents to obtain a diagnosis between the ages of 10-15 years (Haas et al., 2012). Those aged 14 and under may also be more embarrassed than their older peers when talking about matters concerning menstruation (Ackard and Neumark-Sztainer, 2001).

Finally, to be eligible for the study, a diagnosis of endometriosis needed to have been confirmed via laparoscopy (self-report). This ensured that the views and experiences collected in this research were those of people who have endometriosis, rather than a similarly presenting condition.

In summary therefore, participants had to meet all the following inclusion criteria:

- Aged 15 to 24 years.
- Symptom onset between the ages of 10 and 19 years.

- Confirmed self-reported diagnosis of endometriosis (laparoscopically confirmed)
- English speaking

5.5 Recruitment

Participants for this study were based in the United Kingdom, and were recruited through social media and Endometriosis UK, via both their support groups and social media platforms. The use of support organisations to recruit participants in health research is well established, and has been widely used in previous endometriosis research (e.g. Cox et al., 2003a; Gilmour et al., 2008; Seear, 2009b). Their use as a recruitment platform is particularly effective when the study sample stems from a highly defined group, and they have the additional benefit of being low resource-intensive (Patrick et al., 1998). In line with technological advances, the support provided by organisations, such as Endometriosis UK, is not confined to traditional face-to-face settings, and is also readily accessible on the internet. Obtaining support online is popular due to its flexibility, allowing those who's time or locational restraints prevent them from attending face-to-face groups (Potts, 2005). Online support groups are accessed by those with endometriosis, who have described many therapeutic benefits of such use, including the ability to find others with the same condition, and to access support and information (Shoebotham and Coulson, 2016).

Through the development of social media, such online support is now also available on platforms such as Facebook, Twitter, and Instagram. Social media platforms are those described to "provide space for social interaction, communication, collaboration, and community formation" (Zhao et al., 2013: 290). These sites are particularly popular amongst teenagers, with recent estimates suggesting that 96% of 16 to 24 year olds in the UK are social media users (Office for National Statistics, 2017). Given the widespread use of social media, it is often utilised as a research recruitment tool. Social media can enhance the recruitment of historically marginalised/underrepresented communities (King et al., 2014), and is also cost and time effective (Fenner et al., 2012). It has successfully been used in engaging teenagers and young women in research (Fenner et al., 2012).

Therefore, this research used support groups (online and physical) and social media sites as recruitment settings. The support organisation Endometriosis UK was contacted to seek their permission to recruit through their support groups and social media accounts. After providing their permission (see Appendix 13), they shared a research advert at local face-to-face support groups and on their Facebook page. The research advert was also shared on the researcher's own social media pages (Facebook, Twitter, and Instagram), using #endometriosis, to ensure it was noticed by the target audience. For these research adverts, two research flyers were produced (see Appendix 3) which provided a brief overview of the study and instructed those who were interested in the research to contact the researcher directly.

These advertisements, and particularly those shared by Endometriosis UK, received a large amount of attention, and 104 respondents made contact to express their interest; 92 who had heard about the research from Endometriosis UK's Facebook post, 4 from a local Endometriosis UK support group, and 8 from my own Twitter post. All respondents were sent a standard reply, thanking them for their interest and informing them that due to the large amount of interest, it may take some time to get back to them. If they hadn't already provided it, they were also asked for their age, and their geographical location. There were 7 respondents who immediately did not meet the study criteria, because they did not meet age requirements (2), or lived outside the UK (5), and these were each sent an email thanking them for volunteering but informing them that they would not be able to participate.

Due to the qualitative nature of this research, it would not have been possible to interview all those that responded to the advert, and therefore a sampling procedure was adopted. Respondents were initially prioritised based on age, as previous research had little inclusion of the experiences of teenagers, and so all those aged 19 and under were approached first. This resulted in 11 potential participants. Next, sampling focussed on attempting to include the views of people from varied ethnic backgrounds. In the absence of any direct information on respondents' race or ethnicities, demographic data was gleaned from their names, where possible (Tzioumis, 2018). However there did not appear to be much indication of diversity amongst the respondents, with the exception of one respondent, who did not have a diagnosis (and thus did not meet inclusion criteria. In an attempt to target those from more ethnically diverse backgrounds, contact was made with a local organisation who aim to ensure that those from ethnic and racial minoritized communities have their voices heard, with one of their key focuses being on menstrual and reproductive health. However, they were unable to find any potential participants for the study.

Following these attempts to recruit a younger and ethnically diverse sample, selection was guided by the view that it was beneficial to interview people with very varied symptoms and experiences. However, to avoid raising the hopes of respondents in case they were not interviewed, they were not contacted to ask for more information about their experiences, and it was instead gleaned from their initial emails, many of which included descriptions of their symptoms, treatments, and diagnosis.

Those selected as potential participants were asked via email to provide their phone number, and a suitable day and time to phone them, to complete the initial telephone screen. They were then contacted according to the information they provided, and all were given the same verbal information about the research (see Appendix 4). Once their willingness to participate was confirmed, they were asked a few short screening questions to ensure they met the eligibility criteria, including their current age, age at symptom onset, and whether they had a confirmed diagnosis. If they met inclusion criteria, they were recruited into the study and a research interview was arranged. The final sample size (24) was determined as data collection progressed, when a point of data saturation was achieved.

5.6 Measures

5.6.1 Interview Guide

An interview topic guide was developed specifically for use in this study, which was derived from a thorough review of the literature. To assess the relevance of the content of the interview guide, it was shown to women belonging to a local endometriosis support group. Following their consultation, the interview guide was amended, including the addition of key questions and minor prompts. Following this, it remained a developmental document, which was edited after the conducting the first few interviews to include particular issues which had emerged (Holloway and Galvin, 2017). The final topic guide, used for most interviews, is available for reference in Appendix 5.

The topic guide opened with a set of structured questions, to gather demographic data about participants, and information about their endometriosis, including their age at symptom onset, number, and type of surgeries etc. Questions such as these help to build a rapport with participants, and put them at ease ready for the more unstructured questions (Gill et al., 2008; Holloway and Galvin, 2017). The narrative part of the interview guide began with an open question: “Can you tell me about what happened when you first started to experience symptoms of endometriosis?” This was followed with several prompts, and follow up questions, to address key areas of exploration. To yield as much information from participants as possible, and to allow them to express their own views and experiences, questions were open-ended and neutral.

Some participants were able to provide a narrative of their entire story of living with endometriosis following the opening question. Such participants were then questioned according to the interview guide if more clarity was sought, or if they had not addressed key areas of further exploration. However, many participants needed more direction and prompting, which was apparent from the outset of their interview, and so they were interviewed using a more semi-structured approach.

5.6.2 Timelines

For the timelines task, participants were given (either verbally or written) a standard set of instructions, which can be seen in Appendix 6. As suggested by Bagnoli (2009), the instructions for the timeline were kept as broad as possible, and participants were asked to “draw a visual representation of your journey with endometriosis, something like a timeline, river or path”, rather than explicitly stating they had to do a timeline. It was important to ensure that participants structured the drawing in their own way, and therefore took ownership of it. Some participants did ask for a little more guidance, and they were told that it was really up to them how to draw it, as long as it captured their journey from when their symptoms began up until the present day, and included any significant events along the way. They were also reassured that their drawing skills were not under any scrutiny, and that it was simply a way to get an overview of their journey (Jackson, 2013).

5.7 Ethical Considerations

A foundational code of ethics is the Declaration of Helsinki, first established by the World Medical Association in 1964 (World Medical Association, 2013; most recent update). This Declaration was developed to provide a set of ethical principles, which safeguard human subjects who are involved in medical research. A key feature of the Declaration is to always ensure that the health, well-being, and rights of those involved in research are protected, and that this takes precedence over scientific interest. This principle is common across the codes of ethics adopted by different disciplines, including that of the British Psychological Society (BPS, 2018) which was followed in this research.

The ‘Code of Ethics and Conduct’ of the BPS (2018) sets out four ethical principles, with which psychologists must aim to adhere to. These principles are respect, competence, responsibility, and integrity. Complementary to this document is the BPS ‘Code of Human Research Ethics’ (2014), which specifically outlines the ethical conduct involved in research with human subjects. The principles in this latter document correspond to those in the ‘Code of Ethics and Conduct’. These principles are outlined below, as well as the methods taken to abide by them in this research:

1) ***Respect for the autonomy, privacy and dignity of individuals and communities.*** This was achieved by ensuring participants made their own fully informed decision to take part in the research, and in doing so were provided with adequate information about the research and their rights as a participant such as confidentiality, consent, and withdrawal.

2) ***Scientific integrity.*** This was ensured through the process of obtaining ethical approval, in which the design and rationale for the research were independently scrutinised and confirmed.
3) ***Social responsibility.*** Key stakeholders (including Endometriosis UK) we contacted for both guidance and permission of access, which ensured this research created knowledge that was beneficial to society, and that social structures would be respected through the conduct of the research.
4) ***Maximising benefit and minimising harm.*** While generating such knowledge that would be of benefit, it was of upmost importance to safeguard the well-being of research participants.

Further details about how the ethical principles of both BPS codes of ethics were considered and actioned in this research are subsequently outlined. As indicated by the guidelines, ethical principles were considered from the initiation of the study, through to the writing up of study findings.

5.7.1 Obtaining Ethical Approval to Conduct the Research

Prior to commencing any research activities, approval was sought, and granted by the University Ethics committee (FAEC) at Birmingham City University (see Appendix 7).

5.7.2 Consent, Confidentiality, and Withdrawal

Participants were aged 15-24 years at the time of study participation. Those who were aged at least 16 years old were able to give their own permission to consent to research. Those who were under 16 needed additional consent from a parent or guardian before they could take part in the research, as well as providing their own written consent. Potential participants, and parents/guardians if under 16, were presented with an information sheet which detailed the research in full, including the research methods and their right to withdraw (see Appendices 8 & 9). Prior to taking consent, participants were asked to confirm they had read and understood the information sheet, and were given the opportunity to ask any questions they wanted to about the research. Participants then provided their fully informed consent, by completing a consent form, which listed several statements to which they had to initial, such as their right to withdraw and their confidentiality rights, before signing and dating at the bottom (see Appendix 10). Those under 16 would also need their parent/guardian to sign a consent form (see Appendix 11).

To maintain participant confidentiality, participants were given an ID number upon recruitment into the study, and all their data was stored according to that number. Therefore, neither their name, nor any other identifiable information, was associated with any of their research data. Furthermore, no identifiable information is reported in the results and all participants were given a pseudonym. Pseudonyms were chosen by the researcher at random, and none of the names chosen were the real names of any participants. Participants could also opt out of giving consent for their direct quotes to be used in the research report, publications, or presentations, however no participants chose to do this.

Data was stored in accordance with the Data Protection Act 1998, where by physical data was encrypted and stored in a locked cabinet at Birmingham City University, and electronic data was stored under password protection on a secure server.

5.7.3 Protecting the Well-being of Research Participants

During study design, consideration was given to the potential for distress to arise because of the exploration into participants' experiences of endometriosis, particularly if relaying very personal stories. Procedures were put into place should this occur, including showing sensitivity towards the participant, giving them the option of having a break, stopping the interview, and returning to it another day, or stopping the interview and not returning to it. An appropriate follow up procedure was also put in place to ensure there was no on-going distress after the interview, whereby participants were given a debriefing information and support sheet (see Appendix 12). This adhered to the guidelines for research with children and young people as proposed by the National Children's Bureau (Shaw et al., 2011). If a participant were to have shown signs of very marked distress during interview, they would have been followed up by a phone call within 48 hours, to ensure that there was no ongoing distress and that they had made contact with the appropriate additional supports.

During the conduct of the interviews, a small number of participants showed minor signs of emotion while relaying their experiences, and they were asked if they would like to take a break, or move on to a different topic. They each expressed a desire to continue, and said they were eager to tell their story. There were no signs of marked distress shown by any participants, either during or after the interview, and therefore none of them needed to be followed up after the interview process.

A safeguarding procedure was also put into place in the design of this study, which participants were informed about in the information sheet. No safeguarding issues were raised during the conduct of the study.

5.7.4 Respecting the Potential Power Imbalance Between Researcher and Participants

It was considered that there may have been scope for a potential power imbalance to occur, between the researcher and the participant, due to factors such as age and status. Power relations were considered at each stage of the research process, including the design, recruitment, data collection, and interpretation stages (Karnieli-Miller et al., 2009). Attempts were made to minimise this imbalance, such as building a rapport, avoiding the use of leading questions during data collection, and giving participants the opportunity to ensure their views were interpreted correctly.

5.8 Data Collection

Potential participants were initially contacted by telephone to relay study information sheet and confirm eligibility criteria. Following this, an interview was arranged at a date and time suitable for the participant. These interviews were conducted either face-to-face, if geographically possible, or over the telephone. Data collection procedures differed slightly depending on whether a face-to-face or telephone interview was conducted.

In total, 13 telephone interviews were conducted. Participants completing a telephone interview were sent the information sheet and consent form either by post or by email, and were asked to complete and return the consent form prior to the arranged date of interview. During the initial phone conversation, participants were told about the timeline drawing exercise, and were asked if they were willing to complete this, to which all agreed. They were given both verbal and written instructions for the timeline (see Appendix 6), and were asked to send a scan or photo of their completed timeline via email prior to the arranged interview. All but one of the participants completed the timeline exercise. On the day of interview, all participants were called at the arranged interview time on the numbers they provided, and it was confirmed that they were in a private space, which in all cases was a room within their home. Then the rest of the interview proceeded (detailed below).

The remainder of the interviews (11) were conducted face-to-face, 9 of which were done at participants’ houses, and 2 on the university campus. These were conducted in a private space, in a private meeting room if on campus, or a private room within a participant’s house. During two home visits, participants had their mum present in the room, and so it was confirmed prior to starting the interview that the participant was willing to discuss the potentially sensitive topics in front of them, to which both agreed. Their mothers were informed that the interview would be audio recorded, and anything they said would be picked up by the recorder, however it would not be used in the subsequent analysis (or any publications resulting from such). At the start of the interview, participants were asked to complete the consent form. Participants were then told about the timeline drawing exercise, and all participants agreed to complete this. For this exercise, they were provided with a blank piece of A3 paper and some pens. They were given the same verbal instructions as those who completed timelines for phone interviews, and they were then given approximately 10-15 minutes to draw their timeline. Some chose to talk their way through their timeline, in which case it was audio recorded (with consent), and some completed it in silence.

Once consent was obtained and the timelines were complete, both face-to-face and telephone interviews then followed the same procedure. Participants were asked to provide their demographic and background information, and were then told about the structure of the remainder of the interview. They were told that we would be talking through their timeline, and discussing their experiences of living with endometriosis, and that the audio recorder would now be turned on (unless already on due to talking through timeline). They were also informed that they did not have to answer any questions they felt uncomfortable with, and that they could take a break if needed.

Using their timelines and the interview topic guide (see Appendix 5), participants were then asked to tell their story of living with endometriosis. Interviews lasted between 50 and 90 minutes. There was little difference in the average length of time between face-to-face interviews (66.2 minutes) and telephone interviews (69.2 minutes). Most participants did not require a break, although one needed to abruptly stop the interview due to unforeseen circumstances, and so it was completed at a later date. At the end of the interview, it was confirmed that the participants had nothing further to add, and any questions they had were answered. They were then thanked for their time and were given (or sent by email) an information sheet detailing sources of further support (see Appendix 12). All participants consented to being contacted again, should the need arise. The process of data analysis began after the completion of the data collection phase, and therefore did not influence the data collected.

5.9 Data Analysis

The data collected in this study included the demographic information, timelines, and audio recorded interview files for each participant. The demographic information was collated on an excel file, to enable an overview of the participant characteristics of the sample. The audio files were transcribed to produce text documents, which allowed for the subsequent data analysis. All were transcribed by the PhD candidate. The method adopted was intelligent verbatim transcription, and the written text was annotated in order to maintain the emotional overtones of the spoken text (i.e. using **bold** to show speech emphasis). Other nuances of the spoken text were also recorded, including pauses (p) and “break-offs” (–); when one interrupts self or stops idea mid-stream (as described by Riessman, 2008). The main goal was to ensure consistency across transcripts, and that each transcript remained as true to the original conversation as possible (Bazeley and Jackson, 2013; Braun and Clarke, 2006). Finalised transcripts were uploaded onto QSR NVivo version 11; which facilitated the qualitative analysis process.

5.9.1 Choice of Analysis Method

The method of analysis used for the interview transcripts was thematic analysis (TA), using the framework outlined by Braun and Clarke (2006). TA is considered to be “a method for identifying, analysing, and reporting patterns (themes) within data.” (Braun and Clarke, 2006: 79). It was therefore appropriate for use in this research study, which aimed to describe the patterns, or themes, which occurred across AYWs experiences of endometriosis. It is also an approach which can be used with narrative interview data (Anderson and Kirkpatrick, 2016). However, the “thematising” of data (Holloway and Todres, 2003: 347) is a strategy used in much qualitative analysis, and as such TA has been criticised as being merely an analysis tool, and not a method of analysis in its own right. Braun and Clarke (2006) refute this, stating that what is missing is clarity around the method, and they therefore propose a methodological framework for conducting thematic analysis.

According to Braun and Clarke (2006), TA differs from many other analytic methods that aim to describe patterns across a dataset. Unlike methods such as interpretative phenomenological analysis (IPA) and grounded theory, it is a flexible method of analysis, which is not tied to any particular theory or epistemology. IPA, for example, is bounded to a phenomenological epistemology (Smith, 1996), and has a dual focus, aiming to describe the meaning of experience at both a general and individual level (Holloway and Todres, 2003). Furthermore, IPA is not just an analysis method, but it provides a framework for conducting an entire research project (Smith and Osborn, 2004). In a similar vein, grounded theory can be viewed as a methodology and not simply a method of analysis, however it is also directed towards the development of a plausible and effective theory of the phenomena under study, which is grounded in the data (Holloway and Todres, 2003). Grounded theory analysis therefore is more suitable to research questions which focus on social and psychological processes, and noting changes or influencing factors on the area of interest (Holloway and Todres, 2003).

TA contrasts to IPA and grounded theory (among other methods) because it has no fixed theoretical underpinning, and therefore can be used within numerous theoretical frameworks, in many different ways (Braun and Clarke, 2006). The theoretical freedom offered by TA therefore makes it appropriate for use in the current study. However, for the analysis to be methodologically sound, it is important that epistemological assumptions behind the analysis are made explicitly clear. TA can be; essentialist/realist, reporting the experiences, meaning and reality of participants, or; constructionist, examining how events, experiences meanings etc. are affected by the discourses operating within one's socio-cultural context (Braun and Clarke, 2006). The aim of this study was to report on the experiences and reality of AYW with endometriosis, and therefore a realist approach to TA was taken.

Furthermore, Braun and Clarke (2006) state the importance of making explicit the decisions about how themes were identified; and in this research, an inductive semantic approach was taken. An inductive, or data driven, approach allows for participants' experiences to emerge from the data, and is not restricted by theoretical constraints or a researcher's preconceptions (Braun and Clarke, 2006). As there was a lack of existing literature on adolescent experiences of endometriosis, an analysis approach which was exploratory and inductive was therefore needed. Finally, the semantic approach ensures that the identification of themes is based on the explicit or surface meanings of the data, and does not aim to go beyond what participants have said, to seek their underlying meanings (Braun and Clarke, 2006). Once patterns have been identified in the data, they are then interpreted in an attempt to understand their significance and implications.

5.9.2 Analysis Process

The six phase framework for TA proposed by Braun and Clarke (2006) was used. The first phase involved familiarisation with the data, through a process of 'immersion'. By the time the data analysis commenced (after completing the data collection phase), there was already a good level of familiarity with the data, which followed from having conducted and then transcribed each interview. Transcription occurred shortly after each interview, which allowed for the recognition that data saturation had been reached. It was a lengthy process; each recording was often listened to 3 times in its entirety to produce the final transcript. However, this process was seen as a key phase in the data analysis (Bird, 2005), it was an integral way to obtain data familiarisation, and to form initial analytical ideas (Bazeley and Jackson, 2013). Once all the transcripts were produced, they were uploaded to NVivo, and the formal process of data analysis was commenced. This began with the reading and re-reading of all transcripts, and noting down initial ideas and patterns within the data.

Once the process of data familiarisation was complete, phase two of the analysis process began; 'generating initial codes'. This involved the systematic coding of the entire data set, looking for interesting features in the data, and patterns across the data set. In selecting which interview to code first, a decision was made to choose one which was lengthy, and which was remembered to be rich in detail. A second interview to code was then selected because it contrasted in several ways from the first, such as symptoms experienced, time to diagnosis, etc. This process of selecting contrasting interviews continued, and enabled for the generation of the majority of codes, and a wide variety of codes, while coding the initial few transcripts (Bazeley and Jackson, 2013). Coding was extensive; using an inductive approach meant that the contents of the entire data set were coded, ensuring that nothing was left uncoded in case it was relevant/interesting later. Many data extracts were assigned to multiple codes (Braun and Clarke, 2006).

At the completion of phase two, a long and exhaustive list of codes had been developed, and phase three, 'searching for themes', was initiated. Themes were considered as: "…an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole." (DeSantis and Ugarriza, 2000: 362). To develop such themes, the list of codes was sorted and collated to produce a number of potential themes. The relationship between codes, subthemes, and themes were considered, and codes which did not obviously fit into themes were placed into a 'miscellaneous' theme. At this stage, the size of the themes was not considered to be important, but rather whether they were of relevance in answering the research question (Braun and Clarke, 2006).

Once a set of potential themes had been devised, they were reviewed in phase four of the analysis. This involved the examination of the coded data extracts, to ensure that they formed a coherent pattern. At this stage, refinements were made to both the themes and subthemes, and coded extracts which were an ill-fit for their theme were either moved or discarded. The number of themes reduced significantly at this stage of the analysis, as themes were collapsed together to provide a more concise representation of their content. For example, the themes 'living with endometriosis' and 'impact on teenage life' were collapsed to form 'living with endometriosis as a teenager'. It was important to ensure that there was meaningful correspondence of data within a theme, but that there was a clear difference of data between themes (Braun and Clarke, 2006). In addition, this phase of analysis ensured that the themes accurately represented the entire data set.

After the themes had been reviewed and refined, phase five of the analysis began; 'defining and naming themes'. This phase involved providing a definition of each theme and subtheme, as well as a 'concise' and 'punchy' name which captures the 'essence' of what the theme is about (Braun and Clarke, 2006). To do this, the original data was consulted to try to identify names which reflected the language used by participants. Aligning with the feminist lens, this also ensured the acknowledgement that the participants were the experts of their particular experiences.

The final phase in the analysis process was ‘producing the research report’, which aimed to provide a concise, coherent, and interesting account of the data (Braun and Clarke, 2006). Prior to beginning the report writing, the data within each subtheme was scoured to find the data extracts which best encapsulated the essence of each subtheme. These extracts included shorter segments, which were particularly useful for making specific points, and more extensive extracts which provided context and flavour of the original text (Nowell et al., 2017). Furthermore, themes and/or subthemes which were particularly prevalent in the data set were demonstrated through the provision of numerous data extracts in the final report.

5.10 Ensuring Trustworthiness in the Research Process

The concept of trustworthiness was introduced by Lincoln and Guba (1985) as an alternative to the concepts of validity and reliability used in quantitative research. Trustworthiness can be understood as the methodological soundness and the adequacy of the research (Holloway and Galvin, 2017). The criteria upon which trustworthiness can be assessed, as proposed by Lincoln and Guba (1985), are credibility, dependability, transferability, and confirmability.

Credibility corresponds closely to the concept of internal validity used in quantitative research, and is therefore concerned with the level of truth in the study findings, and how accurately they represent the phenomenon under study (Holloway and Galvin, 2017). To ensure credibility in participants’ accounts, it was important to establish and maintain a level of rapport and trust with them both prior to and during the interview process. It was hoped they would feel at ease when describing their experiences of endometriosis, thus providing an accurate account. However, participant accounts were produced through the process of an interview, and although this might appear to take the form of a conversation, it is not a naturally occurring one. Therefore, participants may have only spoken about aspects of their experience that they perceived to be important for the research (Riessman, 2008). While it is important to acknowledge this, as it may mean some aspects of their experience were missed or downplayed, it should not have impacted on the accuracy of their accounts.

In order to seek credibility in the analysis process, it was important to ensure that these accounts were adequately conveyed in the results of the analysis; that there was a good level of ‘fit’ between participants’ views and the researcher’s representation of such (Tobin and Begley, 2004). This was facilitated by prolonged engagement with the data, and peer review during phases of the analysis process (Nowell et al., 2017). The provision of sufficient participant quotes in the research report also supports the credibility of findings.

Dependability is comparable to the concept of reliability; that findings are consistent and accurate (Holloway and Galvin, 2017). This can be demonstrated by maintaining an audit trail, which clearly documents the analysis process and decisions made (Tobin and Begley, 2004). In this research, the audit trail was facilitated by using NVivo analysis software, and a researcher diary. The research report provides an account of key decisions in the research process, such as contextual, methodological, and analytical decisions.

Transferability relates to the generalisability of the research findings; the extent to which they can be transferred to other situations or participants (Holloway and Galvin, 2017). Qualitative studies are usually based on small samples, which limits the transfer of findings onto the wider population, and therefore only case-to-case transfer can be made (Tobin and Begley, 2004). To enable readers to evaluate the transferability of the research to their own settings, a thick description of the research process is provided. This includes a rich description of factors such as the context, the participant characteristics, and the analytical process.

The final criterion for establishing trustworthiness is confirmability, which is akin to objectivity; whether the research findings derive from the data and not the researcher's prior assumptions. This too can be established with a thorough description of the analysis process (Holloway and Galvin, 2017). Furthermore, the use of extensive quotes within the research report provides evidence that findings and interpretations are rooted in the raw data.

5.11 A Reflective Account of the Research Process

Reflexivity is a key component of feminist research (Hesse-Biber, 2010), and therefore in accordance with the feminist lens, this section provides a reflective account of the role of the researcher on the research process. This account is written in the first person. It is important to consider the nature of my relationship to those I interviewed; how my social positioning might have influenced both the interview process and the data obtained (Hesse-Biber, 2007). It may also have influenced the questions posed, and the analysis process. Consideration is first given to my personal characteristics; my position as a white woman, in her early 30s, and a non-endometriosis sufferer, before moving on to a reflection on my professional background.

In some respects, participants may have viewed me as an 'insider'; I am female, and could be considered a 'young adult', although a few years older than participants. At the time of data collection, I was relatively recently out of adolescence (if you consider it up to age 24) and could identify with aspects of adolescence/young adulthood that my participants discussed. I also chose to dress casually for interviews, in jeans, trainers, etcetera, in attempt to mitigate any power imbalances based on age.

I believe that my status as a woman was beneficial when recruiting and interviewing participants. Much of the interview involved discussing symptoms related to menstruation, and as a woman, this is something which I have experienced. I believe this helped participants to feel comfortable to discuss their experience and symptoms openly. In addition, sensitive issues, such sex and relationships, may have been discussed with less hesitance than if I were male (Padfield and Procter, 1996).

A key characteristic that denoted me as an 'outsider' to those I interviewed was my health status; that I do not have endometriosis. However, endometriosis is not visible, and unless asked, I did not disclose to participants whether I had it or not. A small number of participants did ask, however, they all did so at the end of the interview, and so it is unlikely to have had an impact on the data collected. Some participants asked why I was doing the research (either at the beginning or the end of the interview), and they may have expected that if I were to have endometriosis, I would have mentioned it. Seeing as I did not, they may have assumed I did not have it.

When in consultation with WWE at a support group (while constructing the interview guide) I asked their opinion about me conducting this research given that I don't have endometriosis. They said they viewed it largely as a positive thing; they were somewhat appreciative that someone who did not have endometriosis would want to spend time studying it. One woman in the group also commented that she thought it would be beneficial due to me being more likely to be objective. I therefore never perceived my 'outsider' status as a non-endometriosis sufferer to have a negative bearing on the research process. I were an 'insider', I may have projected my own experience and values onto the research process, possibly impacting the research questions posed, the interview, and the interpretation of the data (Dwyer and Buckle, 2009), and so my impartiality may have been somewhat beneficial.

My ethnicity may have influenced the data I was able to obtain; I am White, which could have influenced recruitment as I was unable to recruit anyone from any other ethnicity. However, I have an Asian surname ('Randhawa') and so potential participants may not have known I am white. There are several potential reasons for being unable to recruit non-white participants, which are discussed in section 7.6 of the discussion chapter.

A final attribute to mention in relation to reflexivity is my professional background. I came to this thesis having worked for many years in mental health research, and then completing a masters in health psychology. While I do have a strong background in psychology, I do not feel I am tied to any one discipline. Previous qualitative endometriosis research has been conducted by those who are nurses, sociologists, and psychologists, to name a few, all of which I drew upon in the design of my study, and the questions I chose to ask.

Chapter 6. Study 1: Results

6.1 Introduction

This chapter details the findings of the qualitative study, which used semi-structured interviews to explore the experiences of adolescents and young women with endometriosis. The demographic characteristics of the participants are presented, followed by the results of the thematic analysis.

6.2 Participant Characteristics

The study sample consisted of 24 female participants, the characteristics of which can be seen in Table 6.1 below. They were aged 18 to 24 years at the time of participation, with a mean age of 21.1 years. The sample all described their ethnicity as 'White British'.

Participants reached menarche between age 9 and 14 years, and thirteen participants (54.2%) experienced the onset of endometriosis symptoms from menarche. The mean age at symptom onset was 13.1 years (range 9-15 years), however their mean age at diagnosis was 18.3 years (range 16–22 years). Therefore, the average time from symptom onset to receipt of diagnosis was 5.2 years (range 2-9 years).

Table 6.1: Participant Characteristics

Participant Pseudonym	Age at Interview	Age at menarche	Age at Symptom Onset	Age at First GP Visit	Age at diagnosis	Number of laparoscopies *(additional surgeries)*	Relationship status	Number of children	Occupation	Ethnicity
Eve	23	14	18	18/19	22	1	Living with partner (m)	0	Marketing	White British
Alexandra	20	11/12	14	14/15	20	1	Boyfriend	0	Student	White British
Louise	18	14	14	?	18	1	Single	0	Student	White British
Anna	21	11	13	14	17	2	Boyfriend	0	Student	White British
Jessica	21	12	12	12	18	2	Single	0	Student	White British
Daisy	19	10	10	10	18	1	Single	0	Student	White British
Kate	18	13/14	15	15	17	1	Boyfriend	0	Student	White British
Helen	24	9	14	14/15	18	4 *(Hysterectomy)*	Living with partner (m)	0	Typist	White British
Lucy	22	12/13	13	?	18	1	Married	2	Sales Assistant/Student	White British
Olivia	18	11	11	11	18	1	Boyfriend	0	Children's entertainer	White British
Caroline	18	12	12	13	16	2	Boyfriend	0	Unemployed	White British
Zoe	19	9	9	11	18	1	Single	0	PT work/Student	White British
Emma	22	15	15	15	21	1	Boyfriend	0	Administrator	White British
Claire	21	11	14	15	20	1	Boyfriend	0	Student	White British
Alison	19	12	14	17	17	1	Single	0	Retail Assistant	White British
Hannah	22	13	13	13	18	2	Boyfriend	0	Student	White British
Laura	22	12	13	14	19	1	Single	0	Student	White British
Rebecca	21	13	13	17	20	1	Single	0	Student/Full time work	White British
Natalie	21	13/14	15	15/16	19	1	Single	0	Early years educator	White British
Sarah	20	13	13	14	17	1	Girlfriend	0	Student/Part time work	White British
Megan	23	14	14	14	18	3	Single	0	Pensions service executive	White British
Gemma	19	12	13	16	18	1	Boyfriend	0	Student	White British
Sally	22	14	14	15/16	18	3	Living with partner (m)	0	Not working	White British
Lynsey	21	11	12	12/13	17	4 *(Oophorectomy)*	Boyfriend	0	Nursery nurse	White British

6.3 Thematic Analysis

This section outlines the results of the thematic analysis. The final analysis produced seven overarching themes, characterising the experiences of these AYW with endometriosis. These themes, and their subthemes, are summarised in Table 6.2. It is important to emphasise that these themes and subthemes are not mutually exclusive, and their interaction provides an understanding of the complex experience of having endometriosis as an AYW. Themes are illustrated using verbatim quotes from the interviews, which are annotated with the quoted participant's pseudonym and age (i.e. Eve, 23).

Table 6.2: Themes and Subthemes Resulting from Thematic Analysis

Theme	Subthemes
Symptom Onset: 'In the Dark'	• Beliefs at symptom onset • Speaking to others • Menstrual health awareness and education • Endometriosis awareness
Symptoms: 'Communicating Something Invisible'	• Pain • Dyspareunia • Bleeding • Bowel and bladder Issues • Other symptoms
Medical Experiences: 'Getting Help'	• Medical encounters • Treatments • Diagnosis
Teenage Life: 'Missing Out'	• School and work • Social life and sports • Relationships
Support and Information: 'Nothing for my Age Group'	• Support • Information
Emotional Wellbeing: 'Not Just a Physical Thing'	• Emotional Health • Perceptions of the self • Isolation
Future: 'Uncertainty'	• Fertility • An ongoing battle: Future surgeries and treatment • Intimate Relationships • Education and career outlook • Hope

6.3.1 Symptom Onset: 'In the dark'

This theme portrays the experiences of participants when their symptoms of endometriosis began; a time in which they described feeling bewildered or 'in the dark' about what was happening. To try to make sense of their experiences, participants drew on their prior understanding of menstruation, and sometimes spoke to those close to them. This often reinforced their confusion about their symptoms.

Some aspects of feeling 'in the dark' were not confined to the period around symptom onset, however, and were also evident in participants accounts of living more generally with endometriosis.

6.3.1.1 Beliefs at symptom onset

Participants described several different beliefs about their symptoms of endometriosis when they began; some assumed they were just 'normal' periods; some thought they had "*bad*" periods and were just *"unlucky"*; and a small number thought quite quickly that something was wrong. These varying beliefs were in part affected by the timing of symptom onset. Most participants experienced symptom onset at the time of menarche, but others described either a sudden onset some years later, or a gradual worsening of symptoms until they started to interfere with daily living. Often, those who did not experience onset at menarche, did however, indicate that upon reflection their periods had always been quite painful:

> *"…periods were really like excruciating but I think because they'd gradually got worse every single month… I did think that was a normal pain, I just knew that that wasn't normal during sex…"* (Eve, 23).

When trying to make sense of their symptoms, this notion of 'normality' was very prominent in participant accounts. This was particularly evident in those whose symptoms started at menarche, which they indicated was due to a lack of understanding of what 'normal' periods were, and that they had nothing to compare their experience with. Some participants said they drew upon the experiences of family members, such as their mothers or sisters, who also had *"bad periods"*, and so they thought this was normal for them. In addition, some said they acknowledged that their pain was bad, but believed that maybe they just had a low pain threshold, that it just happens to some people, or that they would just grow out of it as they got older. These quotes illustrate some of these beliefs:

> *"…obviously when you're younger, you just think that everything's normal, you don't think that things aren't quite as they should be, you just think 'oh this is how it is, everybody complains about period pain, this must be it'."* (Rebecca, 21).

> *"…and I just thought that I know some people just get bad periods, I just thought I had bad periods and like that was it."* (Zoe, 19).

Beliefs that symptoms were 'normal' or were just the result of having 'bad periods', were almost unanimous among participants. However, a small number of participants, who experienced symptom onset sometime after their periods began, were more likely to think that something was wrong:

> *"I didn't know what was going on, I was very confused, but because I know my body, I knew there was something that wasn't right, you know, I knew it wasn't* ***just*** *a period pain, I knew there was something that had to be wrong because, I know myself, and I know when I'm not right."* (Natalie, 21).

These early beliefs about symptoms affected participants in several ways, including delayed help seeking, suffering in silence, and reduced participation in daily activities, which will be discussed in more detail subsequently. There were several factors involved in how these beliefs were both formed and maintained, which will be discussed in the following subthemes.

6.3.1.2 Speaking to others

When their endometriosis symptoms began, participants often did not discuss them widely, which contributed to feeling 'in the dark'. Most did report to have told their mothers, often telling them they had heavy or painful periods. Many described their mothers as supportive, particularly offering practical solutions such as painkillers and hot water bottles. Most participants also cited their mother as the eventual driving force behind their decision to first seek medical help for their symptoms: *"I think it was probably my mum that pushed me to go [to the doctor]…"* (Olivia, 18).

Although supportive, mothers' reactions to symptom disclosures sometimes initiated and reinforced participants' beliefs that their symptoms were just 'normal' periods. Mothers often likened them to their own experiences with 'difficult' periods, and some mothers implied that it was just one of those things:

> *"…well my mum said she just had bad periods when she was younger, so we just thought that it was that."* (Zoe, 19).
>
> *"…my mum knew but she just said the same, like 'it could just be how your periods are, everyone's different'."* (Sally, 22).

In a few cases, participants also told other family members, such as their grandmother, father, or sister. Early symptoms were very rarely disclosed to friends, however, unless they were already talking about periods. Some stated they didn't discuss their symptoms with friends because they just thought they were normal periods:

> *"…we'd speak generally about periods… [but] I wouldn't really overdramatise it as I just thought it was normal."* (Kate, 18).

A few participants stated feeling embarrassed talking about periods, using labels such as *"taboo"*, *"stigma"* or not *"socially acceptable"*; an issue which many referred to as being standard at their age. Therefore, if their symptoms interfered with school or social activities, excuses such as "*not feeling very well"* or *"I had a bug"* were often used. However, this embarrassment and lack of disclosure limited the possibility for participants to compare their symptoms with others, and they therefore missed opportunities to recognise that they had a problem:

> *"…when you're 12, 13 its embarrassing talking about your periods, you don't tell people you're on your period, you don't talk about it to your friends, so there's none of this comparison of what's right and what's wrong, you just assume everyone's going through it." (*Anna, 21).

If friends were told, some participants reported that friends also suggested that their symptoms were normal: *"all my friends around me were saying 'it might just be period pain, it's just growing up'."* (Natalie, 21). In addition, some participants reported friends who said they were *"over-exaggerating"* or *"making it up"* to get out of school*.* It was not only mothers and friends who normalised symptoms, but also doctors (discussed in Section 6.3.3) and schoolteachers:

> *"…people like teachers… were like 'oh, everyone gets periods, it's nothing to complain about',"* (Zoe, 19).

By having their symptoms normalised by others, participants continued to feel 'in the dark', and it further limited their ability to recognise that their symptoms were of concern. Factors such as these delayed help-seeking and prolonged the wait for a diagnosis. However, on rare occasions, through speaking to others at symptom onset, participants were able to identify that there was a problem. This typically occurred when someone they knew (i.e., mother, relative, or family friend) had also suffered with endometriosis, or because their symptoms could clearly not be mistaken for a normal period:

> *"I told her [my mum] when I first started, and then I told her probably after about 2 weeks of bleeding I was like 'is this still meant to be happening?' and she was like 'no, not really'. And that's when she first took me to the GP."* (Hannah, 22).

6.3.1.3 Menstrual Health Awareness and Education

As highlighted above, participants often used the word 'normal' when discussing their initial symptom beliefs, which suggests that at the time, they had some notion of what they thought a 'normal' period was. For some, these beliefs were attributed to their age, and the fact that periods were new, and they had nothing to compare them with. Many participants drew on what they had been told about periods, that they were to expect some pain and discomfort. These points are illustrated by Helen and

Daisy:

> *"It's hard to tell because when you're that age you just assume that what is happening to you is normal, you don't have any sort of experience,"* (Helen, 24).:
>
> *"I first started experiencing these symptoms when I was about 10, but then, I didn't always think that they were very significant if that makes sense, because you know, you are always told that everyone gets painful periods, or that's what everyone experiences."* (Daisy, 19).

One source of information about periods discussed by participants was menstrual health education (MHE) at school. Most descriptions of such were negative, with the words *"basic"* and *"brief"* occurring often, and even words like *"appalling"* and *"shocking"*. Some participants stated that too much emphasis was given to sexual health, avoiding pregnancy and STIs, and little given to reproductive health. Some said that their education about periods was scientific, only covered in biology lessons, or was otherwise just about the practicalities of having a period, such as how to use a pad or tampon. Common across participant accounts of MHE was that there was a vast lack of information about the 'experience' of a period; what they should be like, what is 'normal' and what is 'not normal'. These quotes by Anna and Eve summarise these issues:

> *"I remember being taught you have a period, every month, or every 28 days, you bleed, it's quite painful, and then your body goes round in the next cycle again. But I was never told about to what extent the periods* ***should*** *hurt you, what extent* ***should*** *you let it affect your life, what extent do you need help?"* (Anna, 21).
>
> *"I can remember we had like one lesson on it before you got to middle school and they just basically tell you this is probably what's going to happen to you really soon and this is what a sanitary towel is and that kind of thing but that was it, they kind of just tell you what a period is, not what's normal and what's not normal."* (Eve, 23)

With a lack of understanding about the experience of a period, participants were unable to recognise that their symptoms represented a deviation from what might be expected. Participants also received little to no education about common reproductive health conditions. Although some noted that they had heard about polycystic ovaries and fertility issues, none of the participants had heard about endometriosis at school. Some exclaimed their surprise at this in terms of how prevalent endometriosis is:

> *"…absolutely not during any sex ed I had [had endometriosis been discussed], which being at an all-girls school, I am now in hindsight quite surprised about, because we had probably about 80 girls in our year, so statistically probably about 8 or 10 girls in our year probably would have*

> *had it"* (Gemma, 19)

Participants unanimously agreed that they thought endometriosis should be taught about in school. Some were very passionate about this; Olivia had recently taken part in a media interview, talking about how more education is needed in schools, and Laura had designed and piloted an information booklet about endometriosis to be used in schools. In summary, participants felt that their education at school, about menstruation and reproductive health issues, was insufficient, and contributed to their confusion and notion of being 'in the dark' at symptom onset.

6.3.1.4 Lack of Awareness of Endometriosis

> *"I literally didn't know that it existed. Neither did like my mum, or my sister, or anyone."* (Olivia, 18)

This opening quote encapsulates participants' views; that there is a distinct lack of awareness of endometriosis, not only amongst themselves, but also those around them. Family, friends, teachers, and even some medical professionals were all reported to lack an awareness of endometriosis. Some felt this was attributable to the lack of education they and others receive about endometriosis, as discussed above.

Participants reported rarely having heard of endometriosis prior to symptom onset. The few who had heard of it generally had a family history. Some participants only acquired awareness about endometriosis through the internet, when attempting to search for a cause of their symptoms. Two participants described how they stumbled across endometriosis through the media, and noticed that it fit their symptoms, and one first learned about it whilst undergoing training at medical school. These quotes illustrate these issues:

> *"…yes [I had heard of it], but that's because my family had it. There's been no health professional, or teacher, or anyone who has told me about it"* (Kate, 18).

> *"So I started to do my own research, just online and things… and I came across endometriosis, and it sort of fit what I was experiencing."* (Helen, 24).

It was common for participants to report that endometriosis was first mentioned to them during a medical consultation, however, this was often at a hospital visit or gynaecology appointment, and was rarely mentioned by GPs. A small number of participants only heard about endometriosis when they were given their diagnosis:

> *"No I'd never heard of it. Like I say it was that time when I'd just had the laparoscopy and really*

> *I'd got the diagnosis and that's when it was. They came to me after my operation and were like "you've got endometriosis" and I couldn't even say the word never mind understand it."* (Lynsey, 21).

Participants almost universally attributed their delays in help-seeking to their lack of awareness of endometriosis. They also stated that if they had known about it, they would have been more assertive when seeking medical help and pushed for a referral. A small number of participants felt that this also delayed obtaining effective symptom-management. Laura and Zoe illustrate these issues:

> *"I feel like if I'd have known about it when all the symptoms started happening… it would be something I would of considered I had a long time before, because… I didn't get it looked into until I was 19, and I started experiencing symptoms when I was 13."* (Laura, 22)

> *"…if I had of knew what it was, I could have maybe thought that it would have been that earlier on and maybe like, I would have had things more under control now"* (Zoe, 19).

Participants reported that those around them were also largely unaware of endometriosis. Most often discussed were friends; and participants felt that they were therefore unable to understand what they were going through. Friends would often liken participants' symptoms to their own period pains, which caused frustration. In addition, friends' lack of awareness and understanding meant that their provision of support was limited. Participants often compared the awareness of endometriosis to that of other long-term conditions, particularly diabetes:

> *"…so like if I said to my friends I had diabetes they'd be like 'oh shit', do you know what I mean? I say I've got endo and they're like 'oh'… nobody has a clue what it is, and then you just don't get any sympathy, you don't get any understanding, it's just awful."* (Emma, 22).

The lack of awareness and understanding of endometriosis amongst friends, family, and partners impacted relationships, discussed further in Section 6.3.4. This occurred both at symptom onset and while living with endometriosis. Therefore, it was not only participants who were 'in the dark' about endometriosis, but also those around them:

> *"…it seems to be that you have to be in the secret endometriosis club to know what it is."* (Laura, 22).

Summary

Many participants described feeling 'in the dark' at symptom onset, which resulted from a complex interplay of several different factors; their own beliefs, the beliefs and experiences of those around them, their hesitance in discussing menstruation, and their lack of understanding about menstruation and endometriosis. Many stated that they would have liked to receive more education about these issues, which would have improved their understanding and shortened delays in help seeking. Increased education would also improve the understanding of friends and family, which they believed would help improve relationships, and enhance the support they received.

6.3.2 Symptoms: 'Communicating Something invisible'

6.3.2.1 Pain

Pain was described by all participants, and it was a central feature of their experience of endometriosis. Pain was typically located in the pelvic area, but was also reported in the back, and down their legs. A small number of participants stated that they found it difficult to put their pain experience into words. Among those that did describe their pain, several similarities between participants' accounts emerged. Words like *"stabbing", "shooting"* and *"sharp"* were frequently used, and some rated their pain numerically out of 10. Many participants used similes to describe their pain, which often involved metallic objects like knives, hooks, and rods, as well as some form of mechanical action:

> *"It was like stabbing, it felt like somebody had basically put a knife through and just cut across."* (Caroline, 18)
>
> *"…sometimes it feels like you're being punched…"* (Kate, 18).
>
> *"The only way I can describe it [the pain], is that it feels like someone's got a round of sharp nails, and is literally putting it in your stomach and just turning it and turning it"* (Anna, 21)

Participants often compared the intensity of their pain to real physical experiences, such as *"really really bad period pain"*. One participant had experienced childbirth and likened their endometriosis pain to that of labour. Another compared the pain to her experience of a miscarriage:

> *"it feels like somebody is pulling your uterus out, it's horrendous. I've had a miscarriage and I can tell you it's quite similar pain to that."* (Emma, 22).

Many participants described the physical impact of their pain, using words like *"debilitating", "crippling",* and *"paralysing"*. A commonly reported physical reaction to the pain was sickness or nausea, and some participants described needing to curl up in a ball, bend over, or confine themselves to bed:

> *"I mean there was times where I'd be throwing up and vomiting because the pain was so much I couldn't control myself"* (Natalie, 21).
>
> *"I couldn't get out of bed, I couldn't walk because of the pain."* (Sarah, 20).

When describing their pain, participants often commented on the duration and frequency. Initially, it was common for pain to occur around the time of menstruation, sometimes starting a few days prior to period onset, and lasting either the first few days or the entire period. The intensity of the pain might come and go, or stay constant throughout:

> *"…[I'd get pain] from the moment I'd wake up on the first day of my period until when it completely finished, for like the whole week."* (Olivia, 18).

Almost all participants noted a progression in their symptoms, and particularly in the frequency of their pain, starting to occur outside of periods. Some experienced short bursts of intense pain, which appeared seemingly at random in their cycle, or else at the mid-point (perhaps around ovulation). Most participants, however, began to experience more frequent pain, on a weekly or daily basis, and some described their pain as being *"constant"*. Sometimes, pain could be a reaction to overexertion. The below comments further illustrate these points:

> *"…when I was 16, 17, it started to be all the time and not when I was just on my period."* (Alison, 19)
>
> *"Well I'm in constant pain every single day, but it does – it comes in like waves, so say if I was to go out for the day, or if I was to go and like walk to the shops, I would then be in pain after."* (Olivia, 18)

Participants also described pain arising from tampon use. Although described as a somewhat similar pain to dyspareunia (discussed below), tampon use usually occurred prior to first sexual encounters, and so this symptom was present much earlier. The pain was said to occur while wearing a tampon, as well as when putting them in or taking them out. This feeling was described by many as *"uncomfortable",* but again, words like *"stabbing" "sharp"* and *"burning"* were used*.* As a result, most participants stated that they had stopped using tampons, or only used them when absolutely necessary. Often, tampons did not offer enough protection for their volume of blood loss anyway:

> *"it was like, like a stabbing pain again in my lower abdominal, but yeh, I just couldn't use it after that because I don't think there's any point using something that's going to cause you more pain than you should have to be in."* (Daisy, 19).

Pain arising from internal examinations was described by about a third of participants, who used adjectives such as *“sharp”*, *“uncomfortable”*, and *“excruciating”*. This was an internal pain, likened to both tampon use and sexual intercourse. One participant, when asked about experiences of painful sex, stated that she was a virgin, but that her internal ultrasound *“was just excruciatingly painful and I just had to tell them to stop”* (Laura, 22).

6.3.2.2 Dyspareunia

Eighteen participants in this study complained of dyspareunia, which occurred during and/or after sexual intercourse. Due to the age of this sample at symptom onset, many participants had endured this symptom from their first sexual encounter, and some had never experienced sex without it. Although most participants agreed it was an internal pain, there was otherwise a lot of variation in participants’ descriptions of the pain, which are highlighted in Figure 6.1 below.

Pinching. It’s like a pinching pain. All across your tummy, all in there. Yeah it’s like lots of pinches, that’s the only way to describe it. (Anna, 21)

It was like, it first starts off as just like uncomfortable, like it’s just uncomfortable, and then as it progresses, the sex progresses, it gets more and more unbearable to the point where it is just so painful you’re like ‘you have to stop, I can’t do it anymore.’ (Kate, 18)

It’s like (p), really, the only way I can describe it is it’s like cervixy, (Lucy, 22)

It was this sort of, internal pushing feeling, like – I’m trying to think back now, like it was sort of as if my pelvis was like pushing down, and it just felt horrible, like this dull sort of, um (p), it wasn’t like the hole hurting, it was this internal pushing feeling like inside. Yeah, that’s the only way I can really describe it. (Rebecca, 21)

It’s like being torn, it’s horrible. It leaves a burning sensation again, it’s just absolutely the worst thing ever. (Megan, 23)

…this was almost like you were being stabbed in your stomach, like it was really kind of deep (Gemma, 19)

It’s like a dull aching pain, it’s like something’s there that’s not supposed to be there kind of pain. It’s hard to describe (Sally, 22)

…it’s like, really bad pain, it’s like a stabbing pain, like being stabbed with a knife, oh it’s just really painful. (Lynsey, 21).

Figure 6.1: Participants' Descriptions of Pain Experienced During Sexual Intercourse

Again, participants frequently used similes and mechanical notions to describe dyspareunia, of being *“stabbed”*, or *“pushed”* etc. Participants often avoided sex (or relationships) altogether, or sometimes did it out of feeling guilty. Many participants were in a long-term relationship and described their partners as very supportive. However, some indicated the difficulty in explaining this symptom when a relationship was new, or when having more casual sexual encounters:

> *"…if it was someone that I was having a more casual thing with, it was kind of really awkward to be like 'oh yeah by the way I have this thing', and trying to tell them the whole back story of like 3 years of what's happened in like 2 minutes."* (Gemma, 19).

This symptom could really impact intimate relationships, often causing tension and arguments, and it was cited by five participants to be the cause of a relationship breakdown. One participant stated that her boyfriend was unfaithful because she was unable to have sex, and another said she broke up with her boyfriend because she felt so guilty that she was unable to have sex with him. A few participants made explicit reference to their age when talking about dyspareunia, and the impact it had:

> *"We're just young and we want to have fun and we want to have sex and it's hard to get over that"* (Kate, 18).
>
> *"When he eventually broke up with me his entire reason was 'you have endometriosis and I can't deal with it, and I'm 18 and I need to be having sex and you can't give me that, so I've slept…' – he slept with like 8 other girls while we were together"* (Alison, 19).

Dyspareunia was experienced by most participants, who not only discussed the physical manifestations of the symptom, but also how it influenced their intimate relationships. At an age where sexual relationships were often quite new, or more casual, participants' found difficulty in explaining this symptom to others. It had additional impact on the way they viewed themselves, which is discussed further in Section 6.3.6.

6.3.2.3 Bleeding

One of the key symptoms experienced by participants was heavy menstrual bleeding (HMB), which was the most common symptom after pain, and began for most at symptom onset. Descriptions of HMB were largely given in terms of the number of pads or tampons used, and participants often said that such products were unable to contain their bleeding, and so they experienced leakages onto their clothes/beds. These quotes illustrate descriptions of HMB:

> *"…when I was 16, I would be bleeding really heavily, through a super plus tampon and through a pad, um, and I'd just be changing them hourly"* (Emma, 22).
>
> *"…it would be literally like every time, I'd wear 2, 3 pads, and then I'd go onto the bigger maternity ones, but even then I'd have to – I'd still go through onto my pants and onto my*

> *trousers."* (Sally, 22).

Some participants stated that the heavy bleeding would not relent over the course of the period, being at the same level from beginning to end, sometimes lasting over a week. A small number of participants said that their blood loss made them feel faint, or caused suspected anaemia. Many participants recalled missing school due to HMB, often due to leaking, or even just because of the fear that they might leak at school. It also interfered with sports and physical activities:

> *"I couldn't go in and do my dance classes… cos obviously I wasn't going to dance around when there was gallons of blood coming out of me"* (Anna, 21).

In addition to HMB, most participants also experienced some form of abnormal bleeding at some point. Spotting, or random bleeds between periods, were a frequent occurrence, affecting almost half of the participants. Some commented on the unpredictability of this, and so they always had to be prepared, carrying pads or tampons wherever they went. Most participants were on some form of contraception to help manage their symptoms, and therefore these bleeds were unexpected:

> *"I take the pill back-to-back so I don't have a proper period, but I just bleed at random times."* (Zoe, 19).

It was also common for participants to experience episodes of prolonged bleeding, which could last for weeks, with little break. Two participants experienced particularly extended periods of bleeding; Emma had periods lasting "*months on end*", and Megan described a reaction to the coil, in which she bled for 287 days in a row, from when it went in until it was taken out.

6.3.2.4 Bowel and Bladder Symptoms

Symptoms affecting the bowel and bladder were very common in this sample, experienced by 19 participants. Bowel symptoms were more common, and many participants received a diagnosis of IBS at some stage, although for some this was offered as an explanation for their symptoms prior to their diagnosis of endometriosis. Symptoms associated with the bowel included pain during defecation, irregular bowel movements, diarrhoea, and switching between diarrhoea and constipation. Participants were often embarrassed about bowel symptoms, and they also interfered with daily life. For example, Lucy said that they interfered with *"going to school and going to other people's houses".* A few participants commented on the considerable impact that bowel symptoms had on their lives, sometimes causing more disruption than other symptoms of endometriosis, as illustrated in Figure 6.2.

"actually the pain that I've had sometimes with those bowel symptoms have been as painful as my period pain was in the past." (Laura, 22).

"it was really embarrassing and horrible, it like ruined my first and second year [at university], I would get this like urge to go to the toilet, (p) like not for a wee, I'd have to go (p), like 6 or 7 times a day" (Claire, 21).

"they've [bowel symptoms] really impacted upon sort of my independence and my freedom, because now I never know when they're going to happen and I'm sort of more scared of going out, because I have had experiences of being on a train and then suddenly having these awful symptoms, and sort of that feeling of being trapped somewhere" (Laura, 22).

Figure 6.2: Participants' Descriptions of Disruptions Caused by Bowel Symptoms

Half of the participants experienced bladder related symptoms, most of whom also had bowel problems. Some experienced very frequent urges to urinate, feeling unable to 'hold' their bladder, or a feeling that their bladder was not fully empty after going to the toilet. Others experienced pain when going to the toilet, or symptoms like a urinary tract infection (UTI). One reported constant UTIs and said she was now left 'incontinent'.

Again, these symptoms could cause significant impact on participants' lives. Multiple toilet visits were said to cause embarrassment and could interfere with sleep if occurring at night. One participant was afraid to make plans due to her bladder issues:

> *"I don't like car journeys, I panic if I don't know where a toilet is. I'll actually avoid plans, it'll stop me making plans if I don't know that - if I can't get to a toilet quickly"* (Eve, 23).

These bowel and bladder symptoms were often not immediately linked to periods, or to endometriosis, and so some would not mention it to their doctors or gynaecologists. Some participants had to undergo additional intrusive investigative procedures (i.e. colonoscopy, endoscopy, and cystoscopy) to identify the cause of these issues.

6.3.2.5 Other symptoms

The participants reported a range of additional symptoms including dizziness or fainting, nausea, vomiting, migraines, bloating, and fatigue. As described earlier, sickness could be a result of pain, however some experienced it as a separate symptom. This caused issues such as reduced appetite and weight loss, because participants struggled to eat or hold down food. Fatigue caused problems at school, affecting concentration and even attendance, and many stated they often wanted to just stay in bed. One participant felt this was particularly at odds with her age:

> *"…it impacts me so much, like mentally and physically because I think 'oh, I can't do anything, I'll just lie in bed', and I just want to sleep all the time or I'm so tired all the time. I have no energy and like, I just don't live the life of a normal 19-year-old..."* (Zoe, 19).

Bloating was mentioned by almost half of the participants, and as well as causing them to feel physically uncomfortable, participants felt that it affected their self-image, which is discussed further in Section 6.3.6.

Summary

The many experiences of pain, as described here, impacted participants' lives in several ways, affecting school attendance, social activities, and sleep quality, as illustrated in subsequent themes.

6.3.3 Medical Experiences: 'Getting Help'

A significant feature of participants' narratives was their experience of medical care, including encounters with medical professionals, and descriptions of their medical and surgical treatments. In addition to finding a way to manage their symptoms, this experience focused largely on the pursuit of a diagnosis of endometriosis.

6.3.3.1 Medical Encounters

Participants encountered a range of medical professionals, and this sub-theme describes their experiences of the care they received, and how they navigated their way through the system. Their GP was usually the first and most frequent medical professional visited, particularly prior to referral to a gynaecologist or specialist. However, over half of the participants also attended an accident and emergency (A&E) hospital at some stage in their journey, to seek additional help.

Most participants reported encounters with medical professionals in which their symptoms were dismissed or normalised. There was little specific discussion about the gender of the medical professionals who dismissed them. A small number of participants stated they were taken more seriously by female clinicians, and on the contrary, one said she found females to be very dismissive, which she found surprising given that they would have had experience of periods.

Dismissals often delayed referrals and subsequent receipt of a diagnosis. This issue was predominantly reported in interactions with GPs; participants were frequently told that their symptoms were *"normal"*, *"just bad periods"* or that they would *"settle down"*. Some participants continued to experience these dismissals when seeing specialists, however. They reported to be sent away after being given little to no treatment or investigation, which they found frustrating given the often-long wait for referral. Many participants believed that these dismissals were due to their age, and perhaps therefore not being taken seriously. Some were directly told by medical professional that their age played a factor. Quotes illustrating these points are shown in Figure 6.3.

Like just your GP that you go to… they just think, especially when you're at a young age, they think you're just being over dramatic. (Alexandra, 20).

And then I started going to the doctors, and so many doctors would turn me away and say 'no, no it's nothing to worry about, you're just a young girl going through periods', you know. (Natalie, 21).

…this is the age problem as well, it's just, you know you don't want to do an ultrasound scan on a young person, you don't want to get them worried and stuff. (Daisy, 19).

…when I first when I just explained all my symptoms and he [the gynaecologist] said 'there's a possibility you could have endometriosis, but we won't ever know until you've had a laparoscopy. I don't really want to do a laparoscopy on you because you're so young…' (Kate, 18).

Figure 6.3: Age References Regarding Medical Encounters

Some participants reported that such dismissals caused them to question themselves and the validity of their own pain, and a few lost faith in the healthcare system. Many participants described having to be "*pushy*" or "*persisten*t" to obtain appropriate care or referrals. For example, they often described visiting the GP surgery multiple times, and sometimes confronted their GP with possible endometriosis after doing their own research. Many took their mothers with them for additional support and advocacy:

> *"I remember going back almost 3 or 4 times in that month, with these pains… Um yeah, eventually in February I went with my mum one time and my mum was like 'I think she needs to go and see a gynaecologist, or have an ultrasound', so they eventually referred me to that."* (Olivia, 18).

A significant number of participants decided to seek private treatment, either when they were unable to receive a timely referral to a specialist, or when specialists dismissed them. This was usually paid for by parents or was covered under their parents' medical insurance as they were under 18. Participants reported feeling lucky to be able to go privately, and feared the delays they would have encountered otherwise. These points are further illustrated in the below comments:

> *"So I went private after the third bad pain… because, I didn't want to wait forever to have - to*

> *be diagnosed with something."* (Daisy, 19).

> *"…the reason I was referred straight away is cos I'm on private medical healthcare, which I think has made a massive difference in me getting diagnosed as quickly as I did. I always say this to my friends all the time, if I didn't have private medical I really don't know how people do this without it*." (Anna, 21).

Participants also described some positive encounters with healthcare professionals. For many, this occurred once referred to a specialist or gynaecologist, as their symptoms were taken more seriously in this setting. They described being listened to or believed, with one stating it was like *"a breath of fresh air"* (Rebecca, 21). Although more rare, some participants described positive interactions with GPs, who took them seriously and gave them appropriate treatment or prompt referrals. In these cases, participants stated that they assumed the GP had undergone training in gynaecology, or were recently qualified and therefore keen to impress:

> *"…[the GP was] a very just newly qualified doctor actually, she was just – she'd obviously just recently been trained on endometriosis, which maybe doctors from 20 years ago haven't been. Do you see what I mean? So she just obviously knew, and she just referred me, and it was like an angel, honestly I was just like 'oh my god'."* (Emma, 22).

Although specialists were described as more likely to take participants' concerns seriously, some participants still said their appointments were brief, with little suggestion other than to have a laparoscopy. While this was generally the desired outcome, participants reported that they received little information about endometriosis and/or the procedure. In addition, a small number of participants who were referred for laparoscopy were told that it was just to rule out endometriosis, but they were probably too young to have it. These quotes highlight some of these points:

> *"It was a very very very quick appointment, very brief, "we think you've got this, we'll find out more from the laparoscopy, the laparoscopy is going to be in 2 weeks" – along those lines, that was all the information I got on that day."* (Anna, 21).

> *"…so I got referred, and went for my consultation and my pre-op stuff, and … they sat and went through the illness with me… but every person was saying 'but you won't have it. We have to do this to check but you will not have it'. And I mean they didn't say 'you probably won't', it was 'you won't have this, you are too young, you will not have this disease'."* (Emma, 22).

Participants often described communication issues in healthcare settings; being given conflicting information, misinformation, or no information at all. Adding to this issue, participants reported a tendency to move between residences in their late teens/early 20s, perhaps going between home and university, and some therefore had their care covered by healthcare providers in different areas. Such participants sometimes reported issues with continuity of care; undergoing repeated investigations and increased wait times, while healthcare providers in different areas failed to communicate with each other. Some also travelled the sometimes-long distances between home and university for appointments as it was easier than registering elsewhere and starting over.

> *"…when these problems started happening in about August time and I went to my doctors, I started getting investigation happening at home, so I was having blood tests done, blood tests re-done, ultrasounds which hadn't revealed anything… But then when I went to university my GP surgery changed to my university GP surgery so when I went to them about this problem I had to start all over again, so back with having blood tests again."* (Laura, 22).
>
> *"…sort of during all this time, I was trying to fight to see different consultants, cos I moved around a lot, I was at university in York, and then Exeter, and then I got a job near London, um and so each time I moved it was another 6 months to wait to see a consultant, and sort of getting different opinions when I did see them."* (Helen, 24).

In numerous instances, participants also sought help from A&E when symptoms got severe, and some described being *"in and out of A&E"* quite frequently. However, without a diagnosis, they were often unable to obtain the correct help, and many described having several investigations before being sent home with strong painkillers. Again, some were told it was just their period and were sent on their way. Some participants felt that unless they were in a specialist ward, hospital staff often had no awareness of endometriosis.

6.3.3.2 Treatment

Participants had tried an extensive range of medical treatments, and all had undergone at least one laparoscopy. It was common for participants to attempt to self-medicate with paracetamol, ibuprofen, and other OTC painkillers before seeking medical help, yet these were reported to be of little help. In addition, almost half of the participants reported applying heat to help manage their pain:

> *"I just sort of went about with constant heat patches attached to me, on my front and on my sides at school. So I was like a walking hot water bottle."* (Rebecca, 21).

After seeking medical help, most participants were initially given the contraceptive pill or injection to try to manage their symptoms (prior to referral to specialists). However, some felt they had to lie to obtain the prescription, stating that they wanted these for contraception, rather than the symptoms they were experiencing. Conversely, some reported that they believed their GP thought they were lying about their symptoms to obtain contraceptives, as highlighted in this quote:

> *"I wanted to try the pill because… lots of my friends were starting to go on the pill, for painful periods... Um, I didn't see my usual GP, I saw this other guy, and he was a bit dismissive because I think he just thought, cos I was 15 I think he just thought I like was using it as an excuse to get contraception, you know he was asking me if I was sexually active and stuff."* (Claire, 21).

A small number of participants attended a family planning clinic to obtain treatment after being directed there by a nurse/GP, and one participant self-referred after being refused the pill by a GP due to being "*too young*". Participants felt there were connotations of attending such clinics:

> *"…it was the local family planning clinic, it's where people used to go for the STI checks around that age and, so I guess you were there and all these rumours went round about how you got seen there by one person and that was it."* (Anna, 21).

Participants often described many years of trial and error with different contraceptive treatments, both prior to and following diagnosis, because the efficacy of such treatments varied greatly. The pill was used most, and in only rare cases was it said to completely control participants' symptoms. However, many participants stated that at best, the pill helped to regulate their periods, so they knew when to expect them and could plan around them, but it did little in the way of controlling their symptoms. Over half of the participants had tried the hormonal coil, which after a period of 'settling-in', often lead to improvement for most. Yet it was still common to experience random bursts of pain and breakthrough bleeding, and some experienced prolonged bleeding, lasting many months.

Some participants' treatments had escalated; trying much stronger hormonal injections, which put them into the medical menopause. In addition, they often took painkillers, ranging from NSAIDs, up to morphine and tramadol. Some participants commented on the large volume of medication they were taking, expressing concern about taking so many medications, and particularly the potential to become addicted:

> *"…during the flare up I was taking 2 tramadol tablets, plus 3 ibuprofen, plus a naproxen every 4 hours. And even that, all them tablets, it was **just** taking the edge of it."* (Natalie, 21).

Furthermore, all participants experienced side effects from their medications, which affected them physically and mentally. The painkillers predominantly caused issues with drowsiness and concentration and could interfere with school and work productivity. Hormonal treatments caused a range of significant side effects including spots, weight changes, mood swings, hot flushes, sickness, and anxiety. Aesthetic issues could alter a participant's self-image, and even their mental health, and some indicated that the level of symptom relief they got from the medical treatments was not worth it given these substantial side effects:

> *"I've got really hairy from my chin down to my neck, and my top lip… it's really affecting my mental health actually."* (Sarah, 20).
>
> *"I felt I was sort of replacing one pain for the other and as I said it didn't seem to touch my level of pain very much so I felt that that's when it was nearing the point where I was getting absolutely completely fed up with everything, cos it was relentless and nothing seemed to be helping me."* (Laura, 22).

All participants had undergone one or more laparoscopic surgeries. In addition to being performed for diagnostic purposes, most participants also underwent surgical removal of endometriosis during their laparoscopy. Prior to surgery, participants reported differing levels of information provision; some received adequate, clear information; some said they were just given a leaflet; and some had neither and often had to do their own research online. A few participants said they did not understand the information they were given:

> *"…well I had information on it [laparoscopy], but it was almost really scientific information, and I felt as a patient that it needed to sort of be de-coded, as only doctors who had PhDs in that would understand the information that was given. So I had to look everything up on Google, which I don't think is fair either because I had to do all the research rather than them giving me the information."* (Daisy, 19).

Some participants commented that their laparoscopy was their first experience of surgery, and so they were often apprehensive. However, many participants reported that the surgery was not as bad as anticipated, and they generally reported a good level of care from the hospital staff. During post-operative recovery, many participants reported experiencing pain, particularly in their shoulders where they said the air was often trapped. Some participants stated they were not prepared for this level of post-operative pain, and that the surgery was more major than they expected.

Most participants recovered within a few weeks, although some took a while longer. During recovery, participants took time off school/university and work, and had to avoid certain activities like driving and walking too far. Once fully recovered, most of the participants who had undergone treatment during their surgery reported improvement in their symptoms, particularly pain. Some exclaimed they were "pain free", or it was the "best" time in their lives. However, most participants stated that these improvements were short-lived, as within a few months, their symptoms had returned, sometimes worse than they were before:

> *"And it went away [after surgery], and all the symptoms were really good for about a year… I still had periods and stuff but it wasn't anywhere near as bad as it was, so it was almost back to normal. And then after a year it came back, but even worse than the time before, and I was just missing school and missing college..."* (Hannah, 22)

Some participants indicated feeling quite distressed when their symptoms returned; it was unexpected. Those still under the care of a gynaecologist went back to see them, but others said they had to see the GP and start the referral process from scratch. Treatment could therefore feel like an ongoing cycle of referrals, investigations, and operations. Some worried about facing a future of this, and particularly about how it would affect their career. For Helen, who had undergone four laparoscopies by the age of 22, this ongoing treatment cycle had already taken its toll, and she therefore decided to have a hysterectomy:

> "*So then I had to quit my job and then after that it was sort of like, I can't let this take any more of my life, I have to sort of think of something more permanent because I can't have different surgeries and different horrible treatments every year*." (Helen, 24).

Drastic measures such as this illustrate the importance participants place on obtaining adequate treatment for their endometriosis. The focus of treatment for this sample was largely to manage their symptoms, particularly pain and heavy bleeding, so that they could get on with their life like others their age. However, the treatment process was not straightforward, and participants often endured years of experimentation with different treatments, as well as the side effects they produced. There was a lack of permanence with the treatment options available to participants, and they therefore faced an ongoing cycle of help-seeking in their futures.

Alternative Therapies/Self

In addition to medical treatment, approximately half of the sample had tried alternative therapies, most commonly reflexology, yoga, exercise, and dieting. Many stated that they would like to try alternative therapies, but that they were too expensive: *"I would really like to try things like acupuncture and reflexology to see if that helps, but all of that is quite like expensive really like if you go lots of times."* (Olivia, 18), especially for teenagers: "*I mean, normal 16, 17, 18-year-olds wouldn't have the money for that sort of thing*" (Anna, 21). Reflexology was said to provide short term help, but mainly with relaxation rather than pain. Yoga and exercise were said to be beneficial, but participants struggled to do them when symptoms were bad:

> *"I do try to keep active but before like everyone was like "oh do yoga during your period", like there's no way I could have done **anything**, so. But I do a lot of yoga now, so hopefully that helps me"* (Lucy, 22).

Several participants had tried dieting, including the *"endo diet",* and may had cut out alcohol. Dieting was reported to have varying levels of effectiveness. Some believed it *"massively"* helped, and others said they had not noticed any changes. A few participants said dieting mainly helped with bowel symptoms, including bloating. There were some barriers to dieting, including the cost and accessibility of the food, and the taste, with Daisy (19) exclaiming it's like eating *"rabbit food"*. It could also pose additional barriers to attending social situations:

> *"I feel the thing that does make it difficult is in terms of being social and going to eat out somewhere, because [the diet] is very very specific, being able to eat out somewhere is very difficult. So that sort of cuts out like 'oh, we're all going to go for a meal', and you're suddenly in the position where you can't like be in that social situation, or you feel uncomfortable in that social situation."* (Laura, 22).

Further discussion about the impact of limiting alcohol consumption is discussed below in Section 6.3.4.2.

6.3.3.3 Diagnosis

It took participants between 2 and 9 years to obtain their diagnosis of endometriosis after their symptoms began (see Table 6.3). As found in previous research (Ballard et al., 2006), this was attributable to both a delay in help-seeking after symptom onset, and a delay between seeking help and obtaining a diagnosis. In this sample, the initial delay was generally shorter than the latter, and was largely attributable participants' beliefs and awareness about their symptoms, as discussed in Section 6.3.1.

Table 6.3: Participants' Delays Obtaining a Diagnosis of Endometriosis

	Mean Delay (years)	**Range (years)**
Total Diagnostic Delay (n=24)	5.2	2 - 9
Length of time before seeking medical help (n=22)	1.0	0 - 4
Length of time from seeking medical help to obtaining a diagnosis (n=22)	4.2	0 - 8

The medical level delay was much longer in this group and included delays in both primary and secondary care. The subtheme ‘Medical Encounters’ above provides insight into factors behind this delay, including being dismissed/having symptoms normalised, having multiple GP appointments before being referred for investigation, and trying various/numerous types of medical treatment. Some believed their age was also a factor in these dismissals, and they assumed, or were told, that gynaecologists did not want to perform invasive procedures on young women. In addition, some participants stated that they were misdiagnosed during this time. The most common diagnosis given was IBS, and as a result, participants were told to change their diet, were sent to a nutritionist, or even had to endure invasive investigations such as colonoscopies. These misdiagnoses not only added to the delay, but sometimes incurred financial costs as well. Kate summarised her experiences with misdiagnosis:

> *“…when I was on the pill and I was having symptoms like feeling sick and having problems with my digestive system, they diagnosed me with irritable bowel syndrome, and said ‘you’ve got irritable bowel syndrome so you need to change your diet’. So I changed my diet, I tried everything and they said ‘well what’s the food that triggers you’ and I said ‘I don’t have a trigger food, I’m just always ill’, and they said ‘well you have to have a trigger food if you’ve got IBS’, and I was like ‘well I don’t, I don’t know what to say, I don’t have one’. Um, so they continued to say that I had irritable bowel syndrome until I went to them and said “the pill’s not working, I think I have endometriosis”.* (Kate, 18)

Some participants only obtained a diagnosis after seeking private medical care, or through undergoing emergency surgery. Participants expressed feelings of annoyance and anger about their diagnostic delays, which took up to 9 years. A small number of participants, who obtained their diagnosis in under 7.5 years (i.e. the national average: Endometriosis UK, 2011), commented that they felt almost *“lucky”* to have received a diagnosis in this time, despite the fact that it still took them a number of years:

> *“About 4 or 5 years [to diagnosis]. Which I know is quite quick compared to some people.”* (Eve, 23).

The diagnostic delay played a significant part in participants’ narratives, and many indicated that they thought that addressing this delay was a key priority in endometriosis care. Jessica, who waited 6 years for a diagnosis, stated she specifically wanted to be involved in this research to highlight the issues with receiving a diagnosis:

> *“The reason why I contacted you was to show how long of a process it’s been for me to get a diagnosis and how much pushing I’ve had to do like with the gynaecologists and the doctors*

> *to actually get the answers, and like the help…"* (Jessica, 21).

All participants received their diagnosis because of laparoscopic surgery, and the majority were given their diagnosis immediately after the surgery, when just awoken from the anaesthetic. At this time, participants described themselves as feeling *"out of it", "drugged up"* and *"dizzy"*, and were therefore unable to fully process the information given. In addition, many did not have a post-op appointment, and therefore stated they never received adequate information or an explanation of their diagnosis. A small number of participants were not actually given their diagnosis, and only found out much later. Participants described feeling bewildered and frustrated about these encounters, as illustrated in this quote:

> *"I was kind of told it went fine, they found some endometriosis… but I was really drugged up, because I had only come around about an hour or so before… and my mum hadn't actually arrived at that point, so I was trying to take everything in while I was still quite drugged up, which probably wasn't the best time to have that conversation with me to be honest. So that maybe could have been handled a bit better."* (Alexandra, 20).

When participants obtained their diagnosis, the majority described an initial feeling of relief; that after many years, they finally had an explanation for their symptoms. Many expressed reassurance that they were not *"crazy"* after previously questioning the legitimacy of their symptoms, and some felt angry that they had been made to feel that way, or that they waited so long for a diagnosis. Having a diagnosis enabled participants to explain themselves more easily to others, and to access appropriate support. In numerous instances, participants described their relief at diagnosis to be short lived, as the realisation set in that endometriosis is an incurable condition that they would have to manage for a long time. Kate's quote is representative of the participants' narratives about diagnosis:

> *"Relieved, but also quite scared and nervous. I was relieved cos I had a name to something… and relieved that it wasn't me like it wasn't me just in my head making all this up… and no one can disprove me now, no one can turn around and say 'well you've just got IBS' or 'you just need painkillers'. I can actually say 'no, I do have a condition and this is what causes this'. And also so I could actually justify when I wasn't feeling well that I didn't have to do anything… I could say 'Well I've got a condition where it makes me unwell, I can take time for myself'. So yeah, I was relieved but also scared cos it doesn't go away, it never gets better and I knew that this would be a long term thing that I would have to deal with for the rest of the time that I am reproductive, and maybe even after that I don't know. So yeah, it was scary."* (Kate, 18).

Summary

A significant motivation for participants when help-seeking was the pursuit of a diagnosis; they wanted an explanation for their symptoms. However, the journey to obtaining a diagnosis was often long, obtained after years of varied encounters with medical professionals, and the trial and error of different treatments. Their experience with healthcare providers was often negative, as they were subject to dismissals, poor communication/information, and misdiagnoses. The eventual receipt of a diagnosis of endometriosis was described as somewhat “bittersweet”, because although they had a name for their symptoms, it was something that could not be cured.

6.3.4 Teenage Life: ‘Missing Out’

This theme describes the various impacts of endometriosis on the lives of the AYW who participated. All participants noted that interruption to daily activities, such as school, socialising, and sport, caused them to feel as though they were missing out on things that others their age were doing. In addition, while living with endometriosis, they found their relationships were both strained and strengthened; they relied heavily on their families, but often missed out on forming/maintaining friendships and intimate relationships.

6.3.4.1 School and Work

All participants stated that they missed school and/or university during their teenage years, because of debilitating symptoms, doctors’ appointments, or surgery. Absences ranged from a few days here or there, to a week every month, or even weeks or months on end. Some stated that when they did attend, it was difficult to concentrate due to their pain or fatigue, and some were extremely paranoid about ‘leaking’ (i.e. bleeding through their garments during menstruation). As a result of their absences, participants fell behind on schoolwork, but also missed out on the social aspects of school life, and even weekend activities, which were arranged by friends during school hours:

> *“…I had a lot of time off school, which obviously doesn’t just affect your work and grades but it’s your social life, and emotional wellbeing, and (p) everything really.”* (Lynsey, 21).

As illustrated in the above quote, most participants reported that their absences also affected their grades. For many participants, endometriosis caused disruption at crucial points during their GCSE and A-Level years, which affected their ability to revise for and sit exams, sometimes missing them altogether. For some participants this caused a knock-on effect, whereby missed exams meant an extra year at school, and therefore delays in moving forward in life:

> *"And my original plan was to apply to university for this year, couldn't do that with 2 A levels, so that meant I had to take a year out, and I have to do another one this year, before I can go to university. So that's one of the big ways it's impacted my life, everything had to be pushed back."* (Alison, 19).

Some participants had experience of paid employment at the time of interview and noted significant impairment. Many reported missing work, or getting sent home, typically due to pain or exhaustion, and some participants stated that they had lost jobs due to endometriosis. Some had found that endometriosis restricted the kind of work they could do; they were unable to do particularly physical work, and some opted to choose jobs in which they could work from home or which were part time. As a result, participants reported concerns about a limited career outlook and restricted income:

> *"I struggle to get a job, no one wants to know… Just, I've got nothing at the moment, I've got no money and no work, I don't go out anywhere cos I've got nothing to go out with."* (Sally, 22).

6.3.4.2 Sport and Social Life

All participants reported that at some time, endometriosis had significantly impacted their social life. When in their younger teenage years, they missed weekend social activities and struggled with things like sleepovers, due to pain and fear of leaking. As they got into their later teens, many participants described the difficulty of attending nights out with friends, which was further complicated by the tendency for alcohol to be a trigger for their symptoms. Missing out on nights out was a key factor in participants' descriptions of being 'unlike others their age':

> *"I'd say it definitely has affected my social life, because there's weekends where I've had to cancel plans with my friends, and - especially as I turned 18, and going out clubbing was the next best thing, but obviously cos of the pain, I couldn't go because I couldn't physically move from my bed."* (Natalie, 21).

This was particularly noted by participants who were at university, who felt that nights out were a key aspect of university life. Some also mentioned the interruption to their social life caused by bloating. Having to wear *"baggy clothes"*, which none of their friends wore, or looking *"six months pregnant"* were cited as reasons that participants might stay home and miss social activities. Participants stated that interruption with social activities increased feelings of isolation, and sometimes damaged friendships; they said that friends would not ask them out anymore:

> *"…alcohol is a huge thing that is a really bad for your endometriosis, so I really don't drink as much as other people at all, so I don't ever get invited out anywhere or anything… but I mean I miss out on* ***so*** *much with my friends because of that, and it's pretty shit if I'm honest with you, I can be like a bit invisible sometimes."* (Emma, 22)

Again, friends' lack of awareness of endometriosis was reported to be an issue, because participants were unable to explain why they could not attend social events. This was particularly so pre-diagnosis, when participants stated that friends would question why they weren't coming out, as it was *"only a period"*.

Another area of life in which participants reported to miss out was sport and physical activities. Most participants said they often missed PE at school, due to either pain or heavy bleeding. Many who had taken part in sports prior symptom onset found that their continued participation was limited; either having to give up altogether or stop until their symptoms were under control. For some, this meant missing out on hobbies, or having to forgo playing at a highly competitive level. Sport was also viewed by some as a social activity; it was something they did with their friends, or they participated in a team sport like netball. As a result, by foregoing sporting activities, it caused additional impact on participants'' social lives. The following quotes highlight some of these issues:

> *"I used to be really sporty actually. I used to like run in stadiums and stuff, up until about the age of 15. I did kind of want to take that further, and that was going to be my career, but endo's kind of put a stop to that."* (Louise, 18).

> *"Before I had the really bad pain I used to do running, I used to go to dance classes, and do rock climbing and do all these great adventurous things, and then when I got this pain I just couldn't do any of that which was really rubbish. Cos I used to do it with my friends, I used to go out rock climbing as a social event, and I just couldn't do that anymore which wasn't great."* (Daisy, 19).

Endometriosis caused an impact on many other aspects of participants' lives, such as driving and going on holiday. Due to the vast range of interference as illustrated in this theme, many participants described endometriosis as having a largescale effect on their lives, for example stating that it *"affects everything you do"*, or that *"you can't do anything"*. Further complicating this was the unpredictable nature of endometriosis; most participants stated they never knew when symptoms might arise, therefore impeding plan-making. In addition, they always had to be prepared in case symptoms started unexpectedly. Olivia sums up these issues:

> *"So I'm in a position now where I'd literally say it's literally taking over my life, cos I can't do anything without thinking about being in pain or 'oh, have I got paracetamol, oh have I got co-codamol if this happens, oh have I got this, have a got a pad in case I start bleeding, have I got this drug, this drug, this drug', that kind of thing. And it's just, urgh, frustrating."* (Olivia, 18).

6.3.4.3 Relationships

Through living with endometriosis, participants described their relationships as being both strained and strengthened. Key relationships were those with family members, friends, and intimate partners. Participants noted strain on all relationship types, which they believed was largely because others did not understand the severity of their symptoms, or the nature of endometriosis. Adding further complication, participants said they found it difficult to explain to people, because they did not fully understand it either. There was a tendency for others, particularly friends, to try to downplay their symptoms, saying things like *"we all have period pain"*. They were therefore described by some to lack appropriate sympathy, and to get annoyed when participants cancelled plans:

> *"…obviously relationships were strained, both with my family and my friends, because more for the fact that they wouldn't really understand, because there'd be times where say there was a family event coming up, or my friends wanted me to come out at the weekend, but I was literally bed bound, and they wouldn't get that, they wouldn't understand that I couldn't physically move my body because my pain was so intense…"* (Natalie, 21)

Some participants experienced mood swings, which they said their family often bore the brunt of because they were closest to them. Strains on family relationships did not usually result in any long-term damage though, and many said their families were very supportive. However, friendships were not always so resilient; many participants stated they lost friends while living with endometriosis, or found it difficult to make and maintain new friendships. Some lost friends pre-diagnosis, when they didn't have a concrete reason for missing social events, and were embarrassed to divulge issues with their periods:

> *"I think the big thing for me as well is that I didn't have a diagnosis so I could never say to my friends "oh guys, it's going to flare up my endometriosis", so I'd just be like "I'm just in pain and I don't really want to come out" …and obviously to them that was like "oh Olivia doesn't want to see us", "what's she doing that's more important" kind of thing. Yeah so I'm definitely quite isolated now I would say, because of it."* (Olivia, 18)

In contrast, some participants mentioned the strengthening effect of endometriosis on their relationships. Some spoke of close friends, who showed remarkable understanding and support, and who stuck by them throughout their journey. They indicated that because of this they would be *"friends for life".* Family relationships were also strengthened, particularly due to their support in seeking treatment and a diagnosis:

> *"I think it's made me like, love my parents more because they really fought for me and they believed in me when no one else would."* (Lucy, 22)

Many of these points were also raised when talking about relationships with intimate partners, who showed varying levels of understanding and support. However, these relationships were also affected slightly differently, often due to their sexual nature. Many participants experienced dyspareunia, and were therefore unable to engage in sexual activity as often as they or their partner would have liked, which they said caused *"tension", "arguments"* and *"frustration"*. In addition, due to symptoms such as pain, some participants stated that they often did not feel 'in the mood' for sex. These issues caused relationship breakdowns in a few cases, or for participants to avoid relationships. Participants often said they attempted to partake in sexual activity because they felt guilty, but in doing so, sometimes their partner then felt guilty because they were in pain. The extent to which this symptom strained a relationship was usually mediated by how supporting they thought their partner was.

In addition to the strain on relationships, some participants worried that their endometriosis had a direct impact on those around them, particularly family. Reasons for this included having to see the participants in so much pain, or having to sacrifice things to help them out. Therefore, endometriosis could be described as something that not only the participants themselves had to live with and adapt to, but those close to them as well.

6.3.4.4 Coping and Resilience

Despite the widespread impact of endometriosis on teenage life, many participants communicated a notion towards resilience, and not letting the endometriosis define them. Participants often stated that they tried to just *"get on with it"* as much as they could, or that they were *"determined"* to succeed despite their endometriosis. In a few cases, participants described a sense of acceptance; that this was their life now and they had to try to live as normal a life as they could:

> *"…I say I don't want it to* ***be*** *me, and it's not, it's just something that I have to deal with, but I've never known anything else, so that's just what it's like."* (Claire, 21).

> *"I often go out with a hot water bottle on my belly. I'll go to the pub with a hot water bottle*

> *on my belly now days, cos it's either that or I don't socialise, I don't have any friends, do you know what I mean…"* (Emma, 22).

Summary

This theme illustrates the extensive impact of endometriosis on the lives of the AYW in this study. They missed out on many aspects of life including school, sports, and relationship building. The interference caused to their lives was not only felt on a daily basis, but could have repercussions that were long-lasting. However, many did not want their lives to be taken over by endometriosis and tried to live as normal a life as possible.

6.3.5 Support and Information: "Nothing for my Age Group"

6.3.5.1 Support

Most participants stated that their mothers were a key source of support, who were often alongside them throughout their journey. As described in Section 6.3.1, mothers were said to provide both practical and emotional support, and were instrumental in their help-seeking process.

> *"…she [my mum] just talks through it with me and just gives me a hug. Um, if I need her she'll come and get me or she'll look after me and (p) yeah, she's been there all the way with me, so that's good."* (Hannah, 22).

Fathers were discussed to a lesser degree, but in general were found to be a valuable source of support, particularly providing practical support, i.e. shopping for products and researching treatment options. Participants stated they were generally quite open about their condition with most family members and frequently mentioned grandmothers and siblings. A small number of participants had a family member with endometriosis, who were also described as supportive.

Over half of the participants were in a relationship at the time of interview, many of whom mentioned their partner as a source of support, again providing both practical and emotional support. Many participants said they were *"lucky"* to have found someone so supportive, as they had often had former partners who had not been understanding. Some described that their partner's support and understanding was the result of them being there and seeing the participant's struggles first-hand.

A final part of the immediate support network described by some participants were their friends. However, they often stated that friends had not always been supportive, particularly when they were younger and had not received a diagnosis, as friends were often unable to grasp their level of pain. Some participants said they had therefore lost friends, and subsequently found it difficult to turn to friends for support. Most participants only discussed telling close friends. Those who did not seek support from friends often said it was because they didn't think their friends would understand, or they didn't want to be a burden.

> "*I wouldn't really talk to any of my friends about it, just because they don't really understand it, and they're not the most supportive people about it..."* (Kate, 18).

A small number of participants stated that they found it difficult to turn to those they knew for support. For some, this was because of the lack of awareness of endometriosis by those around them, which made it hard to explain the condition to others. Some stated that they felt like there was not really anything others could do anyway, so why bother.

Many participants also received support from others with endometriosis. Participants mainly accessed these connections online through social media, sometimes because face-to-face groups were unavailable in their area. Participants discussed the pros of communicating with others with endometriosis, particularly their ability to understand what they were experiencing, and to provide relevant support and information. An additional benefit of online support was the ease of access; there is always someone there to talk to. Through communicating with others with endometriosis, participants often said they felt less alone. Some of these points are illustrated in the following quotes:

> *"I think the people on the Facebook page, they* ***know*** *how it feels and I kind of, I take comfort in them, cos you know what there, like they've kind of experienced exactly what you have."* (Eve, 23).

> *"I know that if I want to I can always post and ask a question to one of them on Facebook or whatever, and people will respond. Everyone's really nice, everyone gets it, so you don't feel quite so alone."* (Alexandra, 20).

While support from others with endometriosis was largely positive, participants also noted some associated cons. One issue reported was the sheer size of the community, and that participants therefore had difficulty in deciphering through many conflicting opinions. Another issue reported by a small number of participants was the tendency for group discussions to be negative, which could sometimes bring them down. In addition, people talking about having multiple surgeries, or struggles with infertility, was also a source of discomfort, as participants said it invoked fear and worry:

> *"…I find that talking to people with endo really scares me more than anything, because I've only met people that can't have children…"* (Emma, 22).

A significant number of participants stated that some of these issues were in part due to the older age of most of those using endometriosis support groups. They felt that their concerns were very different to those a bit older than them, who had issues such as infertility, or juggling endometriosis with looking after children, and therefore much of the support available was irrelevant to them. This finding was not confined to support groups alone, as most participants stated that support in general was lacking for their age group. This quote summarises these points:

> *"…but there's not really any support groups specifically for people of my age. I mostly see people who are like 20s, 30s, 40s. There's no one really there who is 18 and has got diagnosed recently. It just feels quite isolating, especially in the support groups, there's no one there really for me. I don't mind speaking to someone that's 20 or 30 but they've got different problems in their lives, they've got different experiences. When I say to them 'well I just don't feel great and I want to go out and party with my friends', it's very different from them who are like 'I don't feel great, and I can't go to work and I can't support my child'. It's different."* (Kate, 18).

In addition, some participants noted that there was a lack of support for people their age when going through the diagnosis process. This was partly because it was a little-known condition, and therefore those around them, for example schoolteachers, were unable to guide them through the process. Finally, some participants said that they would have liked some support about how to explain their condition to others, particularly new boyfriends.

An important part of living with endometriosis was having a support network who could provide practical and emotional support at times of need. Support networks could be classified as those immediately known to participants, i.e. family, friends, partners etc., and those who were more remote, such as people at online or face-to-face support groups. While participants drew on a wide range of support, they felt that support targeted to their age group was missing.

6.3.5.2 Information

Participants sought information at many stages during their journey, such as after their symptoms began, during the medical process, and after receiving their diagnosis. The internet was the most popular source of information and was used by almost all participants. They stated they often used Google to search for information, and looked on the Endometriosis UK and NHS websites. Many participants said that Endometriosis UK was the most *"useful"* source of information, and that they could trust the information they provided.

Participants also described the use of a range of online platforms for information, including YouTube, Instagram, Facebook, and Ted Talks. This information was mostly provided by others with endometriosis, and one of the reported advantages of such was that it was from people who had experienced it, as compared to doctors who had not. While this was useful, some questioned the trustworthiness of information from this source. Some participants stated that websites, such as Endometriosis UK, were useful for more factual information on symptoms and treatments, but information through support groups/social media provided more on the emotional aspects of endometriosis, and what it's like to live with it day to day:

> *"…not everything is listed on websites… things like emotions and your mental state, that's more on the support groups than anything else because the NHS doesn't cover it, it only covers symptoms and actually what happens."* (Alison, 19).

In numerous instances, participants exclaimed that there was not enough information targeted at their age group. They said there was a lot of information about issues such as fertility, but this was less relevant for people of their age, as they wanted to know more about living with endometriosis as a teenager:

> *"…it's more sort of catered towards people having fertility issues and things, and you know at this age again, you don't really want to think about that."* (Rebecca, 21).

Some participants reported that they had received information leaflets from medical professionals, and a minority stated they would turn to medical professionals if they wanted more information. However, many said they had to search for further information themselves, because they had not received enough from medical professionals. In addition, the information they did receive from medical professionals was sometimes described to be difficult to understand.

Summary

Having adequate support and information was key to managing endometriosis, however, most adolescents felt as though the support and information available to them was not age appropriate.

6.3.6 Emotional Wellbeing: 'Not Just a Physical Thing'

Endometriosis affected many aspects of participants' lives, and as such, had a strain on their emotional wellbeing. They described impacts on their mood and mental health, diminished confidence and self-esteem, and feelings of isolation and loneliness. Therefore, despite the physical nature of endometriosis, the disruption it caused to lives of AYW meant it was often experienced on an emotional level as well, as summarised in this quote:

> *"So many people think about the physical effects, but no one really talks about the social and psychological effects that it has on people."* (Daisy, 19).

6.3.6.1 Emotional Health

Most participants discussed the impact of endometriosis on their emotional health, often using words like *"sad"*, *"upset"*, *"fed up"*, *"miserable"*, *"down",* and *"worried"*, as well as describing behavioural displays of emotion like *"crying".* These emotional impacts were brought on by several factors. Often, they were a response to experiencing severe symptoms, or the impact of those symptoms on their lives. Participants expressed sadness, anger, and frustration about the medical journey; at receiving inappropriate care, lack of improvement in symptoms, and at the receipt of a chronic diagnosis. Many experienced emotional impacts as a side effect of the hormonal medications they were taking. These quotes further illustrate these emotional impacts:

> *"Um, and the pain, like I can't – I took a week off school every month, I mean like it was severe, and I would be curled up in a ball screaming and crying, um non-stop…"* (Emma, 22).

> *"…especially on the coil you get really emotional, like I notice I get really emotional and really upset really easily."* (Kate, 18).

> *"As it's gone on, the past year, knowing that that's what I've got, I just feel sad, and it's upsetting, and more like, yeah it's just like, it is life changing I suppose, and just fed up."* (Eve, 23).

Many participants also described more serious emotional impacts, affecting their mental health. The most reported issues were anxiety and depression, feelings of which were discussed by numerous participants. It was unclear as to the extent of clinical depression and anxiety in this sample, however some participants did state that they had been diagnosed and/or treated for either. A small number of participants illustrated how severe the impact on mental well-being could be:

> *"I did try and – I took an overdose, because of the pain and everything, it was just getting me down. I've had my low patches, and depression."* (Sally, 22).

> *"I remember saying when I was on holiday actually… I was laying on the bathroom floor, crying, … and I just said [to my mum] 'do you know what, if there was like something right now that would just put me to sleep I'd make you do it', because the pain was just (p) – the thoughts it*

> *makes you think are really scary actually."* (Sarah, 20).

Participants often said they struggled to get to grips with these emotional issues, which some said could spiral out of control. Furthermore, some participants reported that they would have liked some form of counselling to deal with these issues, however many struggled to obtain referrals for this additional support. Some implied that treatment was often aimed at the physical aspects of endometriosis, but that it was more than just a physical condition.

6.3.6.2 Perceptions of the self

Participants almost unanimously reported that endometriosis had an impact on the way they viewed themselves. The most common issue conveyed by participants was a lack of self-esteem, resulting from changes in their physical appearance. These were often a result of treatment, for example weight gain, hair growth, and acne, as side effects from hormonal treatments, and scarring after surgery. In addition, many participants experienced bloating as a symptom of their endometriosis, which was often cited to affect self-esteem:

> *"I feel like, cos I get really bad bloating from it as well, I just feel like I look disgusting, like if I want to wear something, I just feel like it's not going to look very nice and things like that because (p), I look huge."* (Zoe, 19).

As this quote illustrates, changes in physical appearance were cited to restrict participants clothing choices. They often reported dressing in *"baggy"* clothing, and not being able to wear *"tight"*, *"skinny"* or *"revealing"* clothing like others their age do, and therefore viewed themselves as 'different'. In addition, low energy levels caused a lack of motivation to make an effort with their appearance, which in turn increased their negative view of themselves. Some participants said that this impacted on their social activities, as they would avoid going out when they felt like that.

A small number of participants indicated feelings of sexual inadequacy. This could be in part due to clothing restrictions; for example, Emma stated that her heavy bleeding meant she had to wear big knickers, and therefore didn't feel *"sexy"*. For most however, these feelings arose due to their experiences with dyspareunia. Some stated they felt embarrassed that they were unable to have sex, or that they should be enjoying it but weren't, especially at their age. These feelings of inadequacy impacted on participants' self-esteem. These quotes illustrate some of these points:

> *"It [dyspareunia] kind of makes me feel a bit of a failure, because you know, it's the most basic thing that we're meant to do, and my body isn't willing to do it…"* (Meghan, 23).

> *"…I didn't want to be like you know, 21 years old and have like problems having sex. That's not what you should be, what society thinks you should be doing when you're 21."* (Claire, 21).

Participants also described a loss of confidence in themselves and their abilities, such as being able to play sport, and socialise. They worried that cancelling plans and not going out would make them lose friends. In addition, they were hesitant to tell people why they had to cancel, either due to embarrassment about the condition/symptoms, or in case they weren't believed. Participants often described several years of having their symptoms not believed by others, including friends, teachers and especially doctors, and therefore many said they began to doubt themselves. Participants said they questioned whether they were being *"dramatic"*, *"hysterical"* and *"psychotic"*, or whether they were just *"weak"* and unable to deal with their periods. This quote illustrates these feelings of self-doubt:

> *"I feel that with all the problems that I've been experiencing, because of my past experiences of people you know, presuming that you're making something up or you're being hysterical or overreacting, it's hard not to think that yourself. When you're experiencing these symptoms it's hard not to think 'oh maybe I am just making this all up…'"* (Laura, 22).

6.3.6.3 Isolation

A small but significant subtheme was the isolation reported by participants. Some felt alone because they found it difficult to talk to others about their symptoms. Others often did not understand endometriosis because the symptoms were invisible, and there was a lot of overlap with periods. In addition, participants reported that they often had to miss out on social events, and as a result could end up feeling quite isolated.

> *"When I was really ill when I was 17, my friends would ask me to go out and I'd just have to say 'no, I'm just not well'. And then that isolates you more, so then you feel more alone… and no one else – you can't really explain it to anyone else cos as soon as you explain it they say 'well I have bad pain when I'm on my periods'…"* (Kate, 18).

As illustrated in this quote, others' lack of understanding or awareness of endometriosis could contribute to feelings of isolation. Participants stated that talking to others with endometriosis, who understood the condition, made them feel less alone:

> *"I like to read what people are posting and it's nice to know that other women are in the same situation… it helps to know that other people are experiencing it, cos when you're the only – when you don't know many people who have it, um it can feel quite isolated, cos no one really*

> *gets it…"* (Alison, 19).

Summary

As this theme illustrates, endometriosis caused much more than just physical impairment, as it also affected many aspects of participants' emotional health and wellbeing. It disrupted their self-esteem and made them feel different to others their age.

6.3.7 Future: 'Uncertainty'

All participants indicated some concern about their future due to endometriosis. Many worried about their long-term future, questioning their fertility, relationships, and employment. Some had said they did not like to think too far ahead, and just took each day as it came. One of the issues when considering their future was the uncertainty associated with endometriosis; that they did not know when their symptoms might return, or how it may impact their lives.

6.3.7.1 Fertility

The biggest concern participants had about their futures, expressed almost unanimously, was whether they would be able to have children. Participants stated they were *"worried", "anxious"* and *"scared"* when thinking about their fertility. A small number of the younger participants reported that while it was a concern, they did not want to think about it too much yet, because they were so young. Some said that as they were getting older, it had become more of a worry. Many participants stated that they had not realised how important their fertility was to them until it became something that might be taken away from them:

> "…I don't know I suppose being told 'oh, you might struggle to get pregnant', like a few years ago that wouldn't have been an issue for me, I'd be like 'oh, I don't want kids anyway', but now, now I'm getting older, and the potential of me maybe not being able to have a child, then yeah, it is quite upsetting really, it does play on your emotions." (Jessica, 21).

One of the key issues reported about fertility was the uncertainty; participants had no idea whether their fertility was affected or not. Many said they had asked their specialists and had been given varying responses. Some were told that they did not have endometriosis on key reproductive areas, such as their ovaries or fallopian tubes, and so their fertility should not be affected. Others had difficulty in receiving much advice, or were told to worry about it in a few years' time, which they assumed was due to their age:

> *"So I always try and talk to them [doctors] about it but they just won't talk to me about it, they're like 'oh well, think about it in 10 years, think about it in 10 years'."* (Olivia, 18).

Due to the uncertainty surrounding their fertility, many participants stated they needed to re-evaluate future plans. There was a common narrative amongst such participants that ideally, they would like to have established their career before having children, however they were now unsure if this would be possible, and they may have to have children earlier than planned. Two participants, who were told by their specialist after surgery that it would be a good time to get pregnant, decided to act on this advice; one had already had two children at the time of interview, and one was in the process of trying. Both stated this was earlier than they would have anticipated in their life plan. This quote summarises these points:

> *"I expected to have children when I'm like, really late 20s, 30s, you know I wanted to get my career set before I have children. But it's made me really think that maybe I don't have that choice anymore."* (Kate, 18).

Some participants indicated that they had already considered the measures they may have to take to have children, such as IVF, adoption, egg freezing, and surrogacy. In addition, some stated that they contemplated their fertility when making treatment and lifestyle decisions.

6.3.7.2 An ongoing battle: Future surgeries and treatment

Participants had all tried a range of different medical and surgical treatments for their endometriosis, however, the relief they provided was rarely long term. This, coupled with the lack of cure for endometriosis, meant that participants viewed a lack of permanency in the treatment options available, and were concerned about their ongoing need for future treatment, and in particular future surgeries:

> *"…so I was thinking 'I do not want an operation every 2 years', or for it to be so bad that the pain comes back every 2 years, you know, I want to have one and it's done and it's gone …I don't think I can necessarily deal with going through this same cycle every few years."* (Gemma, 19).

A small number of participants stated that they wished to consider more permanent treatment, such as a hysterectomy. However, this may mean either not having children, or waiting until after they had

had children. One participant described how difficult a decision this was:

> *"I do want children but I don't really want to live with the endo, so it's a double edged sword. But it concerns me that the older I get, the less the chances are [to have children] anyway. So I think that's kind of what sort of pushed me towards the hysterectomy idea in the first place, you know it could be 10 to 15 years before I'm in a place to have children or starting to consider it, and you know, leaving it for that long it could be substantially worse".* (Megan, 23).

In addition to the potential need for multiple surgeries in future, a small number of participants also worried that more surgeries meant that more scar tissue would develop, and the worsening therefore of symptoms. Some also reported concerns over the long-term effects of taking their medications. The unpredictability of endometriosis created much uncertainty about future treatments:

> *"I think it's hard to tell really, cos you never know when it's going to flare up, so I think it's just a case of waiting to see when the next thing you try isn't going to work anymore."* (Jessica, 21).

6.3.7.3 Intimate Relationships

A small number of participants were concerned that future friendships might be affected by endometriosis, largely because they doubted others would understand. However, the main relationships that participants were concerned about were intimate relationships. This was mostly described by participants who were not in a relationship at the time of interview. They were worried that they would not be able to find someone who was understanding, or who would be willing to take on someone with a chronic condition:

> *"…I feel like I'm just sort of a little bit harder to cope with than someone who wouldn't have endometriosis. So there is that worry that would someone ever bother with me because I'm - I feel like I'm a trial to cope with."* (Laura, 22).

Sometimes these fears stemmed from past relationships, some of which had ended due to endometriosis. A particular concern was issues with intimacy, due to pain/dyspareunia, which participants said they would find difficult to explain to someone new. These concerns, as well as the perceived difficulty of finding someone understanding, meant that they were hesitant to *"bother"* with future relationships. These points are illustrated by Alison, who stated that her ex-boyfriend had cheated on her because she could not partake in sexual intercourse:

> *"I don't have relationships, since what happened with my last boyfriend, I don't let myself*

> *connect with people… I'm worried that there won't be anybody that will understand, or will be willing to put up with it, and I worry about telling men. How are you meant to tell somebody that you can't have sex because it's painful, and it's (p), I just don't bother, I just don't let myself connect with somebody and like them, because I know that this has a massive impact on a relationship. And it's not worth getting into something that's going to (p) end eventually because they can't cope with it."* (Alison, 19).

As this quote indicates, participants also reported apprehension about how and when to tell a future partner about their condition. In addition, they worried about telling them they might not be able to have children.

> *"…well if I have a partner and I've got to tell him 'I might not be able to give you a child one day', that could affect the relationship that you have."* (Jessica, 21).

6.3.7.4 Education and Career Outlook

Most participants had already experienced interruptions in their work or education, and as such were worried about further impact in the future. Those still in education were concerned that they might not be able to complete the course they were on, especially if they had experienced setbacks in the past. However, the main concerns centred around their work and career. A small number of participants thought that their symptoms of endometriosis might restrict the type of work they could do:

> *"I used to work in a care home, and that on top of endo was just no good, it was heavy work – well not heavy work but it was just too much for me to cope with and having that. So I'm looking for more like a reasonable work place instead of one that's going to have an impact with it."* (Sally, 22).

In addition, some participants stated concern over both securing and sustaining a job. They worried about having time off due to their symptoms and/or surgeries, and whether employers would be understanding about their condition. Again, a key issue in participants' accounts of future work and career was the uncertain and ongoing nature of endometriosis:

> *"…last year I lost like a month of my life from recovery, so then it makes you think 'what if I want a career, is that going to affect my career because every few years I'm going to have to have a month off recovering from an operation'."* (Olivia, 18).

6.3.7.5 Hope

Despite several sources of apprehension, a small number of participants expressed a slight degree of hope about their future. This was only a minor subtheme, and was mainly described by those who stated they had some sense of control of their endometriosis. This was either because their symptoms were under control at the time of interview, or because they were taking active steps, such as dieting, to try to control their endometriosis. They did acknowledge some uncertainty as to how long this feeling might last:

> *"I think, I feel quite positive at the moment because it's all under control, which is great, but yeah, it just varies from day to day really."* (Daisy, 19).

However, a small number of participants who didn't describe themselves as necessarily in control, simply had hope that they would find a treatment that would work. In addition, some described a sense of strength and determination; that they had already lived through their previous experiences with endometriosis, and they could therefore cope with whatever they were presented with.

Summary

Participants had concern about how endometriosis may affect their future, particularly given the uncertainty associated with endometriosis. They did not how their symptoms and treatment might affect their fertility, relationships, and employment. Some were hopeful that they would be able to live with endometriosis.

6.4 Chapter Summary

This chapter has reported on the thematic analysis of the interviews conducted with AYW with endometriosis, which characterises their experiences. These themes and subthemes, as well as the way they interact with each other, highlight the complex experience of having endometriosis as an AYW. These results will be discussed in the following chapter, in the context of previous research, and in relation to the key objectives of the study.

Chapter 7. Study 1 Discussion: Adolescent Endometriosis as 'Biographical Threat'

7.1 Introduction

The key aim of this qualitative study was to characterise the illness experience of adolescents with endometriosis, and additionally to compare this to both the experience of endometriosis described by adult women, and the experience of other chronic illnesses during adolescence. Comparable to previous research with adult women with the condition, the findings of this study indicate that the symptoms of endometriosis in adolescence are wide-ranging, and significantly interfere with many aspects of life, including school, work, sport, social life, and relationships. Like adult women, adolescents face a struggle to receive a diagnosis, and their support and information needs are often unmet. This study, however, evidences how adolescents' experiences are significantly shaped by their age/life-stage. Participants' narratives described their experiences as discordant with being 'young' when compared to their peers' lives, as exemplified by Zoe (age 19): *"I just don't live the life of a normal 19-year-old..."*.

Much previous sociological research on adolescents with chronic illness (AWCI), draws on Bury's (1982) concept of 'biographical disruption' to understand how young people simultaneously navigate adolescent developmental transitions alongside a chronic condition (see Section 2.5) (see e.g. Grinyer, 2007; Kirk and Hinton, 2019). This body of work argues that the experience of illness during adolescence and young adulthood is somewhat distinct, resulting from fundamentally altered life trajectories at a crucial transitional moment. This study expands on this body of knowledge, demonstrating how endometriosis in adolescence is experienced as a 'biographical threat', to both their present and imagined life-trajectories. The novel contribution of this study is how this 'biographical threat' is further contextualised by the nature of endometriosis, which is a gendered, contested, and stigmatised condition (Denny and Weckesser, 2019). Endometriosis therefore threatens their lives and self-concepts as adolescents/young women, and their imagined futures as possible mothers, intimate partners, and career women. This chapter will discuss the significance of the study findings in relation to participants' life-stage and female identities.

7.2 The Impact of Endometriosis on Adolescent Lives

As detailed in the previous qualitative results chapter (Chapter 5), adolescents' accounts of endometriosis focused largely on their symptoms and how they caused them to 'miss out' on important aspects of their day-to-day lives, including school, sports, and social events. In turn, missing out threatened their grades, relationships, and emotional well-being. The most dominant symptom causing these disruptions was pain, described in-depth by all participants, thus supporting previous research with adolescents (Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006) and adults (see e.g. Culley et al., 2013) with endometriosis. However, heavy bleeding, and bowel/bladder issues were reported to have significant disruption, and surgeries/recovery time could also interfere.

7.2.1 Disruption to School, Sports, and Social Participation

Supporting previous research with adolescents (Bodén et al., 2013; DiVasta et al., 2018; Moradi et al., 2014; Staccone, 2006), symptoms including pain, heavy bleeding, and bowel issues, caused significant disruption to school, college, and/or university attendance. This in turn affected their ability to keep up with schoolwork and impacted their grades, with some reporting that they obtained less satisfactory results in major exams, and/or needed to re-sit entire school years. These findings are common to the literature concerning AWCI (see review by Taylor et al., 2008). This disrupted their current biographies, but also threatened their future life-trajectories; they were faced with a 'reconfigured future' (Kirk and Hinton, 2019), having to alter their educational and career choices from those they had planned. Research with adults has highlighted the effect of endometriosis on school attendance, productivity, and academic attainment (Huntington and Gilmour, 2005; Manderson et al., 2008; Moradi et al., 2014), however it often does not describe the wider impact of school absence. Adolescents spend more waking hours at school than any other setting; in addition to the academic aspect, school also involves spending time with friends, extracurricular activities, and exposure to cultural knowledge (Eccles and Roeser, 2011). As such, school experiences can influence many aspects of adolescent development, including cognitive, social, and emotional development (Eccles and Roeser, 2011). In this study, participants indicated that school absences also affected their social life (both within and outside of school) and participation in extracurricular activities.

Many participants missed physical education lessons at school, and were unable to play competitive sports or partake in hobbies. Most often this was due to pain or heavy bleeding. A unique finding in the present study, reported by most participants, was pain with tampon use, which occurred both at insertion and during use. Most participants stated that they were unable to use tampons because of the pain, and one implication of this was their ability to participate in sports. It is of interest that this symptom was first relayed in research with a younger sample. Given its links with dyspareunia (Landry and Bergeron, 2009) it is unlikely to be a symptom constrained to adolescents, however it may be an issue that is more pertinent to this age-group – perhaps because of the disruption it causes. Limited sports participation further disrupted social lives, and for some participants, their plans of playing competitively.

In addition to the social impacts of missed school and reduced sports participation, adolescents reported a marked disruption in their ability to attend social events, which supports findings in research with AWCI (Taylor et al., 2008; Winger et al., 2014; Woodgate, 1998). Missing out on social activities that are often taken-for granted amongst others their age contributed to feeling different to others, and thus disrupted their self-concept as an AYA. This supports findings by Plotkin (2004) in her research with adolescents with endometriosis. For younger adolescents, such normative activities included going to friends' houses and/or attending sleepovers, which was limited by symptoms such as pain and the fear of leaking blood, an anxiety which appears to be particularly concerning for young people (Briggs, 2021; Burrows and Johnson, 2005; Donmall, 2013; Jackson, 2019; Lee, 2008; Newton, 2016; Plan International UK, 2018), and is rooted in concerns around stigmatisation and bullying around menstruation (Burrows and Johnson, 2005; Newton, 2016; Roberts et al., 2002; Seear, 2009a). In their older adolescent years, participants noted that their attendance at nights out with friends was limited. In addition to pain, for many this was because they were unable to consume alcohol because it triggered their symptoms, which increased feelings of being 'different' to peers. Drinking alcohol is often considered a normative behaviour in older adolescence/young adulthood, particularly in the UK drinking culture, and findings suggest that those who do not drink can feel like 'outcasts' (Seaman and Ikegwuonu, 2010).

In addition to missing out on planned social activities, the unpredictability of symptoms meant that participants were hesitant to make plans, and thus felt endometriosis was taking over their life. Of particular concern due to their unpredictability were bowel and bladder symptoms, affecting things like car journeys and university attendance. Research with adult women with endometriosis has also described bowel and bladder complaints (Huntington and Gilmour, 2005; Moradi et al., 2014), however, discussion of these symptoms is somewhat modest in comparison to this study. Bowel and/or bladder issues were discussed at length by this sample, which suggests that they found them a significant issue. It may be that their life-stage posed certain restrictions on their management, for example, having limited access to a toilet during lessons/lectures/classes or having to seek permission to go. In addition, compared to older women, adolescents may be more reliant on other people for transport, or on public transport, and so are unable to make comfort breaks when needed. Participants also discussed bowel and/or bladder symptoms with reference to feelings of embarrassment (see Section 6.3.2.4), which appeared a significant issue. In their focus group study, Gupta et al. (2018) found that bowel symptoms were perceived by adolescents (male and female) to be a particularly embarrassing symptom of endometriosis. Together with their findings on adolescents' views of painful sex, the authors underscored the importance of social context when determining one's perceptions of endometriosis symptoms. This was evidenced in the current study, which highlighted the significance of certain symptoms during adolescence.

7.2.2 Altered Relationships

Consistent with findings in research with WWE (Denny, 2004a; Gilmour et al., 2008; Jones et al., 2004c), missing out on social events widely affected participants' peer relationships. However, this must be considered in the context of life stage; adolescents are in the midst of major transitions in their social development, and consequently their peer relationships are one of the most important aspects of their life (Brown and Larson, 2009). Indeed, qualitative studies including both adolescents and adults, have found that the impact of endometriosis on social life was more prominently highlighted by adolescents, as compared to older participants (Moradi et al., 2014; Rush and Misajon, 2018). During adolescence, friends begin to take on roles that family members are unable to fulfil (Buhrmester, 1996), and they provide a sense of belonging (Thomson, 2007). Friends also take over parents in the provision of social support (Bokhorst et al., 2010), and peer acceptance can be a protective factor in one's well-being and self-esteem (Corsano et al., 2006; Rueger et al., 2010).

Many of these aspects of peer relationships were threatened by the presence of endometriosis for participants in this study. Thus, missing social events had deeper repercussions; it damaged friendships, impacted feelings of peer acceptance, challenged participants' self-concept as a 'teenager', and triggered feelings of isolation. Given the importance of friendship at this age, it is not surprising that the loss of, or impact on, peer relationships was a significant factor in the experience of endometriosis described by the adolescents in this study. Such impact also contributed to issues with emotional wellbeing, which were widely reported by participants, one of which was feeling isolated or lonely. Corsano et al. (2006) found that psychological well-being in adolescence depends on peer group acceptance and integration, and that unsatisfactory peer relationships can intensify feelings of loneliness. They highlight that while independence is an important part of adolescence, being alone is multidimensional, and includes being alone by choice, which can be positive for developing autonomy and independence, and being alone due to social rejection, which can cause unhappiness, isolation, and damaged psychological well-being.

These feelings of isolation and issues with emotional well-being have also been noted in research exploring adolescents' experience of other chronic illnesses (McEwan et al., 2004; Winger et al., 2014; Woodgate, 1998). In this study however, these feelings were further compounded by the stigma associated with menstruation, and the lack of awareness or understanding about endometriosis amongst peers. Stigma was a particularly apparent issue in the pre-diagnosis stage, as participants felt they did not have a concrete reason for missing social events, and were embarrassed to disclose issues with their periods. This has also been reiterated in research with women with endometriosis (Gilmour et al., 2008), and Seear (2009a) suggests is part of the practice of upholding ‘menstrual etiquette’ (Laws, 1991), to avoid the stigma (actual or anticipated) that might occur following disclosure. When they did disclose, friends often normalised their pain and other symptoms, stating that everyone has periods/period pain, and implied they should just ‘get on with it’. Seear (2009a) suggests that other women may do this because of their own discomfort in talking about menstruation, because it is an inherently embarrassing/taboo topic. Furthermore, Bury (1982; 1991) argued that when presenting symptoms are widely found in the general population, although to a much lesser degree of severity, then it makes it particularly problematic for them to be legitimised, both by the self and others. Participants’ reports of friends saying ‘it is only a period’ supports this idea. Even once a diagnosis was obtained, the widespread lack of awareness of endometriosis meant that friends were often unable to understand it, the symptoms of it, and how it affected participants. This could impact on their friendships, increase isolation, and reduce the support that friends were able to provide. This was also highlighted in previous research with adolescents with endometriosis (Plotkin, 2004; Staccone, 2006).

Participants social relationships were therefore altered, and to some extent controlled by their endometriosis symptoms. There was, however, some mention of the strengthening effect of endometriosis on peer relationships, as some had close friends who had been understanding and supportive throughout their journey. This was therefore dependent on friends’ legitimisation of symptoms and their awareness of endometriosis.

Relationships with parents were largely strengthened, particularly due to their support in seeking treatment and a diagnosis, as also evidenced by adolescents with MS (Kirk and Hinton, 2019). Participants did, however, feel they were reliant on their parents, and worried about the burden of endometriosis on them as well; some described their endometriosis as something the whole family had to deal with. Other research with AWCI has indicated that the reliance on parents, as well as their over-protective practices, disrupted adolescents’ biographies in terms of a loss of independence (Grinyer, 2007; Kyngäs, 2004; McEwan et al., 2004). In the current study, adolescents did not specifically imply that they craved independence from their parents; they were more concerned with the burden on their parents. Perhaps this finding is in part because all the participants were female. The idea of adolescence as a time for finding one’s independence comes from Erikson’s theory of psychosocial development (1968), however Sorell and Montgomery (2001) highlight the potential androcentric bias of some of the assumptions of this theory. They argue that the idea that identity formation results from obtaining independence from others is a stereotypically masculine notion, whereas women often ground their sense of self and identity in their relationships with others. Thus, for the females in this study, their lack of independence, and their closeness with their parents, may not be seen as a negative experience compared to in other research with AWCI, which has included both male and female participants.

Another relationship type discussed at length by participants in this study were those with romantic partners. These were also described to be strained and/or strengthened by endometriosis, often mediated by how supportive participants viewed their partner. As evidenced here, research with AWCI has described issues with unsupportive partners (Coyne et al., 2018), and concerns about physical attractiveness, either as a result of symptoms or treatments (Grinyer, 2007; Jones et al., 2011). However, an additional romantic relationship burden posed by endometriosis is dyspareunia. As observed with adults with endometriosis (see e.g. Denny and Mann, 2007; Huntington and Gilmour, 2005; Seear, 2009a), dyspareunia was a significant concern for most participants in this study. They provided detailed descriptions of the symptom and its' impact, therefore enhancing findings in previous qualitative research with adolescents, in which dyspareunia had been given relatively brief attention (Plotkin, 2004; Staccone, 2006).

Dyspareunia affected participants' willingness to engage in sexual activity, with some avoiding it (and relationships) altogether. Adolescents concerns regarding dyspareunia were broadly similar to those of adults with endometriosis, including the significant impact on relationships (Denny and Mann, 2007; Jones et al., 2004c; Moradi et al., 2014), and the challenge to their perceived femininity (Griffith, 2017). However, expanding on previous evidence (Plotkin, 2004), participants raised the additional concern that this symptom threatened their self-concept as a young person. They perceived adolescence/young adulthood as a time in which they should be having fun and enjoying sex, and the fact that they weren't made them feel different. According to Ayling and Ussher (2008), adolescents and younger women might be particularly sensitive to sociocultural representations of sex in the media, in which women are portrayed as permissive, and eager for sex; thus the experience of dyspareunia may cause them to feel different, immature, and constrained. Further compounding this, participants also alluded to feeling 'unsexy' because their clothing and/or underwear choices were restricted by their symptoms.

In comparison to older women, who may be in more established relationships, adolescent relationships may be more transitional and short-lasting (Grinyer, 2007). Adolescence is the life-stage associated with sexual exploration, in which casual sex is considered a normative behaviour (Lyons, 2009). While many participants described themselves to be in long-term relationships, some discussed casual sexual encounters, and in particular the difficulty in explaining dyspareunia in this context. They also expressed concern about future relationships; how to explain it in a new relationship, as well as finding someone who would ‘put up with it’ – supporting previous evidence (Rush and Misajon, 2018; Staccone, 2006). Thus, it appears that the experience of dyspareunia in adolescence altered participants’ self-concept as an AYA, but also threatened their life trajectories. Some discussed associated feelings of sexual inadequacy and low self-esteem. Sexual relationship experience during adolescence can have long-lasting implications into adulthood (Lyons, 2009), and thus the onset of dyspareunia at a young age may have a more lasting impact on the development of self-concept and of healthy intimate relationships as compared to those with an onset much later in life (Donaldson and Meana, 2011).

7.2.3 Emotional Well-being

The discussion so far has emphasised how the different symptoms of endometriosis threatened participants ability to partake in ‘normal adolescent life’, and thus disrupted their biographies. The effect of such included altered self-concept, isolation, and low self-esteem. One symptom which seemed to have a direct effect on self-esteem was bloating; mentioned by several participants. Although a physical symptom, references were often made to how the bloating made them look and feel emotionally, rather than physically, and may reflect the importance of body image and appearance in this age group (Voelker et al., 2015). Changes in physical appearance impacted their self-esteem; in addition to bloating, they also often experienced side-effects of their treatment, such as scarring, weight gain, and acne, which could alter their appearance and distort their body-image. Adolescence is a critical period for the development of body image (Voelker et al., 2015), and while a change in physical appearance can be detrimental at any age, it can be particularly distressing to adolescents given the importance they place on their appearance (Bowker, 2006; Grinyer, 2007), and perhaps even more so for adolescent girls (Lock, 1998). For some participants in the current study, this damaged their confidence, thus interfering with sexual relationships, and reducing participation in physical and social activities, which further increased their social isolation.

Endometriosis therefore had a profound effect on the emotional wellbeing of the participants in this study. In addition to altered self-perceptions, many experienced impacts on their mood and mental health, which could be a response to the severity of symptoms, the impact of those symptoms on their lives, or others’ dismissal of their symptoms. This supports findings in other qualitative research with adolescents with endometriosis, who have described feeling stressed, emotional, miserable, depressed, and even suicidal (Conboy et al., 2008; Moradi et al., 2014; Plotkin, 2004; Rush and

Misajon, 2018; Staccone, 2006). Again, this is not restricted to adolescents, as research with adults has also documented such effects (see e.g. Cox et al., 2003a; Facchin et al., 2018; Jones et al., 2004c). However, mental health during adolescence is particularly fragile; issues that arise during adolescence can have long-term mental and physical health consequences, and can also cause negative social and educational outcomes (Knapp et al., 2016). Furthermore, poor mental health can lead to negative health behaviours during adolescence, such as smoking, drinking and substance use (ibid). There was no mention of substance/alcohol misuse in the current study, however, one of the participants in Plotkin's (2004) study of adolescents with endometriosis reported drinking to ease the pain and to dull the feelings of depression and loneliness. Therefore, it is something that needs careful consideration in this age group.

7.2.4 Summary

This section has highlighted that the symptoms of endometriosis impacted many aspects of participants lives, including school, social life, relationships, and sexual encounters. Many of these are considered key aspects of adolescent life, and therefore, this altered participants' biographies and made them feel different to their peers. This affected their self-concept, self-esteem, and emotional wellbeing. Although adolescents do experience similar symptoms of endometriosis as described by adults, their priorities and concerns about their symptoms appear to differ due to their age and life-stage. Certain symptoms, such as heavy bleeding, bowel issues, and painful tampon use, appear to be particularly disruptive during this life-stage. Symptom management was a key instigator for participants in their decision to seek medical help, their experiences with which are discussed in the following section.

7.3 Adolescents' Accounts of Obtaining Treatment and a Diagnosis of Endometriosis

A significant portion of the stories told by participants involved their pursuit of a diagnosis of endometriosis, which as shown in Table 6.3, took them between 2 and 9 years. Delays in obtaining a diagnosis are well documented in endometriosis literature (see Section 2.7.2), including that pertaining to adolescents (see Section 3.3.1.2). Some evidence shows that when symptoms begin during adolescence, it can take longer for a diagnosis to be obtained than when symptoms start during adulthood (Greene et al., 2009), suggesting there may be differences in the diagnostic experiences of adults and adolescents. To shed light on this, this section discusses findings around participants' experiences of diagnosis and medical care, and highlights the age-specific challenges reported.

Participants waited 0 to 4 years between symptom onset and seeking treatment. According to Bury (1982), at the onset of a chronic condition, there is a disruption to 'taken-for-granted' assumptions and behaviours, and therefore one has to asses 'what is going on here?' – i.e. recognising there is a problem. Through attending to their bodily states, which are not usually brought into their consciousness, they then make decisions about seeking help (ibid). However, there are several aspects of endometriosis that made recognition of a problem, and thus seeking help, quite difficult for study participants. Firstly, the symptoms of endometriosis are closely aligned with menstruation (and in particular dysmenorrhea), and according to Bury (1982; 1991), if presenting symptoms are widely found in the general population, albeit to a milder degree, then it can be particularly problematic for them to be recognised and legitimised. This was evidenced in the current study, in which participants stated they often just assumed their periods were 'normal'.

Wood et al. (2007) propose that young women's judgements about the normality of their periods are based on what they have learned, their previous menstrual experience, and if they consider their periods to be problematic/extreme. The first, and to some extent the third, of these criteria relate to learned norms (ibid). However, as found in the current study (see Section 6.3.1.3) and evidenced elsewhere (Betty for Schools, 2017; Brown et al., 2022; Koff and Rierdan, 1995b; Plan International UK, 2018), girls often receive limited education about menstruation. Participants reported that they did not receive adequate information on the embodied experience of periods, and were therefore unable to recognise that their symptoms were problematic. They were also largely unaware of endometriosis. Although experiencing severe pain and heavy bleeding, most participants thought this was to be expected with menstruation, part of their gendered biography (Manderson et al., 2008), and therefore believed that their periods were 'normal'. Even those who did think their periods were bad just assumed that they must be unlucky. This corroborates other research with adolescents with endometriosis (Bodén et al., 2013; Moradi et al., 2014), and is also found in the literature conducted with WWE (Ballard et al., 2006; Denny, 2004b; Moradi et al., 2014).

While the issue of normalising one's symptoms is not unique to adolescents, it does appear to be a particular issue when symptom onset coincides with menarche. When this occurs, research suggests there is a tendency to normalise, whereas if symptoms begin later (in the 20s/30s), after several years of unproblematic menstruation, women are more likely to consider there may be a problem (Denny, 2009; Manderson et al., 2008). Many participants who experienced symptom onset from menarche considered their symptoms to be 'normal', whereas the few whose symptoms began later were more likely to believe that something was wrong quite quickly. This is consistent with Wood et al. (2007), who found that young women construct their own 'normal' based on their previous experiences, and even if symptoms are extreme, as long as they are consistent across menstrual cycles, then they are believed to be ‘normal’. If symptoms *become* extreme or unpredictable, young women begin to consider they may be ‘abnormal’ (Wood et al., 2007). Thus, if symptom onset coincides with menarche, an adolescent’s frame of reference is limited, and with nothing to compare to, they may consider them normal.

The process of recognition was rarely aided by talking to others about symptoms. Participants most often cited talking to their mothers, who were very supportive, but could further ‘normalise’ symptoms, either by likening them to their own ‘difficult’ periods, or by suggesting they were just ‘one of those things’. This supports previous findings in research with adolescents (Bodén et al., 2013) and adults when reflecting on their teenage years (Denny, 2004b). Participants discussed symptoms with friends more rarely, and some reported that friends also suggested their symptoms were ‘normal’. They cited others’ lack of awareness of endometriosis, or knowledge of menstruation, as contributory to these assumptions, which reiterates recent findings with young women with endometriosis and severe dysmenorrhea in Canada (Le Roux et al., 2022). Some participants, however, said that they did not discuss their periods very widely, feeling embarrassed, or stating they felt there was a “stigma” or “taboo” towards discussing menstruation. This has also been reiterated in research with WWE (Gilmour et al., 2008; Seear, 2009a). Participants’ lack of disclosure to others limited the possibility for them to compare their symptoms with them, and they therefore missed another crucial opportunity to recognise that something may be wrong.

Stigma associated with menstruation, normalisation of symptoms, and lack of awareness of endometriosis all therefore made recognition of ‘illness’ difficult, and contributed to delays in seeking help for their symptoms. The eventual recognition that there may be something wrong occurred either after doing their own research, usually online, or by the intervention of another person. In this sample, most participants discussed the instrumental role of their parents, particularly their mothers, in recognising that their symptoms were suggestive of a problem and making them seek help. This ‘intercession’ (Manderson et al., 2008) often occurred after some period of living with the symptoms, when mothers recognised that the disruption to adolescents’ lives was becoming too significant. On rare occasions, intervention occurred because someone they knew (i.e. mother, relative, or family friend) had also suffered with endometriosis, and thus encouraged them to seek help, but in general, endometriosis awareness was described to be low.

After the process of recognition, participants presented to medical professionals to get help for their symptoms. However, they described several challenges, and so the path to ‘official recognition’ (Bury, 1982) was rarely straightforward. Issues obtaining treatment and a diagnosis are discussed widely in endometriosis literature (see reviews by: Culley et al., 2013; Young et al., 2015), but some research finds that those with adolescent onset take longer to receive a diagnosis after presenting for medical help (Arruda et al., 2003; Ghai et al., 2020; Greene et al., 2009), so they may face unique challenges. In the current study, the eventual diagnosis for some was obtained either because of emergency surgery, or by using parents' private medical insurance, so the diagnostic experiences might not be representative of all those with adolescent onset. Yet, the 'medical level' delays were four times that of the 'patient level' delays, and participants described several challenges, some age specific, when seeking medical help.

One challenge consistently reported by participants was frequent dismissals of their symptoms by health professionals. This is also a common finding in previous endometriosis research with adults (i.e. Cox et al., 2003a; Denny, 2004b; Markovic et al., 2008). However, research suggests that those with adolescent onset are more likely to report being told by physicians that nothing was wrong, or that they weren't taken seriously (Greene et al., 2009). Arruda et al. (2003) suggest this may partly be because adults are more likely to present with fertility issues, which are taken more seriously. In this study, participants almost unanimously presented with pelvic pain, a symptom of endometriosis which closely resembles that of menstruation, albeit to a much higher degree of severity. Participants reported having their symptoms dismissed as just being part of normal menstruation (see Section 6.3.3.1). Adolescents with polycystic ovary syndrome (PCOS), another condition affecting menstruation, have also reported such dismissals (Jones et al., 2011), and Denny and Weckesser (2019) suggest that medical professionals often view menstrual problems with a degree of scepticism. Furthermore, findings indicate that female adolescents are more likely than male adolescents to report having chronic pain dismissed by a physician, despite there being no differences in the cause of the pain (Igler et al., 2017), reflecting a gendered bias in the treatment of pain (Hoffmann and Tarzian, 2001; Samulowitz et al., 2018). Therefore, adolescents with endometriosis might experience dismissal due to a failure to legitimise their presenting symptoms, (closely resembling those of menstruation), and due to their gender.

Some participants were specifically told by medical professionals that they were 'too young' to have endometriosis, which has been noted in research with women, when recalling their teenage years (Cox et al., 2003a; Denny and Mann, 2008; Moradi et al., 2014). In some of these studies, the women are referring to interactions with medical professionals that could have occurred well over 15 years ago. However, the concurrent finding in this study indicates that this is a myth which still prevails amongst the medical community. In the past, endometriosis was considered to be rare, or even non-existent in adolescent girls, and only very recently, in 2017, the NICE Guidelines were updated to acknowledge the occurrence in this age group (Kuznetsov et al., 2017). Evidence obtained from doctors suggests that they may prefer to be cautious when treating young women with suspected endometriosis, so as not to trigger anxiety (Dixon et al., 2021). While such an approach is understandable, and may be necessary, it must be acknowledged that being cautious is very different from the perpetuation of myths, which this research importantly highlights is still a problem.

Some participants experienced issues in obtaining contraceptive treatment, and one reported being told she was 'too young' for them. Some girls felt they had to lie and said they wanted them for contraception rather than for period pain, and others were concerned about the connotations of taking contraceptives at their age. They believed health professionals would think they only wanted them because they wanted to have unprotected sex. To knowledge, this embarrassment concerning contraceptive use has not been highlighted in previous research with WWE, so it could be a more significant concern for adolescents. Indeed, research has indicated that young people are embarrassed about contraception, and this embarrassment extends to contraceptive services (Baxter et al., 2011); something expressed by the girls in this study, if having to attend family planning clinics to obtain their contraceptives. These are often the places one would attend to be screened for sexually transmitted infections (STIs), and young people associate STIs with stigma (Cunningham et al., 2002). This stigma therefore extends to such clinics, and may put some young people off attending (Baxter et al., 2011). In this study, girls were anxious that other people might find out they had been to such a clinic, however some were forced to, because they struggled to obtain treatment from their GP.

An additional challenge to receiving appropriate care and referrals illustrated in this study was a lack of continuity of care, which was due to the tendency for some participants to frequently move between residences. As evidenced in this study, AYAs have a higher tendency than adults to lack one permanent residence (Arnett, 2004; Stone et al., 2011), for example if parents are separated, or they live away from home when attending university. University students may enrol with healthcare providers in a different NHS trust than their familial residence, and will often return home during holidays (Stone et al., 2011), which can extend up to 4 months in the summer; a lengthy period in which those which chronic illness might need medical care. In this study, participants with transient addresses described issues with their care, as healthcare providers in different areas failed to communicate with each other. They therefore reported undergoing repeated investigations, and increased wait times, which all contributed to their diagnostic delays.

Many participants discussed the instrumental role of their parents, particularly their mothers, in their eventual receipt of a diagnosis. Parents often acted as an advocate, recognising symptoms suggestive of a problem, and pushing for treatment and referrals. They also took on an intervening role by accompanying participants to appointments after they had failed to be taken seriously when attending on their own. It is frequently reported that problems with menstruation are viewed with scepticism by medical professionals (Denny and Mann, 2008; Gupta et al., 2018), however, the fact that they are given more attention when a parent is present may suggest that adolescents experience additional problems in their solo interactions with medical professionals. Research has suggested that adolescents are often more dissatisfied with medical consultations than adults; their appointment times are often shorter, and they leave without adequate information (Jacobson et al., 2000). AWCI have noted that if parents are present, the conversation is often directed toward them and not the adolescent (Beresford and Sloper, 2003; Jones et al., 2011). In this study, the parent's presence often helped with the progress of the consultation, but it is unfortunate that they should need to be there for the adolescent's concerns to be taken seriously. Furthermore, this itself caused additional barriers/delays, as the parents' required presence meant appointments had to be facilitated around an extra person's commitments.

In addition to advocating for treatment and referrals, some parents also offered financial assistance, such as paying for private treatment, to try to speed up the medical process. This kind of support was beneficial to the girls in this study, yet they acknowledged that it would not be available to everyone. The aid of parents in these ways may partly explain the shorter average delay in diagnosis observed in this study (5.2 years) as compared to the national average (7.5 years: Endometriosis UK, 2011). While many studies have observed lengthier diagnostic delays for those with adolescent as compared to adult onset (Arruda et al., 2003; Greene et al., 2009), this study corroborates findings from DiVasta et al. (2018) and Fong et al. (2017), who found that those obtaining a diagnosis *during* adolescence received it more quickly than when a diagnosis is obtained during adulthood. DiVasta et al. (2018) suggested that factors such as parental advocacy and health insurance coverage may play a role, support for which was found in the current study. Adolescents who do not have financial support or parents to advocate for them might suffer much lengthier diagnostic delays than identified in this study. It is also worth noting that studies finding a lengthier delay for adolescents are some years older than those which found a smaller delay, which could reflect an improved understanding of endometriosis in this age group in recent times.

Despite some of the barriers outlined above, all girls in this study eventually obtained a diagnosis of endometriosis. Receipt of diagnosis provided legitimisation of symptoms by medical professionals (Bury, 1982), which prompted feelings of relief for most, supporting previous findings with adolescents (Moradi et al., 2014; Plotkin, 2004; Staccone, 2006) and symptomatic women with endometriosis (see review by Culley et al., 2013). As found in such literature, diagnosis also brought about feelings of anger and vindication for some, at having to wait for so long, or being made to feel 'crazy' by medical professionals in the process. Many participants reported to receive their diagnosis verbally, immediately post-operatively, sometimes before their parents had arrived. They were often given little information, and still being “drugged-up” (under the effect of anaesthesia), lacked the capacity to ask questions. Many also stated they did not have a post-operative follow-up. This ill-timed provision of diagnosis has been mentioned by women in previous research (Cox et al., 2003c). However, adolescents may experience additional difficulty comprehending the information if they are not yet at an adult’s level of understanding (Christie and Viner, 2005). They would likely benefit from information provision that is developmentally and cognitively appropriate (Yeo and Sawyer, 2005), and perhaps to have their parents present.

Having a diagnosis allowed for participants to explain absences etc. to others, and as found previously (Ballard et al., 2006), it sanctioned access to support services, although these were often not age-appropriate (see section 7.4). However, the legitimacy offered by having a diagnosis also prompted a re-evaluation of the self in light of having endometriosis, which ignited feelings of fear, anxiety, and uncertainty towards the future (see section 7.5). According to Bury (1982), this can trigger a ‘mobilisation of resources’, to try to face a now altered biography. Participants drew on medical knowledge, but with unsuccessful treatments/side effects, some had turned to alternative ways to treat their endometriosis. As found in WWE (Cox et al., 2003b; Roomaney and Kagee, 2016), diet, exercise, and relaxation techniques were used to try to cope with symptoms, which could provide some relief, and helped participants feel as though they were being proactive. However, they could prove costly, and therefore are unlikely to be accessible for all adolescents.

7.3.1 Summary

The adolescents in this study faced significant challenges in obtaining treatment and a diagnosis of endometriosis, some of which were compounded by their age. The overlap of symptoms with those of menstruation raised issues related to stigmatisation, and made legitimation problematic. Symptoms were therefore often normalised or trivialised, causing significant delays in the diagnosis of endometriosis. Without a diagnosis, adolescents were unable to explain absences to others, or seek appropriate support, intensifying the feelings of isolation already caused by the interference of life participation. Given the importance of peer relationships during adolescence, the isolation associated with delayed diagnosis poses a risk for those in this critical period of identity development (Wren and Mercer, 2021). Furthermore, disbelief and being made to feel ‘crazy’ could further impact on the already fragile state of mental health associated with adolescence (Knapp et al., 2016). Thus, it is important to take an age-specific approach when considering experiences of treatment for endometriosis, which appear to be both affected by, and affective on, one’s life-stage.

7.4 Support Networks and Information Needs of Adolescents with Endometriosis

To meet the various challenges associated with living with endometriosis, adolescents described the need for considerable support. Mothers were a significant source of support, which confirms findings in previous research with adolescents with endometriosis (Plotkin, 2004; Staccone, 2006). They provided both practical and emotional support, and many acted as an advocate in getting their daughters the correct medical help. This supports research with AWCI, in which parents are described as allies in helping with illness management and offer emotional and practical support (Cartwright et al., 2015; Kyngäs, 2004; Taylor et al., 2008). There was more specific emphasis on the role of mothers in the current study when compared with the AWCI literature, however fathers were said to provide more practical based support (i.e. travel to appointments, financial support etc.). This may be due to the gendered nature of endometriosis, and adolescents' higher comfort in discussing menstruation with their mothers (see Study 2 findings, Section 9.8.2).

In agreement with findings from adult women, adolescents often received little peer support because others were often not understanding (Manderson et al., 2008), or were not disclosed to due to embarrassment (Gilmour et al., 2008). Research with AWCI has also evidenced peers' lack of understanding (Cartwright et al., 2015; Winger et al., 2014; Woodgate, 1998), but has indicated that disclosing illnesses to friends can be beneficial in eliciting support (McEwan et al., 2004), particularly for girls (Cartwright et al., 2015). In the current study however, disclosure to peers was not always straightforward. In the pre-diagnosis phase, disclosure sometimes did not occur due to the stigma associated with menstruation, and if it did, participants often noted their friends to normalise or dismiss their symptoms. As discussed previously, this may be partly because the symptoms of endometriosis are like those of menstruation, and therefore others fail to legitimise them. Even once diagnosis had been obtained, other's lack of awareness of endometriosis meant that few were able to understand or sympathise. As will be highlighted in Study 2 of this thesis, less than 10% of adolescent girls are aware of endometriosis (see Section 9.9), which is considerably lower than adolescents' awareness of a number of other illnesses such as asthma (88%), arthritis (84%), diabetes (81%), breast cancer (72%) and epilepsy (31%) (Austin et al., 2002). While methods of measuring awareness might differ, it does seem that girls are much less aware of endometriosis than they are of other chronic conditions which have similar prevalence rates, such as diabetes and epilepsy. Adolescents in this study did perceive others' lack of awareness of endometriosis as a barrier to accessing their support.

As illustrated in this study, issues with peer support can increase feelings of isolation for AWCI, and enhance concerns around being different to peers (McEwan et al., 2004; Winger et al., 2014; Woodgate, 1998). They therefore seek comfort in talking to those with a shared illness experience, who can understand (Cartwright et al., 2015; Coyne et al., 2018; Kirk and Hinton, 2019). In this study, participants valued supportive connections with others who had endometriosis, who were able to understand what they were going through, and could also provide information. This corroborates other findings with adolescents (Plotkin, 2004), and with adults (Shoebotham and Coulson, 2016) with endometriosis.

However, a novel and significant finding uncovered in this study is that adolescents felt they lacked support that was age appropriate. They felt the concerns of many women at support groups (both physical and online) were different to their own, owing to their different life-stage. Older women may have concerns about their fertility, jobs, families, and marriages, whereas adolescents may be more concerned about their schoolwork, friendships, and dating. Online support groups have been noted to be beneficial because they foster connections to those in a similar position (Shoebotham and Coulson, 2016), yet this research has highlighted that for adolescents with endometriosis, finding others at a similar life-stage may be difficult, particularly given the diagnostic delays, and thus they may miss out on some of those benefits. Furthermore, such environments can be somewhat daunting for adolescents, as they are faced with a glimpse of what they may have to contend with in their future.

Another significant finding was that participants felt there was no information specifically targeted at their age group, and the information provided by medical professionals was sometimes difficult to understand. This supports findings in research with AWCI, in which adolescents have reported the use of complex terminology by clinicians, (Jacobson et al., 2001; Jones et al., 2011), not being given enough information (Jacobson et al., 2000), and that information/care provision was not focussed on issues relevant to their life-stage (Grinyer, 2007; Suris et al., 2004). In the current study, participants reported that information often emphasised fertility, but little was given on the day-to-day aspects of living with endometriosis as a teenager. Lacking adequate information, many sought their own information online, something WWE have also described the need to do (Gilmour et al., 2008; Markovic et al., 2008; Roomaney and Kagee, 2016; Seear, 2009b). However, using the internet as an information source does pose issues; there is a lack of high-quality, accurate, and credible information about endometriosis available online (Hirsch et al., 2017). That which does meet such criteria is often difficult for a lay audience, and therefore possibly for teenagers, to understand (ibid).

Adolescents also described difficulty in explaining their illness to others, including how and when to tell intimate partners. Similar findings were revealed by Coyne et al. (2018) who interviewed young adults living with chronic kidney disease. Participants in the current study stated that they wished for information specifically targeted at how to tell such people. AYAs may benefit from information around managing disclosure of their endometriosis to others, particularly peers and romantic relationships, as this is an especially pertinent time for the development of such relationships.

7.5 Futures: The Threat to Life Trajectories

One of the key disruptions of endometriosis on the lives of the adolescents in this study was how they viewed their futures. Almost all talked about a ‘reconfigured future’ (Kirk and Hinton, 2019); one which was altered to incorporate potential effects of endometriosis, and thus different to what they had imagined. Previous research with both women and adolescents has described the high degree of uncertainty involved in living with endometriosis. Endometriosis cannot be definitively cured, and there is a high rate of symptom reoccurrence following surgery, therefore women/girls have described fear of continued pain and additional surgeries in their futures (Conboy et al., 2008; Denny, 2004a; 2009; Moradi et al., 2014; Plotkin, 2004). This uncertainty surrounding symptom management and future surgery was discussed by most of the participants in this study, and compounded their concerns about educational attainment, job stability, and future career prospects. Similar fears have been highlighted in research with AWCI (Cartwright et al., 2015; Suris et al., 2004; Taylor et al., 2008; Woodgate, 1998).

In addition to academic/career concerns, endometriosis threatened participants’ personal life plans. Given the impact on relationships and issues with dyspareunia, many were concerned about future relationships, and being able to find an understanding partner, as evidenced in previous research with adolescents with endometriosis (Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006). Although not experiencing dyspareunia, similar concerns were raised by adolescents with a diagnosis of chronic kidney disease, who worried about finding a partner who would be able to take on the extra ‘baggage’ of their illness (Coyne et al., 2018).

Adolescents’ major concern towards their future, however, was their fertility prospects, supporting previous findings with adolescents with endometriosis (Conboy et al., 2008; Moradi et al., 2014; Plotkin, 2004; Rush and Misajon, 2018; Staccone, 2006). Fertility concerns have also been evidenced by WWE (see e.g. Denny, 2009; Facchin et al., 2018). However, as previously demonstrated (Plotkin, 2004), the adolescents in this study really felt that these concerns were not something that others their age should have to think about, and thus were incongruent with their life-stage. Indeed, research conducted with adolescents with PCOS indicated that they were three times more concerned about their future ability to conceive than healthy adolescents (Trent et al., 2003). In the current study, these fertility concerns threatened adolescents’ life-trajectories, and prompted them to re-evaluate their futures; particularly with regards to having children earlier than planned, perhaps before establishing their career. Such altered life-trajectories have also been highlighted by AWCI, in which their illness also threatens their fertility (Coyne et al., 2018; Jones et al., 2011).

Participants received limited information about fertility from health professionals, with some being told not to worry about it yet – presumably because of their age, and some told to start trying young. Being told to start a family young may be daunting for those who are still developing their own identities (Plotkin, 2004). Alternatively, being told there is little chance of conceiving might lead to unprotected sex and unplanned pregnancies (Jones et al., 2011), which may pose additional burden on the somewhat transient nature of adolescent romantic relationships. Adolescents and young adults with endometriosis may therefore benefit from more targeted, age-relevant fertility information and support, which addresses fertility issues, contraception, and STI prevention.

Despite these numerous concerns, a small number of participants expressed a feeling of hope towards their future. This sense of hope and optimism for the future has been previously found in another study with adolescents with endometriosis (Staccone, 2006), and in research with AWCI (Kirk and Hinton, 2019; McEwan et al., 2004; Winger et al., 2014). Together, these findings offer some support to Denny's (2009) argument that younger women with endometriosis may be more hopeful because they have not experienced the same amount of false hope and relapses as some older women have. However, due to the exploratory nature of this research and the comparatively small number of participants that displayed hope, the study is limited in the extent to which conclusions about this can be drawn.

7.5.1 Summary

Participants discussed the high level of uncertainty involved in living with endometriosis. This not only threatened their biographies on a day-to-day basis, but also their imagined life-trajectories. Kirk and Hinton (2019) researched adolescents with MS, who described a 'reconfigured future', in which their future biography would now need to incorporate the potential effects of their chronic illness. This concept was also evidenced in the current study, and supports Bury's (1982) notion that chronic illness causes a re-examination of the expectations and plans for the future that an individual holds. This research contributes to our understanding of biographies and chronic illness, to explore how adolescents with endometriosis experience a 'biographical threat'. The condition threatens their lives and self-concepts as adolescents, but also their future biographies as wives/partners, professionals, and mothers. The uncertainty threatens their self-concept and identity.

7.6 Strengths and Limitations

There has been very little previous qualitative research conducted with adolescents with endometriosis. Two previous studies were conducted in the USA (Plotkin, 2004; Staccone, 2006) and the remainder in Australia (Moradi et al., 2014; Rush and Misajon, 2018), making comparisons with healthcare experience less transferable given the differences in state provided healthcare outside of the UK. To knowledge, this is the first study to explore the experience of endometriosis amongst an adolescent sample in the UK, thus allowing an understanding of their particular healthcare experience.

Moreover, while previous research has been conducted with women in the UK, samples often include a broad age range (i.e. 18-60), which means that acute age-related concerns are being concealed (Brady et al., 2017). This therefore does not allow for theoretical discussions of the specific effect of endometriosis on development trajectories in adolescence (Sawyer et al., 2007). Building on previous research with adolescents with endometriosis, this research has therefore allowed for these discussions to take place, within a UK sample.

By focusing on an adolescent sample, this research enabled an understanding of the symptoms that are important to adolescents, and how they impact them. This will be crucial knowledge to those that provide healthcare and support to them. This is the first study to explore dyspareunia in depth in a young sample, as it had been given relatively brief attention in past research with adolescents. Perhaps it was not specifically asked about in such research, or it may reflect the slightly younger age of the participants in such studies compared to this research. Indeed, while many of the adolescents in this study did experience dyspareunia, few initiated discussions about it until specifically asked, possibly reflecting an embarrassment to discuss sexual matters at this age.

There were also some limitations to this study. Firstly, although the target age range for recruitment was those aged 15 to 24 years, there were no participants aged under 18 years. Specific attempts were made to recruit younger participants, such as targeted recruitment advertising, but these were unsuccessful. This could potentially be due to the delays in obtaining a diagnosis of endometriosis, as few younger adolescents receive a diagnosis (Greene et al., 2009; Haas et al., 2012; Manderson et al., 2008). It was anticipated that recruiting a younger sample may be difficult when designing the study, and therefore the upper age limit was 24, which also aligns with contemporary definitions of adolescence (Hagell et al., 2013; Sawyer et al., 2018). All participants however experienced symptom onset prior to the age of 19, which ensured that when they discussed the time around symptom onset, they described experiences which occurred during their teenage years. As such, it is believed that the adolescent experience of endometriosis is well represented in this research, and the overlap of findings with research on those aged 15 to 19 years, for example by Plotkin (2004), provides further confirmation of this.

Participants were also exclusively White-British, despite attempts to recruit an ethnically and racially diverse sample. Therefore, the experiences of adolescents outlined in this study are not representative of those from a culturally diverse population. The lack of ethnic diversity in research addressing the experience of endometriosis is an issue raised previously (Young et al., 2015), and was further highlighted in the narrative review conducted in chapter 3 of this thesis. There has been some discrepancy over the prevalence of endometriosis amongst different ethnic and racial groups, however differences observed are likely to be due to different study designs or populations (Jacoby et al., 2010). It is also important to consider that due to racialised health inequalities, people from racially minoritized backgrounds, Black women in particular, maybe less likely to get a diagnosis (Bougie et al., 2019), which would have prevented them from being able to participate. There may be other factors which affect the participation of those from ethnic and racially minoritized communities in endometriosis research. One possibility is the typical avenues through which recruitment occurs, such as via Endometriosis UK's support groups and social media as used in this study, may not reach and engage those with endometriosis from marginalised communities. The lack of racial and ethnic diversity of participants is a limitation, and therefore, there is a critical need for further research with adolescents from ethnically/racially underrepresented communities with endometriosis.

A third limitation is the method of recruitment used, as most participants were recruited via Endometriosis UK. The use of this platform might pose limits on who has access to the study information, as not all those who have endometriosis will use such organisations. There may also be key differences in those who use online support, and who therefore took part in the research, and those who do not. For example, online support users might have increased suffering, fewer real life support networks, or increased loneliness. Furthermore, it was a finding of this study that such online platforms might not provide the right support for adolescents, and therefore, recruitment via this platform for this demographic in particular may have been limited. It could account for why fewer younger adolescents volunteered to participate. The study information was also openly shared on twitter and Facebook using '#endometriosis', but few potential participants made contact as a result of these postings.

Another potential limitation is that just over half of the interviews were conducted over the telephone, instead of face-to-face. As discussed by some researchers, there is often concern that interviews that are not face to face can negatively impact the ability to establish a rapport with participants (Holt, 2010; Novick, 2008). However, as highlighted in Section 5.8, telephone interviews were on average longer than face to face interviews, so this is unlikely to have been an issue here. Using telephone interviews allowed for the inclusion of participants from a more geographically diverse sample (Holloway and Galvin, 2017), and some participants may have felt more comfortable in talking about sensitive topics in this manner (Drabble et al., 2016).

The final limitation, but one that is important to reflect on, is that the experiences described in this research are by those adolescents/young women who have managed to obtain their diagnosis of endometriosis. As the extensive literature into the diagnostic delay suggests, many others who will already have symptoms, and perhaps be on their diagnostic journey, would not have had a diagnosis, and therefore would not have qualified for inclusion in this research. Their experiences, and the impact on their lives might differ due to having an even lengthier time of living without a diagnosis. This may be something to consider for future research, although there are obvious obstacles in drawing conclusions from those without a diagnosis.

7.7 Conclusion

To knowledge, this is the first UK based research to explore the experience of endometriosis in an adolescent sample, and highlights that this experience is significantly shaped by their age and life-stage. Endometriosis not only impacts on many of the key aspects of adolescent life, including school attendance, peer/romantic relationships, and gaining independence, but also threatens their self-concept as a teenager/young adult, and their life-trajectories. In this way, the findings support those in other research with AWCI, which use the concept of 'biographical disruption' (Bury, 1982) to assert that the experience of illness during adolescence and young adulthood poses a distinct effect, resulting from fundamentally altered life trajectories at a crucial transitional moment (see e.g. Grinyer, 2007; Kirk and Hinton, 2019). However, this research contributes to this body of knowledge on biographies and chronic illness, demonstrating the importance of contextual factors such as gender, and the nature of the condition under study. Endometriosis is a poorly understood, gendered, and stigmatised condition, which significantly affects the illness experience for adolescents. The concept of 'biographical threat' is therefore introduced, to demonstrate how the experience of endometriosis in adolescence threatens their lives now as adolescents/young adults, and their futures as mothers, intimate companions, and professionals. The implications of this research, and recommendations for future research, are discussed in Chapter 11.

Thesis Part 3: Quantitative Study

Chapter 8. Study 2: Method

8.1 Introduction

This chapter describes the methods employed within the quantitative study, including their rationale and justification. It begins with an overview of the aims of the research, followed by a description of the exact methods used.

8.2 Research Questions and Aims

This research study was guided by the overarching questions: *'What are the experiences of menstruation in UK adolescents? What symptoms do they perceive to be typical, and are they aware of endometriosis?'*. This research aimed to provide an up-to-date indication of the menstrual experiences of a UK based adolescent sample, and to provide insight into their perceptions of the typicality of menstrual symptoms. Their attitudes around menstruation, and their comfort at discussing it with other people were also explored, to identify any evidence of stigma or taboo surrounding menstruation. Finally, it was hoped that by providing a snapshot of the level of awareness of endometriosis in a UK setting, it would enable comparisons to international studies and would indicate areas for improving MHE. The following more in depth research questions were addressed:

1. What are the typical menstrual characteristics of a large sample of adolescents in the UK?
2. Do they seek help for their periods, and what is the outcome of help seeking?
3. What characteristics of menstruation do adolescents perceive to be 'typical'?
4. What are adolescents' attitudes towards menstruation, and who do they prefer to communicate about menstruation with?
5. Are adolescents aware of endometriosis? Is their awareness associated with their own menstrual experience, their demographic characteristics, and their attitudes towards menstruation?
6. Do adolescent girls want to learn more about endometriosis? Is this associated with their attitudes towards menstruation, own menstrual experience, or demographic characteristics?

As outlined in Chapter 4, the research questions for this study were best addressed using a quantitative method.

8.3 Quantitative Approach: Surveys

The aim of this research study was to determine the menstrual experience and the awareness of endometriosis amongst adolescent girls in the UK, which required a quantitative approach, to produce numeric data. Data on this topic could not be collected via secondary data analysis, as there were no existing sources of data which held such information. Therefore, the data needed to be collected directly from a sample of the population of interest; adolescents in the UK. An appropriate approach to obtaining such data is a survey, as it can provide a snapshot of the phenomena of interest (Kelley et al., 2003).

A descriptive cross-sectional survey design was appropriate for this study, which aimed to gather data on the menstrual experience and awareness of endometriosis from adolescents at one time point, rather than over several time points (i.e. longitudinal studies: Bowling, 2014). Descriptive research is often used to estimate a certain phenomenon within a population (i.e. the prevalence), and can also describe factors associated with it (i.e. demographic characteristics, health behaviours, attitudes etc.: Kelley et al., 2003).

Survey research methods have many advantages. They allow for the inclusion of a large number of participants, which increases the likelihood of obtaining a representative sample upon which generalisations can be made (Bruce et al., 2008; Kelley et al., 2003). Having a large sample also allows for comparisons to be made across the data set, between groups, such as those which differ on characteristics like age or ethnicity. Survey methods also enable the collection of a large amount of data in a short space of time, which can be both time and cost effective (Kelley et al., 2003). This is particularly valuable when used for a PhD thesis, which has strict time and budget constraints. From a feminist standpoint, the use of a survey allows for a large number of repressed female voices to be heard (Miner-Rubino and Jayaratne, 2007). Finally, surveys are familiar to most people, they are likely to have completed a questionnaire of some sort in their lives, and so the method is easy understood.

There are also some disadvantages of a survey design. Surveys on their own do not allow for the inference of cause and effect relationships (Bowling, 2014). However, this kind of evidence was not required in the current study, which aimed to identify descriptive data, such as percentages, and variables of association. In addition, cross-sectional surveys can only capture ‘fleeting’ data, which only allows conclusions to be drawn at that period of time (Leedy and Ormrod, 2010). However, the use of a survey in the current research was only intended to produce a snapshot of phenomena of interest, to identify the need for further education, and so this posed no restrictions.

The survey approach can employ several different methods of data collection, including interviews, and self-completion questionnaires (Kelley et al., 2003). Interview methods are often used in qualitative research, as they allow for the use of open-ended questions to explore the phenomena of interest. However, they are sometimes used in quantitative research, with a more structured interview using closed-ended questions. When using interviews for survey completion it allows researchers to build rapport with participants and seek clarity over ambiguous answers. However, they are time consuming, and may be impractical when a large sample size is important (Leedy and Ormrod, 2010). In addition, as compared to self-completion questionnaires, using interviews for survey completion is associated with increased social desirability bias, and lower levels of disclosure of sensitive information (Bowling, 2005). Therefore, a self-completion questionnaire was appropriate for this research, which aimed to collect data about a sensitive topic, from a large sample.

8.4 Sample and Research Setting

The population of interest for this research was adolescent girls aged 15 to 19 years old. A discussion around the definitions of the age range for adolescence was provided in the methods chapter of the qualitative study (see section 5.4), with definitions typically ranging from 10-19 years, or up to 24 years in some instances. In the qualitative study, the upper age limit of the sample was 24, to enable those who began to experience endometriosis symptoms during adolescence to have obtained their diagnosis. However, as this was not needed in this study, the upper age limit of 19 years was chosen. For the data to be comparable in the two studies, the lower age limit of 15 was also chosen in this study.

The minimum sample size required for this research was 400 participants. When the population of interest is large, such as the case here, then Gay et al. (2012) suggest striving for a sample size of at least 400 participants. By using a large sample size such as this, it increases the chances of obtaining a representative sample of the population of interest (Kelley et al., 2003). A sample this size would also ensure that the number of participants surpassed the ‘rule of thumb’ of 10 participants per variable (or events per variable), which is needed to run logistic regression analysis (Peduzzi et al., 1995).

To obtain access to a large sample of adolescent girls, schools were chosen as the research setting. Consideration was given to using the internet to access this population; up to 98% of adolescents have access to the internet (Office for National Statistics, 2018), and previous research on menstrual experience (Armour et al., 2020a; Armour et al., 2021a) and endometriosis awareness (Shadbolt et al., 2013) in adolescents has used the internet for recruitment. However, by accessing potential participants through the internet it is not possible to verify that their characteristics meet the study inclusion criteria, i.e. age, gender, UK resident, etc. (Kramer et al., 2014). When these criteria are pertinent to the research, such as in this case, then recruiting in this way might impact the validity of the research (British Psychological Society, 2017). McKellar and Toth (2016) therefore advise the use of a more controlled medium, such as a school. A similar approach was taken in another study on adolescent menstrual experience (Parker et al., 2010).

In addition to being able to verify participant inclusion criteria, it was envisaged that recruiting in schools would enable access to a representative sample. In England, it is a requirement to stay in full time education until age 16, and to remain in some form of education or training until age 18 (Department for Education, 2015). It was hoped that this setting would therefore provide a large and diverse pool of potential participants from which to recruit.

The final factor in the decision to use schools as a recruitment setting was because they were identified as a key stakeholder group for this research area. It was anticipated that education providers would be interested in the research findings, which offer insight into adolescents' educational needs around endometriosis and menstruation. Given the significant impact of both on adolescent school life and education (Armour et al., 2020a; Plotkin, 2004), it would be in the interests of education providers to be aware of the research results. By recruiting participants directly from schools, it would increase the validity of the research findings to stakeholder groups including schools and other education providers, and they maybe more likely to take note.

8.5 Recruitment

8.5.1 School Recruitment

Secondary schools within Birmingham and the West Midlands area were the target recruitment sites. Potential schools were identified on the local city council website, and on Google and Google Maps. Information about each of the schools was gleaned from school websites, to identify those which were eligible as potential recruitment sites. To be eligible, schools needed to have students in the target age range and be a girls' school or a mixed school. School websites were also used to identify an appropriate contact person within each school, and their contact details. Contact persons included the head teacher (or principle), the head of pastoral care, designated safe-guarding leads, and heads of years. In addition to using the internet to identify potential schools, the researcher and PhD supervisors appealed to their own professional and personal networks for contacts within schools.

Each potential school was contacted between May 2017 and February 2018. Forty schools were contacted, including 7 identified via researcher/supervisor networks. Schools were contacted via email, using a standard email and further information attachment (See Appendix 14). There was a poor response to these emails, and they were therefore re-sent after at least a month, and/or another contact person at the school was emailed. Schools were contacted up to 3 times each, and eight schools in total responded, six of which were identified via researcher/supervisor networks. Of these eight schools, seven agreed to hear more about the research, and one declined to participate.

A face-to-face or telephone meeting was arranged with the contact person at each of the seven schools, to provide further study information, and to obtain details about the number of eligible students at the school. Following these meetings, six schools agreed to participate in the research, providing their written consent as a recruitment site. After discussions with the final school, it was mutually agreed that they would have very few students eligible to participate, and it was therefore not pursued.

Each of the six schools were contacted to arrange a date for survey completion. At this stage, 2 schools became unresponsive to all communication attempts. The final four schools provided a date for survey completion, and supplies were delivered to them accordingly. One school became unresponsive at this point. The final number of schools therefore included in this study was three. This included one independent mixed boarding school, one independent girl's school, and one government run mixed academy school. This therefore represented a diverse range of recruitment sites.

8.5.2 Participant Recruitment

Once the schools had agreed to participate, a date for survey completion was planned at each school. At least a week prior to survey completion, all female school students within the target age range were brought together to be given information about the research, either by the researcher or by a teacher. These information sessions were conducted 'en-masse' at two schools, and during tutor group sessions at one school. During these sessions, potential participants were given verbal and written information about the research, and the parent/guardian information sheet if they were under age 16 (see Appendices 15-17). On the day of survey completion, those who had decided to participate (and where necessary, had obtained their parents' consent) attended a designated session. They were given the opportunity to ask questions, and if still happy to participate, they provided their consent, and then completed the survey. See further information below about the consent process (Section 8.7.2).

8.6 Measures: Survey

Following the literature review, and in conjunction with the supervisory team, a self-completion survey was designed specifically for this study. During construction, potential survey items were thoroughly scrutinised according to why they were being asked, and how they would help to answer the research questions, to ensure that all survey items were essential to the research problem (Leedy and Ormrod, 2010). The survey consisted of questions which were either newly developed or were existing questions which had been used in similar research. By using the questions of other researchers, it allowed for those questions to have already been pilot tested in a previous similar sample, and enabled comparisons to be drawn with such other research (Bryman, 2016). In addition to pilot testing the survey (described below in section 8.6.1), the survey was shown to school teachers to assess the content and comprehensiveness of the survey, and thus ensuring its validity (Bowling, 2014).

The final survey used in this research can be found in Appendix 19. There were several question types in the survey, including single and multiple response questions, rating scales, and a few free-text questions. The free-text questions were used for 'other' answer options throughout the survey, and when respondents were asked to describe what they thought endometriosis was. The use of free-text questions allowed respondents to answer in their own words, rather than those imposed upon them, and allowed for the generation of unanticipated or unusual responses (Bryman, 2016). The survey consisted of four sections; 'about you'; 'about your usual periods'; 'attitudes about periods'; and 'about endometriosis'.

The first section, 'about you', gathered demographic characteristics of the sample, including their age, ethnicity, religion, and school type. These were collected to allow for the investigation of any differences between participants based on such variables. Ethnicity is a complex, and debated term; it incorporates aspects of one's ancestry, culture, history, and homeland (Baumann, 2004). In surveys, it is common to ask for one's self-defined ethnicity (Burton et al., 2010), which was the initial approach taken in this survey (using a free text response), however, after data collection in the first school, it became apparent that many participants were unable to understand this complex term, and therefore some example options were given (e.g. White, Black, Asian, Mixed, etc.).

Section 2, 'about your usual periods' included questions about respondents' age at menarche, cycle patterns, and menstrual experiences. These questions were asked to identify the typical menstrual pattern in this sample, and to measure any associations between menstrual experience and knowledge of endometriosis. Some of the questions in this section were a modified version of those used by Parker (2006), who explored menstrual patterns and menstrual disturbance in teenagers (see also Parker et al., 2010). Such questions included the length of menstrual cycle, rating of period pain, using medication for periods, and missing school for periods. In addition to these questions, this section of the survey also asked about contraceptive pill use, seeking medical help for periods, and perceived typicality of periods. Contraceptive pill use and school absenteeism were used in a survey of teenagers by Zannoni et al. (2014), due to their associations with a subsequent diagnosis of endometriosis in adulthood (Chapron et al., 2011b). Questions about seeking help for periods were included, firstly to identify the number of teenagers who had sought help (to make comparisons to other research, i.e. Parker et al., 2010) and secondly to obtain information on their reported outcome of help seeking. Finally, questions about the typicality of periods were asked to gain insight into what aspects of menstruation adolescents perceived to be typical. In this survey, the word 'typical' was used instead of 'normal' (as has been used elsewhere). This was simply to avoid inciting concern among participants because of the connotations of the word normal (that it implies anything else is abnormal: Ji, 2017).

In section 3, 'attitudes about periods', respondents were asked about their attitudes towards menstruation and communicating with others about menstruation. To obtain information about their attitudes, a number of items were taken from the Menstrual Attitudes Questionnaire (MAQ; Brooks-Gunn and Ruble, 1980) and it's Adolescent version (A-MAQ). These questionnaires each comprise of a number of items to measure attitudes towards menstruation based on five common factors of menstruation as; bothersome, debilitating, natural, predictable, or denial of any effect of menstruation. The A-MAQ has an additional factor; embarrassment. As attitudes were not the primary aim of this research, and to prevent the survey from being too long, then neither the MAQ nor the A-MAQ were used in their entirety, and instead, several items were chosen from these scales to obtain an indication of participants' attitudes towards menstruation. In addition to items from these scales, respondents were asked about their overall attitude towards periods, choosing between 'positive', 'negative' and 'don't mind'. It was anticipated that those with more negative attitudes may not wish to learn about endometriosis. In the final part of this section, participants indicated their comfort level in discussing menstruation with friends and family members, and were asked about past and future sources of information about menstruation.

Finally, section 4 addressed respondents' awareness of endometriosis, and preferences for learning about it in future. The opening question was 'do you know what endometriosis is?' and participants who answered 'yes' were asked to describe endometriosis in their own words. This was believed to be an effective way of assessing their awareness. Previous research has asked 'have you heard of endometriosis?' (i.e. Armour et al., 2021a; Zannoni et al., 2014), however, it was assumed for the current study that having heard of something was not necessarily synonymous with knowing what it is. By giving a description in their own words, this research allowed for an evaluation of respondents' levels of awareness and understanding (Bryman, 2016), and to identify what aspects of endometriosis were most salient to them. A similar method of assessing understanding was used by Shadbolt et al. (2013).

To ascertain respondents' preferences for learning more about endometriosis, a short description of endometriosis was provided to them. This was purposely put on a separate page to the question asking if they know what endometriosis is, in the hope that they would not see this description when answering that earlier question (see 5th and 6th pages of the survey, Appendix 19). This description needed to be written in simple terms, and not be complicated by medical jargon, and therefore a modified version of that given by Endometriosis UK (2014), in an information leaflet aimed at teenagers, was used. To ensure it met these criteria, the description was shown to schoolteachers and teenagers during survey construction. Following this description of endometriosis in the survey, respondents were asked their preferences for learning more about endometriosis, including how they would like to learn about it, who they would be comfortable talking to about it, and whether they also thought boys should learn about it. These questions were similar to those used by Shadbolt et al. (2013).

The survey was designed as a pen and paper survey, to be completed at school during school hours. Consideration was given to administering the survey through an online survey platform, which has many advantages including a quicker completion time, less missing data, and significant time saved on data entry. However, there is a lack of control over the settings in which online surveys are completed (McKellar and Toth, 2016). Control was important in this study, as one of the key aims was to identify participants' knowledge about endometriosis, and if the survey was completed online, there would be nothing stopping respondents from opening an additional webpage to search for information, thus affecting the outcome. An additional benefit of this pen and paper format is that staff/researchers could ensure participants did not talk between themselves while completing the survey, and therefore the opinions provided were more likely to be their own. A pen and paper survey was also used in similar past research (Parker et al., 2010).

8.6.1 Piloting the Survey

The survey was piloted with adolescent girls from the target population, to assess the format, clarity of wording, and ease of implementation. Hertzog (2008) suggests that when the objectives of the pilot study are such, then a sample size of 10 participants will suffice. The survey was therefore piloted with 10 teenage girls, who adequately represented the age range of the target population (15-19). These participants were recruited using a snowballing method, through friends, colleagues, and other acquaintances, who were asked if they knew someone in the target age range who could complete the survey (with parental consent if under 16). Three of the pilot sample were teenagers with endometriosis who took part in the qualitative study. These participants were additionally able to assess the information about endometriosis provided in the survey, and ensure the relevance of the survey’s content, thus aligning with the feminist lens.

The participants in the pilot study completed the questionnaire individually and were given the standardised instructions prior to completing the survey. The length of time it took them to complete the survey was measured, and once they had finished, they were asked for feedback on the design, wording, and contents of the survey. All participants agreed that the contents and the wording of the study were age appropriate. The layout of the survey was also described as easy to follow. Participants indicated that there were only minor issues with the survey, such as the omission of instructions for how to answer some of the multiple answer questions, such as *‘please tick any that apply’*, or *‘please tick only one answer’*. They agreed that the information sheets provided were also clear and easy to understand. As there were no major changes to the survey following the pilot (other than to clarify some instructions), the data collected by the pilot sample was included in the final analysis, however the surveys completed by the three teenagers with endometriosis were excluded (as a key research aim was measuring awareness of endometriosis).

8.7 Ethical Considerations

The importance of following standards of ethical conduct was outlined previously in Section 5.7. The principles outlined in the BPS ‘Code of Human Research Ethics’ (2014) were adhered to in this research study by the following methods:

5) ***Respect for the autonomy, privacy and dignity of individuals and communities.*** This was achieved by ensuring participants made their own fully informed decision to participate in the research, and in doing so were provided with adequate information about the research and their rights as a participant such as confidentiality, consent, and withdrawal.

6) ***Scientific integrity.*** This was ensured through the process of obtaining ethical approval, in which the design and rationale for the research were independently scrutinised and confirmed.

7) ***Social responsibility.*** Key stakeholders (Endometriosis UK and schoolteachers) were contacted for guidance in the research/survey design and for permission of access (school

staff), which ensured this research created knowledge that was beneficial to society, and that social structures would be respected through the conduct of the research.

8) ***Maximising benefit and minimising harm.*** While generating such knowledge that would be of benefit, it was of upmost importance to safeguard the well-being of research participants.

Further details about how the ethical principles of the BPS code of ethics were considered and actioned in this research are subsequently outlined. As indicated by the guidelines, ethical principles were considered from the initiation of the study, through to the writing up of study findings.

8.7.1 Obtaining Ethical Approval to Conduct the Research

Prior to commencing any research activities, approval was sought, and granted by the University Ethics committee (FAEC) at Birmingham City University (see Appendix 20).

8.7.2 Consent, Confidentiality, and Withdrawal

Participants were aged 15-19 years old at the time of participation. Those who aged 16 or over were able to give their own permission to consent to research. Those under 16 also provided their own consent, however they needed additional consent from a parent or guardian before they could participate. Consent was obtained from parents/guardians using either an active (opt-in) or passive (opt-out) measure of consent, the decision of which was determined by each individual school. The use of active consent required parents/guardians to complete and return the parental consent form before the survey completion day to enable their child's participation. If passive consent was used, then parents/guardians who did *not* wish their child to take part in the research were advised to return an opt-out form on/before survey completion day. Passive parental consent has been previously used elsewhere in research with adolescents in a school setting in the UK (Kyle et al., 2012; Spence et al., 2015) and with adolescent girls completing questionnaires about menstruation (Parker et al., 2010).

Potential participants (and parents/guardians if under 16) were provided with an information sheet prior to planned survey completion day, which explained the research in full, and their right to withdraw (see appendices 15-17). It was important that the information distributed to both students and their parents used accessible language, with no complicated medical jargon, and that it clearly explained the research procedure and their rights as participants (Drews et al., 2009). Parents of those under 16 were given the date by which their opt-in, or opt-out, consent forms needed to be returned. Prior to taking consent from the adolescents, the researcher or school staff read through the information sheet with them, and gave them the opportunity to ask questions. Participants then completed a consent form, which listed several statements to which they had to tick to confirm they had read, such as their right to withdraw and their confidentiality rights. They also had to sign and date the consent form (see Appendix 18).

Two schools chose to use opt-out (passive) parental consent to obtain parents/guardians permission for under 16s to be involved in the research. One school decided that they wished to obtain opt-in (active) parental consent from the parents of *all* participants, regardless of their age (as it was their usual school policy to do so). In this instance, the procedure outlined above, regarding obtaining parental consent for those aged under 16, was employed for those aged over 16 as well.

To maintain participant confidentiality, participants were given an ID number upon completion of the survey, and their data was stored according to that number. Therefore, neither their name nor any other identifiable information was associated with any of their research data. Furthermore, no identifiable information is reported in the results. Data was stored in accordance with the Data Protection Act 1998, where by physical data was encrypted and stored in a locked cabinet at Birmingham City University, and electronic data was stored under password protection on a secure server.

8.7.3 Protecting the Well-being of Research Participants

This research involved only the completion of a short survey, therefore there was very low risk of it causing any upset to participants' well-being. The survey explored participants' understanding of endometriosis, and other matters of menstrual health, which may have caused participants to become more inquisitive about such matters. Therefore, all participants were provided with a further information sheet on completion of the survey, which included more information about the topics covered in the questionnaire, and indicated the organisations to contact should they wish to seek further information or advice (see Appendix 21).

8.7.4 Respecting the Potential Power Imbalance Between Researcher and Participants

There may have been the potential for a power imbalance to occur between the researcher and the participants, due to factors such as age and status. Power relations were considered at each stage of the research process, and attempts were made to minimise this imbalance, such as involving those from the sample population in questionnaire development (i.e. in the pilot phase), and by ensuring all participants were aware that they did not have to answer any questions which made them feel uncomfortable.

8.7.5 Obtaining Necessary Permissions

Access to the study population required permission to be granted from gatekeepers, which were usually the school head teachers or year leaders. Further details of how this access was achieved is provided in section 8.5 ‘Recruitment’ above.

8.8 Data Collection

Survey completion took place between November 2017 and March 2018. Prior to each school’s planned survey completion date, they were provided with the materials necessary to conduct the study. These included participant information sheets, parent information sheets/consent forms, participant consent forms, surveys, and further information/support sheets. As described in section 8.5.2, participants (and their parent/guardian if required) were given the study information at least a week prior to the planned survey completion day.

There were slight differences in the survey completion settings and patterns for each of the schools, due to individual school constraints. At the first school, one survey completion session was arranged at a given date/time, and participants completed the surveys in one sitting, ‘en-masse’. At the second school, participants attended one of several survey completion sessions, which were held during form time over the course of a week. At the final school, participants completed the survey during their tutor group sessions. These slight variations were considered reasonable within the design of the study, and they ensured that school participation was retained.

When they attended their survey completion session, participants were provided with a consent form and a survey to complete. They were asked to read the consent form carefully before ticking all boxes and signing at the bottom. They were all given the same verbal instructions (see Appendix 22), such as working through the survey in order and not conferring with friends. It was also reiterated at this point that the survey was confidential. Participants then completed the survey, and once finished, surveys were collected and the further information/support sheets were distributed.

8.9 Data Analysis

This section details the steps that were taken to prepare the raw data for analysis, including data cleaning and coding, and then describes the methods of analysis that were conducted with the data.

8.9.1 Data Preparation and Cleaning

The raw data in this study comprised of a large number (n=442) of completed paper surveys. The first stage in the data preparation was to mark each paper survey with a unique ID number. Each participants' data would be stored according to that ID number, and subsequently, the data entered into the electronic database could be compared to the raw source if any queries arose. Prior to inputting the data into an electronic database, a code book was constructed to define the rules for translating the responses into numerical codes, ready for analysis. As a rule, the codes '0' and '1' were assigned to 'no' and 'yes' respectively for no/yes answer questions. When there were more answer options available, such as for religion, all potential answers were numbered, i.e. 1 for Christian, 2 for Buddhist, 3 for Hindu and so on. For missing data, a code of 999 was used, and when an answer was not applicable (i.e. respondents answered no to the question before and were told to skip a question) the code of 888 was used. Once the code book had been constructed, data was inputted onto an electronic database, hosted by Microsoft Excel.

At this point, codes had not been constructed for the free-text items on the survey, including numerous 'other' options and the question relating to their knowledge of endometriosis. Respondents' answers for each of these questions were initially written out in full into excel, and once data entry was complete, the answers to these questions were transferred into NVivo, to be coded. As described by Bryman (2016), a method similar to content analysis was used to code this data. The answers were read and re-read to enable familiarisation, and then they were grouped to obtain themes or categories. Each category was then given a number, and these numbers were entered into the spreadsheet in place of the words.

Data entry for the entire sample was performed by the candidate. Once complete, the data was checked for data entry errors and anomalies, through a process of data cleaning. The 'sort and filter' function of Excel allowed for the identification of data that appeared erroneous, and when such was found, it was compared with the original paper survey and corrected if necessary. For example, when answering the question about their experience of period pain, the response options were 'no' (coded 0), 'yes, with every period' (coded 1) and 'yes, with some periods (coded 2), as well as missing data (999) and not applicable (888). If any response other than 0, 1, 2, 888 or 999 was found, it was apparent there was an error. This check was performed for each item on the survey. Once data cleaning was complete, the data from the Excel file was uploaded onto SPSS to begin data analysis.

8.9.2 Data Analysis

Data was analysed using SPSS Version 24. The medians and ranges were calculated for continuous variables, and the frequencies and percentages were obtained for categorical variables. To analyse the data further using inferential statistics, tests for normality (calculating the *z*-scores of the skewness and kurtosis, and visual inspection of Q-Q plots and histograms) were performed on the continuous variables (i.e. current age, age of menarche); all were found to be not normally distributed. Therefore, subsequent analysis of data used either the Mann-Whitney U test or the Kruskal-Wallis test for continuous data, and Chi-squared tests for the categorical data. For the latter, if expected cell counts were less than 5 for more than 20% of the cells, then a Fisher's exact test was used for 2x2 tables (Field, 2018), and a likelihood ratio chi-squared test for larger tables (McHugh, 2013). A *p* value of <0.05 was considered to be significant (Fisher, 1925). Inferential statistics were conducted when they were required to answer the research questions. Table 8.1 provides further information on the analyses performed for this study.

Table 8.1: Key Data Analyses for Research Questions

Research Question	Variable Type and Analyses	Variables
1. What are the typical menstrual characteristics of a large sample of adolescents in the UK?	Continuous variables: Medians and Ranges	Age of first period, Duration of menstrual bleeding, Duration of menstrual cycle
	Categorical variables: Frequencies and percentages	Regularity of menstrual cycle, Experience of period pain, Severity of period pain, Medication use for period pain, Effectiveness of medication, Missing school due to periods, Contraceptive pill use
Further analysis of period pain severity and associations with menstrual related behaviours (to compare to previous research)	Categorical IVs: Chi-squared test	DV: Period Pain Severity (mild/moderate/severe) IVs: Medication use for period pain, Missing school due to periods, Ever seen doctor about periods, Contraceptive pill use
2. Do they seek help for their periods, and what is the outcome of help seeking?	Categorical variables: Frequencies and percentages	Ever seen doctor about periods, Outcome of doctor's visit, Feeling reassured following visit
3. What characteristics of menstruation do adolescents perceive to be 'typical'? All menstrual characteristics, and menstrual related behaviours, were used in these analyses, providing they did not have large amounts of "not applicable" data (i.e. length of menstrual cycle, for which many participants ticked 'don't know').	Continuous IVs: Kruskal-Wallis test (as perceived typicality has 3 levels)	DV: Typicality of periods (Typical, unsure, not typical) IVs: Age of first period, Duration of menstrual bleeding, Severity of period pain, Effectiveness of medication
	Categorical IVs: Chi-squared test or Fisher's exact test	DV: Typicality of periods (Typical, unsure, not typical) IVs: Regularity of menstrual cycle, Experience of period pain, Medication use for period pain, Missing school due to periods, Contraceptive pill use, Ever seen doctor about periods
	Multinomial logistic regression[a]	Items in the above two analysis rows that were significant[a]
4. What are adolescents' attitudes towards menstruation, and who do they prefer to communicate about menstruation with?	Categorical variables: Frequencies and percentages	AMAQ/MAQ Items, Overall attitude towards periods, Communication about periods items, Learning about periods items
5. Are adolescents aware of endometriosis?	Categorical variable: Frequencies and percentages	Knowledge of endometriosis (yes/no)
Is their awareness associated with their own menstrual experience, their demographic characteristics, and their attitudes towards menstruation?	Continuous IVs: Mann-Whitney U test	DV: Knowledge of endometriosis (yes/no) IVs: Age, Age of first period, Severity of period pain, AMAQ/MAQ Items
	Categorical IVs: Chi-squared test or Fisher's exact test	DV: Knowledge of endometriosis (yes/no) IVs: Ethnicity, School Type, Regularity of menstrual cycle, Experience of period pain, Medication use for period pain, Missing school due to periods, Contraceptive pill use, Ever seen doctor about periods, Perception of periods as typical, Overall attitude about periods
6. Do adolescent girls want to learn more about endometriosis? Is their awareness associated with their attitudes towards menstruation, own menstrual experience, or demographic characteristics?	Categorical variable: Frequencies and percentages	Wanting to learn more about endometriosis (yes/no)
	Continuous IVs: Mann-Whitney U test	DV: Wanting to learn more about endometriosis (yes/no) IVs: Age, Age of first period, Severity of period pain, AMAQ/MAQ Items
	Categorical IVs: Chi-squared test or Fisher's exact test	DV: Wanting to learn more about endometriosis (yes/no) IVs: Ethnicity, School Type, Regularity of menstrual cycle, Experience of period pain, Medication use for period pain, Missing school due to periods, Contraceptive pill use, Ever seen doctor about periods, Perception of periods as typical, Overall attitude about periods

[a] The theoretical basis for using logistic regression models includes measuring associations, predicting outcomes, and/or controlling for the effects of confounding variables (Stoltzfus, 2011). Each was important in this study, however, it was largely used to control for confounding variable effects, hence why all significant associations from the above analyses were entered in.

DV = Dependent Variable, IV = Independent Variable

8.9.2.1 Missing Data

Thorough data cleaning, and the assigning of codes for missing data (i.e. 888 & 999) ensured that there was no “system missing” missing data to be handled in the analyses. Missing data analysis was performed on the key variables (i.e. those to be used in inferential statistics) to decide on how such data would be handled. This analysis can be viewed in Appendix 23, and shows that on the whole, missing data was very low (generally <5%). Items that were not applicable to some respondents showed a higher amount of missing data (i.e. severity of period pain = 7.5%, and effectiveness of medication = 39.8%). The item ‘length of cycle’ showed the highest amount of missing data (60%), as many ticked ‘don’t know’ or ‘irregular’. This item was therefore not used in any inferential statistics.

As explained above, SPSS was used for the data analysis, which removes missing cases listwise by default (removes from the analysis the entire case if it contains missing data for a variable of interest). In the current study, this approach was adopted, rather than an alternative such as imputation methods, because the amount of data missing was negligible (usually 0.2 - 5%), or because those answers were left blank because they were not applicable, and so to give a mean/median/mode response would be incorrect (Mirzaei et al., 2022).

Chapter 9. Study 2: Results

9.1 Introduction

This chapter details the findings of Study 2, which aimed to explore the experiences of menstruation in an adolescent sample, the menstrual symptoms they perceive to be ‘typical’, and their awareness of the symptoms and definition of endometriosis. The chapter begins with an outline of the response rate and characteristics of the survey sample. Following this, the chapter will aim to address the study research questions, as outlined in Section 8.2.

9.2 Response Rate

Table 9.1 shows the participant response rate at each school. The overall response rate was an estimated 53.0%. Schools B and C used opt-out parental consent, and both received very few non-consent forms from parents. Despite collecting data at multiple time points, schools reported that some of the data collection coincided with exams and other school events, which was likely to explain why some eligible students were not able to participate. School staff at both locations were unable to provide exact figures for how many students *chose* not to participate, hence why the overall response rate is estimated. At school A, all those who took part had obtained parental consent. Reasons for non-consent from parents were not obtained, and therefore it is unclear whether it was the parent’s choice for their daughter not to participate, or if the student chose not to participate, and therefore did not obtain parental consent.

Table 9.1: Response Rate Within Schools

School	Number of Eligible Students	Parental consent type	Number of parents not giving consent	Final Sample size (n)	Response rate (%)
A	104	Opt-in all ages	75	29	27.9
B	450[a]	Opt-out under 16s	3	215	47.8
C	272	Opt-out under 16s	1	194	71.3

[a]Approximate number

9.3 Participant Characteristics

The sample consisted of 442 girls aged 15 to 19 years, with a median age of 17.00 years. The full demographic information of the sample is shown in Table 9.2. Almost half of the participants were Asian (49.1%), just over a third were White (35.8%), and a minority were Black and Mixed-Race (15.1% total). Compared to census data for England (Office for National Statistics, 2011), this sample is over-representative of those of Asian ethnicity (census = 7.8%) and under-representative of those of White ethnicity (census = 85.4%). However, in Birmingham, where the majority of the data was collected, it is more ethnically diverse than in England as a whole (i.e. Asian ethnicity = 26.6%, White ethnicity = 57.9%) (Office for National Statistics, 2011). Furthermore, the ethnic diversity in this sample is likely to have been influenced by the location of one of the schools, which recruited almost half of the sample, as it is in an area of Birmingham in which 60.1% of inhabitants are of Asian ethnicity and 11.6% are of White ethnicity (Office for National Statistics, 2011), which was reflected in the data from that school. The other two schools were independent schools (one of which was a boarding school), and therefore they may have been less likely to be affected by the demographics of the immediate area.

Table 9.2: Demographic Characteristics of the Sample

		Sample
Age (in years):	Median	17.00
	Range	15.00 – 19.33
Ethnicity n (%):		
	White	154 (35.8)
	Black	46 (10.7)
	Asian	211 (49.1)
	Mixed Race	19 (4.4)
Religion n (%):		
	Christian	130 (29.4)
	Buddhist	9 (2.0)
	Hindu	18 (4.1)
	Jewish	2 (0.5)
	Muslim	102 (23.1)
	Sikh	40 (9.0)
	None/Atheist/Agnostic	112 (25.3)
	Mixed/Other	7 (1.6)
School Type n (%)		
	Independent Girls	29 (6.6)
	Independent Mixed Boarding	194 (43.9)
	State Academy Mixed	215 (48.6)
	N/A (pilot participants)	6 (0.9)

9.4 Participants' Menstrual Experiences

9.4.1 Menarche and Menstrual Bleeding Patterns

At the time of survey completion, all but 2 participants had started their periods (440/442, 99.5%). As shown in Table 9.3, the median age of menarche for the sample was 12.50 years (12 years, 6 months), and ranged from 6.00 to 16.42 years. While age 6 to 8 years may be deemed young for menarche, these responses were not considered to be mistakes/anomalies, as there is some evidence that menarche can occur this early, and they may represent those with precocious puberty (Cesario and Hughes, 2007).

Table 9.3: Menstrual Bleeding Patterns

	Median/number	Range/Percentage
Age at first period (years) *(n=433)*	12.50	6.00 – 16.42
Duration of menstrual bleeding (days)		
All responses *(n=438)*	5.00	0 – 31
Responses between 2 and 10 days *(n=429)*	5.00	2 - 10
Duration of menstrual cycle (days)		
All responses *(n=214)*	28.00	0 - 45
Responses between 14 and 45 days *(n=177)*	28.00	14 - 45
Regularity of menstrual cycle: *(n=409)*		
Irregular periods	128	31.3%
Don't know	121	29.6%
Regular periods	160	39.1%

As outlined in Section 2.4.1, the average age of menarche has been shown to differ between ethnicities. To establish whether these differences existed within this sample, a Kruskal-Wallis Test was conducted. This test indicated that age of first period was significantly different between different ethnic groups, $H(3) = 17.544$, $p = 0.001$. Subsequent pairwise comparisons, using a Bonferonni correction with adjusted p-values, showed that the median menarcheal age for participants who were Black (median=12.00) was significantly lower compared to White participants (median=13.00) ($p = 0.001$, $r = 0.26$). In addition, participants who were White had a significantly higher age of menarche (median=13.00) compared to those who were Asian (median=12.17) ($p = 0.014$, $r = 0.16$). There were no other statistically significant differences between the menarcheal age of any other combinations of ethnicities.

Participants were asked the usual length of their periods (menstrual bleeding) over the 3 months prior to survey completion (see Table 9.3). Answers ranged from 0 to 31 days, however 98.0% of responders (429/438) reported their menstrual bleeding to last between 2 and 10 days. Of these, 94.6% reported menstrual bleeding duration of 2 to 7 days, and the median length of bleeding was 5.00 days. A small number of participants indicated their menstrual bleeding lasted 0 days, some of whom were using the contraceptive pill.

The respondents were asked the usual duration of their menstrual cycle. They could indicate the number of days and/or tick 'irregular' or 'don't know'. Just under half of the participants that had reached menarche (48.6%, 214/440) recorded a response for the number of days of their cycle, which ranged from 0 to 45 days. Of these, 17.3% (37/214) reported a cycle length of 2 to 7 days, which was likely to be an error, whereby they reported the length of menstrual bleeding. When excluding those responses, the reported length of the menstrual cycle ranged from 14 to 45 days, with a median length of 28.00 days, and 98.3% of responses fell between 21-45 days[3]. Irregular menstrual cycles were reported by 31.3% (128/409) of responders, and 29.6% (121/409) indicated that they did not know the length of their cycle. Those who provided an answer in the space for 'number of days', who did not tick 'don't know' or 'irregular' were assumed to have regular menstrual cycles (39.1%).

As outlined in section 2.6.3, irregular cycles are quite common when periods first begin, and they tend to settle down with time. To assess if this pattern occurred in this sample, a Kruskal-Wallis Test was conducted to compare regularity of cycles with the length of time since menarche. This test indicated that the number of years since menarche was significantly different between those reporting regular, irregular, or unknown menstrual cycles, $H(2) = 7.08$, $p = 0.029$. Subsequent pairwise comparisons, using a Bonferonni correction with adjusted p-values, showed that the number of years since menarche was significantly higher when periods were regular (median=4.75) compared to when they were irregular (median=4.08) ($p = 0.023$, $r = 0.16$). There were no other significant differences.

N.B. Subsequent analysis using the variables 'length of period' and 'length of menstrual cycle' will use the data for those reporting a period length between 2 to 10 days and a cycle length between 14 to 45 days, as it is unclear whether data falling outside of these perimeters are outliers or errors.

9.4.2 Experience of Period Pain

Participants' experiences of period pain are shown in Table 9.4. Period pain was reported by 93.6% of responders (411/439). Of those, 46.2% (190) reported pain every month, and 53.8% (221) reported pain some months. Participants were asked to rate their pain severity on a scale from 0 to 10. Following the method used by Parker (2006), these responses were categorised into 'no/mild pain' (answers 0 to 3), 'moderate pain' (4-7), and 'severe pain' (8-10). Over half of the responders experienced 'moderate pain' (54.8%) and almost one third experienced 'severe pain' (31.3%).

Many participants took medication for their period pain (266/416, 63.9%). Of those, the most used analgesic was paracetamol (72.2%), followed by ibuprofen (47.4%). Some participants used the free response option 'other' to report the medications they had tried. The most used 'other' medications were prescribed NSAIDs (including Mefenamic Acid), and Buscopan. One responder had used tramadol for her period pain. Participants were asked to rate the effectiveness of their chosen medication on a scale from 0 to 10. Again, following the method used by Parker (2006), these responses were categorised into 'low effectiveness' (answers 0 to 3), 'moderate effectiveness' (4-7),

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[3] Menstrual cycles ranging from 21-45 days are considered typical during adolescence (ACOG Committee on Adolescent Health Care, 2015).

and 'high effectiveness' (8-10). Over half of the responders indicated 'moderate effectiveness' (53.6%) and over a third indicated 'high effectiveness' (31.3%).

N.B. Subsequent analysis using the data on the experience of period pain will combine those who answered 'pain every month' and 'pain some months', and compare them with those who did not report period pain. Thus, it will not distinguish between the frequency of period pain.

Table 9.4: Experience of Period Pain and Use of Medication

		Number (n)	Percentage (%)
Period pain experienced *(n=439)*		**411**	**93.6**[†]
Of which:	Pain every month	190	46.2
	Pain some months	221	53.8
Period pain on a scale of 0 to 10 *(n=409)*			
	No/mild pain (0-3)	57	13.9
	Moderate pain (4-7)	224	54.8
	Severe pain (8-10)	128	31.3
Medication is taken for period pain *(n=416)*		**266**	**63.9**[†]
Of which:	Paracetamol	192	72.2
	Ibuprofen	126	47.4
	Aspirin	5	1.9
	Feminax	18	6.8
	Other	44	16.5
Responses to 'Other' medication taken *(n=44)*			
	Prescribed NSAID	13	4.9
	Buscopan	10	3.8
	Over the counter painkillers	4	1.5
	Tranexamic acid	5	1.9
	Contraceptive pill	3	1.1
	Prescribed medication unspecified	4	1.5
	Migraine medication	1	0.4
	Tramadol	1	0.4
	Other	3	1.1
Effectiveness of medication for period pain on a scale of 0 to 10 *(n=250)*			
	Low effectiveness (0-3)	30	11.3
	Moderate effectiveness (4-7)	142	53.6
	High Effectiveness (8-10)	93	35.1

[†] Figures shown in bold are the total number/percentage who answered 'yes' to the question, figures not in bold are percentages *within* those who answered 'yes'.

9.4.3 School Absence Due to Periods

Data collected on school absence due to periods is shown in Table 9.5. Almost a quarter of respondents stated they had missed school due to their period (22.7%: 100/440). Of these, 95 had missed school some months and 5 had missed school every month. Sixty-eight participants reported on the number of school days missed per month; the majority missed 1 day, and 2 days was the maximum reported. Of those who missed school, the reason most often ticked was that their period was 'too painful' (90.6%), followed by nausea (37.5%), and heavy bleeding (24.5%). Participants were able to tick more than one response option.

Table 9.5: School Absence Due to Periods

Survey Item		Number (n)	Percentage (%)
School is missed due to periods *(n=440)*		**100**	**22.7**[†]
Of which:	Missed every month	5	5.0
	Missed some months	95	95.0
Days missed per month:			
(n=68)	0.5 days	4	
	1 day	56	
	1.5 days	4	
	2 days	4	
Reason school is missed:			
(n=100)	Too painful	91	91.0
	Blood flow too heavy	25	25.0
	Nausea	37	37.0
	Sickness	21	21.0
	Other[a]	15	15.0

[†] Figures shown in bold are the total number/percentage who answered 'yes' to the question, figures not in bold are percentages *within* those who answered 'yes'.

[a] Other reasons for missing school included dizziness/fainting (6), migraines (3) and tiredness (5)

N.B. Subsequent analysis using this data on school absence, will only compare those who answered 'yes' with those who answered 'no', and will not distinguish between the frequency of school absence.

9.4.4 Contraceptive Pill Use

Few respondents (60/439: 13.7%) had used the contraceptive pill at some time in their life, and 31 of those were using it currently. Of those to have ever used the contraceptive pill, 27 (45%) had taken it to regulate periods, 34 (56.7%) to prevent pregnancy, 25 (41.7%) to help with period pain, and 10 (16.7%) to help with spots/acne. Two participants ticked 'other' and stated that they had taken it to delay their period. Participants were able to tick more than one response for their reason for contraceptive pill use.

9.5 Seeing a Doctor About Periods

Almost a third of the sample reported they had visited a doctor about their periods (130/441, 29.5%). The outcome of the doctor's visit for the majority was that they were given medication or told to return if problems persisted (see Table 9.6). A small number of participants were referred to a specialist (11/130, 8.5%) or for further investigation (5/130, 3.8%). Of those who responded 'other', most (11/19) stated they were told their periods were fine or normal. When asked if they felt reassured after their visit, 72.1% (93/129) stated they did. Of the 27.9% who did not feel reassured, the main reason given was that their symptoms were not resolved.

Table 9.6: Seeing a Doctor About Periods

			Number (n)	Percentage (%)
Have ever visited a doctor about periods *(n=441)*			**130**	**29.5**
Result of visiting doctor†:				
(n=130)		Given medication	65	50
		Sent to see specialist	11	8.5
		Told to come back if problem persists	51	39.2
		Other:	19	14.6
	Responses to 'Other':			
	(n=19)	Told it was fine/normal	11	8.5
		Sent for further investigation	5	3.8
		Given a diagnosis	1	0.8
		Other	2	1.5
Reassured following doctors visit (n = 129)				
		Yes	93	72.1
		No	36	27.9
	Reason for not feeling reassured: (n=28)			
		Symptoms not resolved	11	39.3
		Symptoms dismissed or normalised	4	14.3
		Lack of information or explanation given	6	21.4
		Medication not effective	3	10.7
		No treatment offered	4	14.3

†Participants could tick multiple answers, and therefore these responses do not add up to 100%

There was a significant association between visiting a doctor about periods and missing school due to periods $\chi^2(1) = 26.712$, $p < 0.001$. Inspection of the standardised residuals indicated that if participants had missed school due to periods, significantly more of them than expected ($z = 3.3$) had visited a doctor about periods, and significantly fewer of them than expected ($z = -2.5$) had not visited a doctor about their periods. If participants had not missed school due to periods, significantly fewer of them than expected had seen a doctor about periods ($z = -2.1$). The association was moderate, Cramer's V = 0.246, $p < 0.001$ (Cohen, 1988).

9.6 Pain Severity and Menstrual Related Behaviours

To further characterise the experience of menstruation in this sample, and to compare to previous research, statistical analysis was conducted to examine the associations between participants' severity of period pain, and their menstrual related behaviours (see Table 9.7). There was a significant association between missing school due to periods and pain severity ratings $\chi^2(2) = 49.776$, $p < .001$. Inspection of the standardised residuals indicated that among participants who reported their period pain as severe, significantly more of them than expected had missed school due to periods ($z = 4.9$) and significantly fewer of them than expected had not missed school due to periods ($z = -2.8$). Among participants who reported their period pain as mild or moderate, significantly fewer of them than expected had missed school due to their period ($z = -2.9$ and $z = -2.3$ respectively). The association was strong, Cramer's V = 0.349, $p < 0.001$ (Cohen, 1988).

Table 9.7: Association Between Pain Severity and Menstrual Related Behaviours

	Pain Severity			
	No/mild	**Moderate**	**Severe**	**Significance**
Medication taken for period pain, n (%)				
Yes	18 (31.6)	133 (40.6)	112 (87.5)	
No	39 (68.4)	91 (59.4)	16 (12.5)	***p* < 0.001**
Missed school due to periods, n (%)				
Yes	3 (5.3)	37 (16.5)	58 (45.3)	
No	54 (94.7)	187 (83.5)	70 (54.7)	***p* < 0.001**
Ever seen a doctor about periods, n (%)				
Yes	11 (19.3)	60 (26.8)	46 (35.9)	
No	46 (80.7)	164 (73.2)	82 (64.1)	***p* = 0.046**
Ever taken the contraceptive pill, n (%)				
Yes	8 (14.0)	24 (10.7)	23 (18.1)	
No	49 (86.0)	200 (89.3)	104 (81.9)	*p* = 0.148

There was a significant association between taking medication for period pain and pain severity ratings $\chi^2(2) = 58.968$, $P < .001$. Inspection of the standardised residuals indicated that among participants who reported their period pain as severe, significantly more of them than expected had taken medication for period pain ($z = 3.3$) and significantly fewer of them than expected had not taken medication for period pain ($z = -4.4$). Among participants who reported their period pain as mild, significantly fewer of them than expected had taken medication for period pain ($z = -3.1$) and significantly more of them than expected had not taken medication for period pain ($z = 4.1$). The association was strong, Cramer's V = 0.380, $p < 0.001$ (Cohen, 1988).

There was a significant association between visiting a doctor for periods and pain severity ratings $\chi^2(2) = 6.150$, $p = 0.046$. Inspection of the standardised residuals indicated that among participants who reported their period pain as severe, more of them than expected had visited a doctor about periods, but this fell just below significance at the 0.05 level ($z = 1.6$). The association was small, Cramer's V = 0.123, $p = 0.046$ (Cohen, 1988). There was no association between taking the contraceptive pill and pain severity ratings $\chi^2(2) = 3.819$, $p = 0.148$.

9.7 Perceived Typicality of Periods

Participants were asked whether they thought their periods were typical for someone their age. In total, 434 participants responded; 274 (63.1%) answered ‘yes’; 44 (10.1%) answered ‘no’, and; 116 (26.7%) answered ‘unsure’. Further analysis was conducted using this data, to compare the menstrual characteristics of participants who answered ‘yes’, ‘no’, or ‘unsure’ (see Table 9.8).

Table 9.8: Comparisons of Characteristics of Menstrual Experiences by Perceived Typicality of Periods

	Do you consider your periods to be typical for someone your age?			
	Yes	**No**	**Unsure**	**Significance**
Age (years)				
Median	17.08	17.08	17.00	*p* = 0.396
Age of Menarche (years)				
Median	12.67	12.58	12.17	*p* = 0.068
Length of Period⁺ (days)				
Median	5.00	6.00	5.00	*p* = 0.302
Regularity of Menstrual Cycles, n (%)				
Regular	117 (46.6)	11 (25.0)	29 (26.9)	
Irregular	56 (22.3)	30 (68.8)	39 (36.1)	
Unknown	78 (31.1)	3 (6.8)	40 (37.0)	***p* < 0.001**
Period Pain, n (%)				
Yes	255 (93.1)	41 (93.2)	110 (94.8)	
No	19 (6.9%)	3 (6.8)	6 (5.2)	*p* = 0.807
Severity of Period Pain, (scale 0-10)				
Median	6.00	7.00	7.00	***p* = 0.003**
Medication taken for Period Pain, n (%)				
Yes	154 (59.5)	33 (80.5)	74 (67.3)	
No	105 (40.5)	8 (19.5)	36 (32.7)	***p* = 0.022**
Effectiveness of medication taken for period pain (scale 0-10)				
Median	7.00	5.00	6.00	***p* = 0.005**
Missed school due to periods, n (%)				
Yes	58 (21.2)	12 (27.3)	27 (23.3)	
No	216 (78.8)	32 (72.7)	89 (76.7)	*p* = 0.640
Ever taken the contraceptive pill, n (%)				
Yes	30 (10.9)	12 (27.3)	16 (13.9)	
No	244 (89.1)	32 (72.7)	99 (86.1)	***p* = 0.013**
Ever seen a doctor about periods, n (%)				
Yes	60 (21.9)	29 (65.9)	37 (31.9)	
No	214 (78.1)	15 (34.1)	79 (68.1)	***p* < 0.001**

Notes: Continuous data: Kruskal-Wallis tests, Nominal data: Chi-squared tests
⁺Length of period includes those reporting a length between 2 and 10 days

9.7.1 Significant Findings

Chi-squared tests were conducted to identify any associations between perceived typicality of periods and nominal variables. There was a statistically significant association between perceived typicality of periods and regularity of menstrual cycle, $\chi^2(2) = 46.42$, $p < 0.001$. Inspection of the standardised residuals indicated that among participants reporting irregular cycles, significantly more of them than expected thought their periods were not typical ($z = 4.4$). The association was moderate, Cramer's V = 0.240, $p < 0.001$.

There was a significant association between taking the pill and perceived typicality of periods $\chi^2(2) = 8.75$, $p < 0.05$. Inspection of the standardised residuals indicated that among participants who took the contraceptive pill, significantly more of them than expected reported that their periods were not typical ($z = 2.5$). The association was small, Cramer's V = 0.142, $p = 0.013$ (Cohen, 1988).

There was a significant association between taking medication for period pain and perceived typicality of periods $\chi^2(2) = 8.75$, $p < 0.05$. An inspection of the standardised residuals indicated that among participants who had not taken medication for period pain, fewer of them than expected indicated that their periods were not typical, but this fell just below significance at the 0.05 level ($z = -1.8$). The association was small, Cramer's V = 0.136, $p = 0.022$ (Cohen, 1988).

There was a significant association between visiting a doctor for periods and perceived typicality of periods $\chi^2(2) = 36.272$, $p < 0.001$. Inspection of the standardised residuals indicated that among participants who had visited a doctor, significantly more of them than expected reported that their periods were not typical ($z = 4.5$), and significantly fewer of them than expected indicated that their periods were typical ($z = -2.2$). Among participants who had not visited a doctor about their periods, significantly fewer of them than expected indicated that their periods were not typical ($z = -2.9$). The association was moderate, Cramer's V = 0.289, $p < 0.000$ (Cohen, 1988).

Kruskal-Wallis tests were conducted to determine any differences between perceived typicality of periods based on continuous or ordinal data. This test indicated that pain severity ratings were significantly different between the perceived typicality of periods groups, $H(2)=11.62$, $p = 0.003$. Pairwise comparisons with adjusted p-values (using the Bonferroni correction) showed that the pain ratings for those who thought their periods were typical (median=6) was significantly lower compared to both those that thought their periods were not typical (median=7) ($p = 0.04$, r = -0.16) and those that were unsure (median=7) ($p = 0.15$, $r = -0.13$).

A Kruskal-Wallis test indicated that the reported effectiveness of medication was significantly different between the perceived typicality of periods groups, $H(2)=10.465$, $p = 0.005$. Pairwise comparisons with adjusted p-values (using the Bonferroni correction) showed that the medication effectiveness rating of those who thought their periods were typical (median=7) was significantly higher compared to those that thought they were not typical (median=5) ($p = 0.02$, $r = 0.20$).

9.7.2 Multinomial Logistic Regression

The results of the above analyses were used to select variables to be entered into a multinomial logistic regression model. Variables which were significant at the $p<0.05$ were included in the model. Multinomial logistic regression analysis allows us to identify which of these variables is independently associated with perceived typicality of periods, when controlling for all other variables, and therefore to generate a model, upon which predictions can be made about group membership (typical vs. not typical vs. not sure). Therefore, multinomial logistic regression was performed to assess the impact of regularity of cycles, severity of period pain, use of medication for periods, use of the contraceptive pill and if ever visited a doctor about periods, on the likelihood that participants would perceive their periods as typical. ‘Effectiveness of Medication’ was not included in the model; there was a large amount of ‘not applicable’ responses for this item, because all those who had answered ‘No’ to taking medication for pain (150) did not have a response for effectiveness of medication and were therefore treated as missing. As the regression model would have taken out all those with missing data, the inclusion of this item would have produced a smaller model, which would not have included anyone who did not take medication for pain.

As outlined above, a multinomial logistic regression analysis can explore how the independent variables will affect the probability of an outcome on the dependent variable. To perform this analysis, the largest value of the dependent variable, ‘periods are typical’, was used as the reference category. By using this model, we can identify how ‘periods are not typical’ and ‘unsure if periods are typical’ differ from the reference category. The independent variables which are nominal also needed a reference category. Those which were dichotomous (medication taken for pain, history of contraceptive pill use, and ever visited a doctor for periods) had the reference category ‘no’. For regularity of cycles, in which the categories were ‘irregular’, ‘unknown regularity’ or ‘regular’, the reference category was ‘regular’. The results of the multinomial logistic regression are shown in Table 9.9.

The full model containing all predictors was statistically significant $\chi^2(12) = 83.295$, $p < 0.001$. The model explained 23.8% (Nagelkerke R^2) of the variance in perceived typicality of periods and correctly classified 64% of cases. The likelihood ratio tests indicated that pain severity, regularity of cycles, and ever visiting a doctor about periods were all significant predictors to the model ($p < 0.05$). Taking medication for pain, and history of contraceptive pill use were not significant in predicting the dependent variable (*p* > 0.05) and did not enhance the capability of the model to predict group membership. As stated previously, part of the theoretical basis for using logistic regression techniques is that confounding variables can be controlled, whilst observing the relationship between other variables in the model. It is likely that the non-significance of the variables 'taking medication for pain' and 'history of contraceptive use' was due to this issue (e.g., those who had taken the contraceptive pill might have been likely to also have seen a doctor about periods).

Table 9.9: Multinomial Logistic Regression Analysis Showing Factors Predicting Perceived Typicality of Periods

	B	Wald	Exp(B)
Periods are Not Typical			
Pain Severity	0.113	1.508	1.119
Irregular Cycles	1.812***	16.211	6.112
Unknown Regularity of Cycles	-0.440	0.394	0.644
Medication taken for pain	0.456	0.855	1.577
History of contraceptive pill use	0.903	3.632	2.467
Ever Visited a Doctor for Periods	1.550***	14.972	4.711
Unsure if periods are Typical			
Pain Severity	0.195**	9.520	1.216
Irregular Cycles	1.015**	10.145	2.758
Unknown Regularity of Cycles	0.829**	7.550	2.291
Medication taken for pain	-0.115	0.161	0.891
History of contraceptive pill use	0.022	0.003	1.022
Ever Visited a Doctor for Periods	0.366	1.627	1.442

Notes: $R^2 = 0.238$ (Nagelkerke), Model $\chi^2(12) = 83.298$, $p < 0.001$,
$*p < 0.05$, $**p < 0.01$, $***p < 0.001$
Reference category is Periods are Typical

An examination of the parameter estimates allows a better understanding of the significant predictors. Participants with irregular periods were 6.1 times more likely than those with regular periods to state that their periods are not typical for someone their age, in comparison with the reference group (periods are typical). In addition, participants who had visited a doctor for their periods were 4.7 times more likely than those who have not visited a doctor to state that their periods are not typical for someone their age, in comparison with the reference group (periods are typical).

An increase in severity of pain was associated with an increase of the likelihood of being unsure of typicality of periods, compared to those who perceive periods as typical. Participants with irregular cycles were 2.8 times more likely than those with regular cycles to say they were unsure if their periods are typical, in comparison with the reference category (periods are typical). Finally, participants who did not know their regularity were 2.3 times more likely than those with regular cycles to say they were unsure if their periods are typical, in comparison with the reference category (periods are typical).

9.8 Attitudes and Communication

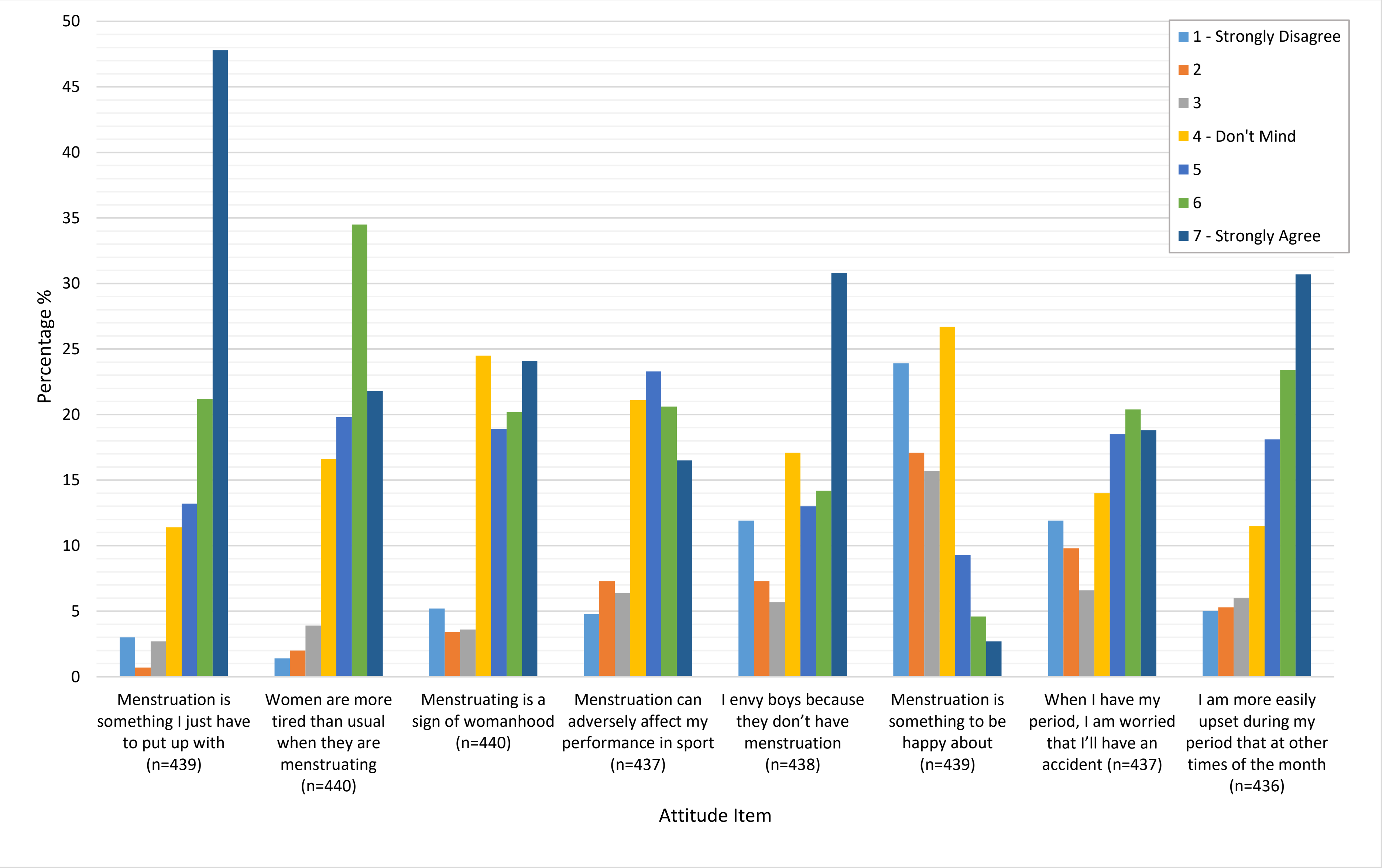
9.8.1 Attitudes Towards Periods

Participants were asked their overall attitude towards periods, and 431 responded to this question. Out of these, 8.1% (35) ticked ‘positive’, 37.6% (162) ticked ‘negative’, and 54.3% (234) ticked ‘don’t mind’.

Participants were also asked to respond to several attitude statements about periods, using a 7-point Likert scale, ranging from 1 – strongly disagree, to 7 – strongly agree. The frequency in the range of the responses for each statement is shown in Figure 9.1. In general, attitude items with a more negative stance, such as ‘Menstruation is something I just have to put up with’, were commonly skewed to the right, indicating more agreement with the statement, and attitude items with a positive stance, such as ‘Menstruation is something to be happy about’, were commonly skewed to the left, indicating more disagreement with the statement. In particular, there was a high level of consensus amongst participants on the item ‘Menstruation is something I just have to put up with’. However, the item ‘When I have my period, I am worried that I’ll have an accident’ indicated more varying views.

More analysis was done using the results of these questions in Sections 9.9 and 9.10.

Figure 9.1: Frequency of Participant Responses on Menstrual Attitude Questions

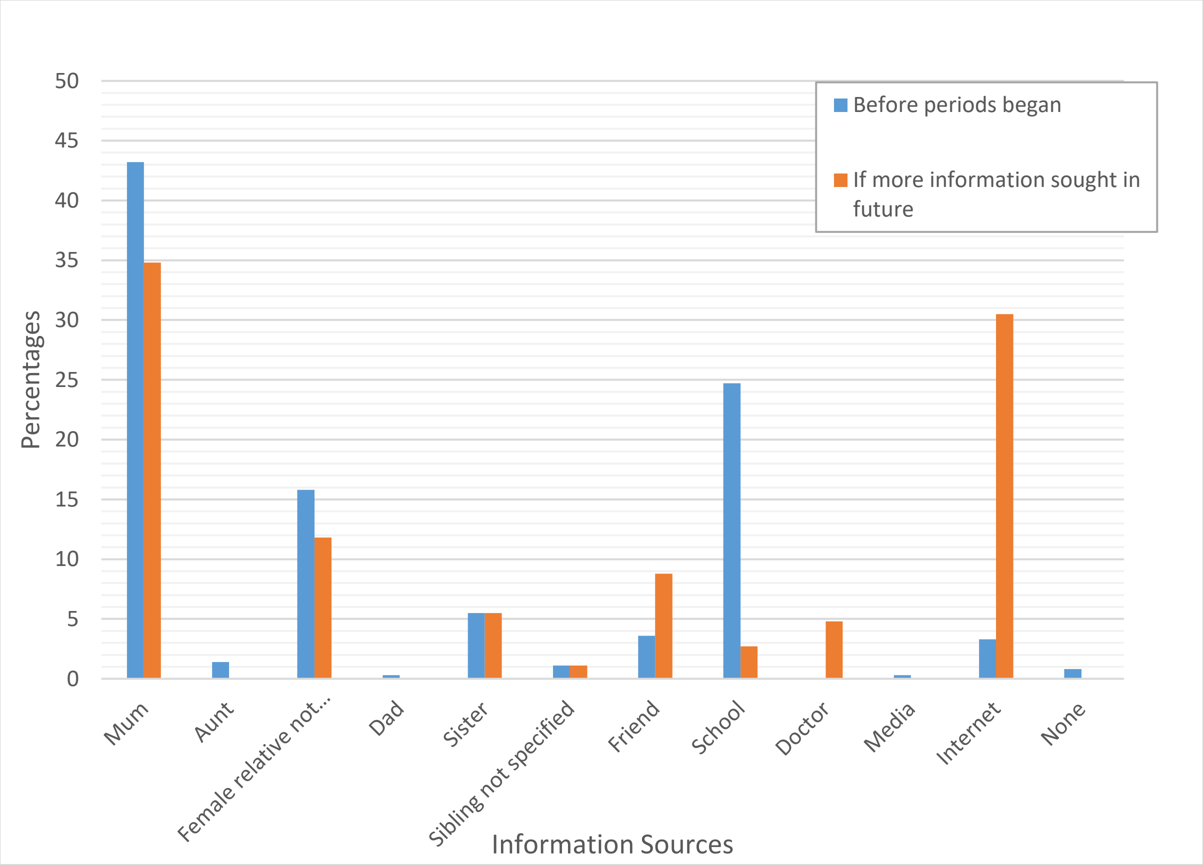


9.8.2 Communication About Periods

Participants were asked to indicate their first information source about menstruation prior to the onset of menarche (see Figure 9.2). The most frequent response was their mother (43.2%), followed by school (24.7%). Three participants stated they had not received any information about periods prior to their onset.

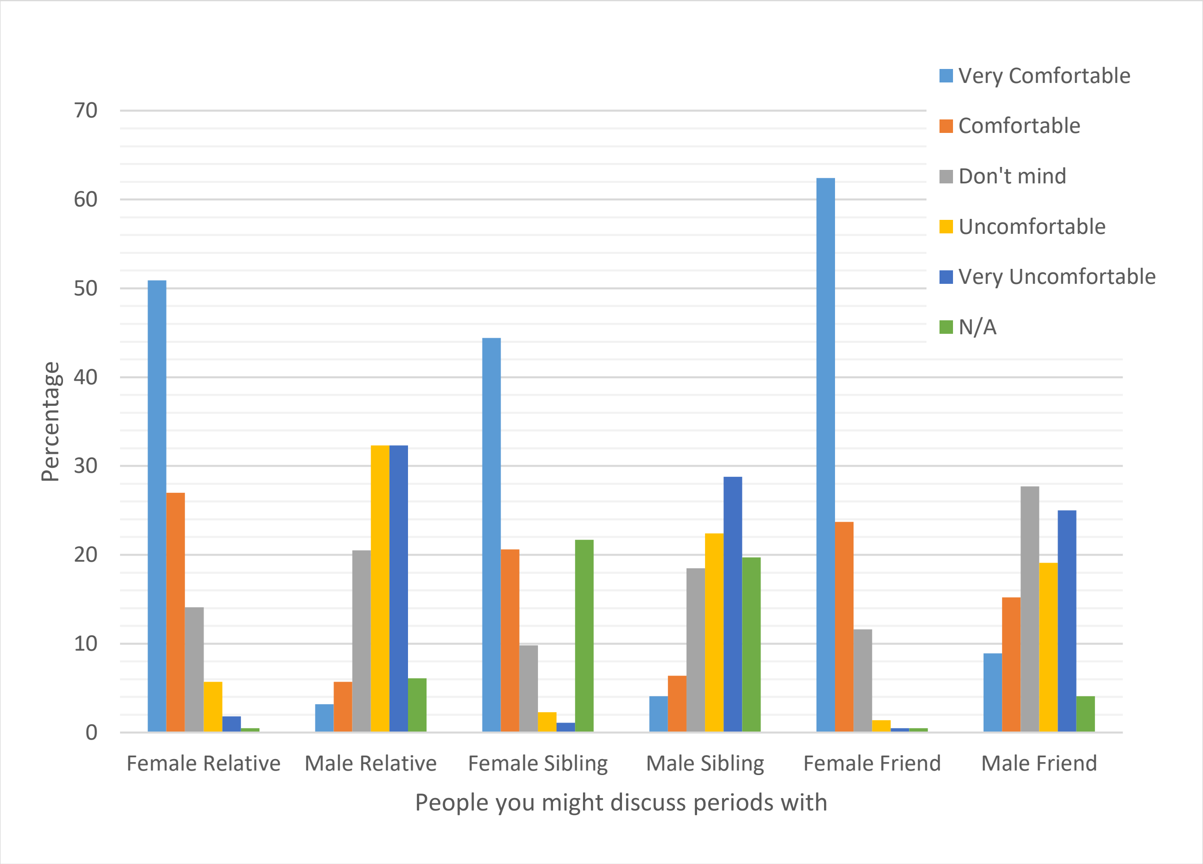
Figure 9.2 also displays the results of the question 'If you wanted more information about periods, who would you approach first?' Again, mothers were the most frequent response (34.8%). In comparison to how many responders had received initial information at school, they indicated a much lower tendency to seek *further* information from someone at school, with only 2.7% stating school as a preferred source. Almost a third of responders (30.5%) reported that they would use the internet for further information about periods and only 4.8% indicated that they would ask a doctor.

Figure 9.2: Sources of Information about Menstruation



Participants were asked how comfortable they were in discussing menstruation with different family members and friends. The results of this question are displayed in Figure 9.3. When excluding those who answered N/A, responses for female friends and relatives tended to skew to the left (indicating more comfort) and responses for male friends and relatives tended to skew towards the right (indicating more discomfort). Responses also indicated higher levels of comfort discussing periods with friends compared to family members. This was true for both female friends compared to female family members and male friends compared to male family members.

Figure 9.3: Comfort Level in Discussing Menstruation with Family and Friends



9.9 Awareness of Endometriosis

When asked 'Do you know what endometriosis is?', 10.1% (44/437) answered 'yes', and 89.9% (393/437) answered 'no'. Those who answered 'yes' (44) were asked to provide a description of endometriosis in their own words, however 46 provided such, including 1 who answered 'no' to if they knew what endometriosis was, and 1 who did not answer that question. These descriptions were coded and subsequently categorised into description types, the frequencies of which are shown in Table 9.10. The descriptions provided by participants were largely based on symptoms (14/46), the biological mechanisms involved in endometriosis (11/46), or a combination of both (11/46). Pain as a symptom was mentioned by 50% (23/46) of the participants who described endometriosis and was therefore the most frequently occurring descriptor of endometriosis. Other symptoms mentioned were heavy bleeding (5/46), painful intercourse (2/46), irregular/unusual periods (2/46) and infertility (1/46). The definitions which included biological mechanisms were often based on the lining of the womb appearing elsewhere (15/46) and blood being unable to leave the body (5/46).

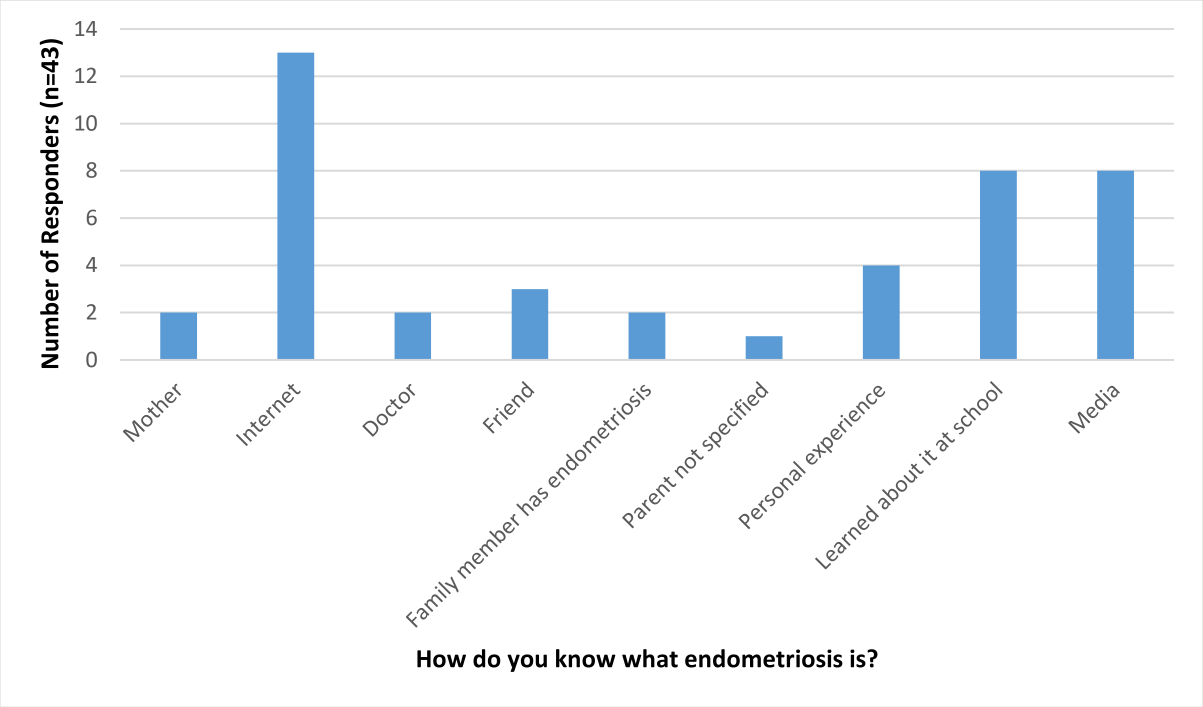
Some of the descriptions given were quite vague or did not quite capture any element of the definition of endometriosis. For example, 5 responders' descriptions were simply of a period, and 4 responders' descriptions could be categorised as 'something to do with a period', which was likely to have been obvious given the nature of the rest of the survey, which they had already completed by this point.

Table 9.10: Examples of Participants Descriptions of Endometriosis

Category	Description Type	Total Sample (n = 46)	Example free response answer
1	Symptoms only	14	Highly intense period pain, stops you being able to move is so painful
2	Biological mechanisms only	11	It's the lining of a womb which can also form in other places
3	Symptoms and biological mechanisms	11	The cells in the lining of the uterus appear in other reproductive organs such as ovaries. This causes pain and can lead to infertility
4	Something to do with periods	4	It affects some women and not all. It's to do with your periods
5	Description of a period	5	The lining in uterus breaking down which results in blood being released during the period
6	Other	1	Other parts of the tissues behave as the lining of the womb, e.g. egg can be fertilised in the fallopian tube and begin to grow

Participants who stated that they knew what endometriosis was were also asked to indicate how they knew. Forty-three participants responded; the response options and frequency of responses are shown in Figure 9.4. Almost half of the participants (21/43) knew about endometriosis from the internet and the media.

Figure 9.4: Information Sources about Endometriosis



9.9.1 Participant Characteristics and Their Awareness of Endometriosis

Further analysis was conducted on the data collected about participants' awareness of endometriosis, to enable comparisons between the characteristics of participants based on their awareness. To run this analysis, a new variable was formed; 'knowledge of endometriosis', which was based on the coded and categorised descriptions of endometriosis that were outlined about in Table 9.10. The researcher and one supervisor independently coded responses and reached agreement on the final categories. Following this, to enable further analysis, those respondents who gave descriptions coded into categories 1, 2 and 3, were considered to have given descriptions demonstrating some knowledge of endometriosis, and were grouped together to form the new category 'Yes' (i.e. yes, they do know). Those whose descriptions were coded into categories 4, 5, and 6 were considered to have given an inaccurate description of endometriosis, and were grouped together, along with those who indicated that they did not know what endometriosis was, to form the new category 'No' (i.e. no, they do not know). These two new categories together form the dichotomous categorical dependent variable, 'knowledge of endometriosis'. There were 36 participants in the 'yes' group (8.2%) and 402 participants in the 'no group (91.8%). Table 9.11 shows the results of the further analysis conducted with this variable.

Table 9.11: Comparisons of Characteristics of Participants by Knowledge of Endometriosis

	Knowledge of Endometriosis		Significance
	Yes	No	
Age (years)			
Median	17.25	17.00	*p* = 0.057
Ethnicity, n (%)			
White	16 (44.4)	136 (34.9)	
Asian	14 (38.9)	196 (50.3)	
Black	4 (11.1)	41 (10.5)	
Mixed	2 (5.6)	17 (4.4)	*p* = 0.609†
School Type, n (%)			
Independent Girls	2 (5.9)	27 (6.8)	
Mixed Academy	13 (38.2)	200 (50.0)	
Independent mixed boarding	19 (55.9)	173 (43.3)	*p* = 0.359
Age of Menarche			
Median	12.00	12.50	***p* = 0.012**
Period Pain, n (%)			
Yes	31 (91.2)	376 (93.8)	*p* = 0.472†
Regularity of Cycles, n (%)			
Irregular	8 (24.2)	119 (32.0)	
Unknown	6 (18.2)	112 (32.1)	
Regular	19 (57.6)	141 (37.9)	*p* = 0.081
Severity of Period Pain (scale 0-10)			
Median	7.00	6.00	***p* = 0.014**
Medication taken for Period Pain, n (%)			
Yes	26 (81.3)	238 (62.6)	***p* = 0.035**
Missed school due to periods, n (%)			
Yes	12 (34.3)	86 (21.4)	*p* = 0.081
Ever taken the contraceptive pill, n (%)			
Yes	10 (28.6)	49 (12.3)	***p* = 0.007**
Ever seen a doctor for periods, n (%)			
Yes	17 (47.2)	113 (28.2)	***p* = 0.017**
Perception of periods as typical, n (%)			
Yes	18 (52.9)	253 (63.9)	
No	7 (20.6)	37 (9.3)	
Unsure	9 (26.5)	106 (26.8)	*p* = 0.107
Attitudes about menstruation (median response) [a]			
Item 1	6.00	6.00	*p* = 0.094
Item 2	6.00	6.00	*p* = 0.518
Item 3	4.50	5.00	*p* = 0.112
Item 4	5.00	5.00	*p* = 0.578
Item 5	6.00	5.00	*p* = 0.535
Item 6	3.00	3.00	*p* = 0.361
Item 7	6.00	5.00	*p* = 0.228
Item 8	6.00	6.00	*p* = 0.308
Periods are: n (%) Positive	5 (15.2)	30 (7.6)	
Negative	12 (36.4)	150 (38.0)	
Don't mind	16 (48.5)	215 (54.4)	*p* = 0.309

Continuous data: Mann-Whitney U tests, Nominal data: Chi-squared tests

† More than 25% of cells had expected count of less than 5, and therefore a Fishers Exact statistic is reported for 2x2 tables, and a likelihood ratio statistic is reported for larger tables.

[a] Item; 1 = Menstruation is something I just have to put up with; 2 = Women are more tired than usual when they are menstruating; 3 = Menstruating is a sign of womanhood; 4 = Menstruation can adversely affect my performance in sport; 5 = I envy boys because they don't have menstruation, Item 6 = Menstruation is something to be happy about; 7 = When I have my period, I am worried that I'll have an accident; 8 = I am more easily upset during my period than at other times of the month

9.9.1.1 Significant Findings

Mann-Whitney U tests were conducted to determine any differences between the knowledge of endometriosis groups based on continuous or ordinal data. There was a significant difference in the age of menarche between groups; those who had knowledge of endometriosis had a lower age of menarche (Median = 12.00) compared to those who did not have knowledge (Median = 12.50), U = 4981, z = -2.504, p = 0.012, r = -0.12. There was also a significant difference in the severity of period pain scores between those who had knowledge of endometriosis (Median = 7.00) compared to those who did not (Median = 6.00), U = 7379.5, z = 2.458, p = 0.014, r = 0.12. All other Mann-Whitney U tests were not significant.

Chi-squared tests were conducted to identify any associations between knowledge of endometriosis and key nominal variables. There was a significant association between knowledge of endometriosis and use of medication for period pain $\chi^2(1) = 4.445$, p = 0.035. This association was small, $\phi = 0.104$, p = 0.035. There was a significant association between knowledge of endometriosis and lifetime contraceptive pill use $\chi^2(1) = 7.313$, p = 0.007. This association was small, $\phi = 0.130$, p = 0.007. An inspection of the standardised residuals indicated that among those participants who had ever used the contraceptive pill, significantly more than expected had knowledge of endometriosis (z = 2.4). Finally, there was a significant association between knowledge of endometriosis and whether participants had ever visited a doctor about periods $\chi^2(1) = 5.732$, p = 0.017. This association was small, $\phi = 0.115$, p = 0.017. An inspection of the standardised residuals indicated that among participants who had visited a doctor, more of them than expected had knowledge of endometriosis, but this fell just below significance at the 0.05 level (z = 1.9). All other chi-squared analyses were not significant.

9.10 Education and Communication Preferences About Endometriosis

After the provision of a brief description of endometriosis, the survey required participants to indicate whether they would like to learn more about endometriosis if given the opportunity. As shown in Table 9.12, out of 434 responders to this question, 85.9% answered ‘yes’. When asked their preferred way of learning about endometriosis, over half of the responders (51.3%) indicated school as the preferred source, via either a lesson or the school nurse. However, when asked who they are comfortable discussing endometriosis with, excluding ‘other relatives’, the response option ‘school teacher’ was ticked least often by responders. Most participants (82.8%) agreed that they thought boys should learn about endometriosis as well.

Table 9.12: Learning and Communication Preferences about Endometriosis

		Number (n)	Percentage (%)
Wish to learn more about endometriosis: *(n=434)*		**373**	**85.1**
How would you prefer to learn about it?			
(n=376)	From a parent	40	10.6
	From a sibling	5	1.3
	During a lesson at school	153	40.7
	From the school nurse	36	9.6
	Through the media	23	6.1
	Through the internet	59	15.7
	From a doctor	54	14.4
	From a friend	6	1.6
Comfortable discussing endometriosis with: *(n=437)*			
	Parents	281	64.3
	Siblings	128	29.3
	Teachers	116	26.5
	School nurse	160	36.6
	Doctor	192	43.9
	Friends	246	56.3
	Other Relatives [a]	37	8.5
Do you think boys should learn about endometriosis too?			
(n=435)	Yes	360	82.8
	No	75	17.2

[a] Other relatives was an open response item and answers given included female relatives (i.e. aunt, grandmother), relatives whose sex was not specified (i.e. grandparent, cousin) and boyfriends.

9.10.1 Participant Characteristics and Their Preferences About Further Endometriosis Education

Further inferential analyses were conducted to compare the characteristics of participants based on their learning preferences regarding endometriosis. The results of these analyses can be found in Table 9.13.

Table 9.13: Comparisons of Participants' Characteristics by Learning Preferences for Endometriosis

	Wish to learn more about endometriosis?		
	Yes	**No**	**Significance**
Age (years)			
Median	17.08	16.92	$p = 0.450$
Ethnicity, n (%)			
White	125 (34.4)	28 (43.8)	
Asian	183 (50.4)	28 (43.8)	
Black	39 (10.7)	5 (7.8)	
Mixed	16 (4.4)	3 (4.7)	$p = 0.518$
School Type, n (%)			
Independent Girls	29 (7.8)	0 (0.0)	
Mixed Academy	187 (50.4)	25 (39.1)	
Independent mixed boarding	155 (41.8)	39 (60.0)	**$p = 0.004$**
Age of Menarche			
Median	12.33	13.00	**$p = 0.005$**
Regularity of menstrual cycles, n (%)			
Irregular	108 (31.1)	20 (33.3)	
Unknown	98 (28.2)	21 (35.0)	
Regular	141 (40.6)	19 (31.7)	$p = 0.382$
Period Pain, n (%)			
Yes	351 (93.9)	57 (91.9)	$p = 0.575^{\dagger}$
Severity of Period Pain, n (%)			
Mild	42 (12.0)	14 (24.6)	
Moderate	196 (56.2)	27 (47.4)	
Severe	111 (31.8)	16 (28.1)	**$p = 0.039$**
Medication taken for Period Pain, n (%)			
Yes	232 (65.4)	33 (56.9)	$p = 0.213$
Missed school due to periods, n (%)			
Yes	89 (23.8)	10 (15.9)	$p = 0.165$
Ever taken the contraceptive pill, n (%)			
Yes	51 (13.7)	9 (14.3)	$p = 0.896$
Ever seen a doctor about periods, n (%)			
Yes	111 (29.6)	19 (30.2)	$p = 0.928$
Perception of periods as typical, n (%)			
Yes	232 (62.7)	40 (65.6)	
No	39 (10.5)	5 (8.2)	
Unsure	99 (26.8)	16 (26.2)	$p = 0.837$
Attitudes about menstruation (median response) [a]			
Item 1	6	6	$p = 0.913$
Item 2	6	6	$p = 0.462$
Item 3	5	5	$p = 0.202$
Item 4	5	5	$p = 0.147$
Item 5	5	5	$p = 0.674$
Item 6	**3**	**2**	**$p < 0.001$**
Item 7	5	4	$p = 0.181$
Item 8	6	6	$p = 0.383$
Periods are: n (%)			
Positive	34 (9.3)	1 (1.6)	
Negative	131 (35.8)	30 (47.6)	
Don't mind	201 (54.9)	32 (50.8)	**$p = 0.048$**

Continuous data: Mann-Whitney U tests, Nominal data: Chi-squared tests

† More than 25% of cells had expected count of less than 5, and therefore a Fishers Exact statistic is reported

[a] Item; 1 = Menstruation is something I just have to put up with; 2 = Women are more tired than usual when they are menstruating; 3 = Menstruating is a sign of womanhood; 4 = Menstruation can adversely affect my performance in sport; 5 = I envy boys because they don't have menstruation, Item 6 = Menstruation is something to be happy about; 7 = When I have my period, I am worried that I'll have an accident; 8 = I am more easily upset during my period than at other times of the month

9.10.2 Significant Findings

Mann-Whitney U tests were conducted to determine any differences between learning preferences for endometriosis based on continuous or ordinal data. There was a significant difference in the age of first period between those who did want to learn more about endometriosis (Median = 12.33) compared to those who did not want to learn more about endometriosis (Median = 13.00), U = 9,025, $z = -2.79$, $p = 0.005$, $r = 0.13$. This represents a small effect size. Groups also differed significantly on their responses to the attitude item 'Menstruation is something to be happy about', U = 16,140, $z = 4.60$, $p < 0.001$, $r = 0.22$. The score was significantly higher for the group who did want to learn more about endometriosis (Median = 3) than those who did not want to learn more about endometriosis (Median = 2); indicating more agreement with the statement. This represents a moderate effect size.

Chi-squared tests were conducted to identify any associations between learning preferences for endometriosis and key nominal variables. There was a significant association between learning preference for endometriosis and school type $\chi^2(2) = 10.936$, $p = 0.004$. Inspection of the standardised residuals indicated that for the school type 'girls independent', significantly fewer participants than expected did not want to learn more about endometriosis ($z = -2.1$), and for the school type 'mixed boarding', significantly more participants than expected did not want to learn more about endometriosis ($z = 2.0$). The association was small, Cramer's V = 0.159, $p = 0.004$ (Cohen, 1988).

A chi-squared test also indicated a significant association between learning preference for endometriosis and overall attitude towards periods $\chi^2(2) = 6.080$, $p = 0.048$. Among participants who had a positive attitude towards periods, a significantly higher proportion of them did want to learn more about endometriosis (9.3%), than the proportion who did not want to learn more about endometriosis (1.6%). The association was small, Cramer's V = 0.119, $p = 0.048$ (Cohen, 1988).

9.11 Chapter Summary

This chapter has provided a breakdown of the results from the survey completed by adolescent girls aged 15-19. To address the research questions arising from the literature review, the results were analysed using both descriptive and inferential statistics where necessary. An overview of the menstrual characteristics of the sample was provided, followed by analysis of girls' help seeking behaviour, beliefs about the typicality of their period, attitudes and communication surrounding menstruation, and understanding of endometriosis. These results will be discussed in the following chapter, in the context of previous research, and in relation to the key objectives of the study.

Chapter 10. Study 2: Discussion

10.1 Introduction

This chapter provides a discussion of the findings from the quantitative study. It reflects on the research questions and objectives of the study and discusses the results in the context of the existing literature. The strengths and limitations of the research are also reviewed. This study aimed to explore the menstrual experience amongst a sample of UK adolescent girls, their perceptions of 'typical' menstruation, and their awareness of endometriosis. In addition, it aimed to summarise their attitudes towards menstruation and their preferences for communicating about it.

10.2 Menstrual Experiences

10.2.1 Age of Menarche

This study characterises the typical menstrual characteristics of a sample of girls aged 15-19 in the West Midlands, UK. The average age of menarche (12.5 years) was slightly lower than recent UK estimates (12.9 years: Millenium Cohort Study, 2016). However, this estimate was based on a sample made up of girls of majority White ethnicity (ibid), and the current sample was made up of a higher proportion of girls of Asian ethnicity, who may be more likely to enter menarche earlier than White girls (Kelly et al., 2017). This was evidenced here, as participants who were White had a significantly higher menarcheal age compared to those who were Asian, and also compared to those who were Black, supporting previous research from the USA (Anderson et al., 2003; Herman-Giddens et al., 1997). A small proportion (7.6%) of the sample had reached menarche before age 11, , which is similar to previous UK findings that approximately 9.5% of girls begin to menstruate before the age of 11.2 years (Kelly et al., 2017). Overall, study findings on average age of menarche were comparable with previous research, thus highlighting their validity.

Average menarcheal age has implications for menstrual health education (MHE) timing. Evidence suggests that many girls in the UK do not receive their formal school-based MHE until they are in secondary school (Plan International UK, 2018), and thus, menarche occurring before such education is received can be particularly distressing. Furthermore, those who reach menarche at a later age, perhaps some years *after* receiving their MHE, can experience a void of information for many years (ibid). This study has highlighted that there can be wide variation in the timing of menarche, with some girls beginning periods before age 9 and others after age 16. Therefore, MHE may need to be ongoing throughout primary and secondary school, as ‘one off’ education sessions are often not suffice (Weckesser et al., 2019).

10.2.2 Menstrual Cycle and Bleeding Length

Most (94.6%) of those reporting their menstrual bleeding length reported a duration of 2 to 7 days, and the median length of menstruation was 5.00 days. These figures are consistent with previous research which found that up to 90% of adolescent girls bleed for 2-7 days (Parker, 2006; Slap, 2003), and an average length of menstruation of 5.93 days (Parker, 2006). Less than half of participants (48.6%) provided a response for their cycle length, which ranged from 0 to 45 days. Of these, 17.3% reported a cycle length of 2 to 7 days, which was likely to be an error, whereby they mistakenly reported the length of a period. A similar proportion of adolescents (19.8%) also made this error in an Australian study (Parker, 2006). These errors may indicate a lack of understanding by adolescents and suggests they may need better education to enable them to differentiate between period length and cycle length. When excluding these responses, the reported length of the menstrual cycle ranged from 21 to 45 days for 98.3% of responders, with a median length of 28.00 days. Most of the girls who answered this question therefore reported a cycle length which is typical during adolescence, between 21 and 45 days (ACOG Committee on Adolescent Health Care, 2015).

Irregular cycles were common amongst this sample, reported by 31.3% of responders. This is high in comparison to previous research with adolescents, in which the prevalence of irregular cycles has varied between 9% (Rigon et al., 2012), 23.1% (Agarwal and Venkat, 2009), and 30.5% (Parker, 2006). Variations between studies may be due to sample age differences; for example, participants in Rigon et al. (2012) had a higher average age, and Agarwal and Venkat (2009) found that increasing age was associated with decreased prevalence of menstrual irregularity. This was also evidenced in the current study, as those with regular menstrual cycles had a significantly longer time since menarche compared to those with irregular cycles. Almost a third of participants (29.6%) did not know the length of their cycle; it is unclear whether this was due to a lack of personal monitoring, or a lack of understanding about the topic.

10.2.3 Period Pain

Period pain was reported by 93.6% of responders, corroborating findings in Australia, in which 93% of adolescents aged 14-19 (Parker et al., 2010), and 92% of young women aged 13-25 (Armour et al., 2020a) reported period pain. The prevalence was slightly higher than in many other adolescent samples, which ranged between 68% (Italy: Zannoni et al., 2014), 73% (Brazil: Pitangui et al., 2013), and 83.2% (Singapore: Agarwal and Venkat, 2009). Two recent international meta-analyses found the prevalence of dysmenorrhea in AYW was 71.1% (Armour et al., 2019b) and 78.5% (Armour et al., 2019a). The wide variation in dysmenorrhea rates between studies is likely due to different ways of measuring dysmenorrhea (De Sanctis et al., 2016). In the present study, the figure (93.6%) includes those who reported pain every month and those who reported pain some months. While clarity on how prevalence rates were deduced is provided in some studies (Armour et al., 2020a; Parker et al., 2010; Zannoni et al., 2014), most of which also provide a total of all those who responded 'yes' to the occurrence of period pain at any frequency, for other studies it is unclear.

Among participants reporting the presence of period pain, 13.9% rated it as 'no/mild pain', 54.8% as 'moderate', and 31.3% as 'severe'. The rate of severe pain sits in the midst of rates found in past research, which is reported at 11.6% (Agarwal and Venkat, 2009), 21% (Parker et al., 2010), and 56% (Rigon et al., 2012). These wide variations may in part be due to different methods of measuring pain severity. Comparable research with adolescents (aged 14-19) using the same measure as this study (Parker et al., 2010), found no/mild pain was reported by 31%, moderate pain by 48%, and severe pain by 21%. Thus, in the current study, rates of 'no/mild' pain were lower, and 'severe' pain higher. Armour et al. (2020a) found corroborating rates to those found here, however they suggest that their higher prevalence of moderate/severe pain may be due to having a wide age range (13-25), and/or the use of online recruitment, which may have attracted those with more severe pain. Neither scenario was true for the current research, and so the prevalence of severe dysmenorrhoea in this sample is critically high. Evidence suggests that severity of dysmenorrhea is unlikely to reduce significantly over time (Weissman et al., 2004), and a considerable number of women with severe dysmenorrhea may develop CPP symptoms in future (Hardi et al., 2014).

10.2.4 Behaviours Related to Menstruation

Most (63.9%) participants reported to have used medication for period pain, a similar rate to comparable research (66%: Parker et al., 2010), but higher than in a recent meta-analysis (48%: Armour et al., 2019a). As found elsewhere (Armour et al., 2021a), most participants managed their period pain with OTC medications rather than seeking a prescription, and the most commonly taken OTC medications were paracetamol (72.2%), and NSAIDs (57.2%). Clinical trials have indicated that paracetamol is less effective at treating period pain than NSAIDs (Marjoribanks et al., 2015), and therefore the higher rate of paracetamol use in this sample may be noteworthy, as they may not be getting optimal pain relief. Most of those taking medication did report moderate (53.6%) to high

(35.1%) effectiveness, however, there did appear to still be some disturbance to activities, as many girls (22.7%) reported school absence due to periods, the most common reason being period pain (90.6%). Previous research has indicated that adolescents/young women often take a sub-therapeutic dose of OTC medication, which might account for some of the continued impact on school or life participation (Armour et al., 2021a). In addition, analgesics are sometimes perceived by girls and their caregivers as being habit-forming, and therefore, their use for dysmenorrhea relief may not be favoured (Agarwal and Venkat, 2009). In the current sample, although the majority of those who reported severe pain took analgesics (87.5%), a minority still did not, and while the reasons for non-use were not addressed in the survey, the potential of medication hesitance cannot be ruled out. It may therefore be necessary for MHE to include pain management strategies for dysmenorrhea, and to dispel the myths surrounding habit-formation (Agarwal and Venkat, 2009; Armour et al., 2021a; Wong, 2011). Furthermore, if education about analgesics can help relieve the pain for some of those who report moderate or mild effectiveness, it may be more evident which girls have pain symptoms that warrant further medical/speciality investigation (Parker, 2006).

As noted above, almost a quarter (22.7%) of participants missed school due to their periods, the main reason being due to pain (90.6%). This aligns with previous evidence by Parker (2006), in which 26% of the sample missed school, 94% of whom stated period pain, and Agarwal and Venkat (2009), who found 24% reported missing school due to dysmenorrhea. Therefore, pain appears to be a significant factor in school absence related to periods. Severe period pain was associated with increased school absence due to periods, as found elsewhere (Agarwal and Venkat, 2009; Armour et al., 2020a; Parker et al., 2010; Pitangui et al., 2013).

Other causes of school absence related to periods were nausea (37%), 'blood flow too heavy' (25%), and sickness (21%), which again is strikingly similar to those of Parker (2006), who found nausea was reported as the reason by 37% of their sample, 'blood flow too heavy' by 24.6%, and vomiting by 13.8%. Finally, some participants indicated their reason for missing school due to periods was ‘other’ and described several physical symptoms such as dizziness, migraines, and tiredness.

In recent years, there has been an acknowledgement of the issue of ‘period poverty’ amongst adolescents, that is, the inability to afford menstrual products (Plan International UK, 2018). Data collected in the UK suggests that 7% of girls regularly miss school because of their inability to afford sanitary products (Procter & Gamble, 2018). This was not reported by participants in the current study; however, the questionnaire largely focused on physical symptoms, and as such they may have assumed those were the aspect of menstruation that was of interest, and not reported it under ‘other’.

Furthermore, the stigma associated with the inability to afford menstrual products (Briggs, 2021) may have meant girls were hesitant to report it.

School absence due to menstruation is an important issue both in the UK and globally. As girls menstruate approximately once a month, it could mean absences occurring regularly throughout the school year. As absenteeism increases, negative educational impacts can occur (Gottfried, 2010). Regular school absenteeism may interfere with academic performance, and thus can negatively influence a student's future (Agarwal and Venkat, 2009). In this study, those who missed school due to their period mainly reported missing 1 day (56%), or 2 days maximum (4%). While this might not appear excessive, there is evidence it can disrupt girls' education, as even just a couple of missed lessons routinely can cause girls to fall behind (Briggs, 2021). Furthermore, study results do not address the issue of 'presenteeism' (lost productivity when present at school), which Armour et al. (2020a) noted as a more prevalent issue in their sample. They found that although 36% of those at school had missed a whole day of school during menses, many more had reported trouble concentrating in class (77%), or not to have performed as well on tests (58%) because of menstruation. Presenteeism is not visible, and therefore is not as easily tracked and quantified as absenteeism (Armour et al., 2020a), and as such, the impact of menstruation on schooling and education may be more complex than the findings in this research suggest. Non-academic activities such as sports participation and physical activities can also be affected by menstruation (Armour et al., 2020a), and thus, observed school absences may only be the tip of the iceberg.

Almost a third of the sample had visited a doctor about their period (29.5%). This is a rate similar to adolescents in Australia (33%: Parker et al., 2010), but higher compared to research with adolescents in Brazil (13%: Pitangui et al., 2013) and Malaysia (14.8%: Wong, 2011). Previous research has found that despite a high prevalence of problematic menstruation, such as dysmenorrhea and disruption to life activities, few adolescents seek medical help for their symptoms (Armour et al., 2021a; Pitangui et al., 2013; Wong, 2011). In the current research, there is some evidence that girls who experienced issues indicating possible problematic menstruation had seen a doctor about their period. Those with severe period pain, those who had missed school due to periods, and those who did not perceive their periods to be 'typical', were all more likely to have seen a GP about their periods. This is encouraging and may suggest that some girls did recognise that their period could be problematic and sought medical help for it.

However, while these associations were statistically significant, they do not highlight that there were many girls with potential problematic menstruation who did not seek medical help. Examinations of the cross-tabular results show that just as many girls who report to miss school due to their periods have not seen a doctor (n=50), as those who miss school and have seen a doctor (n=50). In addition, a higher percentage of those with severe pain have *not* seen a GP (64.1%) than those who have (35.9%). Therefore, this demonstrates that many girls who have potential problematic menstruation, for example severe pain, or missing school due to periods, do not seek medical help for their periods.

There may be several reasons why adolescents do not seek medical help for problematic periods. Firstly, they may initially attempt to self-manage their symptoms with OTC medications (Li et al., 2020). Secondly, adolescents are taught to expect some level of pain surrounding menstruation, and thus, when they experience it, they may believe it is ‘normal’, and not seek medical help (Armour et al., 2021a; Markovic et al., 2008; Wong, 2011). Armour et al. (2021a) found that although 92% of their sample of 13–25-year-olds experienced moderate or greater levels of period pain, with significant disruption to activities (including school absence), more than half of them still thought their period was ‘normal’. Those with more severe pain were less likely to consider them ‘normal’, however it did not translate into help seeking behaviours (ibid). Thus, even when ‘abnormality’ may be recognised, it is not always acted upon. This may be in part due to widely held beliefs that menstrual symptoms of pain are an integral part of female life, and should therefore be endured, even if they are severe (Armour et al., 2021a; Markovic et al., 2008; Wong, 2011). In addition, adolescents may be embarrassed to disclose menstrual concerns to a doctor (Ackard and Neumark-Sztainer, 2001). Seear (2009a) found this hesitance to discuss menstruation, even with healthcare professionals, is part of the practice of upholding ‘menstrual etiquettes’ (Laws, 1991), to avoid the stigma (actual or anticipated) that might occur following disclosure.

Another potential factor in hesitance to help-seeking may be that when adolescents do seek help, their pain is often normalised (Li et al., 2020), which may deter or disillusion them for pursuing it further (Armour et al., 2021a). Dysmenorrhea is the most common gynaecological complaint in adolescence (De Sanctis et al., 2016), and doctors have stated they may prefer to treat such complaints with caution initially, perhaps with medication, so as not to trigger anxiety (Dixon et al., 2021). However, adolescent girls may view such encounters differently, feeling their health issues are not taken seriously, and instead just being given a ‘quick fix’ option such as medication (Gupta et al., 2018).

This study captured novel data on the outcomes of adolescents’ doctor’s appointments for menstruation, and their opinion of their care. Half (50%) of those who reported seeing a doctor were given medication, 39.2% were told to return if the problem persisted, and 8.5% were told it was fine/normal. Most girls (72.1%) felt reassured by their visit, but over a quarter (27.9%) did not. The main reason reported for this was that their symptoms were not resolved. The other primary reasons were a lack of information or explanation given by the health professional, feeling their symptoms were dismissed or normalised, finding medication ineffective, and that no treatment was offered. This suggests that some girls may have felt disillusioned following the doctor’s visit (i.e. not believing the healthcare professionals can help), or that they had had their symptoms normalised. Implications of this may be a reduced likelihood of returning to see a GP if symptoms persist (Igler et al., 2017).

Further medical investigation (specialist referral or other investigation) occurred very rarely in this sample, in 12.3% of those who had visited a doctor about periods, or only 3.6% of the entire sample. This finding was also highlighted by Parker et al. (2010) in their adolescent sample, of whom 33% had seen a doctor regarding menstruation and only 9% (of the entire sample) had been referred to a specialist for further investigation. Furthermore, less than 1% of their sample had received a clinical diagnosis (i.e. endometriosis or PCOS). Given their large sample size (1051 girls), it would be expected for more than 1% of them to have a clinical diagnosis (ibid), particularly since the prevalence of PCOS in adolescence is between 3.4% and 11% (Naz et al., 2019) and the prevalence of endometriosis in adolescents with severe dysmenorrhea is 12.3% (Ragab et al., 2015) to 18.6% (Knox et al., 2019). Participants in the current study were not specifically asked to report clinical diagnoses, but in view of these figures, it would be expected that more of them reported further medical investigation.

According to recent guidelines by the National Institute for Health and Care Excellence (NICE, 2017), individuals who report high pain levels and ineffective pain relief from medication may exhibit atypical periods, and a clinical referral for specialist opinion should be considered. The low rate of medical investigation in these adolescent samples may reflect a reluctance of health professionals to refer or operate on adolescents due to their age (Dixon et al., 2021), and perhaps a lack of acknowledgement that serious pathology can occur in this age group (Parker et al., 2010). Doctors may also attempt to treat adolescents in primary care, for example with hormonal contraceptives, before referring them onto secondary care, particularly if they are under organisational pressure to keep such referrals to a minimum (Dixon et al., 2021). The high proportion of those given medication in the current study supports this. In addition, adolescents seeking help from physicians may experience difficulty in providing their menstrual history, because they do not have a long frame of reference against which to assess their symptoms (Slap, 2003). Therefore, if adolescents do seek help for menstrual symptoms, these encounters may not always result in anticipated or effectual outcomes.

10.2.5 Summary

In this section, the menstrual experience of a UK sample of adolescents has been discussed in relation to key literature within the field. Findings largely corroborate those of such literature, reaffirming the wide variation in timing of menarche, the high incidence of dysmenorrhea in adolescents, and the impact of period pain on school attendance. This study has contributed to existing literature, providing important data on an understudied UK population. In doing so it has identified that a critical number of girls report experiencing severe period pain. The study also provides novel data on the outcomes of seeking medical help for periods during adolescence, which contributes to both the field of menstruation research, and that pertaining to endometriosis.

10.3 Perceived Typicality of Periods

In the previous section there was discussion regarding how adolescent girls' perceptions of the 'normality' of their menstrual symptoms might influence their help seeking behaviours. One of the major aims of this study was to explore which aspects of menstruation girls might consider to be 'normal', or 'typical'. Therefore, their menstrual characteristics were analysed alongside their perceptions of the typicality[4] of their period. Many girls (63.1%) believed that their periods were typical for someone their age. This rate is slightly higher than in an Australian study of 13-25 year-old young women (51%: Armour et al., 2021a), and lower than in another Australian study of 14-19 year-old girls (78%: Parker et al., 2010). In the current study, one in 10 girls (10.1%) believed their periods were not typical, which corresponds to 10% of the girls in the Parker et al. (2010) study who stated they were sure there was something wrong with their period. Finally, over a quarter of girls (26.7%) in the present study were 'unsure' if their periods were typical, which may reflect a lack of understanding of what is 'typical'. Individuals reporting non-typical periods were significantly more likely to report irregular periods, severe period pain, taking medication for period pain, finding medication inadequate for pain, taking OCPs, and seeing a doctor about their periods.

There is a dearth of previous quantitative research examining adolescents' beliefs about the normality of their period within which to discuss this data, however Armour et al. (2021a) also found that the young women they surveyed (aged 13-25) were significantly more likely to believe that their periods were 'abnormal' as their pain became more severe. In the multinomial logistic regression model, pain severity was a significant predictor of typicality beliefs ($p < 0.05$). Compared to those who perceived their periods as typical, an increase in pain severity was associated with an increase in the likelihood of being 'unsure' if one's period was typical. In their qualitative research into how young women (aged 18-22 years) conceptualise the normality/abnormality of their menstrual cycles, Wood et al. (2007) found that they described being given scant information about what level of menstrual pain is considered to be 'typical', and therefore had to make judgements based on their own criteria of what

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[4] As outlined in Section 8.6 of the methods chapter, the word 'typical' was used in the survey because of the potential implications of the word 'normal' (the concern and anxiety of them feeling 'abnormal').

constitutes ‘extreme pain’. Even if they believed their pain to be extreme compared to others, they may still have viewed this pain as ‘normal’ for them, if it was all they had ever known. The subjectivity of pain may therefore be a factor in the association between pain severity and being unsure if one’s periods are typical as observed here. In addition, social sanctions on discussing menstruation with others may mean that girls do not discuss their menstrual discomfort with others (Seear, 2009a), and so may be unable to gauge if their level of pain is ‘typical’. Thus, the literature suggests that there may be many contributing factors as to why those who consider their pain to be severe are unable to identify if this is typical or not.

Regularity of cycles was also a significant predictor in the multinomial logistic regression model ($p < 0.05$). Closer examination of the model revealed that in comparison to those that believed their periods were typical for someone their age, participants who reported irregular cycles were 6.1 times more likely than those with regular cycles to believe that their periods were non-typical. In addition, participants with irregular cycles were 2.8 times more likely than those with regular cycles to say they were ‘unsure’ if their periods were typical. There is a high prevalence of irregular menstrual cycles during the adolescent years, which can last for a few years until a more regular pattern begins to develop (ACOG Committee on Adolescent Health Care, 2015; Slap, 2003). However, the association in this research, between having irregular cycles and believing periods are non-typical, may be indicative of a lack of awareness among adolescent girls about how common irregular cycles can be at this age. MHE can put too much focus on the ‘textbook’ idea of a 28-day regular cycle, and research has indicated that if girls’ periods do not adhere to these notions, they may begin to question if there is something wrong (Donmall, 2013; Wigmore-Sykes et al., 2021). Cycle length variability, particularly if unpredictable, has been described by young women to make them question if their periods are atypical (Wood et al., 2007).

The multinomial logistic regression model also showed that in comparison to those who believed their periods were typical, participants who had visited a doctor for their periods were 4.7 times more likely than those who had not visited a doctor to believe that their periods were non-typical for someone their age ($p < 0.05$). It is not possible to infer the direction of causality behind this association, and one can only speculate. It may be that those who believed their periods were non-typical had therefore seen a doctor about them. Armour et al. (2021a) found that 31.3% of their participants had consulted a doctor about the normality of their periods, and believed them to be a trustworthy source of information. Alternatively, it may be that those who had seen a doctor about their periods believed them to be non-typical following the consultation. For instance, half of those who had visited a doctor about their periods were given some form of medication, which may have served to legitimize their concerns about their period.

This research has identified several menstrual characteristics that were associated with girls' beliefs about the typicality of their period. As mentioned, there is little other research to compare these results with, but there is some evidence of associations between typicality perceptions and both pain severity (Armour et al., 2021a) and cycle regularity (Wood et al., 2007). Although no association was made in the current study, Wood et al. (2007) also noted that menstrual bleeding duration was a salient feature in young women's perceptions of normality. This characteristic, along with length of menstrual cycle, were the menstrual characteristics that the young women primarily discussed when assessing the typicality of their period. Wood et al. (2007) believe this is likely because the 'typical' menstrual cycle length (28 days) and bleeding duration (4-6 days) are the aspects of menstrual information that are most frequently provided in written materials and the media and are therefore easy to make judgements upon.

When judging the normality/abnormality of their menstrual cycles, participants in the Wood et al. (2007) study used three broad criteria; if their cycles conformed to what they had learned is normal; if their cycles were predictable based on previous experiences, and; if their cycles were problematic or extreme. The first and third of these criteria relate to learned norms, yet this is troubling given that girls receive very limited information about menstrual experience (ibid). Girls have described their education to be overly focused on the biological aspects of menstruation, and use of menstrual products, with little information given on the actual embodied experience of menstruation (Betty for Schools, 2017; Marván and Bejarano, 2005; Plan International UK, 2018). This has also been confirmed in research with UK teachers about their perspectives on the provision of MHE (Brown et al., 2022). Adolescents therefore receive little information on the range of physical symptoms that may be expected, and thus considered to be within the 'normal' range.

There are some important implications of girls not being able to recognise what is 'typical' and 'atypical'. Without an understanding of what can be expected, girls might worry unduly over something that actually is relatively 'typical' (Donmall, 2013; Wigmore-Sykes et al., 2021). Conversely, they may not recognise if they are experiencing 'atypical' symptoms, and as such may not seek help when they need to (Bodén et al., 2013; Moradi et al., 2014). Without an understanding of what is 'typical', girls may inadvertently allow their menstruation to cause significant disruption to their lives. Armour et al. (2021a) found that despite a significant negative impact on their academic and extracurricular lives, most of their sample (young women aged 13-25 years) believed their period was 'normal'. Furthermore, Houston et al. (2005) found that most of the girls in their study (aged 12-21) believed it was normal to miss school or other activities due to dysmenorrhea. Therefore, believing their periods to be 'typical', girls perhaps do not seek help when they should, which could have consequences for their health and/or educational outcomes.

Further complicating the matter, even if they experience pain that they do believe to be 'abnormal' in comparison to others', they may still consider the pain to be 'normal' for them, particularly if it is all they have ever known (Wood et al., 2007). Pain or other bothersome symptoms may become normalised over time (Armour et al., 2021a). Indeed, research with women with endometriosis has suggested that even if pain is extreme and disruptive, they often just assumed they were 'unlucky' to have such severe pain (Ballard et al., 2006; Denny, 2004b; Moradi et al., 2014). This was also evidenced in Study 1 of this thesis. Wood et al. (2007) found that only if period symptoms were extreme, or were unpredictable and inconsistent, did young women perceive them to be 'abnormal'.

10.3.1 Summary

The findings of this section, along with those from previous evidence, imply that adolescents' judgement around what characteristics of menstruation are typical or not is complex. Pain is subjective and therefore even those who think pain is severe are unsure if their periods are typical. Despite being a common occurrence in adolescence, irregular periods were associated with being non-typical. Therefore, improved MHE which adequately covers the range of possible menstrual experiences, including those which are 'atypical', is needed. Although symptoms such as pain are subjective, MHE could make efforts to contextualise that pain, using examples such as 'pain that is resistant to painkillers', or 'pain that causes you to miss school', because these ideas are not abstract, and thus easier to distinguish. Information on when to consider seeing a doctor would also be useful (Armour et al., 2021b).

10.4 Attitudes and Communication about Menstruation

Previous research with adolescent girls has indicated that their attitudes towards menstruation are overwhelmingly negative (Brooks-Gunn and Ruble, 1982; Burrows and Johnson, 2005; Donmall, 2013; Marván and Molina-Abolnik, 2012; Plan International UK, 2018). In the current research, a minority of girls stated that periods are 'positive' (8.1%), over a third rated them 'negative' (37.6%), and the rest stated they 'don't mind' (54.3%). While this implies a range of views in this sample, the results of the MAQ/AMAQ attitude items suggest a tendency for more negative attitudes. In general, there was more agreement with attitude items that had a negative stance, such as 'Menstruation is something I just have to put up with', whereas those with a positive stance, such as 'Menstruation is something to be happy about', were more commonly approached with disagreement. In a recent systematic review, menstruation was found to commonly invoke a negative emotional response, despite being regarded as part of ‘becoming a woman’ (Barrington et al., 2021). In the current study, while more negative opinions were commonplace, 63.2% of the sample did show some agreement with the item ‘menstruation is a sign of womanhood’.

Previous research has revealed that a prevailing theme amongst adolescent girls is a of fear about ‘leaking’, or the inability to conceal their menstruating status (Briggs, 2021; Burrows and Johnson, 2005; Donmall, 2013; Jackson, 2019; Lee, 2008; Newton, 2016; Plan International UK, 2018). In this study, the majority of girls (57.7%) reported agreement with the item ‘When I have my period, I am worried that I’ll have an accident’, but more than might be expected, given the reoccurrence of this issue in previous research, showed disagreement (28.3%). Finally, there was a high level of agreement (82.2%) amongst participants with the item ‘Menstruation is something I just have to put up with’, perhaps indicating that they find it ‘bothersome’ (Brooks-Gunn and Ruble, 1980). Research suggests that young people in the UK commonly use words such as “annoying” and “inconvenient” when discussing menstruation (Plan International UK, 2018). In this sample of adolescents, there is evidence that negative attitudes towards menstruation are ongoing, and their views align with previous research regarding menstrual attitudes.

The negativity surrounding menstruation is thought to be a reflection of British “menstrual etiquettes” (Laws, 1991) and societal notions of secrecy, stigma and taboo towards menstruation (Costos et al., 2002; Johnston-Robledo and Chrisler, 2013). These taboos refer to the idea that menstruation should be kept hidden, and not talked about, particularly with men. In the current study, most girls reported feeling ‘comfortable’ or ‘very comfortable’ discussing periods with their female friends (86.1%) and female relatives (77.9%), but much less so with their male friends (24.1%) and particularly their male relatives (8.9%). Thus, there may be some evidence of them upholding the ‘menstrual etiquette’ in terms of discussing menstruation with men.

Girls in this sample did not appear to uphold communication taboos with their female friends. Other research has cited the importance of female peers for discussing, sharing, and learning about periods with (Plan International UK, 2018), and in particular they can provide information pertaining to the ‘reality’ of periods (Kissling, 1996; Newton, 2016). However, some research has indicated that when girls do discuss menstruation with each other, they are often ‘commiserating’ or receiving support from one another about the negative aspects of it (Cooper and Koch, 2007; Jackson and Falmagne, 2013), which may inadvertently sustain the negativity, stigma, and taboos associated with menstruation.

In addition to feeling comfortable discussing menstruation with female relatives, many girls reported that they first learned about menstruation from their mothers (43.2%) or another female relative

(22.7%), and they were a key source if further information was sought (34.8% and 17.3% respectively). In comparison, 24.7% of girls reported school as their first information source. This suggests that many girls receive 'informal' education about menstruation from their mothers/female relatives before they receive their 'formal' education. Mothers are often seen as a key source of information about periods (Plan International UK, 2018; Wigmore-Sykes et al., 2021). They are often a source of emotional support at menarche (Lee, 2008), and can empathise with some of the symptoms girls experience. However, they can sometimes unwittingly encourage notions of silence and concealment, and may also pass on myths and taboos (Beausang and Razor, 2000; Costos et al., 2002). Even if mothers do provide positive messages, they may take daughters aside to have 'the talk', away from other family members, which may reinforce that it is something to be kept a secret (Kissling, 1996). A recent England based study highlighted the potential for parents to transmit stigma, as they made very negative comments about an online video made by a group of girls at a school which addressed the embarrassment about menstruation: "*If you look at the video the girls did and look at the comments […] there were some lovely comments! (with sarcasm). There was: "Oh, is nothing sacred?"; "Why are we talking about this?" and "This is disgusting!" And this from women!"* (Vice Principle: Briggs, 2021).

Although almost a quarter of participants first heard about periods at school, a very small minority reported that they would seek further information about periods at school (2.7%), and as discussed further below, only a quarter (27%) were comfortable in discussing endometriosis with teachers. This ambivalence towards discussing menstruation with teachers has been highlighted elsewhere; only 20% of teens in a UK sample felt comfortable discussing their period with teachers (Plan International UK, 2018), and only 20.7% of young women in an Australian sample reported to trust their teachers as a source of information about periods (Armour et al., 2021a). This discomfort goes both ways; Brown et al. (2022) surveyed teachers about the delivery of MHE in schools in the UK, less than half of whom (47%) felt comfortable teaching MHE, and almost a quarter of whom (23%) were not comfortable. It is worth noting the possibility of bias in this sample of teachers, as it could be the case that only those who were comfortable/confident, or had an interest in the menstrual cycle participated in the survey, and thus teachers may be less comfortable delivering MHE than these results imply (Brown et al., 2022). A large majority of teachers (80%) reported that they would benefit from additional training in the provision of MHE (ibid).

In the current study, the internet was highlighted by almost a third of girls as a source for additional information about periods (30.5%), second only to mothers (34.8%). In a series of focus groups, girls have described the internet as a platform for talking openly about menstruation, providing peer support, and validating each other's experiences (Plan International UK, 2018). The anonymity thus allows them to talk about 'taboo' subjects' (ibid). In an Australian study (Armour et al., 2021a), almost half of young women surveyed (49.8%) used the internet to determine if their periods were 'normal', and as such it was the most popular source (36.3% discussed with their mother and 31.1% with their doctor). While the internet is a readily available and valuable resource, there is little way to vet the resources, and so teens might be subject to a lot of misinformation (Plan International UK, 2018). In addition, young people might be subject to derogatory comments or portrayals of periods online and on social media, which reinforce negative stereotypes (Plan International UK, 2018; Thornton, 2013; Tomlinson, 2021).

10.4.1 Summary

A minority of girls (8.1%) believed that periods were 'positive', and there was evidence of negative attitudes, stigma, and the upholding of communication taboos regarding menstruation among this sample. Most girls identified a female family member as their first source of information about periods, however literature suggests they may (sometimes unwittingly) convey stigma towards menstruation. Formal school based MHE has the potential to deliver education in a non-stigmatised way, however evidence suggest that adolescents find MHE at school to be awkward, and girls in this study showed a preference for the internet (30.5%) over lessons at school (2.7%) for learning more about menstruation.

10.5 Awareness of Endometriosis

One of the major aims of this research study was to explore the awareness of endometriosis amongst a UK sample of adolescent girls. In this sample, 10.1% stated they knew what endometriosis was, and 8.2% were able to provide an accurate description. These figures are considerably lower than previous research conducted abroad, with awareness approximately half that found in Italian girls aged 14-20 (18.8%: Zannoni et al., 2014), and a third of that in Australian girls aged 14-19 (23.6%: Parker, 2006). Furthermore, the awareness of endometriosis in this study was significantly lower in comparison to more recent research in Australia, which is likely to have been conducted at a similar time point to this study, in which more than half of those girls attending school (52.8%) had heard of endometriosis (Armour et al., 2021a).

The much lower rate in the current study may reflect a lower awareness in the UK compared to in other countries, demonstrating the critical need for improved awareness and education around endometriosis in the UK. Improving individuals' awareness of endometriosis may help improve time to diagnosis, and given that many with endometriosis first begin to experience symptoms during adolescence (Greene et al., 2009; Manderson et al., 2008), then targeting educational interventions at this age is crucial. The average delay from symptom onset to diagnosis in the UK is 8 years (Ghai et al., 2020), a figure which has remained constant over the last 3 decades (Hadfield et al., 1996). Yet, diagnostic times appear to be decreasing elsewhere; in the USA the average delay in 1998 was 9 years (Greene et al., 2009), a figure which has halved in more recent research to 4.4 years (Soliman et al., 2017). Similar trends are also being seen in Australia, where specifically those whose symptoms have started more recently, have presented for medical help sooner (Armour et al., 2020b). This may reflect an increased awareness of the symptoms of endometriosis, and the encouragement to seek help, following the efforts of advocacy organizations in Australia (Armour et al., 2020b). Despite similar efforts by Endometriosis UK, these trends are yet to be observed in the UK.

In addition to possible awareness rate differences between countries, the lower awareness in this research may in part be due to the way in which it was measured. The studies with which we have been comparing, measured awareness at a more surface level, asking their participants if they had ever 'heard of' endometriosis, without further embellishment. This measure does not necessarily equate to having any knowledge or understanding of endometriosis. The current study purposely aimed to assess awareness in more depth, to identify not only the rate of awareness of endometriosis amongst adolescents, but what they actually know about it. Thus, the survey asked "Do you know what endometriosis is?", followed by a request to describe it in their own words. This revealed that 10.1% (44/437) stated 'yes', they knew what it was, but only 8.8% (36/438) could provide a description which accurately captured some aspect of it. Using this more rigorous method, it is evident that awareness may be a lot lower than has previously been identified.

Shadbolt et al. (2013) used a similar method to ascertain awareness and communication needs of endometriosis in a sample of young women aged 16-25 in Australia. They found that 52% of their sample had heard of endometriosis prior to survey completion, although among those aged 16-18 it was only 33%. This is higher than in the present study, however they recruited participants online and used an online survey, so it may reflect a motivation bias to complete a survey about endometriosis by those who had already heard of it (endometriosis was mentioned in the recruitment advert). When asked to provide descriptions of endometriosis, most of their sample were unable to provide an accurate description, although they did not classify descriptions according to their accuracy. Similar to findings in this research, descriptions in the Shadbolt et al. (2013) study (including the inaccurate ones) were mostly based on symptoms of endometriosis (11%), biological mechanisms of endometriosis (52%), or a combination of the two (37%). However, in the current study, symptoms were the most salient aspect of endometriosis described by the sample (14/46 responses, 30%), followed equally by biological mechanisms and a combination of both (each 11/46, or 24%). Both studies found pain to be the most frequently described symptom of endometriosis. It is worth noting that through personal communication with the authors of the Shadbolt et al study, copies of the study information sheet were obtained, and in such, participants were given information about endometriosis. Therefore, it is difficult to ascertain what their knowledge and understanding of endometriosis would have been without the description they received prior to survey completion.

Regardless of the reason, the rate of awareness observed in this study is very low. In fact, less adolescents have awareness of endometriosis (8.8%) than may experience it in their lifetime (assuming the prevalence is approximately 10% of women of reproductive age: Eskenazi and Warner, 1997). Furthermore, this is particularly interesting when compared to adolescent awareness of other health conditions. As identified by Austin et al. (2002), adolescents in the general population have shown comparatively high familiarity with asthma (88%), arthritis (84%), diabetes (81%), HIV/AIDS (78%), and breast cancer (72%); and approximately one-third are familiar with Parkinson’s disease (39%) and epilepsy (31%). Girls are considerably less aware of endometriosis than other chronic conditions which have similar adult prevalence rates, such as diabetes and epilepsy.

While most participants did not know about endometriosis (91.8%), a small number (8.2%) showed some awareness. Further analysis revealed that those that knew about endometriosis were more likely (than those that did not know) to use medication for period pain, to have ever used the OCP, and to have visited a doctor about their periods. In addition, compared to those who did not know, they had significantly lower age at menarche, and significantly higher severity of period pain scores. These findings are interesting, particularly given that endometriosis itself is associated with severe menstrual pain, lower age at menarche (Nnoaham et al., 2012), and use of OCPs to treat painful menses in adolescence (Chapron et al., 2011a). This therefore begs the question of whether having knowledge of endometriosis might reflect having experienced some aspect of problematic menstruation. The participants may therefore have investigated endometriosis themselves or heard about it from a doctor. However, only 2 of those who stated knowing what endometriosis was had heard about it from a doctor (4.7%), therefore suggesting the latter is unlikely.

The girls in this study identified the internet or other media as their most common source of information about endometriosis (21/43). This is in contrast to findings from Shadbolt et al. (2013), who found that girls identified friends, doctors, and then parents most often. In both studies, school was identified as an information source at similarly low rates, of 18.6% (current study) and 13% (Shadbolt et al., 2013). The finding of the media/internet as the key source of information about endometriosis in the current study is not unexpected. Almost all teenagers (98%) have access to the internet (ONS, 2018) and are social media users (96%: ONS, 2017). Over the past few years, several high-profile celebrities have publicly talked about their experiences with the condition, often using social media, upon which they have millions of followers, as their outlet. For example, Lena Dunham used Facebook to reveal to her fans that she has endometriosis, and has documented her journey on such platforms (Moore, 2016). She openly discussed her hysterectomy due to endometriosis in 2018. Whether a consequence or coincidence, the search term "What is endometriosis?" was the third highest trending health related search on Google in 2018 (Welch, 2018). There are more than 400,000 Google searches on endometriosis per month in the United States alone (Hirsch et al., 2017). Furthermore, teenagers are increasingly using the internet to seek health information, they trust the information, and even modify their behaviour accordingly (Ettel III et al., 2012). However, the issue with the internet as an information source is the lack of high-quality, accurate, and credible information available on there (Hirsch et al., 2017). That which does meet such criteria is often difficult for a lay audience, and therefore maybe teenagers, to understand. Therefore, platforms other than the internet, may be a more appropriate source for adolescents to learn about endometriosis.

School may be such a platform. This research showed that most girls did want to know more about endometriosis (85.1%), and school lessons were the preferred mode of learning about the condition (41%). However, girls reported to be less comfortable speaking with their teachers (27%) than with school nurses (37%), doctors (44%), friends (56%) or parents (64%) about endometriosis. Similar tendencies were identified by Shadbolt et al. (2013), who found that teachers were the least preferred person with which to discuss endometriosis. Adolescents often report preferring outside experts (specialists, youth workers, sexual health professionals, etc.) to deliver this content (Pound et al., 2016; Shadbolt et al., 2013). Such an approach has been used in New Zealand, where a menstrual health and endometriosis educational program has been delivered in secondary schools by trained educators working for Endometriosis New Zealand (Bush et al., 2017). The program is delivered to girls and boys, and aims to help girls identify symptoms that stray from the norm, as well as to increase the awareness of endometriosis, and reduce stigmas and taboos about menstruation. Since its implementation in 1998, awareness of endometriosis among students in targeted regions has increased from less than 10%, to between 32-41% in 2015 (Bush et al., 2017). Furthermore, data from one region which has consistently delivered the program, shows an increase in the proportion of younger patients attending for specialised endometriosis care.

An educational program such as that used in New Zealand (Bush et al., 2017), which delivers education about endometriosis, and also targets the stigmas and taboos associated with menstruation, is warranted in the UK. As discussed in the previous section, there is some evidence that the girls in this study do display negative attitudes towards periods. These attitudes themselves may affect how girls approach their MHE, as wanting to learn more about endometriosis was associated with a positive attitude towards periods, and more agreement with the statement ‘Menstruation is something to be happy about’. If attitudes are associated with educational engagement, then there is a need to address negative attitudes to ensure that girls do not miss out on the education that could help them to identify any problematic symptoms they might experience. In addition, preferences for learning more about endometriosis were associated with school type: all of the girls at the female-only school stated they wanted to learn more about endometriosis, compared with 80% of those at the mixed boarding school. Research has indicated that girls worry about being shamed at school about their periods, particularly by boys (Newton, 2016). The majority of girls in the study did feel that boys should learn about endometriosis (85.1%), and inclusion of boys in general MHE could reduce period-related bullying (Bodyform, 2018; Plan International UK, 2018). Therefore, striking a balance between ensuring girls’ comfort, whilst also providing adequate MHE to both boys and girls, is necessary.

10.5.1 Summary

Endometriosis researchers (Cox et al., 2003c; Manderson et al., 2008; Markovic et al., 2008) and charitable organisations have argued for some time that there is little awareness of endometriosis, and the results of this study have confirmed this, as only 8.2% of participants had some (even basic) level of awareness. There was a significant association between wanting to learn more about endometriosis and severity of period pain, however, as most girls wanted to learn more (85.1%), it suggests that regardless of their symptoms, girls want to know about things that can and do affect them or their peers/families. Improving adolescents’ awareness may enable them to identify symptoms suggestive of endometriosis and seek help sooner. This is an imperative part of reducing the long diagnostic delays associated with endometriosis.

10.6 Strengths and Limitations

This study has several strengths and limitations. One strength was the large and ethnically diverse sample; nearly half (49.1%) of participants identified as Asian, 35.8% as White, 10.7% as Black, and 4.4% as Mixed Race. Such diversity is important, given that menstrual experiences of ethnic minority populations living within countries in the Global North have been previously underrepresented in similar research, which tend to be of majority White ethnicity (Armour et al., 2020a; Armour et al., 2021a; Parker, 2006; Parker et al., 2010; Shadbolt et al., 2013; Zannoni et al., 2014). However, the research intended to study the UK population, and this ethnically diverse sample might be more representative of a more local (Birmingham) population, rather than being representative of adolescents within the UK as a whole.

The study survey was modelled on those from similar research (Parker, 2006; Parker et al., 2010; Shadbolt et al., 2013; Zannoni et al., 2014), which therefore enabled direct comparisons, and meant many of the questions had already been piloted with the intended demographic (Bryman, 2016). However, a limitation was an absence of validated questionnaires to draw upon. Despite the pilot study indicating that the survey was fit for the purpose, some main survey respondents confused the length of their period with the length of their menstrual cycle (which resulted in 37 respondents reporting menstrual cycle lengths between 2 and 7 days). However, this issue also arose in similar research (Parker, 2006; Parker et al., 2010), and may further support the argument that adolescents need better education about menstruation, as perhaps they are unaware of the difference between these two terminologies. It must also be acknowledged that taking individual items from scales (i.e. the A-MAQ and MAQ) could adversely affect the reliability of the scale. In this survey, the aim was to provide a brief indication of attitudes as opposed to a full representation of a construct, however this must still be considered as a limitation.

When asked to describe endometriosis in their own words, 23 respondents linked endometriosis to pain in their descriptions, which they may have deduced from earlier survey questions, which focused on their period pain experiences. However, as only 5% of the total number of participants surveyed responded to this question with an answer including pain, it does not appear to have overly influenced the results on endometriosis awareness. Furthermore, if it was to have had an influence, it would suggest that awareness is actually worse than indicated in these findings. It is also worth considering that a higher number of girls may have reported wanting to learn more about endometriosis because it was introduced to them in this survey, thus increasing the salience of this item. However, the proportion of those wanting to learn more (85.1%) is comparable to that of similar research (89%: Shadbolt et al., 2013).

The overall participant response rate was somewhat low (53%), however, as recruitment (information provision and data collection) was often facilitated by school staff/teachers, it is not possible to calculate a true response rate. One of the response rate barriers was the use of active parental consent by one of the schools, whose response rate was markedly lower (27.9%) than the two schools who used passive parental consent (47.8% and 71.3%). Previous research with adolescents has indicated that passive parental consent can facilitate both a higher rate of participation and a more representative sample (Spence et al., 2015).

The use of a pen and paper survey was time consuming and entailed more work for the schools to facilitate. Girls may have also been concerned about their anonymity using such a method. These factors may potentially have impacted sample size. Those conducting similar research have used online survey tools, resulting in much larger sample sizes (Armour et al., 2021a). This was considered in the design of the research, however it was felt that using the pen and paper method would produce more robust data, particularly with reference to girls' understanding of endometriosis. As this was a key aim of the research, this was deemed a worthwhile sacrifice. It enabled a more genuine measure of the level of awareness of endometriosis amongst adolescent girls.

The survey did not include questions regarding girls' experience of heavy menstrual bleeding, a common adolescent concern (Friberg et al., 2006; Revel-Vilk et al., 2012) and possible symptom of underlying pathology . Heavy menstrual bleeding (HMB) was only asked about in relation to school absence, but was not assessed any further. However, 5 participants reported taking tranexamic acid when asked about medications for period pains, a treatment specifically for heavy periods. This would therefore warrant investigation in future research.

The survey only asked about the frequency of OCP use but did not ask about the use of any other menstrual management or contraceptive medications (e.g., intrauterine devices, contraceptive injections, etc). The frequency of OCP use was low in this sample (13.7%) compared to previous UK research (Rashed et al., 2015), which suggested that 19% of girls have received a prescription for OCPs. It is possible that OCP use could have influenced cycle length, perceived cycle regularity, and pain levels; however, as described above, the percentage of the sample using OCPs was low.

Painful periods were reported by the majority of girls, and the occurrence of 'severe' period pain was particularly high (31.3%). There is the possibility of bias within this sample, in that those with particularly problematic periods were more motivated to participate. However, given the lack of research on dysmenorrhea and other menstrual symptoms conducted in the UK, it is difficult to establish if the pain severity of this sample differs from that of the general population. More research is needed in this area.

10.7 Conclusion

To knowledge, this is the first UK research to characterise typical menstrual experience among adolescent girls, as well as their perceptions of typical menstruation and knowledge of endometriosis. It has highlighted that most adolescent girls experience moderate to severe menstrual period pain; many miss school due to their periods; many do not know whether their periods are regular or typical, and an overwhelming majority have no knowledge of the common chronic condition endometriosis. This latter finding is of critical importance, as it provides clear evidence of what adult women with endometriosis have been stating for years, that there is little awareness of endometriosis (Cox et al., 2003c; Manderson et al., 2008; Markovic et al., 2008). Findings demonstrate the critical need for better MHE provision to improve girls' knowledge of typical menstruation and pain management options, and the inclusion of content on endometriosis and other menstrual health conditions. Such provision is key to improving girls' menstrual health literacy, experiences, and outcomes. The implications of this research, and recommendations for future research, are discussed in Chapter 11.

Thesis Part 4: Recommendations and Conclusion

Chapter 11. Recommendations and Conclusion

11.1 Introduction

This thesis took a pragmatic approach to the study of endometriosis in adolescents. A thorough review of past research highlighted areas for further exploration, and as such, the research questions were devised. Adopting a feminist lens ensured that the research questions were centred on the lives of women and had the potential to advocate for social change. These research questions stemmed from the same evidence base, and therefore were interrelated, but they addressed slightly different populations, and were therefore best approached by conducting two separate studies. Study 1 was a qualitative study exploring the experiences of endometriosis in adolescents. Study 2 was a quantitative study, identifying the menstrual characteristics and awareness of endometriosis among adolescents attending secondary school. The discussion chapters for each study (chapters 7 and 10) addressed the research questions, discussing research findings at length, and in the context of previous literature. This final chapter draws together the results from Study 1 and Study 2 to summarise the implications of the thesis. This includes the implications for practice and the recommendations for future research. In the conclusion, I demonstrate the contribution to the literature, and the benefits of conducting these two studies for the research field.

11.2 Summary of Key Findings

Study 1 showed that the symptoms of endometriosis in adolescence are wide-ranging, and significantly interfere with many aspects of life, including school, work, sport, social life, and relationships. Adolescents face a long delay in obtaining a diagnosis, which is contributed to by a widespread lack of awareness of endometriosis and frequent dismissals by health professionals. One of the most crucial findings of Study 1 was how adolescents' experiences are significantly shaped by their age and life-stage. Drawing on Bury's (1982) concept of 'biographical disruption', this study demonstrates how endometriosis not only impacts many of the key aspects of adolescent life, but also threatens their self-concept as a teenager/young adult, and their life-trajectories, and thus, the concept of 'biographical threat' was introduced. Adolescents' support and information needs regarding endometriosis are often unmet because they are not tailored to this life-stage.

The findings of Study 2 highlighted that most adolescent girls experience moderate to severe menstrual period pain; many miss school due to their periods (most often due to pain); and many do not know whether their periods are regular or typical. There was also evidence of stigma and taboos surrounding menstruation among surveyed girls, and particularly towards discussing menstruation with males and teachers. Finally, an overwhelming majority (92%) had no knowledge of endometriosis, and most (85%) would like to learn about it given the opportunity.

11.3 Implications for Policy and Practice

These study findings lead to two overarching recommendations; 1) an increased effort to provide de-stigmatised MHE to all, and 2) to provide an age-based approach to endometriosis healthcare and support. In the sections that follow, recommendations are made and evidenced using study findings, and additional literature where required.

11.3.1 Key Recommendation: An Increased Effort to Provide De-stigmatised Menstrual Health Education to all Adolescents

A key finding of this thesis, evidenced in both Study 1 and Study 2, is the need for better menstrual health education (MHE) for adolescents in UK. In Study 1, many adolescents described their school based MHE negatively, stating that it was overly focussed on the practical and biological aspects of menstruation, with little information on the actual experience of periods. These findings are consistent with other UK based research with adolescents (Betty for Schools, 2017; Plan International UK, 2018), and with teachers, who reported on the provision of MHE in their schools (Brown et al., 2022). Without this kind of information, participants in Study 1 discussed being unable to recognise that their symptoms were problematic; they learned to expect some pain and discomfort, and thus they believed that the pain they were experiencing was 'normal'. They relayed that they would have liked more information about what is considered 'normal' or 'abnormal', and how much period pain should hurt or interfere with life. There is further support for these qualitative findings within the quantitative findings. For example, in Study 2, although most girls (68.7%) experienced 'moderate' or 'severe' period pain, many (63.1%) thought their periods were 'typical'. Furthermore, over a quarter (26.7%) were 'unsure' if their periods were typical, which may reflect a lack of understanding of what is considered 'typical'. Therefore, as well as an understanding of the biological aspects of menstruation, girls need MHE that includes the actual lived and bodily experience of having a period, and what might be considered within a typical range.

An implication of the lack of knowledge about menstruation is that girls are not always aware of how to manage their symptoms. In Study 1, adolescents with endometriosis stated that their beliefs that symptoms were just 'normal menstruation' contributed to their delays in obtaining medical help. In

Study 2, there was evidence that many girls with potential problematic menstruation (i.e., reported severe pain or missing school due to periods) did not seek help for their periods either. Thus, these findings suggest that without an understanding of what aspects of menstruation are considered 'normal', adolescent girls are not aware of when they should seek help for their symptoms. Furthermore, previous research has indicated that adolescents often take a subtherapeutic dose of OTC medication to manage dysmenorrhea, or take less effective medications (Armour et al., 2019a; O'Connell et al., 2006). There was some support for this in the current study, as girls more commonly used paracetamol rather than NSAIDs, therefore strengthening these researchers' recommendations on the need for MHE to include dysmenorrhea management. Painful periods appear to be a significant problem in this age group; they affect school attendance and possibly school performance. It is therefore important to provide relevant education to adolescents about the effective treatments that are available for dysmenorrhea, and when to seek further help if these fail.

As evidenced in both studies, adolescent girls are largely unaware of endometriosis. The adolescents in Study 1 described their lack of education about endometriosis; none of them had heard about it at school. Most participants only learned about it by doing their own research online, and some first heard of it during a consultation in secondary care, or even at diagnosis, supporting findings in other research with adolescents with endometriosis (Bodén et al., 2013; Moradi et al., 2014). Qualitative study participants stated that had they known about endometriosis, they would have got help sooner, and that when help was sought, they would have pushed for more to be done. Adding further weight to these findings, in Study 2, only 8.2% of participants had some (even basic) level of awareness about endometriosis. Participants in Study 1 all discussed the need for endometriosis to be taught about at school, which, given their experiences with the condition, is unsurprising. However, 85.1% of those in Study 2 stated they wanted to learn more about it as well. This indicates that most girls want to know about the things that can and do affect them or their peers/families, even if they may not personally be affected. This research has therefore demonstrated the critical need for MHE provision to improve girls' understanding of common gynaecological conditions, such as endometriosis and PCOS. Improving adolescents' awareness may enable them to identify symptoms suggestive of endometriosis and seek help sooner. This is an imperative part of reducing the long diagnostic delays associated with endometriosis. Increased awareness among adolescent girls may also enable those affected to receive more support from peers and teachers, which those in Study 1 felt was lacking.

This research has provided further evidence of the ongoing stigma, taboos, and negative attitudes towards menstruation in England. In Study 1, participants spoke of their embarrassment in discussing menstruation with others. This stigma may have contributed to diagnostic delays; they did not confide about their symptoms to others, and therefore missed the opportunity to compare menstrual experiences, and to identify a problem. In Study 2, many girls stated they thought periods were negative (37.6%) or expressed ambivalence about them (54.3%). Most girls had concerns about 'leaking' and were uncomfortable discussing menstruation with males. Although not investigated here, menstrual stigma such as this can negatively impact girls' education and health. Many girls worry about going to school when on their period; they fear boys knowing, and about getting teased by them (Bodyform, 2018). Girls report being unable to concentrate in class due to a fear of leaking and may also miss out on sports participation (Plan International UK, 2018). Some girls are hesitant or embarrassed to discuss menstruation even with doctors, and consequently may not receive treatment for period pain and/or menstrual related conditions (Burrows and Johnson, 2005).

'Formal' MHE, such as that provided at school, has the opportunity to deliver the key information girls need about menstruation, without conveying the stigma and taboo. The timing of education is critical; Study 2 identified a wide age range for menarche (<9 years to >16 years), and therefore MHE needs to start in senior primary school and continue on an ongoing basis throughout secondary school. It needs to be delivered to boys and girls, using a mixture of mixed and single sex group sessions, to ensure that boys are informed, and that girls have a safe space to discuss their concerns (Plan International UK, 2018). However, girls often display discomfort talking to their teachers about menstruation. For example, in Study 2, while the most popular source of education for endometriosis was at school, teachers were the least popular person with whom the sample would like to discuss endometriosis. Therefore, outside experts maybe best placed to deliver MHE (Pound et al., 2016). Using information sources that adolescents prefer to access, such as the internet, may also facilitate their learning (Shadbolt et al., 2013). Preliminary findings of a web-based intervention used in Australia suggest that such a tool can help improve health literacy, and assist young women to identify when they need to seek medical advice (Armour et al., 2021b). Such a tool may be best used in conjunction with school based MHE, to ensure that education is received by all, and not only those willing to engage in an online intervention.

It should be noted that since this research was conducted, provision was made for MHE to become mandatory in primary and secondary schools in England from September 2020 (Department for Education, 2020b). In this guidance, it outlines that education should be provided to all pupils, regardless of gender, and that pupils should know about menstrual wellbeing, and key facts about the menstrual cycle. In secondary school, guidance states that pupils should be taught about menstrual conditions, including endometriosis, and to be able to understand what is meant by 'normal', how to recognise problems, and when to seek help (Department for Education, 2020a). There has been no formal evaluation yet on whether these changes to MHE provision have improved the menstrual health literacy of adolescents.

11.3.2 Key Recommendation: An Age-based Approach to Endometriosis Healthcare and Support

These recommendations are based on the evidence from Study 1, relating to adolescents' experiences of endometriosis. Adolescence is a distinct stage within the life cycle, and adolescents' experiences of endometriosis reflect this. The results of this study indicate that their priorities and concerns about symptoms appear to differ to adults. Certain symptoms, such as pain, heavy bleeding, bowel issues, and painful tampon use, appear to be particularly disruptive during this life-stage. However, research with adult women has highlighted infertility as a key complaint (Culley et al., 2013; Hudson et al., 2016; Jones et al., 2004c). Differing symptom priorities may mean that adolescents' treatment priorities also differ, and suggests that they would benefit from an age-based approach to their endometriosis healthcare.

Such an approach could also facilitate the detection of symptoms that are more specific to this age group. For example, participants in this study reported pain with tampon use, which may be particularly relevant in a younger demographic, because although this pain is associated with dyspareunia (Landry and Bergeron, 2009), tampon use is likely to precede the onset of sexual activity and may be present in those who are not yet sexually active. This may therefore be something medical professionals could enquire about when assessing younger females presenting with other symptoms suggestive of endometriosis. Although unlikely to be a symptom that is constrained to adolescents, a recognition of the symptom in this age group may indicate medical professionals' awareness of the particular issues relating to adolescents, which may also facilitate the doctor-patient relationship (Grinyer, 2007).

As part of an age-based approach to care, adolescents with endometriosis would also benefit from more age-specific information and support, which participants in this study felt was lacking. Information needs to be targeted towards issues that are relevant to adolescents in their life-stage, and presented in a manner that is cognisant with their level of development. Their biographies and life-trajectories are significantly disrupted at a crucial moment, which can have a lasting impact on their lives, and an effect on their emotional well-being. An awareness of these age-specific issues from healthcare professionals may mitigate this effect (Grinyer, 2007). Adolescents may also benefit from support services specifically tailored for their age group. While support from others with endometriosis is valuable, the support needs of adolescents are very different to those of adults with endometriosis, and participants in this study stated they would value supportive connections to those *with* endometriosis, but of a similar age.

As consistently reported in previous endometriosis research, adolescents in this study experienced a significant delay in obtaining a diagnosis, which was lengthier at the 'medical level'. This research was conducted around the same time that the NICE guidelines were updated to acknowledge the occurrence of endometriosis in this age group (National Institute for Health and Care Excellence, 2017), and as such might not reflect any changes to care brought on as a result of this update. However, recent evidence obtained from doctors suggests that they may prefer to be cautious when treating younger women, so as not to trigger anxiety (Dixon et al., 2021). Researchers have also suggested there may be a higher threshold for performing laparoscopies in adolescents due to their invasive nature (Dunselman et al., 2014; Saridogan, 2017). However, as illustrated in this research, not having a diagnosis itself causes issues, including an inability to explain absences to others, an impact on mental health, and an inability to access appropriate support. Therefore, adolescents may benefit from being included in open discussions about their options, so that they can make an informed decision about having diagnostic surgery, rather than assumptions being made on their behalf. They may also benefit from having a working diagnosis of endometriosis, to enable support access, and to legitimise school, work, or social absences (Ballard et al., 2006).

11.4 Recommendations for Future Research

The narrative review in Chapter 3 of this thesis highlighted the dearth of research addressing adolescents' experiences of endometriosis. Study 1 of this thesis has provided a valuable contribution to this field, but in order to strengthen the recommendations arising from this research, some areas require further exploration. Firstly, in addressing the limitations (see Section 7.6), it is imperative for future research to aim to include the experiences of those from a wider range of demographics, including those under the age of 18, those from racially and ethnically minoritized communities, and those from the LGBTQIA+ (lesbian, gay, bisexual, transgender, queer, intersex, and asexual) community. The findings in this study may not have captured any unique challenges these communities might face.

It would also be beneficial for future research to further explore the support networks of adolescents with endometriosis. All participants were recruited from support groups, of either a face-to-face or virtual format. Participants spoke of turning to online support because they craved connections with those who understood. This research therefore might not represent the views of girls who do have a good support network. It was clear from the findings in Study 1 how valuable the girls found the support from their mothers; they provided emotional support, accompanied them to medical appointments, and often played an advocative role for their daughters. All of those involved in the study had a mother, and their experience may have been very different if they did not. Therefore, future research would benefit from exploring the experience of those without a mother/mother figure in their lives.

The majority of participants in this research said they believed they would benefit from support targeted to their age group. Such a network was developed and evaluated in the USA some 25+ years ago (Thomas et al., 1996), which all participants found helpful. It may therefore be beneficial to run a feasibility trial of a teen endometriosis support network in the UK, which can also utilise and investigate the advances in communication platforms since that research was conducted.

To add strength to the recommendations to improve MHE for adolescents outlined in Section 11.3.1 above, it was necessary to draw on research conducted by charities and companies that sell menstrual products (Bodyform, 2018; Plan International UK, 2018), as there is a lack of up-to-date UK based academic research on adolescents' menstrual experiences and attitudes. While the findings from Study 2 begin to bridge this gap in the literature, there are still several areas that would benefit from further research. In Study 2 there was evidence of a high prevalence of dysmenorrhea in the sample, which was reported as a key reason for school absence during periods. However, other areas of life interference were not explored, such as the impact of periods on 'presenteeism', or on sport, and social events. These have been found to be impacted by menstruation in adolescents/young women in research conducted elsewhere, but there is no current research on these factors in a UK sample. In addition, there was much focus on period pain, with little exploration of other aspects of problematic periods such as heavy menstrual bleeding. Given the associations of this symptom with endometriosis, it's prevalence and impact in a UK adolescent sample warrants further exploration.

This research provides valuable insight into what menstrual characteristics were associated with girls' beliefs about the typicality of their period, however, to help direct future MHE provision, more research is needed in this area. There may be a more direct avenue of exploring the concept of typicality, perhaps asking adolescents which aspects of their period they consider to be typical/atypical. Further research is also required into what boys understand about menstruation. To ensure that MHE is meaningful for all, health literacy efforts need to include all genders, as well as parents/caregivers, who may be called on to inform and support adolescents about menstruation.

As outlined in section 11.3.1, provision has now been made for MHE to become mandatory in primary and secondary schools in England (Department for Education, 2020b). Early data, collected in 2021, suggests that MHE provision is still inconsistent across England, as almost a quarter of young people (24%) reported that they had not learned about menstrual health at all, and 37% reported they had not learned enough (Sex Education Forum, 2022). Teachers have also reported mixed reactions to the information and guidance they have been given on the new curriculum (Brown et al., 2022). In addition, MHE was negatively impacted by the Covid-19 pandemic, which began in early 2020, when schools were forced to close, and much learning was remote (instead of face-to-face). A number of organisations that work with schools to provide MHE to pupils have expressed concern that MHE was deprioritised during the pandemic, as teaching staff were facing pressure to ‘catch up’ on lost learning time (Williams et al., 2022). Further research is needed on the impact of the Covid-19 pandemic on MHE provision, as well as the impact of the changes to MHE provision on the menstrual health literacy of adolescents.

11.5 Conclusion

This thesis has made important contributions to the knowledge pertaining to adolescent menstruation and endometriosis. As outlined in Chapter 4, there were several gaps in the literature, which this thesis has begun to address. Firstly, there was a lack of up to date, UK based research on adolescents with endometriosis. Study 1 has addressed this gap, and in doing so has shown the importance of considering life-stage on the experience of endometriosis. It has therefore contributed to the literature on biographies and chronic illness, by illustrating the ‘biographical threat’ adolescents with endometriosis experience to their current and future biographies. In response to the call from Williams (2000b) for more focus on context in biographical analyses, this research has also contributed to the literature on AWCI, showing the importance of considering gender and condition type. Importantly, this study has also given a voice to adolescents with endometriosis, who until now have had little opportunity to share the issues that are important to them. By giving this under-researched group a voice, the study has contributed to feminist theory (Hesse-Biber, 2010).

There was also a lack of UK based research on menstruation, and the prevalence of dysmenorrhea, which was addressed in Study 2. This study also addressed the research gap of adolescents’ awareness of endometriosis in the UK. Endometriosis researchers (Cox et al., 2003c; Manderson et al., 2008; Markovic et al., 2008) and charitable organisations (i.e. Endometriosis UK) have argued for some time that there is little awareness of endometriosis, and that MHE provision needs to target this. The findings in Study 2 have evidenced this lack of awareness and have also shown that most girls want the opportunity to learn about it. The quantitative exploration of this issue also meant that a large number of female voices could be heard, which aligned with the feminist lens adopted (Miner-Rubino and Jayaratne, 2007). Quantifiable data such as this may enable policy makers and educators to utilise their expertise and funds towards addressing issues and making a change for the lives of girls (Leckenby and Hesse-Biber, 2007).

Completing the two studies alongside each other has been highly beneficial; it enabled a more thorough understanding to emerge than provided by the qualitative or quantitative findings alone. It allowed for some of the issues raised by adolescents with endometriosis to be contextualised to the wider population of adolescent girls. For example, in Study 1, participants almost unanimously stated that they had never heard of endometriosis before, which was supported by the finding in Study 2, that very few adolescent girls were aware of it. This evidence taken together provides strength to the argument for the need to educate adolescents about endometriosis. In a similar manner, the qualitative study provided some significance to issues raised in the quantitative study. For example, in Study 2, many adolescent girls were unsure if their periods were ‘typical’, and large numbers of those with potentially problematic symptoms did not seek medical help. Study 1 highlights the significance of these findings, showing how important it is that girls are aware of what ‘normal’ menstruation looks like, and when to seek help. Without such knowledge, girls who do have underlying pathology, such as endometriosis, may not obtain timely treatment for their debilitating symptoms. Finally, Study 1 indicated that adolescents place much value in fitting in and feeling like a normal teenager, and therefore, having the knowledge and confidence to answer the question “am I ‘normal’?” is of great importance, not only for their health, but also their well-being.

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Appendices

Appendix 1: Data Extraction Form for Narrative Review

Data Extraction Form: Teen Endo Review

Reviewer: …………………………………… Date: ……………………….

Authors			
Title			
Year		**Country**	
Journal			

Participants			
Sample Size		Age Range (mean)	
Recruitment method		Other demographic information	

Study Aims:			
Design	☐ Qualitative	☐ Quantitative	☐ Mixed methods

Qualitative	Data collection:	
	Analysis:	
Quantitative	Study type:	☐ Intervention ☐ RCT ☐ Observation
	Measures	
	Comparison	☐ Norms ☐ None ☐ Control group

Key Findings
Themes

Methodological Limitations

Appendix 2: Quality Appraisal of Included Studies

Qualitative Studies	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Is the qualitative approach appropriate to answer the research question?**	**Are the qualitative data collection methods adequate to address the research question?**	**Are the findings adequately derived from the data?**	**Is the interpretation of results sufficiently substantiated by data?**	**Is there coherence between qualitative data sources, collection, analysis and interpretation?**
Conboy et al. (2008)	✓	✓	✓	✓	✓	✓	✓
Highfield et al. (2006)	✓	✓	✓	✓	✓	✓	✓
Moradi et al. (2014)	✓	✓	✓	✓	✓	✓	✓
Plotkin (2004)	✓	✓	✓	✓	✓	✓	✓
Randomised Controlled Trials	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Is randomization appropriately performed?**	**Are the groups comparable at baseline?**	**Are there complete outcome data?**	**Are outcome assessors blinded to the intervention provided?**	**Did the participants adhere to the assigned intervention?**
Ahn et al. (2009)	✓	✓	Can’t tell	Can’t tell	✓	Can’t tell	Can’t tell
DiVasta et al. (2015)	✓	✓	✓	✓	x	✓	x
Gallagher et al. (2017)	✓	✓	Can’t tell	✓	✓	Can’t tell	Can’t tell
Wayne et al. (2008)	✓	✓	Can’t tell	✓	✓	✓	✓

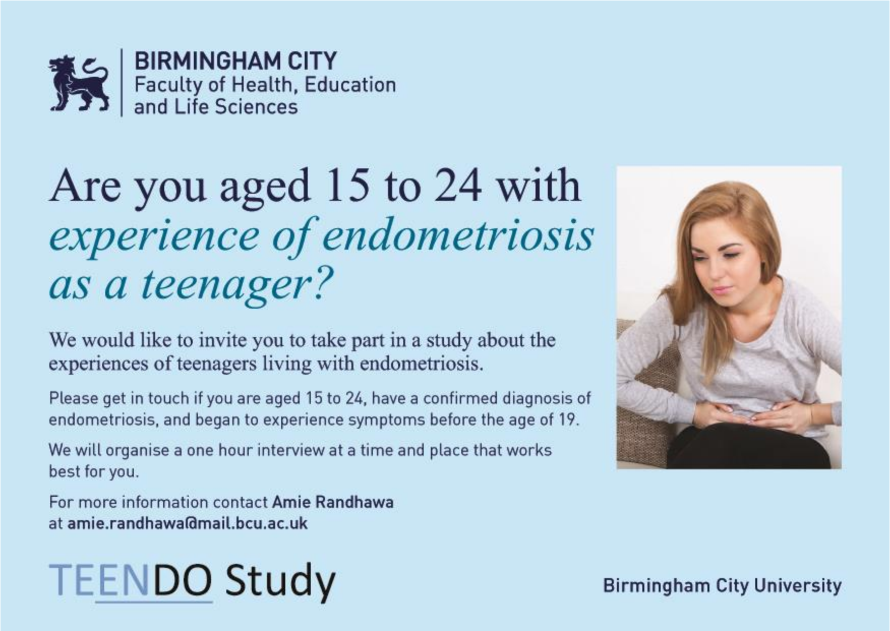
Appendix 2 Quality Appraisal of Included Studies (continued)

Non-Randomised Studies	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Are the participants representative of the target population?**	**Are measurements appropriate regarding both the outcome and intervention (or exposure)?**	**Are there complete outcome data?**	**Are the confounders accounted for in the design and analysis?**	**During the study period, is the intervention administered (or exposure occurred) as intended?**
DiVasta et al. (2018)	✓	✓	Can’t tell	✓	✓	Can’t tell	✓
Estes et al. (2021)	✓	✓	✓	✓	✓	✓	✓
Gallagher et al. (2018)	✓	✓	Can’t tell	✓	✓	✓	✓
Roman (2010)	✓	✓	✓	✓	✓	Can’t tell	✓
Rowlands et al. (2016)	✓	✓	✓	✓	x	✓	✓
Schneider et al. (2020)	✓	✓	Can’t tell	✓	Can’t tell	✓	✓
Quantitative Descriptive Studies	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Is the sampling strategy relevant to address the research question?**	**Is the sample representative of the target population?**	**Are the measurements appropriate?**	**Is the risk of nonresponse bias low?**	**Is the statistical analysis appropriate to answer the research question?**
Dun et al. (2015)	✓	✓	✓	✓	✓	Can’t tell	✓
Fong et al. (2017)	✓	✓	✓	✓	✓	Can’t tell	✓
González-Echevarría et al. (2019)	✓	✓	✓	Can’t tell	✓	✓	✓
Smorgick et al. (2013)	✓	✓	✓	Can’t tell	✓	✓	✓

Appendix 2 Quality Appraisal of Included Studies (continued)

Mixed-Methods Studies	Are there clear research questions?	Do the collected data allow to address the research questions?	Is there an adequate rationale for using a mixed methods design to address the research question?	Are the different components of the study effectively integrated to answer the research question?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Bodén et al. (2013)	✓	✓	✓	x	x	x	x
Rush and Misajon (2018)	✓	✓	x	Can’t tell	✓	✓	✓
Staccone (2006)	✓	✓	✓	x	x	x	x

Appendix 3: Study 1 Recruitment Flyers



BIRMINGHAM CITY
Faculty of Health, Education
and Life Sciences

Are you aged 15 to 24 with *experience of endometriosis as a teenager?*

We would like to invite you to take part in a study about the experiences of teenagers living with endometriosis.

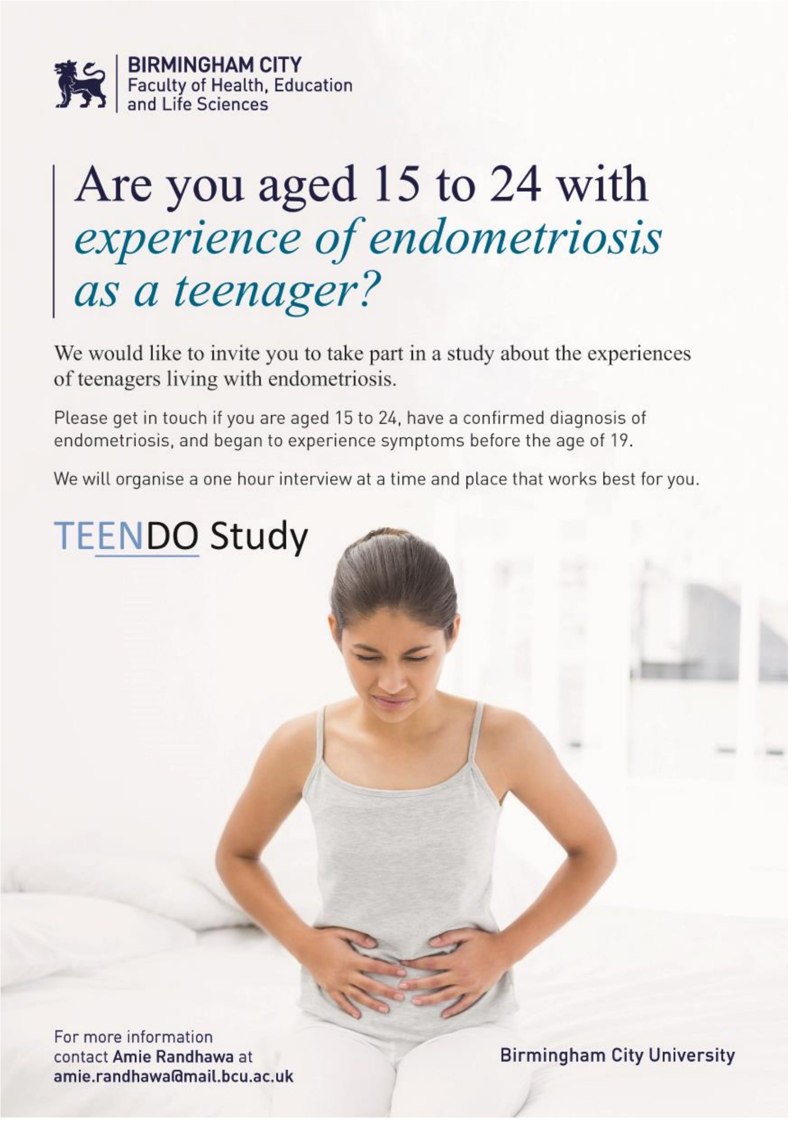
Please get in touch if you are aged 15 to 24, have a confirmed diagnosis of endometriosis, and began to experience symptoms before the age of 19.

We will organise a one hour interview at a time and place that works best for you.

For more information contact **Amie Randhawa** at **amie.randhawa@mail.bcu.ac.uk**

TEENDO Study

Birmingham City University



BIRMINGHAM CITY
Faculty of Health, Education
and Life Sciences

Are you aged 15 to 24 with *experience of endometriosis as a teenager?*

We would like to invite you to take part in a study about the experiences of teenagers living with endometriosis.

Please get in touch if you are aged 15 to 24, have a confirmed diagnosis of endometriosis, and began to experience symptoms before the age of 19.

We will organise a one hour interview at a time and place that works best for you.

TEENDO Study

For more information contact **Amie Randhawa** at **amie.randhawa@mail.bcu.ac.uk**

Birmingham City University

Appendix 4: Study 1 Telephone Screening Sheet

Telephone screening sheet

Date: ....

Initials: ....

Hello ...., this is Amie from Birmingham City University, I'm just calling about the research that I'm doing into teenagers experiences of endometriosis.

Is now a good time to talk?

If no – when should I call back? ....

If yes, proceed:

Great! I just wanted to give you a bit more information about the study and what it would mean for you if you were to be involved, if you're happy for me to go through that with you now?

Ok, so just to give you a bit of a background to the study… Endometriosis can affect women of any age during their reproductive years, and as I'm sure you are aware, for some in can begin during their teenage years. To date, there is a lack of research that specifically explores these teenagers' experience of endometriosis. But I think this is vital research because it will hopefully help to increase the awareness of endometriosis as something that can affect teenagers, and it may also highlight ways to improve the care they receive.

So for my research then, I want to try to explore this area, and give younger people like you a voice.

If you were to be involved in the research then we would arrange an interview at a time and location to suit you. The interview will take about an hour to an hour and a half, and during the interview I will ask you to describe your own story of living with endo. We will cover things like when you first began to experience symptoms, your diagnosis, the medical help you have received and any impact of endo on your day to day life.

Does this sound like something you'd be happy to be involved in?

- ☐ Yes, continue
- ☐ No – If no – Ok, that's not a problem, if you do change your mind though then please feel free to get back in touch with me, I will be running this research for the next few months.

Ok great, I just have a few questions to ask you then if that's ok.

1. How old are you at the moment? .... D.O.B ....
2. How old were you when you first began to experience symptoms? ....
3. Have you received a confirmed diagnosis of endometriosis? Y/N
4. Were you given that diagnosis as a result of a laparoscopy? Y/N
   a. If No – how were you given that diagnosis? MRI/GP
   b. If GP – so have you ever had a laparoscopy? Y/N

☐ **Eligible:** Ok great, well if you are happy then we can arrange a time for me to come and see you to do the research.

☐ **Not eligible**: I'm afraid that for this project we are only able to see those who have a diagnosis that has been confirmed by laparoscopy, as unfortunately that is the gold standard for a diagnosis of endo at the moment. So as it stands, I wouldn't be able to see you for the research. However, I will be running the project for the next year, so if your situation changes and you do get a confirmed diagnosis in that time, then please get back in touch? But I would like to say again, thank you so much for your interest, and I'm so sorry you are unable to be involved at this time.

- ☐ Interview arranged
- ☐ Information sheet sent by email

Appendix 5: Study 1 Interview Guide

TEENDO Interview Guide

Experiences of Teenagers with Endometriosis

Participant Initials: _________ **ID Number:**____________

Date: ________________________

Telephone Interview/Face-to-Face Interview (Location ________________________)

Pre Interview Checklist	
Received and read PIS	
Asked/answered questions	
Signed consent form	
Consented to audio-record	
Under 16s:	
Parent/guardian received and read PIS	
Parent/guardian signed consent form	

Field notes (including details of where interviewed, who present, etc.)

How did the participant hear about the research?

____

Timeline offered? Yes/No Completed? Yes/No

Demographic Information

Date of Birth: ________________ Age: __________

Ethnicity: _____________________ Religion: ______________________

Relationship status:

- ☐ Married
- ☐ Living with partner
- ☐ Boyfriend/girlfriend
- ☐ Single
- ☐ Other

Child Status:

- ☐ No children
- ☐ Children ____ (how many)
- ☐ Pregnant

Occupation: ___________________________________ FT/PT (circle)

Education level:

- ☐ No qualifications
- ☐ GCSE or equivalent
- ☐ A-Level or equivalent
- ☐ University degree
- ☐ Post-graduate Qualifications
- ☐ Other ___________________________

Member of Endometriosis UK?

- ☐ Yes Member since: ___________
  - Attends face to face support groups? Y/N Online only Y/N
- ☐ No
- ☐ No, other support group? _______________________

Endometriosis History

Age of first symptoms: __________

Age at diagnosis: _____________

Medical treatment received:

- ☐ No treatment
- ☐ Medication ____
- ☐ Surgery If yes, how many surgeries? ______Exploratory/To remove endo (circle)

For the next part of the interview, we'll be talking about your experiences of living with endometriosis. I'll turn the recorder on for this bit (if consented). I have noted down a few things that I'd like to ask you about, but I am really interested to hear ***your*** *story, so don't worry if we go off topic, as I want you to chat about what's important to you. If there's anything I think we haven't covered, or if I'd like a bit more information, I'll let you know. Remember you don't have to answer any questions you don't want to, and if you would like a break at any time then just say.*

RECORDER ON

☐ **Initial Illness experience**

Use of timeline as an elicitation tool.

1. Tell me about when you first started experiencing endometriosis symptoms?
    - What were your symptoms?
    - What was *[symptom/symptoms named by participant]* like? **How did you feel about it/them?**
    - How did the symptom(s) interfere with your day-to-day life?
    - Who did you tell? Why?
    - Who didn't you tell? Why not?
    - **What did you think was happening?**

☐ **Experience of care**

2. When did you first see a doctor or medical professional about your symptoms?
    - **What first led you to get help?**
        - i. Did you know where to go for help? Yes/No
        - ii. Where or to who did you go? Did you go alone or with someone else (if so who)?
        - iii. What happened?
        - iv. How did you feel about the care you received from the GP/health professional?
    - How long did it take to receive a referral?
        - i. Who were you referred to?
        - ii. What happened?
            - How did you feel about the care you received?
            - Did you feel you were given enough information?
            - Were you able to understand what they were saying/the language they used?

☐

☐ **Experience of medical/surgical treatment/diagnosis**

3. In the information you provided earlier you said you had tried *[names of medical treatments for your endo]*

    ……………………………………… ………………………………………

    ………………………………………

- Did they work? If yes, how long for?
- Any side effects? If yes, how did these impact on your daily life?
- How did you decide to use this/these treatments?
    - Did you feel involved in the decisions? Did you want to be involved?
- What did you hope the treatment would do? (reduce pain, other symptoms, fertility, etc.)

4. And you've also had ___ laparoscopies
    - Tell me about the experience
    - Did it help to treat the pain/symptoms?
    - **Were you given enough information?** ☐
    - **How long did it take to recover from the surgery?**
    - Did the pain come back at all afterwards?

5. **How did you feel when you were given your diagnosis?** ☐
    - How long did it take to get the diagnosis?

☐ **Impact on daily life**

6. How does endo impact you now? On a day-to-day basis?
    - What symptoms of endo do you usually experience now? Have they changed since your Endo first started (as discussed above)?
        - Pain? Where? *Can you describe what that pain is like, how often?*
        - Bleeding?
        - Bladder/bowel issues?
        - **Painful sex? *(NORMALISE some people experience…)*** ☐
        - **Tampon use?** ☐
        - Vomiting/nausea? Fainting? Fatigue?

    - Do your symptoms interfere with your day to day life? How?
        - Do they stop you from doing anything? i.e. school, work, home, social activities, sport

7. How does endometriosis impact your social life?
    - Going out with friends?
    - Relationships with boyfriends/girlfriends?
    - Have you told your friends about it? Why/why not?

8. How does endo impact your relationships with your family?
    - Mum? Dad? Siblings?
    - Have you told all your family about it? Why/why not?

9. How do you deal/cope with your endo on a day to day basis?

- Do you think your endo effects your mental health? If yes, how?
- Do you think your endo effects your self-confidence or self-esteem? If yes, how?
- Have you felt in control of your endometriosis? If yes – what has helped you feel that way?

☐ **Support**

10. When you need support, who do you talk to about your endo? ☐
    - Family members (Mum/Dad/siblings/aunts/nan etc.)
    - Friends? Boyfriends/girlfriends?
    - Endo support group?
    - Others? (Youth workers/school nurse)
- How do they help you?

11. Are there any support services that you feel are missing? If yes, what are they?
    - Are you able to find support targeted to people your age? Do you think it's needed? Why?
    - Do you know any others your age with endometriosis?

☐ **Information**

12. Where do you go for information about endo?
    - PROMPT: Internet? Which sites?
    - PROMPT: Doctors/Gynaecologists/nurses, School Nurses, Parents?
    - Which have been the most useful? Why
    - Is the information relevant/helpful? Appropriate to your age?
    - Is there any information you feel is lacking? If so, what?

☐ **Use of any alternative therapies/Diet/Exercise**

13. Have you used any alternative therapies to help you manage your endo?
    - What have you tried?
    - Did they work?

☐ **Future**

14. How do you see your future living with endo?
    - How do you think it will impact:
        i. School/work
        ii. Social life/friendships
        iii. Romantic relationships (sex, marriage etc.)
        iv. **Fertility** (having children) – has someone talked to you about this? ☐

☐ **Education**

As part of this research we are also interested in what education teenagers receive about endometriosis and menstrual health.

15. If you can remember… **Had you ever heard about endometriosis prior to your diagnosis/symptom onset?**
    - If yes – where had you heard about it? Who from?
        - Any family history?
    - If no – do you think this had any impact on your endo experience
        - i.e. seeing a doctor when your symptoms began

16. Can you remember your menstrual health education at school?
    - Did you feel it was well explained? Thorough?
    - Do you remember being told about endo or similar conditions?
        i. If no – do you think it is something teens should learn about as part of M H education?
            - If yes – who (i.e. Girls and boys)?

<u>**Concluding Questions:**</u>

Is there anything else we didn't discuss that you would like to talk about?

Do you have any questions for me?

RECORDER OFF

Thank participant – emphasize importance of research

Post Interview Checklist	
Provide Further Information sheet	
Ensure you've answered any questions they have	
Ask if they are happy to be contacted again	

Is the participant happy to be contacted in the future/for any follow up work? YES NO

Appendix 6: Study 1 Timeline Drawing Instructions

Timeline drawing instructions

To start the interview off, I'd like to do a bit of a drawing exercise with you if you're happy to do so?

For this exercise it would be great if you could draw a visual representation of your journey with endo, like a timeline, or a river/path – something to show the key events in your journey so far.

If you start off by thinking back to when your symptoms first began, and then draw your journey up until the present day, making sure you include any significant events that impacted on your journey along the way.

You can decide which way round to put the paper, and use as many or as few colours as you like.

Prompts:

Age at menarche

Symptom onset

Diagnosis

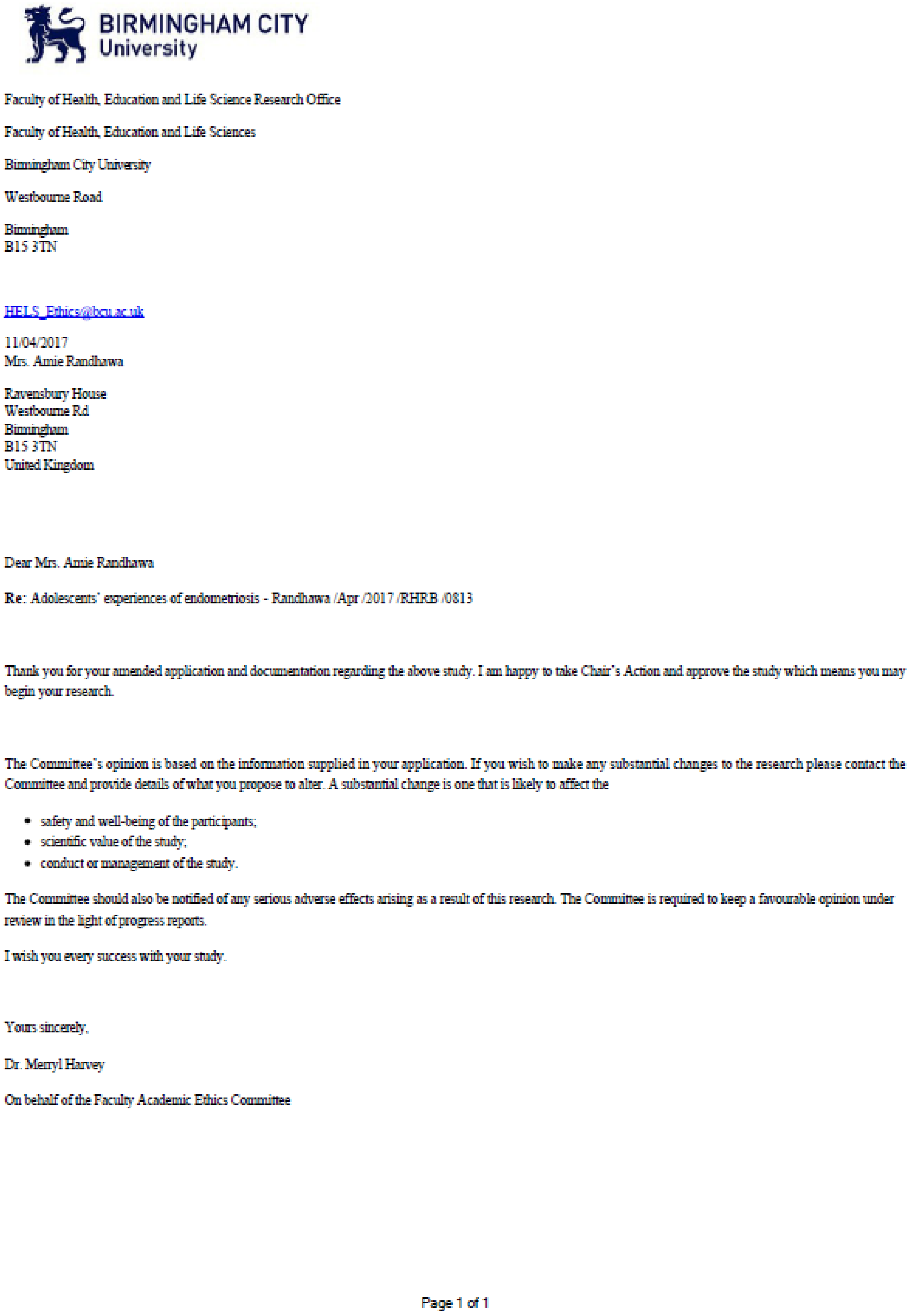
Surgeries

School exams/Uni/College

Relationships

Don't worry – your drawing skills are not under any scrutiny here!

Appendix 7: Study 1 Ethics Approval Letter



BIRMINGHAM CITY
University

Faculty of Health, Education and Life Science Research Office

Faculty of Health, Education and Life Sciences

Birmingham City University

Westbourne Road

Birmingham
B15 3TN

HELS_Ethics@bcu.ac.uk

11/04/2017
Mrs. Amie Randhawa

Ravensbury House
Westbourne Rd
Birmingham
B15 3TN
United Kingdom

Dear Mrs. Amie Randhawa

Re: Adolescents' experiences of endometriosis - Randhawa /Apr /2017 /RHRB /0813

Thank you for your amended application and documentation regarding the above study. I am happy to take Chair's Action and approve the study which means you may begin your research.

The Committee's opinion is based on the information supplied in your application. If you wish to make any substantial changes to the research please contact the Committee and provide details of what you propose to alter. A substantial change is one that is likely to affect the

- safety and well-being of the participants;
- scientific value of the study;
- conduct or management of the study.

The Committee should also be notified of any serious adverse effects arising as a result of this research. The Committee is required to keep a favourable opinion under review in the light of progress reports.

I wish you every success with your study.

Yours sincerely,

Dr. Merryl Harvey

On behalf of the Faculty Academic Ethics Committee

Appendix 8: Study 1 Participant Information Sheet

BIRMINGHAM CITY
University

TEENDO

Participant Information Sheet

Teens' and Young Women's experiences of Endometriosis

Name of Researcher: Amie Randhawa

We would like to invite you to take part in our research study. Before you decide whether to take part, please read the following information to understand why the research is being done and what it would involve for you. If you have any further questions or anything is unclear please do not hesitate to contact us.

What is the purpose of the study?

The aim of this study is to explore teenagers' and young women's experiences of endometriosis. To date, there is a lack of research which specifically addresses the experiences of teens and young women with endometriosis.

Why have I been invited?

We are inviting girls and women aged between 15 and 24 years, and who have had a diagnosis of endometriosis to take part in the research. You may have heard about the research through a support group for endometriosis. We are inviting many girls and young women like you to take part from a number of endometriosis support groups.

Do I have to take part?

This study is voluntary, and so it is up to you to decide whether or not you wish to take part. If you do decide to take part you can give your consent by completing and signing the consent form. Once you have completed the consent form you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

Please note, ***if you are under the age of 16*** you will also need your parent or guardian to sign a consent form to indicate that they are also happy for you to take part.

What will taking part involve?

This research will involve an interview with a member of the research team (Amie Randhawa), which will be conducted either face to face at a time and place to suit you, or over the telephone if preferred. During the interview, you will be asked to tell your own story about your experiences of endometriosis. The idea of this sort of research is to allow participants to talk about their own experiences, and to bring up the issues that are important to them. It is expected that the interview will last for approximately one hour. With your prior permission, the interview will be audio-recorded.

What are the possible benefits of taking part?

By taking part in this research, you will not gain any direct benefit. However, the information you provide will be of great value as it will enhance our understanding of the experiences of teens and young women with endometriosis and we hope to use what we have learned to further educate both patients and health professionals.

Are there any risks of taking part?

Some people find that talking about their illness experience can be beneficial, but some may find it distressing. If at any time during the interview you feel distressed, you can ask the interviewer to move onto another question, take a break or end the interview. If you desire further support then the interviewer can signpost organisations that can help with this.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If your questions are not adequately answered then please contact the project's Director of Studies, Dr Annalise Weckesser (contact details also overleaf).

What will happen if I do not want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. If you wish to withdraw at any time during the interview then please indicate your wishes to the interviewer. If you wish to withdraw after completion of the interview please contact Amie Randhawa (contact details overleaf) to inform her of your decision to withdraw. If you do decide to withdraw, all the information you have provided will be destroyed and will not be used further in the research.

Will my taking part in the study be kept confidential?
We will follow the ethical guidelines as set out by Birmingham City University and all information about participants will be handled in confidence.

If you join the study, then the researcher, Amie Randhawa, will be the primary person who will look at the data collected. The data may also be looked at by the supervisors of the PhD project to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database, accessible only to the primary researcher, Amie Randhawa. Any information about participants which leaves the institution will be anonymised and a unique code will be used so that participants cannot be recognised from it.

Research data will be kept on an encrypted database for 7 years, which only the researcher, Amie Randhawa will have access to. After this time the data will be disposed of securely.

We will not share any of the things we discuss during the interview with your parents or family unless you give us consent to do so. However, ***if you are under the age of 18***, and you disclose to us during the interview that someone has harmed you, we will have a duty to report this to the proper authorities.

What will happen to the results of the research study?
The results of the research will be written up as part of an educational qualification, a PhD thesis and may also get published in academic journals and used in presentations about the study. Please be assured that you will not be identified in any report or publication.

Who is organising the research?
This research is being organised by Birmingham City University.

Who has reviewed the study?
All research at Birmingham City University is reviewed by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Health Research Ethics Committee.

Further information and contact details
If you have a concern about any aspect of this study, please do not hesitate to contact Amie Randhawa, or her Director of Studies, Dr Annalise Weckesser. Their contact details are provided opposite:

Amie Randhawa, PhD Candidate
Ravensbury House
Birmingham City University
Westbourne Road
Birmingham
B15 3TN
0121 331 6067
Amie.Randhawa@mail.bcu.ac.uk

Annalise Weckesser, Director of Studies
Ravensbury House
Birmingham City University
Westbourne Road
Birmingham
B15 3TN
0121 331 7154
Annalise.Weckesser@bcu.ac.uk

Participant Information Sheet
Version Number 2.0
Dated 21/03/2017

Appendix 9: Study 1 Parent Information Sheet

BIRMINGHAM CITY
University

TEENDO

Parent Information Sheet

Version 2.0
Dated: 21/03/2017

Teens' and Young Women's Experiences of Endometriosis

Name of Researcher: Amie Randhawa

We would like to invite your daughter to take part in our research study. Before you decide whether you are happy for her to take part, please read the following information to understand why the research is being done and what it would involve for her. If you have any further questions or anything is unclear please do not hesitate to contact us.

What is the purpose of the study?
The aim of this study is to explore teenagers' and young women's experiences of endometriosis. To date, there is a lack of research which specifically addresses the experiences of teens and young women with endometriosis.

Who is being invited to participate?
We are inviting girls and women aged between 15 and 24 years, and who have had a diagnosis of endometriosis to take part in the research. Potential participants may have heard about the research through a support group for endometriosis, or through someone who is a member of a support group and has passed the study details on to them.

Does my daughter have to take part?
The study is voluntary so it is up to your daughter to decide whether or not she wishes to take part. If she does wish to take part she will be required to give her consent by completing and signing the consent form. As your daughter is under the age of 16, she will also require you to sign a consent form to indicate that you are happy for her to take part as well. Once consented into the study, your daughter is still free to withdraw at any time and without giving a reason.

What will taking part involve?
This research will involve an interview with a member of the research team (Amie Randhawa). This interview will either be conducted face to face (in person) at a time and place to suit the participant, or over the phone if preferred. During the interview, participants will be asked to tell their own story about their experiences of endometriosis. The idea of this sort of research is to allow participants to talk about their own experiences, and to bring up the issues that are important to them. It is expected that the interview will last for approximately one hour. With prior permission, the interview will be audio-recorded.

What are the possible benefits of taking part?
By taking part in this research, your daughter will not gain any direct benefit. However, the information provided will be of great value as it will enhance our understanding of the experiences of teens and young women with endometriosis and we hope to use what we have learned to further educate both patients and health professionals.

Are there any risks of taking part?
Some people find that talking about their illness experience can be beneficial, but some may find it distressing. If at any time during the interview your daughter feels distressed, she can ask the interviewer to move onto another question, take a break or end the interview. If your daughter desires further support then the interviewer can signpost organisations that can help with this.

What if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information

sheet. If your questions are not adequately answered then please contact the project's Director of Studies, Dr Annalise Weckesser (contact details also below).

Will taking part in the study be kept confidential?
We will follow the ethical guidelines as set out by Birmingham City University and all information about participants will be handled in confidence.

If your daughter joins the study, then the researcher, Amie Randhawa, will be the primary person who will look at the data collected. The data may also be looked at by the supervisors of the PhD project to check that the study is being carried out correctly. All will have a duty of confidentiality to your daughter as a research participant and we will do our best to meet this duty.

All information which is collected during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database, accessible only to the primary researcher, Amie Randhawa. Any information about participants which leaves the institution will be anonymised and a unique code will be used so that participants cannot be recognised from it.

Research data will be kept on an encrypted database for 7 years, which only the researcher, Amie Randhawa will have access to. After this time the data will be disposed of securely.

We will not share any of the things discussed during the interview with the participant's parents or family unless they give us consent to do so. However, ***if a participant who is under 18*** discloses during the interview that someone has harmed them, then we will have a duty to report this to the proper authorities.

What will happen if my daughter doesn't want to carry on with the study?
Participation in this study is voluntary and your daughter is free to withdraw at any time, without giving any reason. If she wishes to withdraw at any time during the interview then she can indicate this to the interviewer. If she wishes to withdraw after completion of the interview she can contact Amie Randhawa (contact details below) to inform her of her decision to withdraw. If she does decide to withdraw, all the information provided by your daughter will be destroyed and not used further in the research.

What will happen to the results of the research study?
The results of the research will be written up as part of an educational qualification, a PhD thesis and may also get published in academic journals and used in presentations about the study. Please be assured that your daughter will not be identified in any report or publication.

Who has reviewed the study?
All research at Birmingham City University is reviewed by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Health Research Ethics Committee.

Further information and contact details
If you have a concern about any aspect of this study, please do not hesitate to contact:

Amie Randhawa, PhD Candidate
Ravensbury House
Birmingham City University
Westbourne Road
Birmingham
B15 3TN
0121 331 6067
Amie.Randhawa@mail.bcu.ac.uk

Dr Annalise Weckesser, Director of Studies
Ravensbury House
Birmingham City University
Westbourne Road
Birmingham
B15 3TN
0121 331 7154
Annalise.Weckesser@bcu.ac.uk

Appendix 10: Study 1 Participant Consent Form

BIRMINGHAM CITY
University

Faculty of Health
Seacole Building
Westbourne Road
Birmingham
B15 3TN

Participant Consent Form
Version 1.0
Dated: 15/03/2017

Title of Study: Teens' and Young Women's Experiences of Endometriosis

REC Ref: Randhawa /Apr /2017 /RHRB /0813

Name of Researchers: Amie Randhawa and Dr Annalise Weckesser

Please initial boxes

1. I confirm that I have read and understood the Participant Information Sheet Version Number 1.0 dated 15/03/2017 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

3. I understand that relevant sections of my data collected in the study may be looked at by the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that anonymous direct quotes from the information I provide during the interview may be used in the study reports, presentations and publications. ☐

5. I give permission for the interview to be audio-recorded. ☐

6. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred it will be made anonymous. Data will be kept for 7 years after the study has ended. ☐

7. I agree to take part in the above study. ☐

……………………………………………	………………………	…………………………………………….
Name of Participant	**Date**	**Signature**
……………………………………………	………………………	…………………………………………….
Name of Researcher	**Date**	**Signature**

Appendix 11: Study 1 Parent Consent Form

Faculty of Health
Seacole Building
Westbourne Road
Birmingham
B15 3TN

Parent/Guardian Consent Form
Version 1.0
Dated: 15/03/2017

Title of Study: Teens' and Young Women's Experiences of Endometriosis

REC Ref: Randhawa /Apr /2017 /RHRB /0813
Name of Researchers: Amie Randhawa and Dr Annalise Weckesser

Please initial boxes

1. I confirm that I have read and understood the information sheet for parents/guardians version number 1.0 dated 15/03/2017 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my daughter's participation is voluntary and that she is free to withdraw at any time, without giving any reason. ☐

3. I understand that relevant sections of my daughter's data collected in the study may be looked at by the research group and regulatory authorities where it is relevant to her taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my daughter's participation in this study. I understand that her personal details will be kept confidential. ☐

4. I understand that anonymous direct quotes from the information my daughter provides during the interview may be used in the study reports, presentations and publications. ☐

5. I give permission for my daughter's interview to be audio-recorded. ☐

6. I understand that information about my daughter that is recorded during the study will be kept in a secure database. If the data is transferred it will be made anonymous. Data will be kept for 7 years after the study has ended. ☐

7. I agree for my daughter to take part in the above study. ☐

………………………………………………	……………………	…………………………………………….
Name of Parent	**Date**	**Signature**
………………………………………………	……………………	…………………………………………….
Name of Researcher	**Date**	**Signature**

Name of daughter: ……………………………………………………

Appendix 12: Study 1 Participant Further Information Sheet

BIRMINGHAM CITY
University

TEENDO

Further Support and Information Sheet

Teens' and Young Women's Experiences of Endometriosis

Thank you very much for participating in our research.

The information you have provided will be used to help us understand teens' and young women's day-to-day experiences of endometriosis. We hope that this research will help raise awareness of endometriosis amongst young people, and eventually lead to important advances in endometriosis care, education and support.

If you would like any further support, or require more information about endometriosis, please contact the relevant organisation below:

1. **Endometriosis UK Helpline**
   Endometriosis UK provides a confidential helpline which you can call for free on 0800 808 2227. This helpline is run by trained endometriosis volunteers who can provide you with both support and information about endometriosis. It is not a 24-hour helpline, but the website maintains a regular, up to date schedule of details of its opening hours, which you can find at:
   https://www.endometriosis-uk.org/helpline

2. **Endometriosis UK Website**
   This is a national organisation that provides reliable information about endometriosis and details of a range of support services available through their support network. Their website address is: https://www.endometriosis-uk.org/. It can also help you find a local support group to attend in person, or an online support group: https://www.endometriosis-uk.org/support-groups

3. **The Pelvic Pain Support Network**
   This is a patient led organisation who provides support, information and advocacy for those with pelvic pain, whether or not they have a diagnosed condition, and their families and carers.
   http://www.pelvicpain.org.uk/

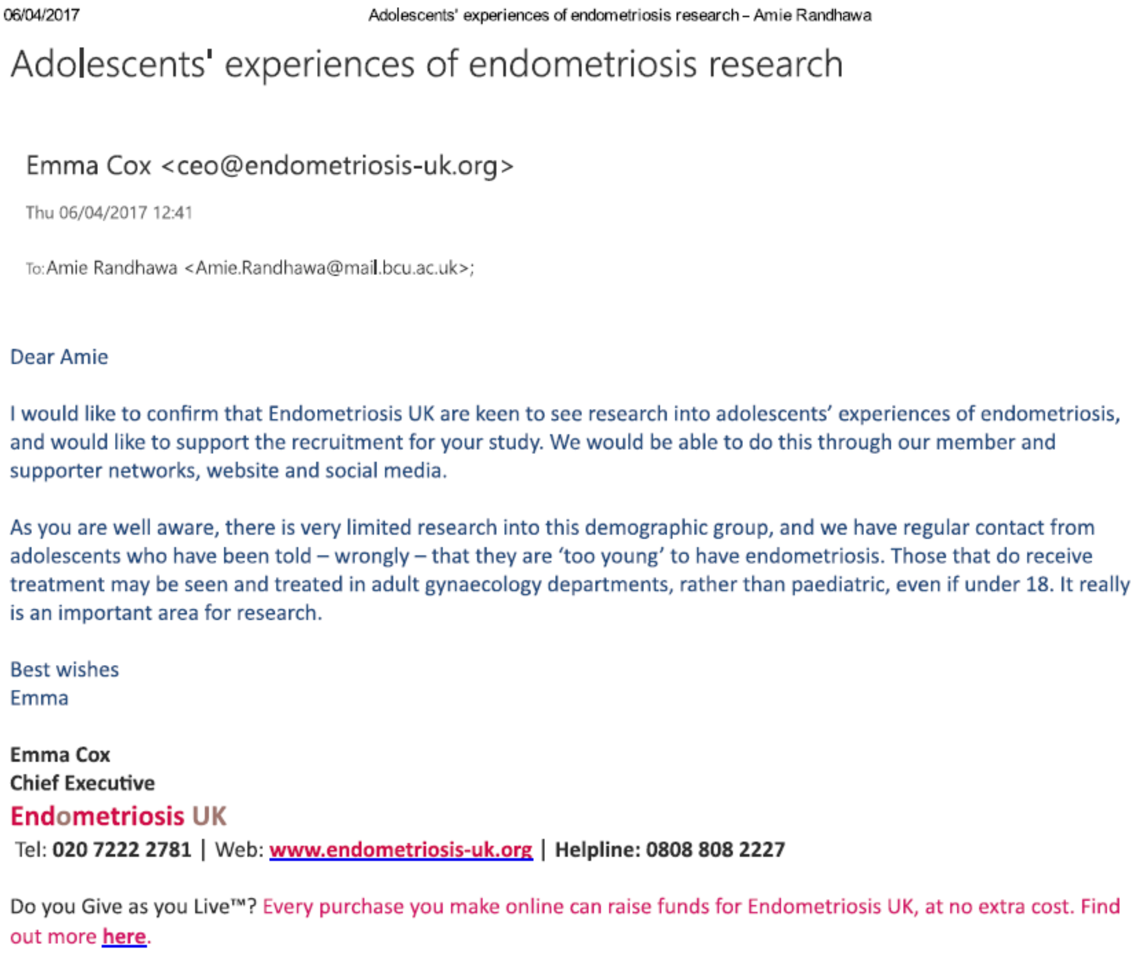
4. **Your Healthcare Providers**
   If you are worried about your symptoms or need advice about your medications, please contact your GP or your specialist endometriosis team. *If you are under 18* and still attend school you may also seek support or guidance from your school nurse.

5. **Childline**
   If you are ***under 18*** and would like emotional support, or want to chat confidentially about any issues that are important to you, then you can call Childline for free on 0800 1111. You can also find advice and support on their website, the address is:
   https://www.childline.org.uk/

If you have any further enquiries about the research, please contact Amie Randhawa, or her supervisor Dr Annalise Weckesser:

Amie Randhawa	**Dr Annalise Weckesser**
Birmingham City University	Birmingham City University
0121 331 6067	0121 331 7154
Amie.Randhawa@mail.bcu.ac.uk	Annalise.Weckesser@bcu.ac.uk

Appendix 13: Study 1 Approval to Recruit Through Endometriosis UK



06/04/2017 Adolescents' experiences of endometriosis research – Amie Randhawa

Adolescents' experiences of endometriosis research

Emma Cox <ceo@endometriosis-uk.org>

Thu 06/04/2017 12:41

To: Amie Randhawa <Amie.Randhawa@mail.bcu.ac.uk>;

Dear Amie

I would like to confirm that Endometriosis UK are keen to see research into adolescents' experiences of endometriosis, and would like to support the recruitment for your study. We would be able to do this through our member and supporter networks, website and social media.

As you are well aware, there is very limited research into this demographic group, and we have regular contact from adolescents who have been told – wrongly – that they are 'too young' to have endometriosis. Those that do receive treatment may be seen and treated in adult gynaecology departments, rather than paediatric, even if under 18. It really is an important area for research.

Best wishes
Emma

Emma Cox
Chief Executive
Endometriosis UK
Tel: **020 7222 2781** | Web: **www.endometriosis-uk.org** | **Helpline: 0808 808 2227**

Do you Give as you Live™? Every purchase you make online can raise funds for Endometriosis UK, at no extra cost. Find out more **here**.

BIRMINGHAM CITY University

TEENDO Study

Teenage Girls' Awareness & Attitudes towards Menstrual Health: A Survey Study*

***Part of a doctoral study on teenage girls' experiences & knowledge of menstrual health in general and endometriosis in particular**

School Information Pack

Research Background & Aims

Issues surrounding menstruation can greatly impact upon the health and quality of life of teenage girls. There is, however, a lack of research addressing menstrual attitudes and awareness among teenagers in the UK. By obtaining such information, through this survey, we may better understand the health and educational needs of adolescents around menstruation.

Researchers suggest that there is a lack of awareness among teenage girls about what constitutes an average, or 'normal', menstruation. Without such knowledge, those who experience menstrual health-related problems (such as endometriosis), often do not recognise that there is an issue. In addition, teens may 'suffer in silence', feeling too embarrassed to talk about their periods. **A recent UK survey (link below) highlights these issues, with half of girls (aged 14-21) missing school due to their period, usually giving an alternate excuse, and many were embarrassed about talking about periods.**

This survey study, which will capture teenage girls' awareness of menstrual health, forms part of a larger mixed methods doctoral study that aims to understand teenage girls' experiences and awareness of menstrual health in general, and of endometriosis in particular. It is hoped that findings from this study will act as a guide for future health education priorities, aimed at increasing teenagers' knowledge of menstrual health and ill health – especially in the form of endometriosis (see below for further information regarding this condition).

School Survey Research Methods

The survey will take approximately 5-10 minutes to complete. It comprises of a few demographic background questions and a number of short answer, closed and multiple choice questions.

All teenage girls (aged 15 - 19 years) attending local secondary schools, able to read and write in English, are invited to participate. School pupils aged 15 and over will be given information sheets about the study prior to the survey. Those interested in participating will then complete a consent form and study survey. Only participants aged 15 additionally require consent of a parent/guardian (this is not a requirement for those aged 16-19).

This research has full ethical approval from the University Ethics committee (HELS FAEC) at Birmingham City University. The researcher (Amie Randhawa) holds an Enhanced DBS Certificate (Dated 1st March 2017).

Additional Information

Endometriosis in Teenagers and Diagnostic Delays

Endometriosis is a chronic condition in which endometrial-like tissue is found outside of the uterine cavity, often on the reproductive organs, bowel and bladder. These tissue deposits respond to monthly hormone cycles, inducing a local inflammatory response, which leads to scarring and adhesion formation. Common symptoms include chronic pelvic pain, dysmenorrhoea, fatigue, heavy menstrual bleeding and infertility.

It is common for women/girls with endometriosis to experience emotional distress and reduced quality of life, and it can also impact on work, social life, school attendance and education. **Endometriosis affects approximately 10% of women of reproductive age, the majority of whom report that their symptoms begin during adolescence.**

One of the significant issues encountered by teenagers with endometriosis is a lengthy delay in obtaining a diagnosis, which can last for many years, during which time their symptoms may worsen. One of the reasons often given for this delay is that teenagers wait a long time to seek help for their symptoms, which could be due to a lack of awareness, of not only endometriosis, but also of what constitutes a typical and healthy menstruation experience. **Thus, it is hoped that findings from this study will help inform future menstrual (ill) health education initiatives for teenage girls, leading to reduced diagnostic delays for those who may have endometriosis.**

***Link to recent UK survey on menstruation*:** https://plan-uk.org/media-centre/almost-half-of-girls-aged-14-21-are-embarrassed-by-their-periods

Further contact details

If you have any questions or require further details about the study then please do not hesitate to contact me:

Amie Randhawa
PhD Candidate, Birmingham City University
0121 331 6067 or 07760 106091
Amie.Randhawa@mail.bcu.ac.uk

Or the Director of Studies for this doctoral study:

Dr. Annalise Weckesser
Senior Research Fellow
Centre for Health and Social Care Research, Birmingham City University
0121 331 7154
Annalise.Weckesser@bcu.ac.uk

Appendix 15: Study 2 Participant Information Sheet

BIRMINGHAM CITY
University

Participant Information Sheet

Menstrual Health Awareness and Attitudes Among Teenagers

Name of Researcher: Amie Randhawa

We would like to invite you to take part in our research study. Before you decide whether to take part, please read the following information to understand why the research is being done and what it would involve for you. If you have any further questions or anything is unclear please do not hesitate to contact us.

What is the purpose of the study?

The aim of this study is to explore the menstrual patterns, attitudes and awareness among teenagers in the UK. There is currently a lack of research which specifically addresses these issues within a UK setting, and it is hoped that by obtaining information on teenagers' awareness and attitudes, we may better understand the educational needs of adolescents around these topics.

Why have I been invited?

This research is aimed at teenage girls aged 15-19, therefore you are being invited to take part. We are inviting many teenagers like you to take part in the research.

Do I have to take part?

This study is voluntary, and so it is up to you to decide whether or not you wish to take part. If you do decide to take part you can give your consent by completing and signing the consent form. Once you have completed the consent form you are still free to withdraw at any time and without giving a reason.

Please note, ***if you are under the age of 16*** you will also need permission from your parent or guardian to take part. You will have also been given a separate information sheet to give to them which explains this to them, and how they can provide their consent.

What will taking part involve?

This research involves the completion of a short questionnaire, which will take approximately 5-10 minutes to complete. The questionnaire will include some brief demographic questions, such as your age and ethnicity, and then a short series of questions about your usual periods and your attitudes towards menstruation. The final part of the questionnaire involves questions about your menstrual health awareness and education preferences. Participants can choose to leave out any questions that they are not comfortable with answering.

Is the study anonymous?

Yes, all the information collected during the study is anonymous. We do not ask you for any information that could identify who you are and when we write up the results of the study they will be reported in a way that does not identify individual participants.

Are there any benefits of taking part?

Although there are no direct benefits for taking part, the information we get from your participation in this study may help to enhance our understanding of the educational needs of teenagers about menstrual health. Therefore your participation is highly valued.

What will happen if I do not want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. If you wish to withdraw when you are part way through completing the questionnaire then please indicate your wishes to the researcher. Alternatively you can tell the researcher when you hand the questionnaire back to them. If you wish to withdraw after completion of the questionnaire then please contact Amie Randhawa (contact details overleaf) to inform her of your decision to withdraw. If you do decide to withdraw, all the information you have provided will be destroyed and not used further in the research.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If your questions are not adequately answered then please contact the project's Supervisor, Dr Angela Hewett (contact details overleaf).

Will my taking part in the study be kept confidential?

We will follow the ethical guidelines as set out by Birmingham City University and all information about participants will be handled in confidence.

If you join the study, then the researcher, Amie Randhawa, will be the primary person who will look at the data collected. The data may also be looked at by the supervisors of the PhD project to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database, accessible only to the primary researcher, Amie Randhawa. Any information about participants which leaves the institution will be anonymised and a unique code will be used so that participants cannot be recognised from it.

Research data will be kept on an encrypted database for 7 years, which only the researcher, Amie Randhawa will have access to. After this time the data will be disposed of securely.

What will happen to the results of the research study?

The results of the research will be written up as part of an educational qualification, a PhD thesis and may also get published in academic journals and used in presentations about the study. Please be assured that you will not be identified in any report or publication.

Who is organising the research?

This research is being organised by Birmingham City University.

Who has reviewed the study?

All research at Birmingham City University is reviewed by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Health Research Ethics Committee.

Further information and contact details

If you have a concern about any aspect of this study, please do not hesitate to contact Amie Randhawa, or her Supervisor, Dr Angela Hewett. Their contact details are provided opposite:

Amie Randhawa, PhD Candidate
Ravensbury House
Birmingham City University
Westbourne Road
Birmingham
B15 3TN
0121 331 6067
Amie.Randhawa@mail.bcu.ac.uk

Angela Hewett, PhD Supervisor
Bevan House
Birmingham City University
Westbourne Road
Birmingham
B15 3TN
0121 331 7177
Angela.Hewett@bcu.ac.uk

Appendix 16: Study 2 Parent Information Sheet and Consent Form - Opt Out

BIRMINGHAM CITY
University

School Logo (if requested)

Parent Information Sheet

Version 3.0
Dated: 17/07/2017

Menstrual health awareness and attitudes among teenagers

Name of Researcher: Amie Randhawa

Dear Parent/Guardian,

We would like to invite your daughter to take part in our research study. We will be attending *[name of school]* on the week commencing *[date]* to ask all girls between the ages of 15 and 19 to complete a questionnaire for our research. Before you decide whether you are happy for her to take part, please read the following information to understand why the research is being done and what it would involve for your daughter. If you have any further questions or anything is unclear please do not hesitate to contact us.

What is the purpose of the study?
The aim of this study is to explore menstrual patterns, attitudes and awareness among teenagers in the UK. There is currently a lack of research which specifically addresses these issues within a UK setting, and it is hoped that by obtaining information on teenagers' awareness and attitudes, we may better understand the health and educational needs of adolescents around these topics.

Why has my daughter been invited?
Your daughter is being invited to take part because she attends a local school that has agreed to be involved in the research. We are inviting many teenagers to take part from a number of schools in the local area.

Does my daughter have to take part?
The study is voluntary so it is up to your daughter to decide whether or not she wishes to take part. If she does wish to take part she will be required to give her consent by completing and signing the consent form. As your daughter is under the age of 16, she will also require your consent to participate as well. If you are happy for her to take part then you do not need to do anything. However, if you would rather she **does not** participate then please complete and return the opt-out consent form at the end of this letter by *[date]*. Please note that once consented into the study, your daughter is still free to withdraw at any time and without giving a reason.

What will taking part in the research involve?
This research involves the completion of a short questionnaire, which will be done during school hours at an allocated time. The questionnaire will include some brief demographic questions, such as age and ethnicity, and then a short series of questions about usual periods and their attitudes towards menstruation. The final part of the questionnaire involves questions about menstrual health awareness and education preferences. There are **no** questions about sexual activity. Participants can choose to leave out any questions that they are not comfortable with completing. The survey will take approximately 5-10 minutes to complete.

Is the study anonymous?
Yes, all the information collected during the study is anonymous. We do not ask for any information that could identify the participants and when we write up the results of the study they will be reported in a way that does not identify individual participants.

What are the possible benefits of taking part?
Although there are no direct benefits for taking part, the information we get from those who participate in this study may help to enhance our understanding of the educational needs of teenagers about menstruation. Therefore each individual's participation is highly valued.

What if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If your questions are not adequately answered then please contact the project's Supervisor, Dr Angela Hewett (contact details also below).

Will taking part in the study be kept confidential?
We will follow the ethical guidelines as set out by Birmingham City University and all information about participants will be handled in confidence.

If your daughter joins the study, then the researcher, Amie Randhawa, will be the primary person who will look at the data collected. The data may also be looked at by the supervisors of the PhD project to check that the study is being carried out correctly. All will have a duty of confidentiality to your daughter as a research participant and we will do our best to meet this duty.

All information which is collected during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database, accessible only to the primary researcher, Amie Randhawa. Any information about participants which leaves the institution will be anonymised and a unique code will be used so that participants cannot be recognised from it.

Research data will be kept on an encrypted database for 7 years, which only the researcher, Amie Randhawa will have access to. After this time the data will be disposed of securely.

Your daughter's school may be provided with a summary of the results of the research. Please be assured that this summary will not identify any individual participants or their responses.

What will happen if my daughter doesn't want to carry on with the study?
Participation in this study is voluntary and your daughter is free to withdraw at any time, without giving any reason. If she wishes to withdraw at any time during questionnaire completion, then she can indicate this to the teacher or the researcher (who will also be present). If she wishes to withdraw after completion of the questionnaire she can contact Amie Randhawa (contact details below) to inform her of her decision to withdraw. If she does decide to withdraw, all the information provided by your daughter will be destroyed and not used further in the research.

What will happen to the results of the research study?
The results of the research will be written up as part of an educational qualification, a PhD thesis and may also get published in academic journals and used in presentations about the study. Please be assured that your daughter will not be identified in any report or publication.

Who has reviewed the study?
All research at Birmingham City University is reviewed by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Health Research Ethics Committee.

Further information and contact details
If you have a concern about any aspect of this study, please do not hesitate to contact:

Amie Randhawa, PhD Candidate Ravensbury House, Birmingham City University Westbourne Road Birmingham B15 3TN 0121 331 6067 Amie.Randhawa@mail.bcu.ac.uk	**Dr Angela Hewett, PhD Supervisor** Bevan House, Birmingham City University Westbourne Road Birmingham B15 3TN 0121 331 7177 Angela.Hewett@bcu.ac.uk

Menstrual health awareness and attitudes study – Parent Form for Non-Participation in Questionnaire

Please only return this form to the school if you **do not** want your daughter to participate in this study.

Please return this form by ***[date]***. Forms to be handed to form teachers.

I **do not** wish for my daughter to participate in this study and ask that she does not complete a questionnaire.

Daughters name: ……..

Class: ……………………………………………………………..

Name of School: ……

Signed (parent/guardian): ………………………………………………………………… Date: ………………………

Appendix 17: Study 2 Parent Information Sheet and Consent Form - Opt In

School Logo

Parent Information Sheet

Version 2.0
Dated: 13/06/2017

Menstrual health awareness and attitudes among teenagers

Name of Researcher: Amie Randhawa

Dear Parent/Guardian,

We would like to invite your daughter to take part in our research study. We will be attending *[name of school]* on the week commencing *[date]* to ask all girls between the ages of 15 and 19 to complete a questionnaire for our research. Before you decide whether you are happy for her to take part, please read the following information to understand why the research is being done and what it would involve for your daughter. If you have any further questions or anything is unclear please do not hesitate to contact us.

What is the purpose of the study?
The aim of this study is to explore menstrual patterns, attitudes and awareness among teenagers in the UK. There is currently a lack of research which specifically addresses these issues within a UK setting, and it is hoped that by obtaining information on teenagers' awareness and attitudes, we may better understand the health and educational needs of adolescents around these topics.

Why has my daughter been invited?
Your daughter is being invited to take part because she attends a local school that has agreed to be involved in the research. We are inviting many teenagers to take part from a number of schools in the local area.

Does my daughter have to take part?
The study is voluntary so it is up to your daughter to decide whether or not she wishes to take part. If she does wish to take part she will be required to give her consent by completing and signing the consent form. As your daughter is under the age of 16, she will also require your consent to participate as well. If you are happy for her to take part then please complete and return the consent form at the end of this letter by Friday [*date – Friday before week of data collection*]. Please note that once consented into the study, your daughter is still free to withdraw at any time and without giving a reason.

What will taking part in the research involve?
This research involves the completion of a short questionnaire, which will be done during school hours at an allocated time. The questionnaire will include some brief demographic questions, such as age and ethnicity, and then a short series of questions about usual periods and their attitudes towards menstruation. The final part of the questionnaire involves questions about menstrual health awareness and education preferences. There are **no** questions about sexual activity. Participants can choose to leave out any questions that they are not comfortable with completing. The survey will take approximately 5-10 minutes to complete.

Is the study anonymous?
Yes, all the information collected during the study is anonymous. We do not ask for any information that could identify the participants and when we write up the results of the study they will be reported in a way that does not identify individual participants.

What are the possible benefits of taking part?
Although there are no direct benefits for taking part, the information we get from those who participate in this study may help to enhance our understanding of the educational needs of teenagers about menstruation. Therefore each individual's participation is highly valued.

What if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If your questions are not adequately answered then please contact the project's Supervisor, Dr Angela Hewett (contact details also below).

Will taking part in the study be kept confidential?
We will follow the ethical guidelines as set out by Birmingham City University and all information about participants will be handled in confidence.

If your daughter joins the study, then the researcher, Amie Randhawa, will be the primary person who will look at the data collected. The data may also be looked at by the supervisors of the PhD project to check that the study is being carried out correctly. All will have a duty of confidentiality to your daughter as a research participant and we will do our best to meet this duty.

All information which is collected during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database, accessible only to the primary researcher, Amie Randhawa. Any information about participants which leaves the institution will be anonymised and a unique code will be used so that participants cannot be recognised from it.

Research data will be kept on an encrypted database for 7 years, which only the researcher, Amie Randhawa will have access to. After this time the data will be disposed of securely.

Your daughter's school may be provided with a summary of the results of the research. Please be assured that this summary will not identify any individual participants or their responses.

What will happen if my daughter doesn't want to carry on with the study?
Participation in this study is voluntary and your daughter is free to withdraw at any time, without giving any reason. If she wishes to withdraw at any time during questionnaire completion, then she can indicate this to the teacher or the researcher (who will also be present). If she wishes to withdraw after completion of the questionnaire she can contact Amie Randhawa (contact details below) to inform her of her decision to withdraw. If she does decide to withdraw, all the information provided by your daughter will be destroyed and not used further in the research.

What will happen to the results of the research study?
The results of the research will be written up as part of an educational qualification, a PhD thesis and may also get published in academic journals and used in presentations about the study. Please be assured that your daughter will not be identified in any report or publication.

Who has reviewed the study?
All research at Birmingham City University is reviewed by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Health Research Ethics Committee.

Further information and contact details
If you have a concern about any aspect of this study, please do not hesitate to contact:

Amie Randhawa, PhD Candidate
Ravensbury House, Birmingham City University
Westbourne Road
Birmingham
B15 3TN
0121 331 6067
Amie.Randhawa@mail.bcu.ac.uk

Dr Angela Hewett, PhD Supervisor
Bevan House, Birmingham City University
Westbourne Road
Birmingham
B15 3TN
0121 331 7177
Angela.Hewett@bcu.ac.uk

Parent Consent Form

Version 1.0
Dated: 18/05/2017

Menstrual Health Awareness and Attitudes among Teenagers

Please detach and return this form to the school if you are happy for your daughter to participate in this study.

Please return this form by **Friday *[date].*** Forms to be handed to form teachers.

In relation to this research, I have read the Parent/Guardian Information Sheet and have been made aware of the following points:

8. My daughter's participation in this study involves the completion of a questionnaire which will ask about her usual periods, her attitudes towards menstruation and her general awareness around menstrual health.

9. My daughter's participation is voluntary and she is free to withdraw at any time, without giving any reason.

10. I understand that the information my daughter provides will be anonymised, and her personal details will be kept confidential.

11. I understand that information about my daughter that is recorded during the study will be kept on a secure database. Data will be kept for 7 years after the study has ended.

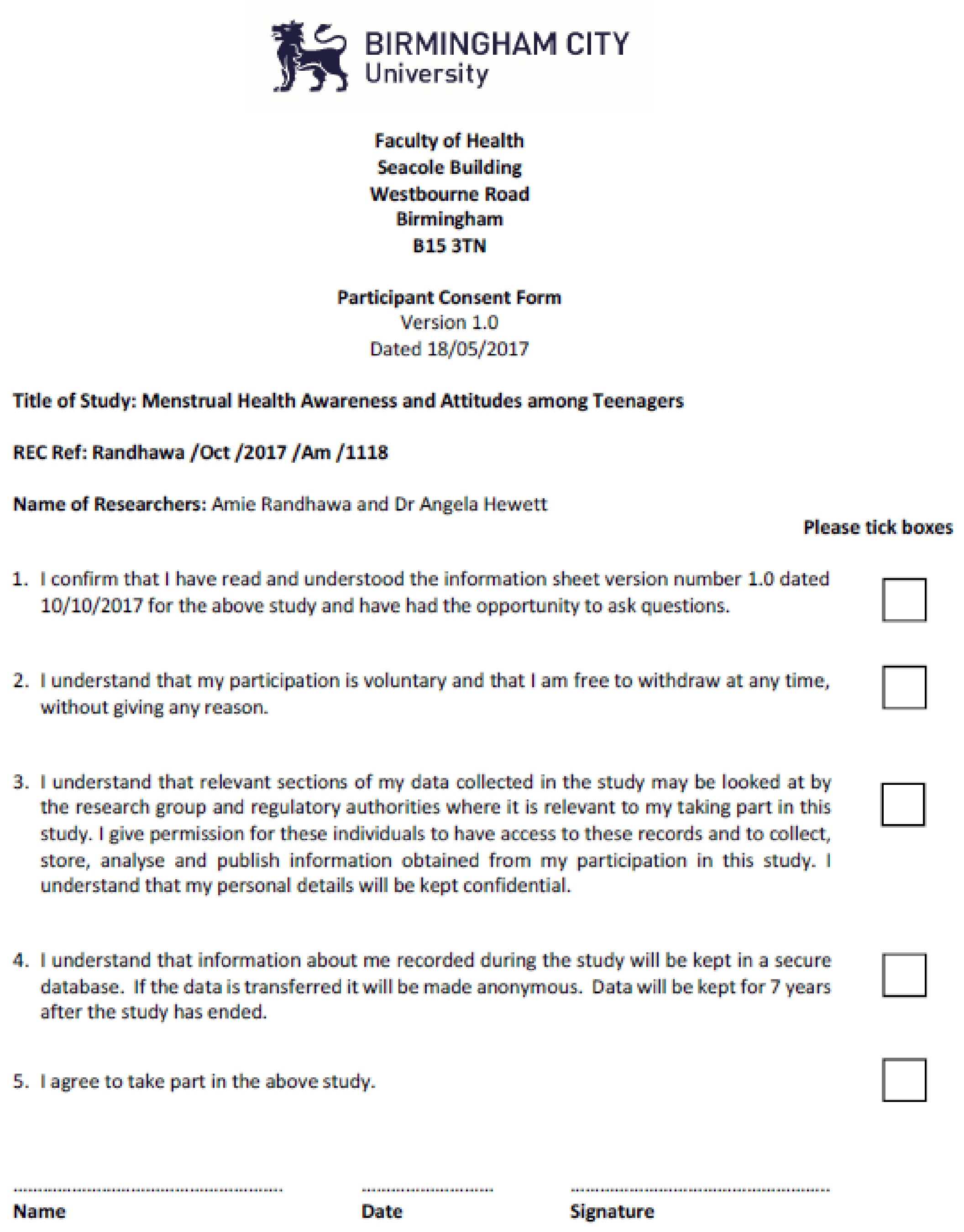
After considering these points, I agree for my daughter to take part in the above study.

……………………………………………….	…………………………………………..	…………………..
Name of Parent/Guardian	**Signature**	**Date**

Name of daughter: ……………………………………………………

Class: ………………………………………………………………..

Appendix 18: Study 2 Participant Consent Form



BIRMINGHAM CITY
University

Faculty of Health
Seacole Building
Westbourne Road
Birmingham
B15 3TN

Participant Consent Form
Version 1.0
Dated 18/05/2017

Title of Study: Menstrual Health Awareness and Attitudes among Teenagers

REC Ref: Randhawa /Oct /2017 /Am /1118

Name of Researchers: Amie Randhawa and Dr Angela Hewett

Please tick boxes

1. I confirm that I have read and understood the information sheet version number 1.0 dated 10/10/2017 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred it will be made anonymous. Data will be kept for 7 years after the study has ended. ☐
5. I agree to take part in the above study. ☐

…………………………………………	…………………	…………………………………………
Name	**Date**	**Signature**

Appendix 19: Study 2 Survey

Adolescent Menstrual Health Survey

Section 1: About You

Please provide the following information about yourself:

Date of birth: ………………………………………… (dd/mm/yyyy)

Ethnicity: ……………………………………………… (e.g. White, Black, Asian, Mixed, etc.)

Religion: ………………………………………………………………………………………

Name of School/University: ………………………………………………………………

Level of education: Please tick any qualifications you have already completed

☐ A Levels ☐ AS Levels

☐ GCSEs ☐ BTEC

☐ I have not completed any yet

☐ Other ……………………………………………………………………… (please specify)

Section 2: About your usual periods

(please tick or circle the appropriate responses)

This section of the questionnaire asks about your usual periods. There are no right or wrong answers and you do not have to answer any question that you do not want to.

1. Have you had your first period?

☐ Yes

☐ No If No, please go to **Section 3** on **page 3**

2. What age were you when you had your first period?

………. Years ………. Months

3. Over the last 3 months, what was the usual length of your period? …………… days

4. What is the *usual* number of days from the first day of bleeding at one period to the first day of bleeding of your *next* period? (i.e. your cycle length)

…………… days

☐ Irregular periods

☐ Don't know

5. Do you ever experience period pain?

☐ No (If no, go to question **10**)

☐ Yes, with every period

☐ Yes, just with some periods

6. Please rate on this scale from 0 to 10, any period pain you have had over the past 3 months *(please circle just one response):*

No Pain 0 1 2 3 4 5 6 7 8 9 10 Worst pain

7. Do you take medication for the pain?

☐ Yes

☐ No (If no, go to question **10**)

8. Which medication do you usually take? *(please tick any that apply)*

☐ Paracetamol ☐ Aspirin

☐ Ibuprofen ☐ Feminax

☐ Other .... (please specify)

9. How effective is the medication at relieving your pain? *(please circle just one response)*

Not effective 0 1 2 3 4 5 6 7 8 9 10 Very effective

10. Do you ever miss school because of your periods?

☐ No (If no, go to question **12)**

☐ Yes, with every period

☐ Yes, just with some periods

If yes, how many days do you usually miss per month? .... days

11. What is it about your period that causes you to miss school? *(please tick any that apply)*

☐ Too painful ☐ Blood flow too heavy

☐ Nausea (feeling sick) ☐ Vomiting (being sick)

☐ Other .... (please specify)

12. Have you ever taken the contraceptive pill?

☐ Yes

☐ No (If no, go to question **15**)

13. Do you take it currently?

☐ Yes

☐ No

14. Please provide your reason for using the contraceptive pill: *(please tick any that apply)*

☐ To regulate my periods

☐ To prevent pregnancy

☐ To help with my period pain

☐ To help with spots or acne

☐ Other ....(please specify)

15. Have you ever visited a doctor or other health professional about your periods?

☐ Yes

☐ No (If no, go to question **18**)

16. What happened as a result of that visit? *(please tick any that apply)*

☐ I was given medication

☐ I was sent to see a specialist doctor

☐ I was told to come back if the problem continues

☐ Other ………………………………………………………………………(please explain)

17. Did you feel reassured about the problem following the visit?

☐ Yes ☐ No

If not, why? ……………………………………………………………………………………………………

18. Do you consider your periods over the last 3 months to be typical for girls your age?

☐ Yes

☐ No

☐ Unsure

Section 3: Attitudes about periods **(please circle or tick the appropriate responses)**

This section of the questionnaire asks about your attitudes towards menstruation (periods) and how you feel about discussing it with other people. There are no right or wrong answers and you do not have to answer any question that you do not want to.

19. For each of the following questions, circle a number between 1 and 7, to indicate how much you agree with each statement, using the following scale:

Strongly Disagree			**Neither agree nor disagree**			**Strongly Agree**
1	**2**	**3**	**4**	**5**	**6**	**7**

a) Menstruation is something I just have to put up with.

1 2 3 4 5 6 7

b) Women are more tired than usual when they are menstruating

1 2 3 4 5 6 7

c) Menstruating is a sign of womanhood

1 2 3 4 5 6 7

d) Menstruation can adversely affect my performance in sport

1 2 3 4 5 6 7

e) I envy boys because they don't have menstruation

1 2 3 4 5 6 7

f) Menstruation is something to be happy about

1 2 3 4 5 6 7

g) When I have my period, I am worried that I'll have an accident.

1 2 3 4 5 6 7

h) I am more easily upset during my period that at other times of the month.

1 2 3 4 5 6 7

i) Overall, I think that periods are:

☐ Positive ☐ Negative ☐ Don't mind

20. In the table below, please indicate, by placing a tick in the appropriate column, how comfortable you are with talking about menstruation (periods) with each of the people listed.

	Very Comfortable	Comfortable	Don't mind	Not comfortable	Very un-comfortable	N/A
A female relative (i.e. Mum, aunt, grandmother)						
A male relative (i.e. Dad, uncle, grandfather)						
Female Siblings						
Male Siblings						
Female Friends						
Male Friends						

21. Before you started your periods, who did you receive the most information from about menstruation (periods)? *(please tick only one response)*

☐ Female relative	Mum/Aunt/Grandmother/Other	*(please circle which)*
☐ Male relative	Dad/Uncle/Grandfather/Other	*(please circle which)*
☐ Sibling	Brother/Sister	*(please circle which)*

☐ Friend

☐ Learned about it at school

☐ Media (i.e. newspaper/magazine article, radio, tv programme etc.)

☐ Internet

☐ Doctor

☐ Other: ……………………………………………………………………(please specify)

22. If you wanted more information about periods, who would you approach first? *(please tick only one response)*

☐	Female relative	Mum/Aunt/Grandmother/Other	*(please circle which)*
☐	Male relative	Dad/Uncle/Grandfather/Other	*(please circle which)*
☐	Sibling	Brother/Sister	*(please circle which)*

☐ Friend

☐ School teacher

☐ Doctor

☐ School nurse

☐ I would search on the internet

☐ Other: ……………………………………………………………………(please specify)

Section 4: About Endometriosis

The following questions are about your knowledge of endometriosis. Please remember that this is not a test. We want you to answer the questions honestly, so it doesn't matter if you don't know what it is at the moment.

23. Do you know what endometriosis is?

☐ Yes

☐ No (If No, please go to the top of **page 6**)

24. Please describe what endometriosis is in your own words:

……

……

……

……

25. How do you know about endometriosis? *(please tick only one response)*

☐	Parent	Mother/Father	*(please circle which)*
☐	Sibling	Brother/Sister	*(please circle which)*

☐ Personal experience

☐ Learned about it at school

☐ Media (i.e. newspaper/magazine article, radio, TV programme etc.)

☐ Internet

☐ Doctor

☐ School Nurse

☐ Friend

☐ Other …………………………………………… (please specify where from)

A brief description of Endometriosis

Endometriosis is a condition that affects approximately 10% of women and it is related to your periods. Each month, a period occurs because the cells that line your womb build up and then break down and leave your body through your vagina, as a period. Endometriosis is when these cells, which usually line your womb, are found in other places, such as your ovaries. These cells respond to the hormonal cycle as if they were in the womb: they grow and then break down ready to be flushed out. But, unlike a normal period, the blood has no way of leaving the body. Because of this, girls can experience a lot of pain, but it can also cause irritation, and in the worst cases infertility. For many women, endometriosis begins when they are a teenager, but it can take many years to diagnose.

26. Do you think this is something you would like to learn more about, if given the opportunity?

☐ Yes
☐ No

27. If you would like to learn more about it, how do you think you would most prefer to learn about it? *(please tick only one response)*

☐ From a parent
☐ From a sibling (brother or sister)
☐ During a lesson at school
☐ From the school nurse
☐ Through the media (i.e. a magazine article, or a tv programme etc.)
☐ Through the internet
☐ From a doctor
☐ From a friend

28. Who would you feel comfortable talking about endometriosis with? *(tick as many answers as you like)*

☐ Parents
☐ Siblings (brothers or sisters)
☐ Other relative ……………………………………………………… (please specify who)
☐ Teachers
☐ School Nurse
☐ Doctor
☐ Friends

29. Do you think that boys should learn about endometriosis too?

☐ Yes ☐ No

END OF SURVEY

Appendix 20: Study 2 Ethics Approval Letter

BIRMINGHAM CITY
University

Faculty of Health, Education and Life Sciences Research Office

Faculty of Health, Education and Life Sciences
Birmingham City University
Westbourne Road
Birmingham
B15 3TN

HELS_Ethics@bcu.ac.uk

27/09/2017

Mrs. Amie Randhawa

Ravensbury House
Westbourne Rd
Birmingham
B15 3TN
United Kingdom

Dear Amie ,

Re: Randhawa /Sep /2017 /RHRB /1118 - Adolescents' awareness of endometriosis

Thank you for your application and documentation regarding the above activity. I am pleased to take Chair's Action and approve the activity which means you may begin.

I can also confirm that any person participating in the project is covered under the University's insurance arrangements.

Please note that ethics approval only covers your activity as it has been detailed in your ethics application. If you wish to make any changes to the activity, then you must submit an Amendment application for approval of the proposed changes.

Examples of changes include (but are not limited to) adding a new study site, a new method of participant recruitment, adding a new method of data collection and/or change of Project Lead.

Please also note that the Committee should be notified of any serious adverse effects arising as a result of this activity.

If for any reason the Committee feels that the activity is no longer ethically sound, it reserves the right to withdraw its approval. In the unlikely event of issues arising which would lead to this, you will be consulted.

If you have any queries, please contact HELS_Ethics@bcu.ac.uk

I wish you every success with your activity.

Yours sincerely,

Ms Nathalie Turville

On behalf of the Faculty Academic Ethics Committee
Health, Education and Life Sciences

Appendix 21: Study 2 Further Information Sheet for Participants

BIRMINGHAM CITY
University

Further Information Sheet

Menstrual Health Awareness and Attitudes amongst Teenagers

Thank you very much for taking part in our research.

The information you have provided will be used to help us understand typical menstrual patterns for teenagers in the UK, as well as how they feel about their periods. We are also interested to learn whether teenagers are aware of endometriosis, and if there is any way to improve education about endometriosis to help people to recognise the symptoms earlier and perhaps get an earlier diagnosis.

If you would like further information about any of the topics covered in the research, then please have a look at the further information sources outlined below:

1. **Teens Health – All about menstruation (for teens)**
   This website provides general information about menstruation (periods) and is written especially for teenagers. Here you will find information about puberty, the menstrual cycle, and some of the symptoms of a period you can expect (such as cramps and spots). There is also lots of other information about teen health on the website which you might find interesting.
   http://teenshealth.org/en/teens/menstruation.html?WT.ac=t-ra#

2. **NHS Choices – Period pain**
   This webpage is run by the NHS and it provides information on period pain, what is regarded as 'normal' pain, and when you should consider seeing your GP about your period pain:
   http://www.nhs.uk/Conditions/Periods-painful/Pages/Introduction.aspx

3. **Endometriosis UK**
   Endometriosis UK is a national organisation that provides reliable information about endometriosis. Their website address is: https://www.endometriosis-uk.org/. They also have a webpage aimed specifically at teenagers, which you can find at the following link:
   https://www.endometriosis-uk.org/Information-teenage-girls

4. **Your Healthcare Providers**
   If you are concerned about any of your symptoms or need any advice then please contact your GP (local Doctor) or speak to your school nurse.

If you have any further enquiries about the research, please contact Amie Randhawa, or her supervisor Dr Angela Hewett:

Amie Randhawa
Birmingham City University
0121 331 6067
Amie.Randhawa@mail.bcu.ac.uk

Dr Angela Hewett
Birmingham City University
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Angela.Hewett@bcu.ac.uk

Appendix 22: Study 2 Verbal Instructions for Survey Completion

Adolescent Menstrual Health Survey

Instruction Sheet - to be read out by Teacher/School Staff/Researcher

Please provide all students with a survey, and then give them the following instructions:

To start with, please read the consent form on the front page, and then place a tick in each of the boxes down the right-hand side next to each point. Then write your name, the date, and your signature where indicated at the bottom of the page.

Before moving on to the survey, I have a few instructions for you:

- Complete the survey using a pen (not a pencil).
- Work through the survey in the order in which it is presented.
- Please read the questions carefully, and the responses that are required for each question. For example, some questions may ask you to tick just one response, whereas others may say to tick as many responses as you like. Please be sure to follow these guidelines.
- Please remember that there are no right or wrong answers to any questions, and if you are asked for your opinions, please give them honestly. The results are anonymous so no one will be able to link the answers you give back to you.
- This is not a test, but please don't talk about your answers while filling in the survey – the researchers are really interested to hear your own experiences and opinions.

You can now begin the survey.

Once surveys are completed, please collect them all in and then ***provide all students with the 'Further Information Sheet'.***

N.B. Please ensure that students don't discuss their answers between themselves, or use phones/tablets to look up any information.

Appendix 23: Study 2 Missing Data Analysis

Survey Item	**N**	**Missing count**	**Missing percent**
Age	437	5	1.1
Ethnicity	430	12	2.7
School Type	438	4	0.9
Had first period?	442	0	0
Age First period	433	9	2
Length of period/bleeding	429	13	2.9
Length of cycle (over 14 days)	177	265	60*
Regularity of cycles	409	33	7.5
Experience period pain?	439	3	0.7
Pain severity	409	33	7.5
Medication for pain?	416	26	5.9
Effectiveness of medication	266	176	39.8
Miss School due to periods?	440	2	0.5
Ever taken contraceptive pill?	439	3	0.7
Ever seen a GP about periods?	441	1	0.2
Consider periods typical/not sure/not typical	434	8	1.8
Menstruation is something I just have to put up with	439	3	0.7
Women are more tired than usual when they are menstruating	440	2	0.5
Menstruating is a sign of womanhood	440	2	0.5
Menstruation can adversely affect my performance in sport	437	5	1.1
I envy boys because they don't have menstruation	438	4	0.9
Menstruation is something to be happy about	439	3	0.7
When I have my period, I am worried that I'll have an accident	437	5	1.1
I am more easily upset during my period that at other times of the month	436	6	1.4
Periods are positive, negative, don't mind	431	11	2.5
Do you know what endometriosis is?	437	5	1.1
Do you want to learn about endometriosis?	439	3	0.7
Do you think boys should learn about endometriosis too?	435	7	1.6

*Many participants left this item blank and ticked 'don't know' or 'irregular periods'

Appendix 24: Study 2 Findings Published in the Journal of Pediatric and Adolescent Gynaecology

Title Page

Title: Secondary School Girls' Experiences of Menstruation and Awareness of Endometriosis: A cross-sectional study

Authors:

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Site of Study: West Midlands, England

Funding: Birmingham City University's Faculty of Health, Education & Life Sciences

Disclaimers: None

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Word count of abstract and main text (excluding title page, acknowledgements, references and tables): 250 (Abstract), 3165 (main text)

Title: Secondary School Girls' Experiences of Menstruation and Awareness of Endometriosis: A cross-sectional study

Structured Abstract

Study Objective: To characterise typical (ie, normal) menstrual characteristics in a large sample of secondary school girls, as well as knowledge of typical menstruation, endometriosis awareness and educational needs. To establish whether self-reported atypical period symptoms indicate menstrual characteristics suggesting the need for further clinical review for a specialist opinion.

Design: Cross-sectional survey.

Setting: Secondary schools in West Midlands, England.

Participants: 442 girls, 15-19 years.

Interventions and Main Outcome Measures: The questionnaire determined demographic characteristics, age at menarche, menstrual cycle patterns and experiences, awareness of endometriosis, and preferences for learning about it.

Results: Period pain was common (94%), with pain reported as moderate/severe (86%). Girls reported missing school due to their periods (23%), mainly due to pain. Most believed their period was typical (63%); however, 27% were unsure, and 30% did not know if it was regular. Self-report of atypical periods was associated with symptoms suggesting need for clinical review and with consulting a doctor ($\chi^2(2) = 36.272$, $p < 0.001$). Only 8% could describe endometriosis, though 86% wanted to learn more about it.

Conclusion: Most secondary school girls report dysmenorrhea. Although most reporting atypical periods had seen a doctor, over a quarter did not know whether their period was typical or regular. The majority do not have knowledge of endometriosis, contrasting with adolescents' familiarity with other common chronic conditions such as diabetes and epilepsy. We suggest Menstrual Health Education (MHE) to improve knowledge of typical menstruation and pain treatment, aiding earlier identification of problematic period symptoms that might indicate underlying pathology.

Key Words: Adolescent, menstruation, dysmenorrhea, endometriosis, delayed diagnosis, education

Introduction

Menstrual pain (dysmenorrhea) is the main gynaecological complaint of adolescents.[1] The majority of adolescents with menstrual pain have primary dysmenorrhea, painful menstruation in the absence of pathology, but a significant minority have secondary dysmenorrhea, painful menses due to pelvic pathology.[2] Endometriosis, the chronic condition defined by the presence of endometrial gland and stroma outside the uterine lining, is the leading cause of secondary dysmenorrhea as well as chronic pelvic pain (CPP) in this age group.[2, 3] Approximately two-thirds of adolescent girls with CPP or secondary dysmenorrhea who undergo laparoscopy have evidence of endometriosis.[4,5]

The true prevalence of adolescent endometriosis is unclear due to delayed recognition and intervention.[3,6] Two to 10% of women of reproductive age have endometriosis,[7] and a majority of those diagnosed as adults report first experiencing symptoms in adolescence.[8, 9] Delays from symptom onset to diagnosis can result in persistent chronic pain, significant adverse impacts on quality of life,[10,11] potential progression of the disease,[12] and possible infertility.[13] Adolescents unaware of typical menstrual characteristics may not recognise, or seek out help for, abnormal symptoms.[14,15] This study aims to characterise typical menstrual characteristics in a large sample of secondary school girls, and to explore this age groups' knowledge of typical menstruation, endometriosis awareness and educational needs. An additional further aim is to establish whether those who experience menstrual characteristics that might indicate the need for clinical review and specialist opinion, report their period to be atypical.

Materials and Methods

Participants and setting

A descriptive cross-sectional survey study was carried out with secondary school girls aged 15 to 19 years old. AR recruited participants from secondary schools in the West Midlands, England. Schools included an independent girl's school (A), an independent mixed-sex boarding school (B), and a government run mixed-sex academy school (C), representing a diverse range of recruitment sites. Non-random convenience sampling was used.

Questionnaire and Procedure

A self-administered pen and paper survey was designed specifically for this research. The survey consisted of questions newly developed to meet the aims of the study and also included existing questions used by other researchers conducting similar studies.16-19,26 AR and AH developed survey questions in consultation with GR and AW. The final questionnaire consisted of four sections: 1) demographic characteristics (e.g. age, ethnicity, and school type); 2) age at menarche, cycle patterns, and menstrual experiences; 3) preferences for communicating about menstruation with others; and 4) awareness of endometriosis, and preferences for learning about it in future.

The opening question to section four was ‘Do you know what endometriosis is?’ Respondents who answered ‘yes’ were then asked to describe endometriosis in their own words. This allowed for the assessment of respondents’ levels of awareness and understanding, in line with previous endometriosis research.[18] After being asked if they know what endometriosis is, as done in previous similar surveys with adolescents,[18] a short lay (non-medical) description of endometriosis, was provided to participants on a separate page. The description was based on a definition of the condition employed in an information leaflet produced for teenagers by Endometriosis UK in 2014. Participants were then asked if they would like to learn more about endometriosis, as well as how they would like to learn about it, who they were comfortable talking about it with and whether they thought boys should learn about it too.

The survey was piloted with 10 girls from the target population (aged 15-19) to assess the clarity of wording, acceptability of formatting, and ease of implementation. Following pilot testing, data collection was completed between November 2017 and March 2018. At least a week prior to survey completion, all female students meeting the target criteria were given verbal information about the research by the first author or a teacher at their school. They were also given a study information sheet, and a parent/guardian information sheet if under 16 years. Schools were given the choice between opt-in and opt-out parental consent as they were best positioned to know which would be most acceptable to students and parents/guardians. One school (A) requested that all students were given the parent/guardian information sheet and used opt-in parental consent, whilst two schools (B & C) used opt-out parental consent for under 16s. Participants had the opportunity to ask questions before providing consent and completing the survey. Survey completion took approximately 5-10 minutes.

Ethics and Data Analysis

The university ethics committee at Birmingham City University granted ethical approval for this study. After survey completion, all participants received a leaflet signposting relevant and locally accessible health and support organisations should they want further information, or have concerns about, their menstrual health. All questionnaires were reviewed and checked for completion and accuracy by the principal investigator before inputting the data into an electronic database using a pre-constructed codebook. Responses to the free-text question asking participants to define endometriosis were transferred into QSR's NVivo 11, to be coded using content analysis, in line with previous endometriosis research.[18] AR read and re-read the answers to enable familiarisation, and then they were grouped to obtain categories. Final categories were reached upon agreement by two researchers (AR & AH). Each category was given a number to allow for further statistical analysis.

Data was analysed using SPSS Version 24. Tests for normality were performed on the continuous variables (i.e. current age, age of menarche), which were found to be non-normally distributed. Therefore, subsequent analysis of data used either the Mann-Whitney U test or the Kruskal-Wallis test for continuous data, and Chi-squared tests for the categorical data. For the latter, if expected cell counts were less than 5 for >20% of the cells, a Fisher's exact test was used for 2x2 tables, and a likelihood ratio chi-squared test for larger tables.20 A p value of <0.05 was considered to show a statistically significant result.

Results

Sample Demographic Characteristics and Menstrual Experiences

A total of 442 secondary school girls, aged 15 to 19 years, participated in the survey, with a median age of 17 years. The overall response rate to the survey was 53%.

At the time of survey completion, 99.5% of participants had started their periods (440/442). The median age of menarche was 12.5 years and ranged from 9 to 16.42 years. Most participants reported menstrual bleeding between 4 and 7 days (88.9%), and the median duration was 5 days. Only 48.6%, of the sample reported the length of their menstrual cycle, and for those reporting between 21-45 days, the median length was 28 days. Irregular periods were reported by 31.3% of responders, and 29.6% indicated that they did not know the length of their cycle. Those who provided the length of their cycle, and did not tick 'don't know' or 'irregular periods' were assumed to have regular periods (39.1%). The full response rates by school, demographic and menstrual bleeding pattern information collected for the sample are shown in Table I.

Table I. Sociodemographic factors and menstrual bleeding patterns.

Table II shows period pain rates for the sample as well as medication usage and school absences. Their pain responses were categorised as 'mild pain' (answers 1 to 3), 'moderate pain' (4-7), and 'severe pain' (8-10), using the similar cut-off scores as in previous research.[16] The effectiveness of their pain medication was rated from 0 to 10, and these responses were categorised into 'no/low effectiveness' (0 to 3), 'moderate effectiveness' (4-7), and 'high effectiveness' (8-10), using the same cut-off scores as in previous research.[16]

School absence due to periods was reported by 100 (22.7%) responders with the majority missing 1 day, and 2 days given as the maximum response. The reason most often stated was that their period was 'too painful' (91.0%). Almost a third of the sample had visited a doctor about periods (29.5%).

Table II. Menstrual pain, medication use and school absence

Perceived typicality of periods

Participants indicated whether they thought their periods were typical (ie, normal) for someone their age, with 274 (63.1%) responding 'yes', 44 (10.1%) responding 'no', and 116 (26.7%) responding 'unsure'. Further analysis was conducted using this data to examine if those who perceive their period to be atypical also report symptoms comparable with National Institute for Health and Care Excellence (NICE) criteria[31] for referral for further clinical review and specialist investigation. NICE guidelines are standard clinical guidelines developed for the UK National Health Service and are developed by independent committees comprised of professionals, members of the public, and relevant stakeholders. Finally, knowledge of endometriosis was compared across the groups according to whether the girls thought their period was typical for someone their age.

Grouping by Self-reported Typicality of Period

The girls who believed that their periods were not typical for someone their age were more likely to report irregular periods ($\chi^2(2) = 46.42$, $p < 0.001$), take medication for period pain ($\chi^2(2) = 8.75$, $p < 0.05$), take oral contraceptive pills (OCPs) ($\chi^2(2) = 9.58$, $p < 0.01$), have knowledge of endometriosis ($\chi^2(2) = 8.75$, $p < 0.05$), and have seen a doctor about their periods ($\chi^2(2) = 36.272$, $p < 0.001$). Pain severity ratings were significantly different between the groups, with those who thought their periods were typical having lower pain scores than those who thought their periods were not typical and those that were unsure ($H(2)=11.62$, $p = 0.003$). Those who thought that their periods were not typical also reported that their pain medication was less effective than those who reported that their periods were typical ($H(2)=10.465$, $p = 0.005$). Although school absence was not significantly related to perceived typicality (i.e., 'normalness') of periods, it was related to pain severity, with those in the highest pain group (8-10 on the pain scale) missing more school ($\chi^2(2) = 49.78$, $p < 0.001$).

Awareness of Endometriosis

Although forty-four participants (10.1%) answered 'yes' to the question 'Do you know what endometriosis is?', forty-six participants provided a description of endometriosis, which were coded and categorised into description types. Only 8.2% went on to accurately describe the condition. Descriptions were based on symptoms, the biological mechanisms involved in endometriosis, or a combination of both. Pain as a symptom was mentioned most frequently, representing 50% (23/46) of descriptions. Descriptions including biological mechanisms were based on the lining of the womb appearing elsewhere (15/46) and blood being unable to leave the body (5/46). Some descriptions were vague, or did not capture any element of the definition of endometriosis. Five responders' descriptions were simply of a period, and four could be categorised as 'something to do with a period', which was likely evident given the nature of the survey. Participants who stated that they knew what endometriosis was also indicated how they knew; almost half (21/43) knew about endometriosis from the internet or media.

The majority of participants (85.9%) indicated that they would like to learn more about endometriosis. Over half (51.3%) indicated school as their preferred source of learning, via lessons or the school nurse. However, only 26.5% indicated they were comfortable discussing endometriosis with a schoolteacher. The majority of participants (82.8%) thought boys should learn about endometriosis as well.

Discussion

This study characterises typical menstrual characteristics for secondary school girls; it explores this age groups' knowledge of typical menstruation and awareness and educational needs regarding endometriosis. It further establishes if self-reported atypical period symptoms indicate menstrual characteristics suggesting the need for further specialist clinical review.

This study demonstrates the critical need for improved adolescent menstrual health education (MHE). One in four girls (27%) were unsure if their periods were typical, 1 in 10 (10%) considered their periods non-typical and nearly 1 in 3 (30%) did not know if their periods were regular. Female pupils report available MHE provision to be overly abstract (focused on the biological aspects of menstruation) and that it does not address their concerns about whether their periods are 'normal.'[21-24] Those unaware of typical menstrual characteristics may not recognise, or seek out help for, abnormal symptoms.[14,15]

Pain remains a significant factor in girls' period experiences, with a majority (86%) reporting their period pain to be moderate or severe, reflecting similarly high levels of adolescent dysmenorrhea from past research[1,17,25-30]. Nearly 1 in 3 girls report visiting a doctor about their periods, a rate reflecting the wide-spread experiences of pain and uncertainties around typical menstruation. Period pain is the primary reason for missing school (91%) and those with severe pain are more likely to miss school (45%). While most girls (66%) have taken medication or OCPs to manage pain, a significant number have not. Girls want to learn more about menstrual cramps and how to manage pain.[24] A key component, therefore, of MHE is the inclusion of discussions of pain treatment options, including medication options such as non-steroidal anti-inflammatory drugs and OCPs.

This study demonstrated that those reporting non-typical periods were significantly more likely to report irregular periods, severe period pain, taking medication for period pain, finding medication inadequate for pain, taking OCPs, seeing a doctor about their periods, and knowing what endometriosis is. Contact with medical services might have resulted in OCP prescriptions, as well as discussions with health care professionals about possible endometriosis. As per recent clinical updates3 and UK and European guidelines,[7,31] those reporting higher pain levels and ineffective pain relief from medication exhibit atypical periods indicative of the need for possible clinical review for a specialist opinion.

Findings also demonstrate the acute need for improved endometriosis awareness amongst adolescents. Only 8% of secondary school girls knew what endometriosis was, approximately half the rate in Italy (19%)[19] and a third of that in Australia (24%).[17] Adolescents in the general population report comparatively high familiarity with other health conditions.32 The majority are familiar with asthma (88%), arthritis (84%), diabetes (81%), HIV/AIDS (78%), and breast cancer (72%); approximately one-third are familiar with Parkinson's disease (39%) and epilepsy (31%).[32] Girls are considerably less aware of endometriosis than other chronic conditions with similar adult prevalence rates, specifically diabetes and epilepsy.

Improving individuals' awareness of endometriosis may help improve time to diagnosis. The average delay from symptom onset to diagnosis is eight years in the United Kingdom.[33] In the United States, where referrals are not needed to access gynaecological specialist care, the average delay is four and a half years.[34] While improving adolescents' knowledge of menstruation and endometriosis may reduce diagnostic times, stigma around speaking about periods must also be addressed, as research shows girls and adult women may be reluctant to speak about their menstrual health even with health professionals.[35] Further, there is evidence health care professionals may dismiss or 'normalise' the endometriosis symptoms of those who come to seek care.[36]

This research showed that girls want to know more about endometriosis (86%), and school lessons are the preferred mode of learning about the condition (41%). Girls are less comfortable speaking with their teachers (27%) than with school nurses (37%), doctors (44%), friends (56%) or parents (64%) about endometriosis. Previous research shows most teen girls (63%) are uncomfortable talking about periods with teachers,[37] thus, as found elsewhere,[38] students may prefer outside experts (youth workers, sexual health professionals, etc.) deliver MHE content. Girls worry about being shamed at school about their periods, particularly by boys.[23,39] The majority of girls feel boys should learn about endometriosis (83%), and inclusion of boys in general MHE could reduce period-related bullying.[24,37]

In addition, MHE needs to allow girls to not just learn about biological factors associated with menstrual cycles and menstrual bleeding, but also provide safe spaces for girls to discuss what having a period is really like for them. Research shows that girls want to discuss the psychological and social aspects of having a period – not just the biological aspects.[21,23,24,40] Gunson et al., (2016)[41] found that overly positive and naturalistic descriptions of menstruation could lead girls to feel that their experiences did not live up to expectations. Most adolescent girls feel comfortable talking about menstruation with female friends,[37] and this allows them to provide support for each other around the aspects of menstruation that girls view negatively.[42] MHE should also take into account a wide age-range since although the average age of menarche was 12.5 in this study, some girls started as early as 9. MHE would therefore ideally start early and continue in an ongoing fashion, instead of as a one-off.

Strengths and Limitations

The survey was modelled on those from similar previous studies[16-19] and designed to address this study's aims. A limitation was an absence of validated questionnaires to draw upon. Despite the pilot study indicating that the questionnaire was fit for purpose, some main survey respondents confused the length of their period with the length of their menstrual cycle (resulting in 37 respondents reporting menstrual cycles of between 2 and 7 days). The 23 respondents linking endometriosis to pain in their descriptions of the condition may have deduced this connection from survey questions focused on their period pain experiences. However, as only 5% of the total number surveyed responded to the endometriosis definition question with an answer including pain, it does not appear to have overly influenced the results on endometriosis awareness. It is also worth noting that a higher percentage of girls may have reported wanting to learn about endometriosis because the condition was introduced to them in this survey, therefore increasing its salience. The survey did not include questions regarding secondary school girls' experiences of heavy menstrual bleeding, a common adolescent gynaecological concern and possible symptom of underlying pathology[43] that warrants investigation in future research. The frequency of OCP use was somewhat low in this sample (13.7%). Previous research[44] suggests that the percentage of girls receiving a prescription for OCPs in the UK is 19%. The low frequency of OCP use may also be due to delays in access reported for adolescents in the UK.[45] It is possible that cycle length, perceived cycle regularity and pain levels could have been influenced by OCP use; however, as described above, the percentage of the sample using OCPs was low. The survey did not include questions regarding use of other menstrual management or contraceptive medications (e.g. intrauterine devices, contraceptive injections, etc.).

To our knowledge, this is the first England-based study on the typical experience of menstruation for adolescents (of any age) as well as their knowledge of typical menstruation and endometriosis. Only two recent similar studies on menstrual characteristics in adolescents and young women have been conducted in Australia[17] and Italy.[19] This study had a large and ethnically diverse sample, nearly half (49.1%) of participants identified as Asian, 35.8% as White, 10.7% as Black and 4.4% as Mixed Race. Such diversity is important given menstrual experiences of ethnic minority populations have been under-represented in the literature previously.[14-19,37]

Conclusion

Most secondary school girls experience period pain, many do not know if their periods are regular or typical, and an overwhelming majority do not know what the common chronic condition endometriosis is. Findings demonstrates the critical need for better MHE provision to improve girls' knowledge of typical menstruation and period pain experiences, pain management options, and common gynaecological health conditions. Such provision is key to improving girls' menstrual health knowledge, experiences and outcomes.

Acknowledgements

The authors thank all those who took part in the survey and the schools that facilitated this participation. Gratitude is also expressed teachers from participating schools as well as representatives from Endometriosis UK whose opinions we sought on the acceptability of the wording of the survey. Thank you also to Dr. Jeffrey Wood who consulted on the statistical analyses for the paper.

Disclosure/Conflicts of Interests

None.

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