Living With Endometriosis In Camden:2024

healthwatch Camden

Contents

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PLEASE NOTE: For the purpose of this report, the term **'Woman'** is used throughout to refer to anyone assigned female at birth (AFAB), i.e., people who menstruate[1] of average menstruating age (12-49 years old), girls of pre-menstrual age, and women post menopause age.

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Lastly, our sincere gratitude to all the women who placed their trust in us by attending the endometriosis support sessions and sharing their endometriosis journey. Each one of them possesses strength beyond measure, and we are extremely grateful for their participation.

About Us

Healthwatch Camden is an independent organisation formed to give patients, service users, carers, and residents a stronger voice to influence and improve how health and social care services are provided to the people of Camden. Our duties (which are set out under the Health and Social Care Act 2012) are to support and promote involvement of Camden residents in the planning, running, and monitoring of services; to produce reports and make recommendations for services based on their views and experiences; and to offer information on choices they can make in accessing and utilising services. Our remit extends across all publicly funded health and social care in the borough.

1. Introduction

Healthwatch Camden conducted a funded project to explore the experience of endometriosis among women in Camden. As part of the project, women across Camden with a diagnosis or suspected symptoms of endometriosis were invited to attend a short program of six support group sessions held locally. Each session followed the traditional peer support group format, where women were provided a safe space to engage in gently guided physical exercises, shared learning, informative talks, and question and answer sessions with various women's health experts.

This report is one of the outcomes of the project and it aims to present women's experiences around the myriad ways in which endometriosis is having an impact on the quality of their health and wellbeing. We hope that the findings and recommendations outlined in this report will add to emerging national evidence, demonstrating the human impact of health inequities faced by women with this disease, and the need for urgent steps to improve support in Camden, and beyond.

1.1. What is Endometriosis

Endometriosis[2] is a chronic inflammatory disease that occurs when cells similar to the ones in the lining of the womb (uterus) are found elsewhere in the body. These cells can grow and change in response to hormones in the menstrual cycle, this can cause inflammation, pain and scar tissue. Endometriosis is most commonly found on the lining of the pelvis (peritoneum) and may occur in the ovaries and involve other pelvic organs, like the bowel or bladder. Less commonly, endometriosis can also be found outside the pelvis, such as in the chest.

Endometriosis affects 10% of women and those assigned female at birth from puberty to menopause, although the impact may be felt for life. In the UK, that's over 1.5 million from all races and ethnicities living with the condition[2].

Symptoms vary from person to person, some may have severe and debilitating symptoms, others may have no symptoms at all. Symptoms are not always related to the location, amount or the type of endometriosis. It's also important to know that endometriosis symptoms can also be symptoms of other health conditions. Common symptoms include pelvic pain, painful periods that interfere with everyday life, heavy menstrual bleeding, pain during or after sex, painful bowel movements, pain when urinating, fatigue, and difficulty getting pregnant (up to 70% of those with endometriosis will be able to get pregnant naturally), with one or more of the above symptoms.

NHS data from 2023-24 show a large number of female patients admitted with endometriosis, polyps, gynaecological cancer (grouping of noninflammatory disorders of female genital tract), with most of them on waiting lists with lengthy waiting times, and high emergency admission rates[14]. In gynaecology, which is the department responsible for this condition (amongst others), waiting times have trebled in the past decade. The average waiting time to see a gynaecologist in 2022 was 15.6 weeks compared to 4.8 weeks in 2012[17]. NHS gynaecology waiting times are so extensive that increasing numbers of women consider going private despite the financial pressures caused by the cost-of-living crisis. In the UK, 1 in 10 women suffer from endometriosis[2]. The most recent census data showed that Camden had a total female population of 110,652 in 2021. The number of those aged 12-49 years old (average menstruation age) is approximately 67,213. Although there is no meaningful data on prevalence of endometriosis in Camden, the potential number of women at risk of living with this condition is too high for health authorities to not take it seriously. Comparing these alarming rates to the rate of diagnosis of endometriosis in the UK is sobering. It now takes an average of 8 years and 10 months, between women first seeing a doctor about their symptoms and receiving a firm diagnosis of endometriosis[2], with the prolonged diagnosis time having severe knock-on effects on a woman's entire health and wellbeing. The fragmented health system also means that women in the UK are shuttled for years between GPs, sexual health clinics, specialist endometriosis units and hospitals while having to advocate for their own treatment[13]. Health inequalities are greatly exacerbated, especially for women at a socio-economic disadvantage, or for whom English is not the first language. Cultural taboos restrict discussions around menstruation leaving women to suffer in silence. It is important for us to address this disease in Camden where ethnic minority groups account for 34% of the whole population and have above-average prevalence of poor health and long-term health condition[40].

1.2. Why did we do the project?

Women make up 51% of the population and 47% of the working population in the UK[12]. They influence the health behaviours of their families and the rest of society, yet female health gap in the UK is the largest in G20 countries, and 12th Largest globally[13, 16]. Reproductive health of women, i.e. “a state of complete physical, mental, and social well-being in all matters relating to the reproductive system”, extends far beyond just pregnancy and childbirth; women spend a greater proportion of their lives, if not all in some cases, outside these events, and a focus on menstrual and gynaecological health needs to be a priority. Much of the emphasis is placed on maternal health outcomes, which leaves almost no room for a positive, rights-based approach to care (away from the ‘professional knows best’ model)[18] that could be directed towards reduction in gender inequalities, violence, discrimination and stigma - the often-hidden issues that determine women's wellbeing. The pattern of overlooking other aspects of reproductive care such as heavy menstrual bleeding, gynaecological conditions, infertility, and menopause in care pathways is at odds with the reality and needs of women's lives. It is imperative to address these issues because women's health and wellbeing is intrinsically linked with important population health outcomes and protection of future generations through the whole life course[15]. Although reproductive health affects both men and women, women bear the brunt of ill health not only as a result of their biological status but also because of a wider social, economic and political disadvantage[4]. Our focus on endometriosis is guided by efforts to highlight a gynaecological condition with extremely poor health outcomes, borne out of entrenched gender bias at each stage of the healthcare journey.

Healthwatch Camden welcomes the government's long overdue commitment to women's health, particularly around conditions like endometriosis. The 2022 Women's Health Strategy for England aims to tackle the gender health gap in relation to endometriosis by raising awareness, improving education on menstrual and gynaecological health from a young age, addressing societal and workplace taboos, improving access to specialist care, and updating NICE guidelines to reflect the most current evidence. By presenting further details of women's experiences with endometriosis through this report, we want to reflect the need for better support and make the case for greater commitment to improving the treatment of endometriosis at a local level. We hope that this report highlights changes which can be implemented locally alongside national strategies in order to increase awareness of endometriosis, reduce diagnosis times, improve the management of symptoms in a holistic manner, and ultimately reduce health inequalities for women in Camden.

1.3. Project Aims

- To capture women's experiences of endometriosis in Camden, through in-depth 1-1 interviews, in order to better understand its wider impact on the quality of their lives.
- To understand women's perceptions around their own health and wellbeing, their perceptions of the gaps in current provisions, and their outlook on health inequalities as well as on measures to reduce it in the borough.
- To put forward recommendations informed by patient voices, for improving endometriosis support in Camden so that it is appropriate, person-centred, and addresses the different areas of need for care beyond biomedical intervention.

FINDINGS

2. The Issue of Female Pain

When individuals experience pain, they seek medical treatment and support from their peers and family network in the hopes of recovery. However, research has consistently shown that the level of support and care received by individuals for chronic pain varies considerably[5,6,7]. Implicit biases in healthcare providers and pain-related stigma[8, 9, 12] plays a significant role in determining disease outcomes in patients. The latter is the fundamental contributor to health inequalities in a population[9], especially due to its negative intersection with other stigmatised identities (gender[5,7,10,11], race, socioeconomic status). There is a well-established body of literature documenting gender bias in the treatment of women's pain, with women significantly more likely than men to be undertreated for pain by doctors[5]. This section delves into women's experiences of this bias in the recognition, diagnosis and treatment of endometriosis, since chronic pelvic pain (period cramps) is the most common symptom experienced by women with this condition. Menstrual taboo means that one third of women take at least four days off work due to period related symptoms per year, but almost half do not feel comfortable to report the reason[4]. A 2023 UK wide survey carried out with 4371 people clearly showed that endometriosis symptoms were often just not recognised by healthcare practitioners, their severity and impact were not believed, and symptoms were more likely to be normalised[2]. All of the women we interviewed echoed this 'phenomenon' occurring in their own cases, and described the despair, confusion, and desperation that ensued.

2.1. "It's All in Your Head"

Women report medical gaslighting at every stage of their disease journey. In the absence of appropriate early education or awareness, their first experience of common endometriosis symptoms like pelvic pain and heavy bleeding were met with apprehension, trivialised, and dismissed as normal 'period pain' by teachers, relatives and healthcare practitioners. Frequently associated complications like fainting, vomiting, being bed-ridden with pain had a material impact on their school experience, including disrupted attendance, difficulty concentrating in lessons, and poor exam performance. However, common across all experiences was the dismissal and hesitation to attribute these issues to a medical condition, partly influenced by societal perceptions around menstruation.

"…for example, in PE, if I would say I have bad cramps, the teacher would be like "what are you talking about, just go run…". For some reason - even with female teachers, it was like "you guys are overreacting."

"Even though I have sisters who have their periods, my older sister would say, "Oh, she's overreacting", because they never had the symptoms like that."

"I feel like more could have been done maybe because I've described how excruciating my pain was. I feel like it was just brushed aside like just another period."

"I had ultrasound for my pain, but that didn't show anything. It was only after speaking to a private GP that they said, 'it wouldn't be seen in a normal scan unless it was really advanced', but based on all the symptoms, they said I should be treated as if this is endometriosis. Because often you can't get the diagnosis without surgery. And I'd been to the GP quite a few times before seeing that private GP, and they said, 'oh, some women just have bad periods'. They didn't give me any medication or talk about any kind of pain management. So, I thought I'd start doing my own research. That's when I decided to go private."

"I think, kind of acceptance of your pain, which helps to improve those feelings of anxiety and dread every time. But when you're not listened to by doctors and you don't know what's happening, that's worrying because you think, 'what's wrong with me? Why is this happening? Why can't I be normal?'"

"When I was younger, people would say, 'oh no, I don't think that's anything to do with that [endometriosis]. What, your back's that bad?' You know, they sort of look at you like, 'really?' And then I thought, oh no maybe I'm being a bit silly. But I wasn't being silly. I was just young, and I wasn't able to say, 'no, actually, you're wrong. This is how my body feels. I'm in pain. This is physically crippling'. It's so frustrating because they don't take you seriously and you've kind of spent so much time with it [endometriosis] and the fact that you knew what it was and you still felt that sometimes, you know, because people were saying it's not that serious to start with."

Although endometriosis can develop at onset of menstruation - nearly 70% start experiencing symptoms before 20 years old, majority of women do not receive a diagnosis until they are 30-40years old[21]. This is attributed to the asymptomatic, broad, and variable symptoms of endometriosis which include severe pain during periods, sexual intercourse, bowel movements and/or urination; chronic pelvic pain; heavy menstrual bleeding; abdominal bloating; nausea, fatigue; sometimes depression, anxiety; and infertility. The subjectivity of experiencing and judging pain leaves room for patient's pain to be dismissed. However, the idea of endometriosis being complex to diagnose is refuted by research which demonstrates that symptoms are often simply not recognised by healthcare practitioners, and patients are not believed, leading to endometriosis not being considered at an early stage[2].

"...there is very much a stigma when you're talking about periods, I've noticed. You're not really taken seriously. I think especially within our community, for some reason, when discussing these things, it is like, "oh, what are you complaining about? It is a normal thing." - especially when you're talking about pain that you're dealing with, I felt very looked over. My mum always took me seriously. She would take me to the doctors where I would have scans and they would say, "You're fine. There is nothing wrong with you". But the pain I'm feeling, I'm not making it up, you know what I mean? So, it was very conflicting".

"When I was 13, once I remember, I got up three times and collapsed back down. And this doctor who had come to see my brother at home, he saw me, and he said it was normal. And if you're telling a 13-year-old child, that's when my period started, that something is normal, they will see it as normal too. I remember getting blackouts where I would just blackout and then I'd be able to see again. I probably thought that was normal too. And then I was going to work to get someone to send me home, to say that I was sick. Almost like not believing myself that I was ill. But knowing that I was, having these blackouts and things..."

"When I was younger and experienced pain, I thought I was being dramatic. Which I think is something that the medical institution does really well to women. Also, bearing in mind I am a white woman, I have far more privilege than most, and my mum used to be a nurse. So, it's not like I'm going into those spaces uninformed. Arguably, I'm a relatively compliant patient. I'll give you a list of my symptoms. I'll give you dates. I go prepared. And I still was treated like I was doing something wrong. They sent me to see a therapist, who dealt with sex basically, because I was saying that I was just in so much pain all of the time and it was really ruining my relationship. They were just also really dismissive, telling me, 'Everyone has really bad periods, you know, maybe you just need to avoid these things [sex]'. And I'm like, 'why are we making this my responsibility? Even though you don't know what's wrong!' It was really bizarre."

2.2. Notions of Normal and Abnormal Pain

Women frequently ignored or minimised their own pain when they first began experiencing endometriosis symptoms. This is partly due to the difficulty in describing and quantifying the threshold that determines normal versus abnormal pain. Significantly, the societal perception of period pain being considered part and parcel of the menstruation "experience", and the notion that any level of pain "is normal", has been engrained into the psyche of all women to such an extent that they initially didn't consider the pain itself as an abnormality that required medical attention. Awareness of what constitutes 'normal' menstruation is even lower in school aged children and adolescents[19]. Women, unaware of pain being indicative of serious conditions like endometriosis, ignore all levels and types of pain and delay seeking medical help.

Cultural perceptions can also shape understanding of what constitutes "normal" menstrual pain, leading individuals to minimise their symptoms and delay seeking help.

"I think pain, in general, on your period is not necessarily normal. I think it's the fact that it's stopping us, for example, going to school. And for me, the first day, I can't move. So, from the fact that it's stopping me to move, I think that signals the seriousness of the situation. I don't know why that doesn't seem abnormal to male doctors or people."

"I truly thought when it happened to me, especially when I was younger that it was all in my head because everyone else had cramps, but no one was crying, no one was lying down. I couldn't walk straight."

"...since I started my period, they were always really heavy and painful. So, I thought it was normal to have periods that heavy. And then it just got worse, the pain over time just got really bad until taking Co-codamol or Paracetamol had no effect. It was like, I was just drinking water, it made no difference to the pain. I had like anaemia because my period was really heavy. And then I kept going to the GP to ask for stronger medication. Initially the doctor I had was dismissive of the pain, she didn't take it that seriously. And actually, she prescribed me the wrong medication. She said it would help with the pain so I was taking it but the pain did not improve at all. I spent the whole night awake and ended up having to go to A&E. There they told me the medication was meant to make your period less heavy, but it wouldn't help with the pain. So, I changed doctors, and they started prescribing Tranexamic acid. Eventually that also stopped working. Finally, I was lucky another doctor who was meant to prescribe the medication again called me and said, 'why don't we get you an ultrasound to check'. And she referred me to the gynaecologist. So, after 7 years now they've said, 'actually, we think it's endometriosis'."

"I did think it [symptoms] was normal because it started as soon as I got my period, so I didn't know what a normal period like heaviness should be. Like the doctors when they asked me, 'Is your period heavy?' It's kind of hard to say. In the beginning, I didn't know that my periods were heavy, what was the normal amount, because I always had it like that. It was always painful; it was always heavy. So, I don't really know what it would be like otherwise to be able to stay, you know?"

"I've always thought it [pain] was normal, I never paid any mind to it even when it was so bad. When you hear from your friends, like, 'Oh my cramps are so bad', I just thought my pain was also normal. But I didn't feel like I understood the full extent to how bad mine was. I just paid no attention to it at all, like honestly."

"When I was a teenager, I thought it [pain] was normal and I think I thought, 'oh, this will get better as I get older'. I always remember, I think it might have been at school, seeing an ad for a period product saying that it's normal to have two tablespoons of blood a day. And that is laughable to me, thinking about it now. But I don't ever really remember anyone saying,

'you've got abnormal amounts of pain'. It's only really because my best friend has endometriosis that I had someone to talk to about it. And she was diagnosed and had the surgery before I really started to see correlating symptoms. Every month we'd have a conversation [about my pain] and she would say, 'this sounds like it's not normal'. That's what made me think it could be endometriosis."

2.3. Role of Cultural Background

Respondents reflected on the cultural aspects of discussing periods and reproductive health, which are often considered taboo subjects. The women pointed out the stigma and silence surrounding menstrual health issues affecting perceptions of pain and health. The normalisation of pain due to societal and cultural conditioning contributed to many women's delayed response in seeking help and understanding the severity of their condition. Women explored the impact of cultural upbringing on their relationship with their body, menstrual health, and expression of pain. Within such communities, bearing children is a significantly important aspect of married life, so the issue of infertility that is sometimes associated with endometriosis has the potential to lead to other serious issues, where the woman is often blamed for her infertility. Acknowledging these factors, the women noted that individuals from different backgrounds are often left alone to manage their pain, potentially leading to feelings of stigma or shame. There is an emphasis on the need for safe spaces where women can openly discuss their experiences and challenges with period pain without shame.

"...in every Muslim household, you pray five times a day. And when it comes to fathers and brothers, they will only know that you're on your period because you've stopped praying now. So that's the way you tell them. Instead of actually going to them [and talking], they will notice that you're on your period because you're not praying. So, the fact that you can't even go up to them and be like, "I'm on my period, I can't do this". It has to be shown through just you not being able to do your daily prayers, is actually quite shocking. It just goes to show that it's an uncomfortable topic to speak about with them. Even some the female members in the family, who can be a little bit weird about the topic as well, it's not just the men."

"...with other members of the community, it's very much like "don't talk about it at all". They think you shouldn't talk about it. That it's disgusting. There's such judgment. I'm very glad that I talk about it with my siblings, and they are very understanding. But in our community, it's very much judgmental. We hear things like "you shouldn't be talking about this with the men" or "it's a disgusting topic". It's just what I'm going through! It's happening to me. I should be able to speak about it. So yeah, there's a judgment, definitely within the Somali community when it comes to period and mental health it's a big, big thing."

"If the people I surround myself with were different, or if I was maybe from a different cultural background, or socioeconomic background, then maybe I would feel more shame around it. I think if you don't have support and

people around you who understand, that would be really challenging and isolating. But because my partner and my best friend both understand it and I can talk to them about it and be very open, it [my pain] doesn't change how I feel about myself. But I can imagine for people that aren't so lucky, that would be awful."

"If you have pain, we should ask for help. It's not embarrassing. Like, my daughter, she's nine years old. She woke up, she was bleeding in bed. She said, 'Mom I'm on my period.' Even to her sister she said, 'Sister, I want to say something. I'm in my period. Don't tell Dad.' In our culture, in our religion, men are powerful. We're not allowed to tell men. Because men are powerful. And we're like saying, 'are you craving sweet? Do you want a sweet?' [instead]. He shouldn't be knowing about these things. Women are women. Men are men."

2.4. 'Female strength' as a Misnomer

Women's ability, and often expectation, to carry out their daily tasks and 'just get on' with day-to-day life, despite experiencing consistent and debilitating endometriosis symptoms, is usually perceived either as a sign that their symptoms are not as bad as they express it to be, or that women somehow possess an innate quality that naturally raises their pain threshold. It is not uncommon that some women may be conditioned to view this 'innate strength' as a mark of pride, much to their own detriment. From our conversations, we uncovered deeply embedded attitudes that stopped women from taking their own pain seriously and seeking help. Participants discussed how pain affected their interactions with friends and family, recognising a tendency to downplay their experiences, potentially due to societal norms or peer comparisons.

"I was thinking about it, because maybe women manage pain so well, then that's why they [health professionals, society] are like, 'yeah, you'll be fine, just take the pill. You've given birth or you're managing your household. You're fine.' Because they talk about female resilience. We take it as such a matter of pride. But I feel like it hasn't done us a bit of good, in that sense. So, then that's why people don't take you seriously until you're just like on the floor. It's just a general feeling of being tired with why do I always have to earn my voice or earn my space or why do I have to fight to be heard? Why can't like I be heard in an instant just the first time I say something, why can't I already be taken seriously?"

"I try not to make myself feel bad because it's not my fault. I guess when the pain is coming. "What can I do?" - especially if it's bad, I can't force myself to like pretend and continue on. So yeah, I try to take myself easy for my day to day. I know that eventually... hopefully... it'll go away, I'll feel better at the end."

"My biggest challenge is just getting out of bed in the morning. And my family, my parents can get a bit annoying about it, literally every single

day I experience this. Even when they know that I'm dealing with this pain. Maybe that's another reason why I downplay it [seriousness of pain] because everyone else downplays it, so I'm just like, 'move on', I guess. Basically, I just get on with day-to-day life because it's just the way it's done."

"From my experience [of describing my pain to people around me], I suppose I've been told that I seem to handle pain quite well, but then I don't know if I describe it more politely than it actually is. If I do say it's painful, bad, or horrendous I almost feel like, 'do they think I'm exaggerating?'"

For a condition like endometriosis where gender biases are deeply rooted, there is need for women to confront the reality that they still 'get on with life' despite their pain/symptoms, not because it is a choice borne out of great inner strength, but a compulsion dictated by societal expectations, and a poor quality of life that is forced upon them. Pushing through activities and social engagements, fulfilling obligations for family and friends, studying, working, and maintaining relationships while feeling severe pain and anxiety - these are consequences of endometriosis that carry an enormous emotional toll. We know that concealing pain and avoiding stigmatizing situations eventually lead to greater isolation & disability[23].

2.3. Period Pain-related Stigma

Several factors contribute to chronic pain-related stigma: the absence of clear medical evidence such as clear tissue damage, the invisibility of pain symptoms, as well as the subjectivity of pain assessment[24]. Since pain is often conceptualised in a dualistic way, where symptoms tend to be viewed as being either biomedical *or* psychological, with something like period pain where there is an absence of immediate signs of injury, the pain is often perceived as psychological and associated with stigma[25]. Gender-based biases regarding women's pain experiences have led healthcare providers to frequently discount women's self-reports of pain, at least until there is objective evidence for the pain's cause[5].

"I feel like if this was someone else, for example, someone suffering from diabetes or another medical condition, doctors would have taken it much more seriously if the person now said, I'm not able to do my bed, I'm not able to do my daily activities. But because it's a woman who's going through her menstrual cycle, I guess it's kind of downplayed like "this happened every single month for you, you should be fine."

"Endometriosis is serious enough that it should be considered by the medical system a lot more. Because if you think about any other health condition, I feel every aspect of your life would be taken into consideration. Especially because it is a monthly thing, other than if you take the pill and it changes your cycles, you can't get away from that."

"One thing actually, just around women's pain and how it's not taken seriously. I was talking to some friends in a men's football club and how

they went to the doctor once about pain in their knee and were given some really strong pain medication. Just the total difference between me going multiple times about pain and just being told to take a paracetamol, and the difference between a man going and talking about pain from playing football was just so contrasting. It made me so angry

One interviewee described how her family, particularly her mother, held certain views about menstruation and associated pain, which affected how she communicated her symptoms. There was an evident generational gap in understanding the seriousness of menstrual health issues, which could lead to feelings of shame or isolation.

"You kind of feel like you can't say anything, you know, because, I mean, even to a certain extent, I love my mum to pieces, but I don't have that relationship with her where we were able to talk about it. It was more kind of, you know, I'd say to her, I don't think this is normal, I don't think this is right. And she's a very stern Irish lady, so it would just be like, 'oh, yeah, you're just unlucky'. That was it, you know, just get on with it."

Children's awareness and understanding of the mother's health conditions demonstrate a progressive shift in dialogue around menstrual health. However, it also reflects the challenge for mothers to balance openness with the desire to shield their child from fear related to health issues.

2.5. Chronicity of Condition

With the defining feature of endometriosis being its cyclical and chronic symptoms, women consistently describe the feeling of "not getting a break" from their pain. The anticipation of pain before their periods are due, is as worse as the experience of it, making the impact of endometriosis on their lives feel relentless and consistent. Unfortunately, this aspect of chronicity also forces women to push though painful symptoms to conduct their day-to-day activities; in the absence of proper treatment or solution, life for women would come to a standstill if they succumbed to the true impact of endometriosis. Trauma can be defined as one incident, or an ongoing event beyond a person's control that happens over an extended period of time[27]. Care pathways fail to recognise endometriosis as a traumatic, chronic condition needing ongoing care, so even those with a diagnosis and prior treatment have difficulty accessing gynaecology or endometriosis specialist centres if symptoms recur.

"Reproductive health is just not taken seriously, and I guess that just comes from the fact that we experience it every single month - so in that sense they see it as, 'you're really coping and dealing. So why should we now just jump in and have to make it a big deal', when in reality the fact that it's happening every single month, along with the pain, it should be taken seriously, because it is every month."

"I think the pain has almost caused this sort of trauma around periods for me now. Even between periods I almost have to block out that I'm going to have one because otherwise, I'd just be thinking about it a lot."

"When it's around my period time, I hate it because I feel so bloated. I get headaches and I'm thinking, 'am I just supposed to live with this?' It's just hard. I hate it. I dread it every month. Like half of the month, I'm in pain, I'm bloated, I'm not myself. And the other half [of the month] I'm anticipating that. Theres no break. I'm just quite sad because I can't be 100%, and I have kids, I want to be 100% for them, but then I just feel..."

3. Impact on Health

3.1. Physical Health

Endometriosis has a profound impact on women's bodies, with chronic pain affecting their daily activities, social life, and emotional well-being. The severity and unpredictability of symptoms create a constant sense of anxiety and fear regarding their experiences and limitations.

"Whenever I have these pains, there's been times I've literally just had to be in bed all day, like, I can't move. I would spend my whole day in a ball to reduce the pain. And I would take stuff like paracetamol, but nothing would get rid of it. So, it stops me a lot from doing a lot of things, I can't even move sometimes. And it keeps me up at night, I can't sleep through it. It's just... it just basically ruins everything I have going on."

"I've had some really bad instances where I've bled so much I've passed out. So, I suspected that I'd grew something else [polyps], but no one's ever done another scan, so I don't know. I mean, it [bleeding] was like a waterfall, terrifying. I'd wake up on the floor."

The need to adapt to their body's limitations underscores the ongoing negotiation between desires for an active lifestyle and the realities of the chronicity of endometriosis.

> *"At some points I couldn't walk without pain. So, it really impacted how I would exercise and how I felt about exercising, which definitely led me to be a much more sedentary person. I had to find specific things. It stopped me swimming, which is my big love in life. Because if it*

> *was just pain but no blood, great, I could swim, it was a very gentle exercise. I could go for a nice walk. But as soon as there was blood, I can't go anywhere near anything. Because it [the bleeding] is so significant."*

The physical impact of endometriosis is particularly challenging for young girls when they first start experiencing symptoms. During this definitive stage of their lives, the lack of support and effective management of endometriosis has far-reaching consequences for their future.

"When I was in year 11, I just remember I'd be at the back of the classroom, and I'd start to get these really bad cramps, and I couldn't concentrate anymore so I just had to leave the class. As soon as I left, I started crying. Other times in A-levels, I would just ask to go home. It happened once or two times that I had to do that because I do want to stay in school. I would get my period cramps mostly around nighttime, so I'd just be in my room by myself, sitting there for hours waiting for it to be over. When I could finally sleep, I'd wake up the next day exhausted, like my whole body is just so tired. And it's kind of unfair that you'd get these really bad cramps, but you still have to go to school. Because I also got cramps on the day I had my History A-level exam. I had just started Tranexamic acid, so I did take it and thank god it started working a few minutes into the exam, but in the beginning, the cramps were getting worse, and I'm doing my exam on my own, and I'm just like, if I tell the teacher it's not really going to help, because this is an A level exam, you know...I wish there was something to help with that, it's not like you can predict it."

"Most recently I was literally going to skip an A-level exam because that was the worst period I've ever had. I was leaking through everything. It started the day before my last A-level exam, and I didn't even want to go to the exam. I was so scared that it was going to just go onto everything. I did go to my exam, but I ended up leaking. Luckily, no one saw I think, but it was really bad. I was going to skip a full exam because of this, it's really bad. Even with revisions, the last week of exams, I didn't really focus, because this affected me so heavily. Many times, I wanted to go to the library to revise because I find it hard to revise at home, and I couldn't go, because obviously the pain was too much. So, I was just lying in my bed the whole day."

"I remember this so well. I had a maths exam during my GCSEs. That was one of my first day of my period and I was literally just clenching into my belly and doing the exam. How can we suffer so much and get the right answer, when we're in pain?"

The impact of women's health on the health of her family cannot be understated. The scope is broad, reaching across other sectors such as mental health and obesity. Women with children described the indirect impact on their children's physical health when their pain rendered them incapable of cooking and providing healthy food, especially those from cultures where the woman takes on this role in traditional households. They described the ongoing impact of endometriosis symptoms in fulfilling their responsibilities as a caregiver, causing emotional distress and leading to feelings of guilt and inadequacy as a mother.

> *"I think people find it hard to understand because you're not switching the on and off button yourself. It's frustrating because, especially with my children, I can be cooking, I'm doing this with them, I'm taking them out, and then there's days where I've got the hot water bottle, or the TENS machine, and I'm like, I don't know. The thought of cooking dinner is just like, "oh gosh."*

One woman's struggle with this was even more profound, with her endometriosis pain intertwining with her seizures, severe learning disability, and limiting cultural beliefs.

> *"Yeah, with Endometriosis I have challenges, especially with learning disabilities. Any condition, any illnesses you do have challenges. Even if housework, wife, you do anything. I can't do housework; I can't cook for my daughters. I feel like crying, you know, sometimes because of the pain. Sometimes you can't even sleep. I feel like crying, I feel like, why has this no end. Because I had mild, then I had moderate, now why has it gone to acute? Go to my house and see, you'll probably say I'm reorganizing my house. [why?] Because I became all disorganised and [that is why] I became ill. Yes. It's a sin. My mum would even tell me it's my fault."*

Reproductive health, which includes menstrual health, is an area that has overlapping features with sexual health[20]. However, the effect of endometriosis on women's sex life is poorly understood and acknowledged. Our interviews echoed the recent Endometriosis UK report which noted that painful sex is a symptom of endometriosis that is often minimised by healthcare practitioners, with no empathy in the medical system despite its potential impact on relationships and pregnancy outcomes should someone want to conceive[2].

> *"[describing the huge impact of painful sex on her relationship] I have a partner that's been really understanding, but I haven't fixed this problem for years. And now it's really threatening my relationship, and I can understand that, because if I were him [pause]. He says, 'I love you and I support you, but I need this in my relationship as well'. So, it really affects…like we might break up, that's the point. And then I think about, okay, if we break up, then am I ever going to be able to build a relationship? Then there's something else about, if I don't have drive, that's a part of me that I miss, you know? So, it's not even about other people, it's also about myself. It just really pisses me off in that sense. And I think in terms of doctors, no one has been able to help. Doctors don't even, haven't even considered this. Then other professionals have seen me. No one has been able to treat me. And then there's so little information, I don't know if I will ever fix it, but I haven't been able to ask anyone. It just sucks."*

3.2. Mental Health

The emotional toll of chronic illness is evident. It is not the pain alone, but the anticipation of pain that also creates a mental burden, reinforcing the idea that endometriosis is not just a physical illness but involves psychological distress. Women experience anxiety, depression, and feelings of isolation. These mental health challenges are intertwined with the physical symptoms of endometriosis, making everyday activities difficult.

"When I was on my period, I just felt so depressed. It's just a wave of depression. I just didn't want to do any of the normal activities where I'd go for a run, or I'd go for walks with my mum, or just be around my family and friends, I'd just want to be by myself. And just isolating myself was never the answer. I don't think I was ever happy being on my period."

"It makes me cry and I snap at people a lot, so it just basically brings my mood down a lot and that affects me as well and everyone else around me."

"I know this is affecting my life, because my family brings it up to me a lot, so I'm always aware of that. Like they mention how my mood is always a lot lower than it should be, and it's unhealthy for me. Basically, that it's going to be detrimental to my health in the future if I do it for such long periods of time. This is what I hear from them. I feel partially, sometimes, they understand that I'm forced to because of my pain. I don't know..."

"I feel better when I eat well, and I do exercise. But sometimes I'm in too much pain to cook properly for myself or go for a run, and then you end up eating comfort food because you feel rubbish about yourself. And so, I would say, you just feel low about it even when you try, when you do all the things you need to do. It's not nice living with chronic pain."

"Some years ago, I had really bad anxiety, I was in a really bad state, and I was referred to CAMHS by my school and GP as well. I was put on the list, and I just didn't hear back from them. My mum chased them up but gave up after two years of trying. That's why I just don't even bother with talking to anyone about my mental health, that's how I see it. I feel like with the anxiety I don't think I can get help with that because I'm always going to have to worry about, 'Oh, am I leaking? Oh, am I going to pass out?'... I'm scared to go out in public by myself because of what happens. I always have to worry about something, when I'm at home, when I'm outside."

The internalisation of pain as described by the respondents is another important risk factor of their poor mental health.

"I think, generally, pain is quite common to me, so I understand it. I think there are times in life where things are already overwhelming, and then you've got the addition of pain, and that makes everything so much less bearable. I think it led me to question, 'Was I making it up, was I doing this for attention, what was I doing wrong?'. It led me to question myself."

"Now because I've been in this pain so long, sometimes I don't even register it anymore until it gets really bad. And half the time when it's really bad it usually means that a cyst has popped. And sometimes I do actually contemplate 'do I need to go to the hospital'? Because there's times where I'm sat in really bad pain going 'I don't know if this is hospital worthy quite yet'. Which is not a good thing to really have in your head. I mean you shouldn't be making those negotiations in your head. You should just be able to seek help when you need it, you know."

There are huge emotional ramifications linked to women feeling isolated in their experiences with pain, as well as concern about how they might impact their family life, particularly with their children. Our respondents illustrated the challenge of wanting to maintain a positive perspective on menstruation and associated conditions for the sake of their children, despite experiencing personal pain and discomfort. They described the impact of the chronic pain on their mental well-being, highlighting feelings of immense guilt and frustration related to their ability to participate in daily activities and parenting.

"Yeah, there's times where I just feel maybe things would be better if I just walked and kept walking…But then, I wouldn't do that. They [my children] are the reason I'm keeping going at times. It gives me so much joy and pleasure to just feed them and laugh with them. But I do feel like when I am in that much pain and I'm being irritable, it makes me feel guilty because they don't deserve that. They don't understand why I'm being like that. I mean, my younger daughter, bless her, she'll ask if I want herbal tea or something, if I need anything. And that's sweet, but unless I was really laid up and couldn't move, I would still force myself to put a wash on or get something together for their dinner. Because I'm not out. Hopefully, it won't get to a point where I'm not doing anything for them. And I don't want them to be taking care of me. That would hurt, I'd be heartbroken. Because they deserve to be children. But sadly, I suppose some situations, there are circumstances like that."

"It impacts my relationship with my kids and partner; they can see that I struggle with pain. Like, my daughters know that I have endometriosis, and I've explained what it is. But I also don't want to go too much into my negative experience in case they start worrying that they may also experience it in the same way. Because I do think it's still important to try and see 'periods' in a positive way. But it's been a hard journey to think that. I mean, only in the last year that I've actually tried to have that outlook. And it's still hard."

"I've thought about going to the A&E so many times because I felt like I'm just going to end my life now. I said, 'Don't go, don't do it. You know you're not going to do it. You're religious, you're a good Muslim, you're not going to do that.' This is before my periods sometimes. Everything comes in. every thought, every emotion. And I just think as a woman…I'm useless as a mother…"

Women also voiced concerns about their children's potential struggles with endometriosis, reflecting the generational implications of the condition. Their desire to protect their children from similar experiences and the urgency to instil knowledge and management strategies early on was evident. However, there was an additional mental burden of supporting their child through the challenges of endometriosis, all the while experiencing the condition themselves.

"I don't want my daughter to go through the same thing [challenges with endometriosis]. Because I see her when she goes through the same pain, I get worried about what could happen in the future and what it could mean. What consequences it can lead to. Because she [daughter] knows, because she's the younger generation, she can speak good English and talk to the doctor better, she should know how to advocate for herself more than the older generation. She should take advantage of that so that she can get diagnosed quickly and then get treatment quickly."

3.3. Social Health

Loneliness and Isolation

Many of our respondents felt unable to share their challenges and experiences with endometriosis with friends and family or felt unsupported when discussing their condition. They also highlighted how cultural attitudes toward menstruation and women's health created additional barriers to open conversation. The impact of social isolation is even more profound in younger women, when the opportunities to network, foster relationships, and explore the world around them is curtailed. Women discussed how the endometriosis affected their ability to maintain social relationships, often leading to feelings of guilt for cancelling plans with friends due to sudden symptoms. This sense of being a burden amplified feelings of isolation and frustration within one's social circle. Feeling isolated in their experience exacerbated their emotional distress until they found others with similar struggles in support sessions.

"If I didn't have this pain, it would be much better really, because I would actually do things that I'd like to do. Because I don't go out sometimes, especially when I'm on my period, I'm so scared that it will go on my clothes. I stay inside a whole week, two weeks, to make sure that nothing happens."

"...When you're in that excruciating endo pain, it's alarming for other people because all the colours will go from my face. I can't move. It can honestly take my breath away. Like, it's so intense. You don't want to bring that to everybody, do you?"

"Talking to friends and family about it, there's actually no point in it really, because like they wouldn't understand it."

"When you're in school and you know you've got heavy periods and you faint in front of your class, that's not pleasant and I definitely think it probably contributes to how I socialise with people now. You become very aware of how you're acting with people when you're in pain and bleeding a lot, or that's about to happen. So, if you look at the calendar and see that there's a likelihood you'll be on your period for an event, you're just so low about that because you know you're not going to be your best self. You dread it."

"It's definitely depressing. Most of the time when someone asks me if I want to go out, I have to say tentative yes, especially if it's something I want to actually do. It's a tentative yes, depending on when the day comes and I

don't feel okay, I have to say, 'please don't be mad at me that I've said no, that I can't come this time'. ***But to be fair, that's why I mostly haven't heard from my friends.*** *When we do get together, it's great. I'm outside, I'm doing something, I'm with my friends, we're catching up, I'm learning about what they're doing nowadays and how they're going on with life, and that's great. Because I want to know...I want to know these things, but trying to get out the house to do them is not helpful because If I try to plan anything in advance, I don't know what I'm going to be like on that day."*

The impact of endometriosis on a woman's relationship with their partner indicates a condition involving great psychological distress.

"Yeah, I do think this is affecting my partner. Because in a sense, when I can't take on the load, then he takes on the load. There's a risk of burnout there. Because he's also working, and it's basically it's just the two of us. So yeah, that's why it's even more challenging. Because if I'm not feeling well. It's not so easy to just say, 'Oh, I'll leave it. I'll leave the kids at my mom's.'"

"[when told that she should consider having children sooner or later at age 21] Weirdly from a young age, I always wanted a family, and I think a kind of clock started ticking and there was a pressure regarding that. So that affected my relationship because he wasn't ready to rush into anything. I was always hoping he'd change his mind and that in itself put a strain on things."

Women frequently describe having to manage their periods and pain carefully, considering their work schedule and social activities, often withdrawing from social situations for fear of an episode or inadequate support. The anxiety of bleeding through clothing while out signifies a constant state of apprehension that affects their lifestyle. They also reflect on how endometriosis affects their quality of life and overall energy levels. This addresses the broader societal implications of chronic pain conditions, illustrating how they hinder individuals from engaging with fulfilling activities, and achieving their full potential.

"The first couple of days of my periods especially, I have to be really mindful of what I wear or taking additional clothing with me. If I know I'm going to be out for a long time, in case I bleed through whatever product I'm using. The fear of leaking through stays on my mind quite a bit! I think I've come to accept it more now, because I can't do anything about it, and I don't want it to stop me doing things as much as I could let it. But I have to take extra trousers with me, which is ridiculous for a 31-year-old."

"In the first job that I was telling you about that dismissed me, I can remember it was shortly after I did my training and it was my first session and I was on my period, I was in a lot of pain. I had to go in and do this session, and there's always that consciousness that, "oh my god I'm going to bleed through my clothes", and it's exactly what happened...You get very self-conscious of yourself all the time; you've got so much bleeding going on and you have to change your pad and then you're worried about

whether you're going to leak through your clothes or not. it does I think mess you up mentally as well because you're having to consider so many different things, and not considering yourself but considering the environment and people that are around you at the time."

"I was out with my family, and I forgot to bring my medication. I got really bad period cramps, and I just couldn't walk around with them, so I was just asking them to go home already, and it feels kind of annoying, you know..."

3.4. Economic Impact

There is a push for recognising the economic implications of endometriosis on overall health outcomes. Due to the severity and unpredictability of endometriosis symptoms and their physical impact, women report that their condition would be much worse if their work did not allow flexible working, or if they did not have the financial means and support of their family. This adds another layer of inequality where women of high socioeconomic status can have slightly better health outcomes, as they have more flexible jobs as well as the means to afford holistic services which have been proven to help in managing the symptoms. Endometriosis already costs the UK economy around £8.2 billion every year in healthcare costs, loss of work and treatments[2]. The NHS confederation report also demonstrates how women's health, the NHS, and the wider economy are closely interdependent and should not be viewed as separate concerns[28].

Work life for women is significantly impacted by endometriosis, with interviewees expressing anxiety about job searches, job security, as well as scrutiny regarding the necessity of absences during each menstrual cycle. This anxiety fuels feelings of not being taken seriously, which in turn affects workplace performance and earning potential for women.

"Yeah, I just started work a couple weeks ago and I checked my app now [period tracker app]. I'm kind of scared when it [my period] comes! Hopefully it'll be alright. I'm definitely going to be scared. For example, in my workplace, you have to hit a number of targets every day. So, if I don't hit a set target, they're going to be like, why? Because I'm on my period. I don't know if my boss is a female, but will she be sympathetic or will she be understanding? Because for her, she may not experience cramps and so won't understand. It's all subjective to their experience, so yeah, it's a very weird thing."

"I used to push myself to go to work even if I didn't feel well with it. Because it's almost like I had to have somebody telling me that I wasn't good. I would go to work and then get them to send me home. They'd have to see me ill and then they'd send me to go home. There was always a fear of losing work or not getting work."

"Yeah, it definitely impacts work. For instance, I'm on the third day of my period today, and I had to take a couple of hours out because I didn't sleep at all. Luckily, I'm able to do that, but I'd rather I didn't have to. And if I didn't have quite a flexible job and understanding manager, which I haven't

in the past, it will impact my annual leave, or I just have to struggle on."

"I think my work ethic never suffered, but it was more probably my sickness being absent at times. That would add to anxiety, thinking, 'do they think I'm pretending?' or 'is it not an actual real problem?' because even working at the hospital there was never any like 'endometriosis awareness month' was never a thing. So yeah, that was hard."

"What else can I do apart from meditate and take the pills I'm taking and research what supplements would be beneficial to me? It's all too much, when I actually need to focus on trying to at least get my body healthy enough to find work of some kind. That's another stress to be fair. Trying to find work while like this."

One woman described a challenging work history and experiences of discrimination based on her health issues, including endometriosis. Two job losses stemmed from a lack of understanding and support regarding her conditions, leading to feelings of unworthiness and anxiety about returning to work.

> *"You kind of go through this kind of silence thing with your condition with endometriosis, because you don't want to not have work, and you know that you need finance. I spent a lot of my time even in between temping, not telling people that I had endometriosis for the fear of [negative implications]."*

Discussions regarding the financial burden of seeking alternate pain relief (e.g., purchasing a TENS machine) highlights the economic disparities in accessing effective treatments and support for chronic conditions. With the intersection of socioeconomic status in determining health and wellbeing outcomes for endometriosis patients, there is a need for accessible pain management strategies that do not exacerbate inequalities for women across all strata of society.

"I think just treatments [pain management] need to be more widely available. I know you can have a referral to a pain clinic but given the number of medical conditions that exist and result in people with chronic pain, I don't think it's that radical to have that available through a GP or a pharmacist, or just more accessible in the community. Because not everyone has the funds to spend £100 on a TENS machine or try different alternative treatments that are available. So, and I think having the space to be able to try things or just know what's available is really important."

"I can go and pay for a massage; I'm paid well enough to do that. Those things do help, but also, they're not accessible to most people. I'm always just a bit concerned about feeding into that narrative. Ultimately what we need is at the first point, a doctor to take it seriously, and for us to move forward with our scanning and diagnostic techniques, so that people aren't left waiting and guessing."

"I had to pay to see a pelvic floor physiotherapist. I had to/went to this other alternative treatment around pain. Then now I'm paying for a course on like relaxing all the area [pointing to pelvis], but it's so hard. Like you need to find it by yourself. No one will tell you."

4. Sense of Self

4.1. "Second Class Citizen"

In their journey with endometriosis, our respondents were forced to confront awkwardness surrounding intimacy, challenges with pain during sex, and being forced out-of-the-blue to confront their own fertility at a very young age, all without a consideration for its impact on their perception of their own self, because reproductive and menstrual health is such an intrinsic part of a woman's identity. The overwhelming sense of unfairness that defines this condition leads to women evaluating their place and status in society, perpetuating entrenched gender-based inequalities that can have negative repercussions on health outcomes.

"Oh, I just think I think it's just hard to be a woman. I think this experience with endometriosis amplifies that feeling. There is still generally a sense of inequality that you already know in theory, but when you see it applied in real life in a quite consistent manner with endometriosis, then you just feel like you're a secondary citizen in society really. Generally, just as a woman. And I feel like if I were a man, they would've given more importance to it. It would be more significant."

"It's just a general feeling of being tired with why do I always have to earn my voice or earn my space or why do I have to fight to be heard? Why can't like I be heard in an instant just the first time I say something, why can't I already be taken seriously? And now that I am expecting another baby, my husband wants a daughter. But I actually said I don't want a daughter because I don't want her to come into such an unequal world and have the same bad experiences as me."

"The doctor tried to get out of giving me a referral saying, "But you don't have pain. So, you're fine. You're already in the treatment [on the pill]'. But for me, I want help with my pain during sex. So, I had to make something up. I had to tell him that I want to have children and because my fertility might be affected, I need to keep track of my disease. Then he accepted it! And I was like, how is it okay that [only] if we fulfil our reproductive destiny, we're attended to. It's such male dominance! I don't think that should be okay. I should be allowed to keep track of my disease and my condition!"

4.2. Identity and Self-confidence

A strong sense of self-identity and self-esteem are important for a person's mental health and overall quality of life. It also plays an important part in cultivating healthy behaviours like physical activity and healthy eating behaviours[37]. The physical symptoms associated with endometriosis, with the chronic pain, confinement, uncertainty, and prohibitive cost of treatment, can negatively affect a woman's sense of self-worth and significantly affects their relationship with their bodies. Furthermore, poor functional health can limit or restrict opportunities for social support and activities that encourage self-esteem. The feelings of bloating and discomfort described by the women lead to broader questions of identity, particularly regarding attractiveness and societal expectations around women's bodies. The awkwardness surrounding intimacy and social engagements reflects the broader implications of chronic endometriosis pain on personal relationships and self-perception. The frustrations and emotional toll of this condition affects not only women's connections with others but also their self-esteem, self-confidence, and personal fulfilment.

"Because we're Muslims, when women are on their period, we don't have to pray when you're on your menstrual cycle because you're 'unclean'. But it's like, when we are praying, that's what makes us sane, and you feel happier because you're praying. But during that week, because you're not praying, you feel like you've lost your purpose."

"I got these womb issues…adult diapers [for excessive nighttime bleeding], that's not sexy. How is someone going to…how am I going to be intimate with someone? How am I going to let someone see me in that state?"

With feelings around a lack of personal agency over their own body, women articulated feelings of grief over a life they could've lived if they didn't have endometriosis. This profound emotion was directly linked to the state of their mental health and well-being. The constant pain made it difficult for women to remain engaged with life around them, i.e., with their interests, ambitions and relationships, and the long-term effects of living with these symptoms have forced them to reconsider their life goals and aspirations, specifically regarding career and daily activities. This has an impact on their socio-economic attainment, which a key determinant of health, as socio-economic status affects society through inequities in health distribution, resource distribution, and quality of life[38].

"If this [endometriosis pain] was not a thing, I definitely would have been much more happier. I think in terms of my faith, that would have been really good. I would have been focused; I would have been headstrong. That would have definitely been a big priority. It's not something I'd have to, you know, think about or worry about every month. Overall, I'd be much

happier. You know, no more mood swings or no more pain. No more things like that."

"To be honest, I wish they took it seriously earlier on because I feel like the delay eventually made my symptoms just kept getting worse. I wish there was something done sooner so it wouldn't get to this stage. But at the same time, I don't want to get like a 100% percent diagnosis for endometriosis because of the fertility and other issues. I just wish they could say, 'oh, it's something else, it doesn't affect these things [fertility]'. I hope they would say it's another thing which isn't that bad and it's not chronic, you know. Because endometriosis, it is most likely to be chronic, so…"

"I think the way that this [endometriosis] impacted me most would've been around my relationships, actually. Because I thought that I was being sensitive and dramatic and like basically imagining it [the pain]. I think I pushed through in personal or intimate circumstances when I shouldn't have. And I think the result of that is when I think about how that impacted on some of my life experiences, my memories, my feelings of self. Because I think I've ended up putting myself in lots of very painful situations, physically and emotionally, as a result of just trying to push through it [the pain]. I think that was very, very harmful to me."

"With this endometriosis, I just feel like I can't be fully myself, my best self, really."

"At the beginning I still had hope to fix it really quickly, but now, every time I went to a different professional, I would just be desperate and crying for help, and that doesn't really help you solve problems. And it just becomes a part of your head as well. So, it's not just physical pain, but like your anticipation of pain. So, I think my life would be quite different in that sense, if I didn't have this condition."

"It [endometriosis diagnosis] kind of threw me off. Because not like I had a life plan or anything, but I had an idea of how I wanted to go about after I finished school, and it kind of hindered that a little bit."

"I definitely do think about it sometimes when I sort of visualize what life would be like if I didn't have this pain. And I actually think that I would have probably been doing something. But I've just been so tired [due to endometriosis] that I'm at the point where I'm just giving up on trying to even do all of that [looking for a job in their field of interest] because I'm just so tired. A person can't function like that; you have to be at least doing something to take your mind off the pain. But then I'm like, I just want to sit here and just sort of…not wallow…but it's just so…I really wish I could explain it in words, how draining it is. To be in constant pain."

"I feel that when I go out in those certain situations [with friends or family], I feel like I'm forcing myself. Even though I want to be there, it feels mentally like I'm forcing myself to be how I used to be before this condition took me out, basically. Because I feel like the person who I was ten years ago compared to how I am now are two completely different people."

"If I hadn't had that [endometriosis] diagnosis, if I was still kind of wondering what it was, is it even a real thing, and then going through my youth, I guess, with that feeling that I'm imagining the pain. Yeah. What it would have done to even my self- confidence now.

5. Perspectives on Support Services

In the UK, research shows that there is a lack of standardised treatments, geographical inequity in accessing care, and a lack of coordinated care nationally[2]. Women spoke to us about their own perspectives of endometriosis support and services that they had accessed or wished to access in Camden.

5.1. Awareness of Disease

Despite its high prevalence, the severity of symptoms and its high socioeconomic impact, many people have not heard of endometriosis, let alone the association with pain symptoms or infertility. The interviews highlight the importance of awareness campaigns around endometriosis not only targeted toward the general public but also aimed at healthcare professionals, with greater awareness supplemented by greater support from medical professionals. Awareness of endometriosis should extend to helping women understand their bodies better, including the impact of the menstrual cycle on overall wellbeing. It must also include better communication about pain management options, so patients are empowered to make informed choices about their health and feel more in control of their health journey.

"I'm scared about- I'm going to have to take it [pills] forever. And then if I stop it, are the symptoms going to come back? Will it be any worse or will it have improved? I kind of wish there was like, a cure instead of just suppressing the symptoms."

"I do feel like, for women to be heard, it's shouldn't just be put into the education systems. I feel like we should sit down with doctors and say, "You guys need to be understanding. You're doctors. You've made an oath to protect life. You should be taking stuff like this seriously and not just brushing off saying 'this is woman's health you're going to go through it for every single month'. Because at the end of the day if people are educated in school, but then we have one side which is the doctors who are just not listening to us, it's just going to be a vicious cycle back and forth."

"I have a couple of friends who are in med school. And because I did take a module this year in women's health and reproductive health, I was just asking them just a couple of questions about what they speak about in med school and surprisingly enough, they barely cover anything. It's just all grouped together with pregnancy, and they don't look into it in detail. Which is why maybe when it comes to GPs addressing these situations, for example, they're less versed on what to do with these situations. I do feel like that should be incorporated into med school."

"If you do more awareness, you need to put more resources into the health system, because that's just bad practice, you know?"

"There's one thing about signposting to other free resources that are not just information, but actually places that you can go to. Then there's

something about sharing experiences and tips that could be useful from women to women. And then there's another one of maybe having that service of looking through your medical information with someone that has experience, and they're not necessarily a doctor but someone who could actually explain further and like it's not just talking about your condition but all the repercussions around it. So, someone that could help you identify, for example, if you have pain in your sexual relationship, can you talk about that with this person? Can they make you aware that it's part of having endometriosis? Because for me, it was me connecting the dots. No one told me, 'This is because of that [endometriosis]'."

It is important for any awareness strategies to include clear communication regarding the range of possible experiences among women with this condition. For many of the participants, the impact of endometriosis is compounded by other existing health problems like anxiety, serious mental illness, PCOS, Adenomyosis, Chronic Fatigue Syndrome. These intersections complicate the diagnosis and management of their health and adds layers of difficulty in navigating the healthcare system. One participant described her experience of the siloed and piecemeal treatment approach, focusing on symptoms rather than addressing underlying issues or the complexity of multiple medical conditions.

"When you're experiencing pain, the level of belief or disbelief shifts with that [BPD] and makes it ten times worse. Or people would often say, 'Oh, let's just focus on your mental health. Let's not worry about that [endo pain] for now.' Like, the two together I think, can be really dangerous, because one will always, in my experience, get minimised. And whether that's me trying to talk about the pain and how that's impacting my sleep, and then my sleep is triggering episodes, or like, I'm in a huge depressive episode, and it's really catastrophic for like 10, 12 months. And you also have this daily chronic pain, but no one is naming it as such. They're just like, 'oh, well, you're depressed so everything feels worse when you're depressed.' And it's like, I mean, most things can be true! I can be in a huge amount of pain. I can also not be able to move. I can also be bleeding a lot. And I can also be in a depressive episode..."

"I have been recommended to take birth control but I'm too scared because I've read some things that have frightened me. So, it's definitely made me read more on this topic. I guess I've definitely read some articles about period pain and the effects, and it's definitely made me learn. I think that's very important."

"It would be nice to speak to other people because even though I just talk, I don't like talking about this to my friends. They don't have this condition, so it would be nicer to speak to someone who knows more about it. Yeah. And talking to clinicians to get more information because most of the time, with the gynaecologists you see them once or twice. You don't really get that much information, and they're just kind of trying to look at the scans and talk about treatment, but they don't really give you that much information about the condition in detail- what are the symptoms that you have that could be related to it. Because I want to know if the other symptoms I'm having [constipation, anxiety, nausea] could be related to the condition or if it's something else."

5.2. Interactions with Health Professionals

Participants often lamented a lack of awareness, empathy, and understanding of endometriosis, and poor communication from healthcare staff, leading to feelings of frustration and mistrust in the system. They also perceived a lack of training among health professionals on the importance of recognizing the multifaceted nature of women's health issues. A feature of endometriosis is that it affects people differently, with symptoms overlapping with other conditions, complicating the recognition and diagnosis of this condition. Such gaps frequently led to delays, misdiagnoses, inappropriate treatments, and frustration, as patients felt their specific health needs were not being met. Several women reported being misdiagnosed with common conditions like UTI or IBS, highlighting the systemic issue in women's health where symptoms are minimised or misattributed. For many of our respondents, endometriosis was only detected by sheer chance, or when their symptoms got progressively worse.

"My actual family GP was fantastic and really wanted to get to the bottom of it. She sent me to some ultrasounds that showed nothing. I was put on courses of various antibiotics quite consistently. I was given advice about how to prepare better for sex. The complication in this, I think is worth acknowledging, is I experienced sexual asssault when I was 17, and so it was a very difficult period for me anyway. I think their assumption was it was psychosomatic, and they treated it as such for a really long time, so they sent me some counselling. In fact, I was at CAMHS to start with. They also did some blood tests, didn't find anything. Then they told me I had, potentially, diverticulitis, they told me I had IBS. When I moved to the borough of Newham. That's when they kept sending me for STI checks. They would not stop sending. Then they said I had pelvic inflammatory, which I didn't have. I only pushed for an ultrasound finally, despite the doctor there advising against it, because an unrelated MRI for my hip problem at another hospital actually revealed what they described as 'polyps'. They showed me my MRI scan, and there were all these little bumps everywhere. I was very surprised! And they told me, 'You need to see a gynaecologist'."

"[Explaining when she finally got a gynaecology referral] At that time I was on the pill, and my body just completely rejected it. I was throwing up…I threw up like 15 times within 10 minutes because of the pill. I was on the floor; it was really bad. So, I called my GP, and they asked if I was having any pains, other than the pill. I mentioned all of these symptoms and then I was sent to the hospital, basically, to get checked."

"I finally had an operation at 23, six years after I first noticed symptoms. And what they did was also awful. I was coming round from anaesthetic and the same consultant [who did the surgery] came to me and said, 'oh yes, you have endometriosis on your bowel, and we've taken it out, but it's probably going to grow back. We're probably going to need a hysterectomy'. I was completely shocked. Then he said, 'but I'm going to let you have recovery now' and he just walked off!"

"I went to the GP with my symptoms at age 16, and they put me on the pill. But that didn't help...Things seemed to sort of get painful over time and my mood was never really great. Again, I always thought it was just hormonal. But the pain, irregular bleeding, and lower back pain got worse so then I kept going back to the GP and I said, 'This is really not right'. Eventually a GP sent me for an ultrasound of the pelvis and they found a cyst. By the time I had the surgery through the endometriosis clinic I was 21. And what was meant to be a routine kind of surgery ended up being a major surgery. I had my left fallopian tube and half of the left ovary removed. And the doctor did say afterwards, 'you know it's best if you want children one day sooner better than later.' And I was like, I'm only 21?!"

"I think when I was in school, we just called it cramps, not even PMS really. And it wasn't until I think when I was in hospital, after the [endo] surgery, during that stay there was a lady in the bed next to me who actually mentioned the word endometriosis and gave me a website where there was information to read up or reach out if you needed. And that was the first time I'd ever heard of it. Throughout the whole hospital stay nobody mentioned it [endometriosis] because they didn't know I had it, they thought it was just a cyst! I mean, comparing then to now, I think it has improved because I am back in the care of an endo clinic. And I did say to the specialist nurse, it has really advanced compared to what it was 10 years ago."

"I had two kids and after the second one was born, that's when the symptoms started coming back again. Early last year, I had so much pain. The endometriosis was on my left side, at one point I thought I was having a heart attack. So, I called 111, and they said, 'Oh, just go to A&E right now, we'll make a referral.' When I went to UCH, they said, 'Your heart's fine'. I did so many tests like blood test, blood pressure, they even made me do a stress test. Everything was fine. So, they said, 'I don't know what it is'. I told them that I really think it's my endometriosis and they were like, 'Oh, okay. Just take pain meds, paracetamol and ibuprofen'. When I said, 'I think it's related to my endometriosis because it's on my left side', the doctor's face was like, 'I can't do anything about it...it's endometriosis'. So, he just said, 'Take paracetamol, if you feel anything else, just call us back'."

"They [health professionals] want you to struggle for a bit and then they'll take it really seriously. For me it was almost like I had to be bleeding on the floor before they took it seriously, because they didn't take it seriously until I had to go to A& E, which is quite ridiculous."

The difficulty in quantifying pain, especially female pain in comparison to males, also made the diagnostic journey even more fraught with uncertainty and anxiety for the women. They contemplated on all the mental negotiations they had to do, trying to figure out a way for their doctors to finally take their pain seriously.

"Especially if they ask you to rate it [pain] from 1-10, it's like- well that's kind of subjective. Like a ten for me might be different for someone else. It doesn't really make sense. Also, If I say it's really painful, and when they ask how painful, if I say 7 or 6, I think maybe they won't [take it seriously], like it's not that bad in their eyes. You see what I mean? Just because, I think 7 is bad, maybe for them it would have been a 9. If that makes sense.

And you also feel that if you say it's a 10, even though it might be a 10, you feel they would think that you're exaggerating."

"Also, the fact that they [doctors] know things like endometriosis doesn't always show up in the ultrasound. I didn't even know that it sometimes doesn't show up in scans. And the fact that no one's ever brought that up to me is shocking."

"I don't really trust GPs anymore. I think I would always second guess what any medical professional said to me, especially if they were dismissing the concern I had. And that's difficult, because of health anxiety I've had to be really mindful of when I go to a GP because I can so easily overthink things. So, I've had to do a lot of kind of self-development work on that. I just decided to take some time out to see how I can manage things myself. But if things do get worse, if I feel like I can't manage so well, then I will definitely go back and ask for that referral from my normal GP. The private GP sort of gave me a template of what to say to them and encouraged me to advocate for myself."

Interestingly, all of the respondents stressed that the responsiveness of a doctor was not dependent on their gender. I.e. male and female doctors were both likely to either dismiss or acknowledge women's endometriosis symptoms, with the quality of care instead feeling like a "lottery" system. Some women also reported a perceived lack of empathy from female doctors compared to their male counterparts, challenging stereotypes, and assumptions regarding women in healthcare. Medical school training, interest in conditions like endometriosis, and an empathetic nature were factors that actually played a part in determining if the doctor was receptive and understanding of women's symptoms.

"At my surgery I had a doctor, interestingly he was a male doctor, but he understood endometriosis, and he would see me regularly so that was good. I don't really listen to that thing when somebody says, 'Oh, well, go and see a female doctor'. It's about the doctor that understands. And the doctor that understands endometriosis and if they've done training in it, then they should have enough interest to understand. Sometimes men understand more because they may not be able to relate to endometriosis, but they understand pain."

"…the gynaecologist who got me a quick referral for a scan, she was really nice. She was really friendly, and I didn't really feel uncomfortable. I was kind of scared at the beginning. But you know, she gave me time. She didn't rush me. It was good."

"Recently there has been one GP who has been caring and taking it seriously. So yeah, quite happy with it, because it's a male doctor as well, you know, which is quite surprising because they're the ones usually dismissing it. He's basically doing further investigation. He's not just telling her to deal with it. He's doing other tests and referring her. I didn't have to beg him to refer, you know.

5.3. “Care in Healthcare” - Attitude Towards the Health System

Women living with endometriosis highlight the inability of the health system in dealing with the disease at every level, and the invalidation of patient experiences from all levels of healthcare. NICE guidelines for diagnosis and management of endometriosis have not been updated since 2018. They stipulated all gynaecological services to provide a specialist endometriosis gynaecologist to patients, but this role has neither been developed nor appointed[19]. Medicine's focus on objective factors and its cultural stereotypes of women combines insidiously, leaving women at greater risk for inadequate pain relief and continued suffering[5]. Greater awareness and changes in behaviour among healthcare providers are necessary for women's voices regarding treatment of their pain to be heard[5].

Women convey little trust in the system, as they are often made to feel that their pain and experiences do not matter. There is an overwhelming perception of being underserved. The lack of joined-up and continuous care, and the perception of being a mere patient number rather than an individual with unique needs, exacerbates patient frustrations.

“For all the women and non-binary people that I know who have endometriosis, it's catastrophic. I can think of three people that do and their lives are so badly impacted. It's terrifying to watch all the people that you love around you just having the worst experiences. It's very sad.”

“I guess it was my wish that I have more touch points [with doctors] because those are really limited and really transactional. No one sits with you and asks you about how it affects in your life, what are the holistic things that you can do. I guess what I was expecting from a diagnosis for me is to monitor my condition, to see if it has got worse, because it usually gets worse. It rarely gets better. If you're lucky, it stays the same. And from what I could read on it, it probably gets worse, but I haven't been able to talk to anyone about it.

“It just feels like most of the doctors, they don't want to change the way that they're doing things because I understand that they have a lot of work, but also, I just think it's a disregard for care. They just stick to the health. They don't care about the care because it's probably how traditionally medicine is taught, that nurses are going to care for patients, you [doctors] are the important person that's there to just bring the [diagnosis]. And at the end of the day, the best support that I've had for all the conditions I've had in my life has been usually by other types of professionals that are not doctors. So, yeah…”

There is a critical need for more consistent and effective pain management solutions tailored to individual needs and responsiveness to treatment. One woman recounted her ordeal with the hormonal coil, which is a common tool used by GPs for endometriosis pain management, due to physical discomfort and trauma related to their history. This highlights how pain management must consider individual patient histories and experiences, especially in cases of trauma.

> *"The pain that I've experienced, because I've got a tilted cervix, it's a real faff. It's so extraordinarily painful to have a coil, I physically cannot bear to have another one, unless they were going to sedate me, and they're not willing to do that. It's mad. They tell me to take a paracetamol [while coil is being inserted] and I'm like it honestly feels like someone is digging into me. I know that lots of women get on with it [coil] really well, but as someone who's experienced sexual violence, those kinds of situations are quite traumatic for me anyway. I think patients should be considered on an individual basis. Last time, they took one out and put one in and I fainted in the street, and they were like, 'oh, you don't need to be so dramatic. It's not that bad.' But my blood pressure had dropped so low. Like, it really, really hurt. So, I just can't do it."*

The importance of self-advocacy is prevalent throughout all the interviews. Women discuss how they have had to persistently push for a diagnosis, referrals and tests, which indicates a necessity for patients to take an active role in their healthcare to ensure their symptoms are taken seriously. This inevitably dents their confidence that the health system will deliver the best outcomes for them.

"I didn't get an ultrasound referral until I really said 'no, the pill is really not helping me. I need someone to look at me.' It's made me cynical, just with the endometriosis stuff [confidence in the health system]. So, in my mind, unless I'm bleeding out like that other woman in the [support] session, I won't go to the doctors, no one will take me seriously. Because her symptoms were extreme, but then she said it still took 10 years for someone to see her. That's insane!"

"I felt to me it would make a difference getting the diagnosis. And it sounds silly because I already knew before the diagnosis that if it is endometriosis there isn't anything they can do, because I'd kind of done a little bit of research as well. And then in one way I was hoping it's not that, but then in another way, I just wanted to know. I wanted to know what was wrong. Because then at least if you know what's wrong, you're not in limbo, if that makes sense. You're not sitting there thinking, 'Well, what is it? What is it?' You know? You don't think you're imagining your pain. Because I think sometimes with doctors they go, 'Is it really that bad?' Yes, it's really that bad. I'm not making it up. I'm not exaggerating. I'm not a hypochondriac. Because I think sometimes as well, you can be made to feel like you're a hypochondriac. And you're not. You're really not."

The interviews also revealed concerns about how pain can desensitise individuals to new or worsening symptoms, leading to a potential delay in seeking necessary care, thus creating a cycle of self-doubt and normalization of pain. This has the potential to affect how the health system meets screening/treatment targets for other conditions.

> *"I think my main concern about how the pain relates to my thinking is like, I've been forced to get so accustomed to this kind of pain that I won't actually notice when something could be very wrong. For e.g. like, I've got pain that's returned last night, that really sharp pain came when I moved, so I thought 'oh, I know this'. And because I know that pain, I won't do anything about it immediately. I'll take some paracetamol, I'll try to move around, I'll do some swimming, I'll do gentle stuff. But what happens if one day that pain's actually an indicator that I've got something wrong, and I don't go and get it checked? That is, I think, a more possible outcome for someone who has had quite significant pain consistently. Like when they talk about cancer screening, the messaging is always, 'come and tell us if you've got any changes'. But then you get told, 'Oh no, you're imagining it, it's just a bad period'. Like, which one is it, guys?"*

The Endometriosis UK inquiry in 2020 found that those from BAME communities experience additional complexities and barriers to accessing menstrual health support. They were misdiagnosed with fibroids, and other menstrual health condition, due to higher occurrence of fibroids in African-Caribbean communities resulting in endometriosis investigations being delayed[22]. There are insights from our respondents into systemic issues related to socio-cultural factors, where the women's experiences highlight disparities in care and understanding, particularly across different demographics. There is frequent standardization of treatment protocols that does not address individual experiences.

"I have heard that having children supposedly makes it better, but I know from my friend's case that's not true. It gets better for a little while and then it comes back, and I just don't think that's a good enough reason to have a child. As a suggestion from health care professionals, and I know other people that have been told that it helps. I just think that's a wild thing to say."

"I think I mentioned I was caring for my wife who also was having similar problems [endometriosis]. But I think for them, I mean, honestly, I have put in so many complaints to PALS about their mental health, about their experience. Because they're black, they're nonbinary, and they're gay, they have been so dismissed for their entire life. They shouldn't have had to wait as long as they did for a hysterectomy given how many blood transfusions they were having. Like, they were just passing out left, right, centre, and they didn't get to the hospital. No one was listening to them."

"Because for me, I've had my best care in sexual health clinics, and I've also had my worst care in sexual health clinics. So, I think there's something to be said about what that looks across the partnership. I mean, I already know the NHS are underfunded, but it's a connected system. I think there should be specialists embedded in those services. So, if I'm going to sexual health with this issue, how are they connecting with gynaecology and my doctors? Like how is the system joining together and not working independently so we got our best outcome?"

The lack of effective pain relief options beyond pharmaceutical intervention, led to a continual struggle for women. The gap between available treatment options and the actual needs of patients further emphasises the inadequacies in treating women with endometriosis. Women need proactive and personalised care approaches in managing their symptoms, instead of a high reliance on prescriptions.

"Having to do loads of research because you get given lots of different tablets by doctors, and a lot of them I can honestly say, really didn't work for me. I'm not somebody who can take high doses of tablets. So, a lot of the times I wouldn't be believed that there was something wrong with me. Like even applying for something like PIP or going to the doctors or going to a hospital or something, and they look at my record and the low doses of medication and they think "she can't be in that much pain", kind of thing. For me, that [medication] just didn't work. It meant I had no life at all taking heavy doses, because I want to have a life, I want to be able to get up in the morning and do what I can do. But for some reason, my body doesn't like taking high doses of tablets. It just doesn't."

"When I got diagnosed, my doctor was like, 'You have this [endometriosis]. I'm just going to give you the pill because that's the only kind of treatment that we have for pain. And then as well for, it could help manage the thing growing'. And that's it. That was end of 2022. And since then, I've been on the pill, but they don't tell me anything else. Like, I have pain in sexual relationships now, no one seems to care about that."

"I'm quite surprised that medication is still very much the same... I was given the pill, Zoladex injections, and Tranexamic Acid, which was meant to reduce bleeding, but I think that made me bleed heavier. Anything I took for my endometriosis, I can honestly say, I don't think it really worked. Every time I had an operation [endometriosis], I got it cut out, but it came back. But the doctor's even though they knew you've been through so many medications, you've kind of experienced the different highs and lows of it, and it didn't work, they still kind of just carried on either increasing the dose or giving you something else, instead of looking at something else that might have helped, like physiotherapy or something."

"With all the contraceptive pills I've tried and the coil, anything hormonal seems to sort of not agree with me emotionally. And I've never been lucky for it to stop my periods, whereas for some people it can stop their periods, which is great. Most recently I did try the mini pill and that was horrendous. Really bad bleeding and clots. I think that's the thing. People shouldn't be treated all the same because different things work for different people. So, it is very like individual cases."

"I found with my doctors they take it seriously. But it's just that, there's just some standard way to treat you. No one does this holistic approach of, 'where does it affect in your life beyond the pain?'. Because for me, it's not the pain right now. For me, it's the contraction in that area which doesn't allow me to have a proper sexual life. So, at this point, I don't even care about the pain, but they only give you pills for the pain. And I know other women, my sister-in-law also has it, she only discovered it [endo] now because she couldn't get pregnant. And they give her the pill and she's like, 'I want to get pregnant. I don't want to [be on the pill]'. So, I found the

opposite as well, that they think it's just about the pain when it's not just about the pain."

5.4. Lack of Educational Support

Menstrual Wellbeing was included in the 2020 mandatory relationships and sex education (RSE) and health education for schools in England guidance. We assessed the 2023 personal, social, health and economic (PSHE) curriculum in state secondary schools in Camden, and the National PSHE planning framework guidance covered puberty, menstrual wellbeing and navigating the NHS as part of Key stages 3-4 curriculum. For Key stage 5, sexual health is covered under H20. As of 2023, two secondary schools had incorporated gynaecological health, fertility and reproductive health topics as part of their PSHE provision. Teenagers with family history of endometriosis, or who experience onset of menstruation at age 11 years or younger have a higher risk of developing endometriosis themselves. Given the greater challenge of diagnosing endometriosis in younger people, educating them about their body, e.g., what is normal period pain and when to seek help, can make a significant impact in improving disease outcomes and foster understanding from an early age among both students and staff. Women recounted the inadequacy of menstrual health education they received in school.

"I think that schools like to talk about it, but they are not good at seeing things through like that as a teenager. And they'll just tell us stuff that we already know, like 'oh talk to someone'. But they don't understand, it's not that easy."

"I remember in year 8 there was this PSHE thing about periods. But at that time, I hadn't gotten my period yet and it was talking more about periods in general, not 'oh, what if your period is like this and this and this, you might have endometriosis or PCOS or whatever'. They just talk about what period is, what the cycles look like. They don't really explain the other aspects."

"I mean PSHE you just learn the basics, but you don't really learn about the pains and stuff like that. You just learn the menstrual cycle, that's it. Yes, for me it would've made a difference if I had learned about what kind of pain is normal or not. Because what we've all learned is just basics, there isn't much about it. Pain is not really spoken about."

6. Need for Holistic Support

Despite the real-term cuts to the NHS budget, and slower growth compared to the rising costs of delivering services, Camden has made strides in integrating health and social care in the borough, working on community engagement to assess health needs and empowering local solutions. Insufficient funding massively limits the implementation of effective community health initiatives locally. In the UK, the provision of holistic treatments for endometriosis, which involve thoughtful access to pain management, mental health support, post-surgery care, and fertility preservation and treatment for those wishing to have children is non-existent[29]. The overt focus on pills and painkillers for pain, without considering holistic approaches like lifestyle changes, stress management techniques, mental health support, pelvic physiotherapy, community support, and alternative therapies (acupuncture) underscores the lack of acknowledgment of the multi-faceted impact of endometriosis on a woman's life. It also demonstrates how poorly researched the condition is by the modern medical system. There is an urgent need for sustainable, non-medicinal options to help manage and cope with the physical and psychological impacts of the disease, not simply to mask symptomatic pain.

6.1. Coping Strategies

Women were left feeling extremely critical of the limited medical treatments available and described the added mental burden of researching effective solutions themselves, acknowledging the difficulties of finding time to care for themselves while juggling family responsibilities. Their exploration of alternative treatments, for e.g., raspberry tea, CBD oil, aromatherapy, indicates the desperation often felt by individuals to find relief when conventional treatments are insufficient. They consistently highlighted the role of diet in managing endometriosis symptoms and reducing pain but received no guidance or information from their health providers at any point. In sharing their journey towards adopting an endometriosis-friendly diet they emphasised the need for healthcare providers to provide resources focused on dietary support and its relationship with endometriosis, also ensuring that healthy food options are accessible and affordable in the borough.

"Honestly just having the motivation to do the best things for yourself when you're tired and in pain. People tell you that if you alter your diet and cut out certain things [caffeine, dairy], the pain sometimes can get better. When I cut out caffeine it helped, but it's hard because caffeine is a bigger part of my diet than dairy. There's also the balance of things you enjoy and including them in your life…I think kind of managing the daily life yourself

and trying to make these changes to improve your symptoms, it would be easier if there was more research to back up why you're doing that and what impact like your nutrition has on endometriosis, and why that happens. But because it is so unknown, that research isn't in place, you're almost like is this just nonsense? You don't understand why it matters. But you're willing to try anything really."

"The doctor just gave me a bunch of general recommendations and a referral but it's months away. He gave me this indication, that I have high cholesterol, and he's like, 'You need to do this'. But then I'm investigating about diet, and I realised a lot of women with endometriosis have high cholesterol due to hormone imbalance. And I was like, no wonder why I do have that, even though I take all the precautions and doing the diet for a year. And now I'm like, I cannot really solve this [high cholesterol] with this condition, you know? So, it's those little things that really piss me off, even if I'm a really informed patient because I've done a lot of research. I read papers sometimes to try to understand things. Reading books. But still, you know, you're basically on your own."

"Many years ago, I remember asking a consultant, I said, 'do you think what people eat may affect them?' And he laughed it off! It's interesting."

The constant need for women to educate themselves on their condition before consulting a healthcare provider, so that symptoms are taken seriously, is indicative of systemic gaps. This presents opportunities for improving outcomes by boosting self-advocacy skills in women with this condition.

"If I'm going to the doctor, I've already started keeping a log of when my pain is bad and tracking it through my period cycle. So that when I go to the doctor, I'm giving them literally all of the details that they need. I find things like that really helpful, but I learnt that from mental health services using diaries and things. I think they can be applied quite well in this situation, so that then I can have more foresight and work out what it is I need to do or not do in relation to any flare ups that I might be having, or if they're linked to a particular part of my cycle."

"I think sometimes women are not really well versed in these conversations, saying like, 'I've missed X numbers of days, um, on 40% of my days, impacted by a level of pain that felt unmanageable.' You know, 'I had to come to four or five occasions in the last week. I felt low, and unable to move four times this week.' Those very specific practical things lead somebody to understand the impact. But when you say, like, 'can you rate your pain from 1 to 10', what does that even mean, you know?"

6.2. Importance of Local Support Groups

Description of isolation and gaslighting makes it important for women to have safe spaces where they feel seen. These spaces not only provide emotional support but also serve as a platform for sharing information and coping strategies that may not be available through healthcare providers, to help individuals better understand their condition, find treatment options, and access community resources.

"Before I used to think it was just me going through this weird thing, but then I met other people like me. "It's not only me". So, it was reassuring to know that I'm not the only one going through it, and that, you know, there are other people like me going through this, and that this condition is common, and everyone's experiences are different, but it's still similar in certain aspects. It was important to know that I was not the only one [going through this] because mental health-wise it used to stress me out a lot when I thought that it was just me [having this experience]. I thought, you know, my body is different. Like, why is it just me? I used to feel doubt. And then when I saw that there's other people, it helped my mental health a lot. My head felt light."

"I think by going to the group, I've realised that I have sort of been, like, sitting and wallowing in my own isolation here. I know I can talk about it with my sister and my mum, and they can understand me. But sometimes it just feels like, I'm on my own. And even though I do have people that understand and empathize with me, I just still feel alone, which is weird, but I guess it happens, you know? I did actually get a few ideas of how to manage my pain from the [Healthwatch Camden support] group which was really helpful."

Participant views align with a growing recognition of the importance of addressing women's health issues holistically and informatively. Interviewees expressed a sense of empowerment through sharing their experiences and learning about endometriosis from others, including online resources and support networks. This highlights the importance of community and peer support as peers with lived experiences can validate concerns and offer insights.

"It would be nice to speak to other people because even though I just talk, I don't like talking about this to my friends. They don't have this condition, so it would be nicer to speak to someone who knows more about it. Yeah. And talking to clinicians to get more information because most of the time, with the gynaecologists you see them once or twice. You don't really get that much information, and they're just kind of trying to look at the scans and talk about treatment, but they don't really give you that much information about the condition in detail- what are the symptoms that you have that could be related to it. Because I want to know if the other symptoms I'm having could be related to the condition or if it's something else."

"I feel like having a place to talk about these things would be helpful, because I always downplay my pain and stuff like that, so I feel like knowing other people are going through it, people can relate to it, I can understand that it's not just me, and it's not something to be downplayed. Basically, I should take stuff more seriously, don't I? Rather than dismissing it."

Women often recollected how a network of friends and family, especially a mother with a similar diagnosis, provided invaluable support and validation of their condition. Despite challenges, the women's journeys highlight a growing resilience. By attending support sessions and learning to advocate for themselves, they reported an increase in confidence and empowerment in navigating their health issues.

"Because my mum was a nurse, she was really great around this because she was like, 'no, I really think something is wrong.' So, I was really lucky like that. And also, because so many of the people I love have it, we're all quite good at chatting about it, and there's a lot of solidarity, I suppose. I think things like support groups are always really helpful. I've been really lucky and accessed loads of groups about other things and always found there to be a learning point. I think when you have an offer like that alongside really dedicated care, it can help somebody. It could help somebody feel really connected."

"My mom's really understanding because she herself, when she was younger, she had really bad period pains. I think the doctors had told her she had like cysts or something. They didn't really say it was endometriosis, but she had really bad period pain herself, she'd end up having to go to like A&E quite a lot when she was younger. She'd end up vomiting and things like this. So, she understands. When I'm on my period, she's really supportive. She's the one who encouraged me to see the gynaecologist."

"I basically had no choice, I had to push herself through it [the pain]. And I used to think, you know, 'Why? Why is it only me like this? Why do I have so much pain?' I didn't know anyone that has endometriosis or would go through the condition. When I went to the sessions, with my daughter, that's where I'm seeing, I found other people. I realised that there are other women struggling like me as well. When I used to go through it alone, it just stressed me out because I thought it would just me, and not a lot of people that go through it. So, when I went to the sessions, it was reassuring because I saw that it is quite common among other women. It was reassuring for me."

7. Conclusion

Our conversations with women in Camden have revealed a rich tapestry of experiences surrounding endometriosis, particularly as it intersects with cultural, social, and systemic factors. The interviews provide a compelling account of the ongoing struggles faced by individuals with this condition and elucidates the broader societal and systemic issues tied to women's health. They illustrate the need for greater understanding, improved healthcare practices, and enhanced support mechanisms for women facing this condition, fostering a society where women's health issues are recognised, understood, and compassionately addressed.

The findings underscore challenges related to diagnosis delays, ineffective pain management strategies, inadequate communication, and disparate healthcare provisions, exacerbating the immense physical and psychosocial toll of this condition on our participants. Additionally, the stigma and social isolation experienced by many serve to compound these challenges, further illustrating the urgent need for awareness and understanding of endometriosis.

The recommendations outline future hopes and needs for local policy in improving endometriosis outcomes, as identified by the participants. There are significant opportunities to enhance understanding, reduce stigma, and improve the quality of life for individuals facing this challenging condition. The recommendations aim to empower patients through education, greater awareness, and self-advocacy; enhance health provider awareness; and promote multi-disciplinary and holistic treatment approaches that prioritise the patient experience. Local policymakers can address the shared challenges outlined in this report and work towards a future where individuals with endometriosis receive not only timely and accurate diagnoses but also comprehensive care that addresses both their physical and emotional needs.

The path forward requires a concerted effort from local policymakers to cultivate an environment of empathy, support, and informed dialogue around endometriosis. Implementing these strategies will not only improve the quality of life for those affected with endometriosis, but also contribute to a broader shift in how women's health issues are understood and managed. Through collaboration and advocacy, Camden can ensure that the voices of individuals living with endometriosis are heard and valued, paving the way for a more inclusive and positive future.

We hope that this report can catalyse the changes needed locally, to mitigate the growing challenges that link to endometriosis education, diagnosis, treatment, and aftercare.

8. Recommendations

Healthwatch Camden acknowledges the pressures faced by the council with reduced public health funding and the ongoing challenges of NHS waiting lists and staffing. We welcome the inclusion of endometriosis in the governments most recent Women’s Health Strategy, and we hope that national policy follows close behind, so that women no longer feel dismissed by the health system. We strongly support the recommendations around urgent clinical and organisational improvements as outlined in the NCEPOD report[30].

From women's accounts of their endometriosis experience in Camden, we identified significant opportunities to enhance understanding, reduce stigma, and improve the quality of life for individuals facing this challenging condition.

1. **Establish a Women's Health Hub in North Central London:** Healthwatch Camden echoes the recommendation made in the government's Women's Health Strategy[39], for NCL ICB to establish at least one women's hub in their footprint.
2. **Local Endometriosis Support Group:** Set up a regular provision of local Camden-based support sessions, to expand support which merges peer, community, and clinical engagement. These informational sessions can provide a safe space for women to find community, become educated on the condition, and to learn and share coping strategies and practical advice for managing symptoms, instead of these groups merely being a space for venting frustrations. The sessions can also serve the function of a women's health hub to expand and disseminate informal support options, like social prescribing, with joint facilitation by different health professionals and peer navigators. This patient-centred approach can have huge impact on health outcomes. Establishing a community support group localised to Camden fosters an environment where women can connect even more based on a shared geography and local landscape of social prescribers.
3. **Women's Health Steering Group:** Set up a Camden women's health steering group or forum, to include various stakeholders like patients, charities like Women+Health, organisations like Endometriosis UK for subject matter expert, representative from public health Camden and NCL ICB. This group could oversee the introduction and implementation of the endometriosis support group, as well initiate cross-sectoral working for the improvement of women's health in the borough. This would help to foster an environment in the borough where discussions about menstruation, reproductive health, and chronic illnesses are normalised and encouraged.
4. **Increase Awareness:** There is a need for public awareness campaigns that aim to destigmatise conversations surrounding menstrual health and chronic pain conditions, fostering an environment where women feel empowered to share their experiences and seek help. Providing clear, empathetic, and readily accessible resources that outline potential symptoms and treatments may empower women to seek help sooner. These campaigns should also promote health literacy and self-advocacy skills so that women feel empowered to

advocate for their care. Targeted awareness campaigns that dispel myths and stigmas around menstrual health, challenging cultural narratives surrounding menstruation and pain, especially among those belonging to the global majority. It is also important that awareness campaigns are not only targeted towards the general public but also aimed at healthcare professionals. Using resources like GP leaflets, distributed widely to residents, and in multiple languages, could promote inclusivity for diverse communities.

5. **Early Education and Support in Schools:** Standardise provision of menstrual health education across all Camden schools, with age-appropriate yet comprehensive education around menstruation and related conditions. With the support of Endometriosis UK in providing teacher training, or development of a specific module, Camden Learning can ensure all schools in Camden have the resources to deliver this education to pupils, both male and female. Education should be framed around period pain and bleeding, addressing myths, stigmas, attitudes, and misconceptions about normal/abnormal pain, describing pain thresholds, and elucidating normal from abnormal bleeding. Older students should be introduced to menstrual health conditions like endometriosis and provided information on how to speak to their healthcare providers about any issues. Schools can also incorporate the Endometriosis UK online training for older students, ‘Menstrual Cycle Support’, into the curriculum for easy online access.
6. **Improve Diagnosis of Endometriosis Locally:** Improve women’s experience at first point of contact, i.e. primary care, as that is the significant factor determining the quality of care and health outcomes of the patient. GPs should provide clear information and awareness on pain management options, for e.g., FAQ leaflets to encourage hormonal treatment use and adherence. Establish clear clinical guidelines for managing menstrual pain, which should include referrals for further investigations when patients present with severe pain. These protocols should guide healthcare providers in recognizing when to escalate care. Streamline the healthcare referral process to ensure faster access to specialists, reducing wait times for diagnosis and treatment.
7. **Continuous Care Pathway:** Due to cyclical nature of endometriosis, patients require regular monitoring for any new endometrial growth. There is a need to establish protocols for regular monitoring of patients with known endometriosis where GPs provide yearly screenings and referrals for scans, instead of discharging the patient after dispensing pain-management medication, or after a surgery for diagnosis/treatment. Referrals should be expedited for imaging studies (like MRIs) if needed when patients report significant changes in symptoms, rather than waiting for acute issues to arise. This could improve long-term health outcomes.

8. **Local Healthcare Coordination:** We echo NCEPOD recommendations around multi-disciplinary healthcare provision. We recommend the NCL ICB to initiate conversations around the development of locally integrated care models that encompass primary care, sexual health, gynaecologists, psychologists, nutritionists, physiotherapists, and also include alternative therapies in pain management plans for endometriosis in Camden. Connecting these various specialities will address both the physiological and psychosocial needs of endometriosis patients. Mental health support should be integrated as a standard offering for women with endometriosis and similar conditions, making it a core component of care. For e.g., Local Mental Health services to recognise and include gynaecological conditions as factors for poor mental health and address it accordingly through counselling and support helplines specifically focused on chronic pain. Integration of care plans should ideally occur at the very beginning of the patient’s journey, whilst they are awaiting formal diagnosis of endometriosis. Understanding the full spectrum of treatment options available can help improve the quality of life for those living with this condition in Camden.
9. **Improve Management of Symptoms Through Expanded Access to Treatments**: Pain management care plans must also be personalised to the individual, considering patients' unique pain descriptions and experiences of symptoms, and they must be made more universally accessible — through community resources, pharmacies, and GP referrals—to help alleviate the burden on individuals managing endometriosis and chronic pain.
10. **Communication and Compassion in Health Professionals:** Advocate for training of healthcare staff in compassionate and empathetic care around women’s health, particularly focusing on integrating lived experiences. Enhancing healthcare encounters can foster greater trust and confidence in the health system, which is especially important with a stigmatised chronic condition like endometriosis.
11. **Publish a Women’s Health Strategy:** Highlight social, economic, public health benefits of good health in women in Camden.
12. **Invest in Further Research**: Conduct more research locally on the health outcomes for women from the global majority, who live with endometriosis and similar conditions, accessing how systemic barriers affect their care.

Appendix

Methodology

We spoke to sixteen women between the ages of 18-49years old, who lived and/or worked in Camden, and who had either a formal diagnosis of endometriosis or were awaiting one from their doctors. We conducted 1-1 interviews using a topic guide, with semi-structured and open questions, around their endometriosis symptoms, its impact on various aspects of their health and well-being, and perceptions around available support services in Camden. From January to June 2024, we conducted 6 support sessions where we invited local women with diagnosis or suspected symptoms of endometriosis. Through those support groups, we advertised the 1-1 interviews to any woman who was interested in sharing their personal endometriosis experience with us. Sampling was purposive, and recorded verbal or written consent was obtained before each interview. We made it clear to our participants that it was not compulsory to answer any questions they were not comfortable with and that they were able to withdraw from the research at any point. Research data was encrypted and accessible only by the research team. Any personal details of participants throughout this report have been anonymised.

For this study, we used thematic analysis to analyse the focus group transcripts. We familiarised ourselves with the data, conducted a round of inductive coding and then followed up with an analysis session to discuss the themes and sub-themes we found. We then refined our final list of themes and sub-themes as a team and produced the skeleton of our report’s framework.

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