EXPERIENCES OF ENDOMETRIOSIS AND ADENOMYOSIS: A THEMATIC ANALYSIS

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*Abstract*

*Aim:*

This research study aims to examine the experiences of body image in women with endometriosis and adenomyosis, both suspected and confirmed, in these chronic gynaecological conditions, along with excluding the evident gap in research surrounding this topic within the field.

*Method:*

The method used throughout this research was an inductive latent approach using thematic analysis (Braun & Clarke, 2013), utilizing a mixed methods approach by the use of online surveys and Microsoft Teams interviews, to ensure a wide range of cultural and diverse populations as well as gaining multi-generational insights from the use of these methods, the total amount of individuals that participated in this study is a combined total of 304 overall from both Microsoft teams interviews and the online surveys.

*Results:*

This study found that there was an important relationship between endometriosis/ adenomyosis and body image in an array of areas from physical body image to mental body image, and the extent of intrusion that the impacts had on the lives of those who suffer from these conditions are extensively large, leaving these women with a negative body image relationship in almost every sense of its form the body image negativity making its way into every situation on a daily basis from going out with friends to intimate relationships.

*Conclusion*

these findings highlight the wide array of ways body image relations and the severity of impacts due to endometriosis and adenomyosis, which suggests that the need for intervention to address body image concerns is extensively needed to aid the ways these women see their bodies on a daily basis and support them with body positivity. In conclusion, these findings provide a holistic understanding of how these conditions affect women’s lives daily.

*Introduction*

the research conducted throughout this project is substantially essential as the area of body image is not complexly looked at in regard to a diverse population, particularly in the younger generation that is more vulnerable to societal expectations on a woman’s body image and expectations, along with looking at the areas that are impacted in grave detail. Furthermore, how these implications in other areas affect the body image aspect in a modern-day society as an overall topic.

firstly, it is important to look at the differences between the two conditions that are being looked at throughout this project, but moreover to look at how they overlap and intertwine as an individual can have one or both of these conditions, with a variety of studies suggesting that around a third of individuals who have endometriosis also have Adenomyosis. Bazot et al. (2004) reported that 27% of women with endometriosis also had Adenomyosis, while a study conducted by Kunz et al. (2012) stated that 34.6% of patients with endometriosis also had adenomyosis. And finally, a third study carried out by Marjorie Hecht (2021) showed that 42.3% suffering from endometriosis also had adenomyosis. This shows that the population suffering endometriosis appears to be climbing higher with a combined adenomyosis diagnosis as time prevails, which again shows a great need for research in this area to be conducted when those who are being diagnosed with one or both of these conditions continue to rise every day.

There is no cure for endometriosis and the aetiology remains unknown. The symptoms of this condition vary from person to person however, the most common across all boards of endometriosis are heavy menstruation, chronic pelvic pain, chronic fatigue, infertility (including difficulty conceiving or recurring miscarriages) leg pain, back pain, excessive bloating, and painful intercourse (ENDOMETRIOSIS NHS UK, 2024).

 All of the above symptoms have lasting negative impacts on the daily lives of these women. Endometriosis is defined by having endometrial-like tissue in areas of the body it should not be in for example the bowels, the stomach lining, intestines lungs and other areas of the body (ENDOMETRIOSIS UK NHS, 2024). The Gold Star standard for diagnosis of this condition is laparoscopic surgery (The Endometriosis Foundation 2025). without this procedure you are only suspected to have endometriosis for example an MRI that shows indications of having endometriosis would only be considered a suspected diagnosis. To gain a full diagnosis of endometriosis the current waiting/diagnostic times are between 3 and 12 years, with the average being 8 years, along with this an individual can have a diagnostic laparoscopy multiple times and still not find endometriosis even when you do have it as they cannot diagnose it often times until it has perforated the tissue barriers so that it is visible (ENDOMETRIOSIS UK NHS, 2024).

Adenomyosis is similar to that of endometriosis however, there is a significant difference between them, with Adenomyosis confined to the womb only. Adenomyosis is defined as endometrial-like tissue that has grown extensively into the lining of the uterus, making the muscle and lining extremely hard, irritated, and inflamed (ADENOMYOSIS UK, NHS, 2024). The symptoms of Adenomyosis are also often the same as endometriosis and can be just as severe and in some cases worse, depending on stage. The symptoms consist of, chronic abdomen pain, back pain, infertility (also ranging from the inability to conceive to recurring miscarriages), painful intercourse, and menstrual menophoria (Smith et al., 2020), along with many others. Adenomyosis can cause other complications such as a hydrosalpinx, cysts on the fallopian tubes, and in some cases, tumours within the womb and fallopian tubes (Mayoclinic, 2023). One difference between the two gynaecological conditions is that Adenomyosis can be cured. The first line of treatment for Adenomyosis often consists of forms of contraceptives such as the marina IUD and IUS (Pontis, et, al., 2016), the combined pill and more, in cases where this form of treatment does not help to minimize menstruation, then Transemic acid is also given and Mefenamic acid for chronic abdomen pain, there are many forms of medication available however, these are the most commonly used (Soave, et al., 2017). A second form of treatment for Adenomyosis is being placed into medical menopause and the last resort of treatment is to cure the adenomyosis fully and have a full hysterectomy. This is in some cases offered straight away depending on the risks, age, and family status of the individual. This condition is easily diagnosed however, as the diagnostic method for this is an MRI (magnetic resonance imaging) and a thickened junctional zone (the area between the endometrium and myometrium) in the ranges of 12mm and above, indicating the condition is present (Chapron, et al., 2020). This method of diagnosis is accepted in the medical field however, an individual will not have a solidified diagnosis until after a full hysterectomy has been performed and examined (DeCherney, et al., 2020).

Overall, both Endometriosis and Adenomyosis have major impacts on a person’s daily life, as they often both experience bloating, both have surgical scars, and both suffer from the same symptoms, which is what often takes receiving a diagnosis so long and often confused with one another. Along with this, it is still unknown as to what causes people to suffer from these chronic conditions.

*Literature review*

Research on these gynaecological conditions to the present time has been aimed towards establishing the root cause of these conditions and the development of treatment and remains open and ongoing. However, research conducted on these areas looks profusely at ‘the psychological well-being of women with endometriosis, this is shown when Van Niekerk, Steains & Matthewson (2022) conducted a study looking at the Correlation of health-related life; body image. This study found statistical relationships between endometriosis and body image factors, demonstrating that individuals with endometriosis have poorer body image outcomes compared to those who do not live with the condition. However, this particular study does not capture detailed personal narratives or direct thoughts and feelings about their bodies, specifically in individuals with endometriosis who reported a negative body appreciation in regards to their “size” along with a lack of body familiarity and dissatisfaction. This study found that both the physical and emotional aspects of body image are intertwined properties of health-related quality of life(HRQoL), with the research emphasising that “lack of body familiarity” is a significant correlate of both physical and emotional well-being in those with endometriosis.

One of the key strengths is the study's quantitative methodology, utilizing an international online cross-sectional survey to gather data from a diverse sample. This approach allows for the statistical analysis of significant correlations between endometriosis, body image factors, and HRQoL outcomes. Along with this, the division of participants into endometriosis (+Endo) and control (-Endo) groups further facilitates comparative analysis, as well as the use of hierarchical multiple regression analyses (MRA) provides a robust method for identifying significant correlates of general, physical, and emotional HRQoL.

However, the study's reliance on cross-sectional data limits the understanding of how body image changes throughout the disease progression and treatment journey. The absence of qualitative data, such as personal narratives or direct thoughts and feelings about their bodies, also restricts the depth of insight into the lived experiences of women with endometriosis. A qualitative study using interviews or focus groups would complement the statistical evidence by exploring the deeper, personal experiences and thoughts of women living with the condition.

Furthering these limitations, it is unclear whether poor body image leads to worse endometriosis symptoms or if the symptoms cause deteriorating body image perception, showing an insufficient understanding of the bidirectional relationship. Along with this, most studies focus on cisgender women, which represents limited research on diverse populations.

Volker and Mills (2022) conducted a quantitative study comparing people with endometriosis and without endometriosis to explore the relationship with pelvic pain. The purpose of this study was to assess body image, specifically in regards to appearance satisfaction and functionality appreciation without endometriosis and to also explore how endometriosis-related pelvic pain relates to body image. The finding of this study was that there was a high likelihood that associated pelvic pain has negative effects on how people view their bodies, the study was carried out via the use of online surveys comparative based on two groups that further found a negative correlation between pelvic pain and body image with the endometriosis+ group showing significantly poorer body image than those without endometriosis.

One of the strengths of this study is that it is one of the first to compare both those with endometriosis and those without, which allows for a better exploration of the differences between the effects that body image has on each group. Furthermore, the mean age of the participants matched in each group allowing for a more accurate representation of data. Finally, the sample size for this study despite it being a limitation is also a strength of the study as a sample size this large for this comparative-based study is a significant size.

Some of the limitations present within this study are that the control groups used “ENDO+(312)” and “ENDO-(74)” were significantly different with the number of participants in each group, this could present as problematic in regards to the statistical comparisons as it may under-represent the ENDO- group. As well as this, the data was subject to self-reported diagnosis, which would be open to recall bias or reporting inaccuracies. Furthermore, this study was also geographically limited to Australia, and the primary mean age of those who participated in the study consisted of a mean age of around 30-32 years old which would under-represent the younger generations who suffer from endometriosis and how they are impacted by the condition.

 Pehlivanet, et, al. (2022) looked at body image and endometriosis, examining self-esteem and rumination as mediators. This study recruited 996 participants to complete a two-part process. The first step in this study was the survey to investigate how self-esteem and rumination might mitigate the relationship between body image and depression in individuals with endometriosis, the second part to this study was a follow-up, one month after the study and another 2 months after the study of which only 451 participants completed the follow-up surveys. This found that self-esteem was a significant mediating factor between body image and depression.

One strength of this study is that they used multiple time points to examine the temporal relationship over time providing longitudinal insight into the mitigating factors and how they develop. Furthermore, the use of sophisticated statistical analysis (bootstrapped analysis) with full information maximum likelihood estimation, as well as the sample size for this study being substantial for this type of research makes the finding more valid and reliable.

Some of the limitations of this study are that only half of the original participants completed step two of the process, and this substantial attrition rate drop-out could have introduced potential bias in the results if those who dropped out differed systematically from those who completed both surveys. Following on from this a further limitation was identified in regards to demographics as this study was only carried out on the citizens of Australia who suffer from endometriosis.

Sayer-jones and Sherman (2022) examined how endometriosis affects body image by the use of qualitative analysis, using written responses from individuals living with endometriosis with a sample size of 40 participants. This study aimed to gain a more complex understanding of the impact of endometriosis on affected perceptual aspects of body image, in doing so this particular study found three key themes which included my body as a barrier highlighting the unreliableness of the body of these women due to the inability of its functions compared to desires as well as disrupted daily tasks such as career and social life. Along with this, they found that participants felt the need to hide their bodies. And finally, the study identified that some people who suffer from endometriosis had developed acceptance and a sense of gratitude for what their bodies could still accomplish. Therefore, this study provides an important insight into how endometriosis affects body image as well as suggests ways to better support individuals with this condition, the findings highlight the complex physical and psychological impacts of endometriosis and the need for comprehensive care approaches that address both aspects.

A strength of this study is that the qualitative design was appropriate for exploring the complex, subjective experiences of body image in endometriosis as well as including a researcher with lived experiences of endometriosis which in turn provided a valuable perceptive. However, there are several limitations present within this study. Furthermore, this study was carried out during the covid pandemic when participants were confined to their homes which may have implicated the findings as during that time the option to exercise, go outside, and socialize was prohibited which could have made the findings of this study more drastic than they would be in a normal space of time. Along with this the study only recruited participants from organizations in Australia, with limited cultural backgrounds and diverse populations making these findings only representative of the Australian endometriosis communities.

Overall, the above studies in combination present several commonalities, this being the focus of each study being on the psychological impact of endometriosis, each one focuses on the psychological and emotional effects of living with endometriosis, with each recognizing that endometriosis as a condition that affects both physical and mental wellbeing aspects and how that, in turn, affects the individual’s quality of life. In turn with this, many of the studies that have been conducted on women with endometriosis within Australia highlighting the necessity for studies to be conducted outside of this location for better understanding and representation across all boards.

Throughout each study above it can be seen that the vast majority of studies conducted on endometriosis are quantitative. Along with this the exploration of endometriosis and adenomyosis when looking at body image as a connected study is very few and far between, which implies the extensively important need for qualitative data on both conditions together to be explored. There remains a largely evident gap in research surrounding the body image of these women. All of these unanswered questions make the study necessary, relevant and immensely important as this area has only been lightly investigated, even though it is a large aspect that these women have to live through on a day-to-day basis.

*Method*

*Design*

The design of this study is a qualitative analysis exploring experiences of endometriosis/adenomyosis and body image. The choice to use qualitative analysis for this study was due to, the in-depth personal lived experiences that qualitative analysis can provide because it allows the participants to write in their own words exactly what they feel, think and have lived through In their own way, which a quantitative analysis cannot provide. This in turn allows for more in-depth data to offer a more profound understanding of the implications endometriosis and adenomyosis have on body image within modern society.

To further aid this, a latent approach was used throughout the data collection process. The decision to use this design was due to the aspect that it allows the participants to lead the data instead of going off of a presumption and searching for that specific set only when that could eliminate an important aspect of data, whereas using the latent approach you gather all important aspects of the participant’s experiences, without a bias being pre-placed.

*Materials*

The materials used in conducting this study were a computer for creating the questionnaires and conducting the interviews on Microsoft Teams as well as the distribution of the participation link, some paper was used to help with the data collection method and creating themes, the decision to do this was due to the large sample size and having the data on paper to allow for better organisation and grouping to create themes, a pen was also used to take notes while creating the themes of the findings and identifying similarities within participants answers.

*Participants*

The sampling method carried out in this study was convenience sampling, this was due to the decision to use social media distribution links for the questionnaire. Furthermore, this was also due to the participation links being placed in specific social media community groups where a particular set of people living with endometriosis and adenomyosis could be recruited.

The participants for this study were recruited between the 8th of January 2025 and the 7th of February 2025, both diagnosed and self-diagnosed women were invited to participate in a research study through adverts placed in community groups specific to those suffering from endometriosis and adenomyosis through the use of the social media apps Facebook and Instagram. The women suffering from endometriosis and adenomyosis have made multiple group pages/community groups on these platforms to stay connected to each other and seek advice and help, as well as make a home where they feel understood and not judged. The people in these groups are from all over the world which increased the reach of this study and aimed to increase the potential for sample diversity. No incentives were offered to participants in return for their participation. The eligibility criteria for this study consisted of having suspected endometriosis or adenomyosis via a GP, full diagnosis, or self-diagnosed after having all aligning symptoms for a minimum of two years. Each participant had to be 18 years old or above to participate.

A social media post on Facebook and Instagram asked participants to choose to take part in either an online survey or an interview via Microsoft Teams, during which they were asked to describe their experiences living with endometriosis and adenomyosis and define if living with these conditions impacts their outlook on body image.

The decision to use social media to distribute the surveys and advertise the research project was due to the previous success rates of studies similar to this one. such as the My body… tends to betray me sometimes (2022), this study recruited 40 participants who have endometriosis in Australia for their study using the same method of data collection and social advertisement. Along with this, there was the incentive of the modern-day society and digital platforms gaining more members each day, which gave access to a larger population and allowed for a larger integration of diversity.

Within this project, the participants consisted of a total of 304 individuals, 157 of participants suffering from Endometriosis and 58 of whom suffered from Adenomyosis and 89 participants suffering from both conditions. The mean age of participants was 31 years old. Participants were also asked what their ethnicities are, with the majority being white British (appendix 4). Furthermore, participants were also asked at what age they were officially diagnosed or suspected by a professional to have these conditions; the mean age for this was 25 years old.

287 individuals chose to participate via the questionnaire, and 17 individuals chose to participate via Microsoft Teams meetings. It is also important to note here that 299 of the participants identified as female; however, 5 participants identified as transgender/nonbinary.

*PROCEDURE*

Firstly, an online questionnaire was created using the Qualtrics software. The decision to use this software was based on the various distribution lines available within this specific software, along with this the consent forms could be attached to the link and completed before anyone went through the participation events, as well as this the information sheet and debrief information was also connected to the questionnaire so that the participants had access to everything they would need in order to know what the study was about as well as the questionnaire itself.

Once the participant had accessed the participation link, they were then directed to a question which asked them to choose whether they would be participating via the questionnaire or if they would rather participate through a Microsoft teams meeting, once they had chosen their preferred method of participation, they were directed to the correct consent form and information sheet (information sheet in Appendix 1), (consent form in Appendix 2).

Following the consent form they were directed to the questionnaire, which consisted of open-ended questions, there was the option to skip the question if they so wished to. These questions were devised to obtain typed qualitative responses, and these responses were in correlation to their body-image perceptions of self and how others view them as well as their experiences, at the end of the survey there was room for them to add any further information they wished for the researcher to know regarding there endometriosis/adenomyosis (survey questions in Appendix 3). The ethical approval for this study was granted by the University of Staffordshire ethics committee.

*Ethical consideration*

some of the ethical considerations taken into account while conducting this project consisted of data protection, to ensure that the participant’s data remained confidential and safe while conducting the research. After, I held all the data collected on a password-protected computer as well as the file itself that had all the data on it was biometrically protected via a password and fingerprint to open it which ensured that no individual who was not granted access to the information could obtain it. Furthermore, once the study was carried out the University of Staffordshire keeps all information pertaining to the research in a secure digital file and/or in locked cabinets on the campus grounds.

During this write-up of this study, I took into account the ethics surrounding anonymity. To help ensure that the participants remained anonymous throughout this study, I did not use participants’ identifiers or participation numbers and avoided the use of any ways in which the participant could be identified. This was crucial within this project as I used direct quotes from the data collected.

Furthermore, participants’ mental health was taken into account due to the sensitive topic of this project, to ensure that all participants’ mindsets remained the same as when they first started their questionnaires and interviews, multiple organisations regarding mental health were shared in case they wished to use them.

*ANALYSIS*

The method used to analyse the data that was collected was an inductive latent approach using thematic analysis. (Braun & Clarke 2013). This data set was analysed using the six-step inductive method, consisting of, familiarisation of the data set in it entirety once, following this the data set was repeatedly read while identifying key themes and meaning through digital note-taking. The researcher then produced codes throughout this process of data organisation to identify similarities between codes to identify the initial themes, any overlap within themes was then condensed to create names for these themes, along with pinpointing the main focal point of each theme and how each theme was dissimilar or built upon a previous theme as well as how it answered the research question. The final stage of results finished with writing the analysis and deriving quotes from the data set for each theme, all while allowing the data to lead and remaining true to the latent approach adopted throughout this study. The epistemological position within this study was constructivism. This approach was due to the author’s previous knowledge regarding endometriosis and adenomyosis, which was derived from personal experience, and acknowledging that any knowledge is produced by the researcher who is actively co-constructing.

*RESULTS*

After transcription and analysis of the data, four themes were identified: The impact of endometriosis/adenomyosis on physical appearance, the impact on psychological distress caused by endometriosis/adenomyosis, the impacts of other people and the impact of endometriosis and adenomyosis on other factors, these are discussed in detail below.

*THE IMPACT OF ENDOMETRIOSIS/ADENOMYOSIS ON PHYSICAL APPEARANCE*

The women talked about experiencing significant negative body image impacts due to the physical symptoms of the conditions, for example, bloating, physical pain, scarring from multiple laparoscopies, along with hormonal imbalances, leading to these women feeling disconnected from their body in a sense of who they truly are. This was often accompanied by the unease of not being able to control their body image/ sense of appearance, which in turn impacted on their self-esteem and social participation.

“I feel self-conscious a lot because I have had to repeatedly change my style due to bloating”

“Yes, my mental health has been affected due to the hormonal imbalances and the process of getting a diagnosis”.

“Yes, I have a very negative view of my body. I am a little overweight, and exercise makes my pain worse. This has impacted my self-esteem quite badly.”

This is then extensively aggravated by the modern concept of body image and the pressures that are accompanied along with it. A lot of the physical symptoms are invisible to the ones who are not suffering from this condition themselves, as scarring is often hidden by those who have had multiple surgeries, and the bloating aspect of symptoms is often covered by loose-fitting clothing to help disguise the unwanted appearance.

“ I swell so much I have to have bands to extend my trousers thought the day, or I wear maternity clothes”

*“It makes a woman feel less of a woman.”*

However, loose clothing also plays a role in comfortability, a lot of the women who suffer, have to wear loose clothing in case they bloat at some point during the day as wearing something such as skinny jeans can cause significant pain especially when accompanied by bloating. This is evidenced when one participant said;

*“I don’t feel like me at all because I can’t find my style and stick with it due to my ever-changing body. I often feel self-conscious about my scars from the multiple laparoscopies’”*

And a second participant stated;

*“ I feel self-conscious a lot because I have had to repeatedly change my style due to bloating, so everyone views me as this person that just never puts herself together and drags herself out of bed without physically realising I can’t wear tight clothing because it puts me in pain”.*

Both statements show the profound impact the symptoms have on an individual suffering from endometriosis and adenomyosis in regard to physical appearance and body image, highlighting the evident gap in helping these women overcome their body image aspects of the condition.

*THE IMPACT OF PSYCHOLOGICAL DISTRESS CAUSED BY ENDOMETRIOSIS/ ADENOMYOSIS*

This participant reported that endometriosis and adenomyosis cause marked psychological distress in those who suffer from these conditions. The psychological side of these gynaecological conditions often goes unseen by those who do not live with the symptoms. However, the long wait times for diagnosis and even to be listened to. overall causing those who suffer to go substantial amounts of time living with the symptoms and no professional help, which more often than not turns into bad mental health, ranging from anxiety to depression.

Along with impacts on mental health, this caused some to not only suffer mentally but also had an impact on external factors due to the mental health implications they were undergoing. For example, across the 304 participants, 96% of them said that it had affected their work (employment/education) along with their mental health, which in turn affected their income, and for those who were still in school, their grades often suffered, which in some cases lead to them not being able to continue with their education or having to repeat a year, which then set them back progress wise. All of this made their mental health worse than it already was and felt like this hole that they could never escape from.

These impacts from the conditions were made evidently clear by how many participants had stated that they had a bad mental health on and off since they presented with symptoms, with some participants reporting needing medication because of how bad their mental health had become. One participant said:

*“ ever since the age of 14-15 when I started presenting with the symptoms and gaining weight I have suffered tremendously with body image issues. This caused me to stop eating regularly and having an unhealthy relationship with food. I’ve had people constantly commenting on my body since then which has affected how I feel about myself. This had a huge impact on my mental health as I didn’t want to go out anywhere as I thought people would judge me for how my body looks because im not ‘thin’ enough for them. My mental health went downhill to the point where I needed therapy twice in the space of 2 years and I didn’t want to be here. It also really made me struggle with my university course and wasn’t attending lectures and placements enough, which set me back a year and now I have to retake half the year again”.*

From an employment perspective, some of the participants talked about being on the verge of losing their jobs due to the implications of having this condition, which their workplaces could not help in supporting. This is evidenced by a participant who stated;

*“I feel that my co-workers look at me differently. Some days I just can’t be productive, and I just sit in pain, crying. I think that maybe my co-workers think I’m just exaggerating or looking for attention”.*

Another participant expanded on this by saying;

 *“I can’t be a normal 30-year-old barely holding onto my career”.*

*THE IMPACTS OF OTHER PEOPLE*

This theme covers the impact of individuals who are not related or friends with individuals who suffer from these conditions (i.e. strangers), and how the participants felt that people often look at those with endometriosis and adenomyosis negatively and without understanding, for example, the participants reported feeling that people often perceive them as being lazy people, or hypochondriacs. One participant said:

 “I feel people don't understand and may have a negative opinion of me when I'm struggling. Invisible illness a lot of the time”.

Quite a few of the participants also talked about the experience of people mistakenly taking their extreme bloating for a pregnancy. This is shown when one participant mentioned her struggles by saying*; “people have asked me if I'm pregnant when my belly has been extremely bloated.”*

At times the participants reported this leaving them feeling like they have to isolate themselves so that they are not subjected to the negativity from other people as well as from the unwanted questions which lead to a conversation regarding their condition which opens them up to unwanted opinions, all of which further leads the individual into self-seclusion which negatively impacts there mental health and view of their own body Image based on other people’s opinion of what they look like and what they should look like.

*THE IMPACT OF ENDOMETRIOSIS/ADENOMYOSIS ON OTHER FACTORS*

Despite this study being about the body image aspects of living with Endometriosis/Adenomyosis, all participants involved were keen to talk about the impacts of these chronic conditions on other areas of their lives.

The participants reported these conditions as having detrimental impacts on relationships in various forms, they stated that they often lose friendships and significant others (husbands, Fiancées, boyfriends) in their lives, leaving them feeling an overwhelming sense of loneliness, isolation and being a burden as they are excluded from social events.

“it made me not want to be as social. I didn’t want to go out with friends. So, they stopped talking to me.”

“I’m often alone or pushed out of events”.

Furthermore, having these conditions leads to the participants unintentionally placing huge amounts of responsibilities onto their significant other, which in turn leads that individual to feel overwhelmed. This often led into the sexual relationship itself leaving both parties involved feeling alone and unwanted due to the intimate needs not being met, which then leads to the relationship oftentimes breaking down or leaving the woman feeling like a huge problem in the man’s life and trying to convince them that they deserve better and should be with someone else. This is evidenced when a participant said;

 “My partner yes, because no matter what positive reinforcement he is giving, I’m completely self-conscious of how I look, and it has affected us in the bedroom.”

and another stating, “My husband barely sees my body. Even during intimate moments, I want to cover myself, be in darkness, and not let him see my imperfections.”

In addition to the impacts these conditions cause on relationships, the participants were extensively clear about the struggles they have faced with their fertility journeys. In some cases, women have had to have a full hysterectomy to help them with their daily lives due to the severity of the symptoms. This sometimes leads to developed jealousy towards other women who do not have issues with being able to get pregnant, which then causes them to self-loathe, asking the question of why me? Why can’t I carry a baby? Send them spiralling into negative mental health. This is shown when two participants said.

“It's only made me feel envious of people who have normal periods and who have been able to get pregnant naturally”.

 “It is a grief and loss cycle every month, I can’t get pregnant”

 This condition can be brutal, in the fertility aspects, as a lot of people suffering from endometriosis/adenomyosis can’t get pregnant, but it taunts them by giving them the body shape of a pregnant woman, the very thing a lot of them are unable to obtain. This is evidenced when a participant stated;

“Endometriosis has affected my self-image, and continuously teased me with a maternal shape during my walk with infertility”.

Finally, the participants were also keen to speak about their experiences within the healthcare systems and getting diagnosed with endometriosis/adenomyosis. With participants going on to explain the hardships with getting diagnoses taking up to 10 years and during that time being “gaslit” by professionals who would continuously tell them there is nothing wrong “it’s just part of being a woman”, the younger generation are mostly targeted by these comments along with “it’s all in your head” and “you can’t possibly have it your too young”, all of which leads to those with the conditions feelings of being unheard and looked down on.

“Gaslit at every step, diagnosis made it a little easier, but most health care professionals still have this underlying tone in their voice as if I’m lying and it’s not a real condition.”

“I feel a lot of anger towards the NHS who I feel have significantly let me down”.

Along with this, participants across the board stated that over the years of being in and out of Doctors’ offices and meeting with gynaecologists they realised that they know more about the condition than the professionals do, due to the extensive amount of research they had to do before they were taken seriously about their Endometriosis/Adenomyosis. This was consistently made clear with multiple participants stating very similar statements, one of which said;

 “On many occasions I’ve had to explain to them what it is because they simply have no idea and have never heard of it before”.

These women have often felt like the healthcare systems disregarded them for many years, which led them to seek help through community pages and take tips and tricks from others who also suffer from endometriosis and adenomyosis to help reduce the symptoms that they suffer from daily.

*Discussion*

This study found that the body image of these women is not a singular aspect of living with endometriosis and adenomyosis but an underlying incentive for many of the extensions of the larger picture to living a life with these chronic conditions, this is due to the way that body image plays a crucial role in almost every sense of their lives. This is shown throughout each theme found that was identified within this project, for example, within the theme of physical appearance, overall, the participants were concerned with hiding their bloating and scarring from other people. Similarly, within the psychological distress theme, participants were most concerned about the lack of help and understanding towards these conditions, particularly within the workplace and education systems.

Furthermore, in the theme of impacts of other people this study found that the participants were overwhelmed with how other people perceive their bodies and consistently offer unwanted opinions without thinking that they may have a condition that’s not always seen, in combination with this in the theme of the impacts of endometriosis and adenomyosis on other factors, this study found that they often feel a cycle of grief and the condition taunting them with the use of bloating by giving them a maternal shape which leads the individuals into a developed envy towards those who are able to get pregnant naturally.

The findings from this project align closely with existing research that consistently identifies significant physiological and social effects of endometriosis and adenomyosis on body image. **For example, Sayer-Jones and Sherman (2022) found themes of bodily unreliability, the need for concealment, and, in some cases, a gradual development of bodily acceptance. These experiences echo the current project, which also highlights the complex relationship between fluctuating symptoms and self-esteem, as well as the coping strategies women employ to navigate unpredictable bodily changes.**

**Furthermore,** Van Niekerk, Steains & Matthewson (2022) also found that both the physical and emotional aspects are intertwined properties of health-related quality of life. This corroborates the finding of this study, with an emphasis on a lack of body familiarity playing a substantial role in the reasoning as to why these women have negative outlooks on their body image.

On the other hand, one key difference between this project and previous findings of similar studies is that the researcher for this study re-conceptualises body image as a foundational issue for this population, rather than a peripheral issue, like previous studies have, such as *Van Niekerk, L., Steains, E., & Matthewson, M. (2022)* . This is due to the fact that body image issues within these women have presented as the building blocks to much larger aspects and deep-rooted troubles that these women face daily, therefore making the body image concept of these chronic conditions a foundational issue. Whereas in the previous studies, the researchers stated the problem as being peripheral because body image is a side issue of the conditions, which they found was not the building blocks of a greater problem.

This project not only affirms and deepens existing theoretical frameworks about chronic illness, mental health, and body image, but also extends the field by presenting nuanced, qualitative evidence that highlights previously under-explored intersections between symptoms, self-image, society, and systemic experience. It provides a strong foundation and justification for the development of more comprehensive, condition-specific theoretical models and integrated care approaches.

**On the other hand the researcher found that there is a lack of resources and targeted interventions to help these women manage or overcome their body image concerns when living with endometriosis and adenomyosis further recognising the gap in healthcare and educational systems along with public awareness which only reinforces those living with the conditions being misunderstood and feeling like they are not being heard or taken seriously, which was not found or spoken about specifically within the previous studies.**

*STRENGTHS, LIMITATIONS AND FUTURE DIRECTIONS*

One strength of conducting a qualitative study is that the data is based on the participant’s perspectives of their lived experiences with their body image and symptoms, and everyone’s experience is different because of how they personally perceived that experience, even if the experience/symptoms themselves are exactly the same which allows for a deeper insight of what they live and how they are affected by these conditions on a day to day perspective.

Furthermore, adding a researcher who has lived with endometriosis provides a valuable perspective however, it can also cause an unintended bias in the interpretation of results as that researcher may feel more sympathetic to the participants and read between the lines, unintentionally connecting their experience with the participants.

*f*inally, Current research relies heavily on cross-sectional data, making it difficult to understand how body image changes throughout the disease progression and treatment journey, demonstrating the need for longitudinal studies.

In the future, to expand on this study the researcher would suggest using both qualitative analysis as well as quantitative to further the overall findings. Furthermore, the researcher would suggest specifically looking at individuals between the ages of 16 and 25 as they are more susceptible to the modern-day conception of body image and female expectations. (UK parliament, body-image results women and equalities, 2020)

For future implementations, the researcher would suggest that these conditions are explained and looked at within the education systems, primarily in high schools. This would be a huge step forward in the lack of knowledge about these conditions and would help those suffering from symptoms of these conditions to get a diagnosis much earlier. This could be implemented in high schools using the same programs as the sexual education days throughout the years in secondary school, this would be a useful way to spread the word of these conditions as periods are often spoken about alongside the sexual education lessons which allows room to expand on the aspects of periods and endometriosis and adenomyosis particularly, giving the younger generation knowledgeable information such as bloating, scarring, and consistent body image changes being symptoms of the conditions, this would allow for those who do not live with endometriosis or adenomyosis to gain an understanding of how the body image of someone who has this condition is affected and reduce the judgement and comments and being more mindful before saying something in regards to a person’s body, for those who don’t know that there symptoms are not normal would learn about their symptoms and potentially what they may be caused by which would enable them to seek help and support.

Furthermore, more education concerning endometriosis and adenomyosis would benefit healthcare professionals, in doing this it would help minimise the amount of “gaslighting” from professionals. Moreover, many patients are often told that they weigh too much to have the diagnostic laparoscopy done and sent on their way home with no other forms of help. They are told to come back when they are within the weight criteria for the procedure. Instead of sending them on their way, it would be beneficial if they were referred to a dietitian to help them with the process. Along with this, healthcare staff could refer patients to a therapy specifically designed to help those suffering from body image concerns, such as a body dysmorphia counselling clinic. This would benefit the health care systems with lessening the weight times around diagnostic processes for these conditions while patients don’t feel let down and angry at the staff making the entire process less traumatising for those suffering with the conditions while gaining help, they need to have a better outlook on their body image and learn ways to help them cope with the forever changing body image they have.

Body dysmorphia counselling would benefit individuals suffering from endometriosis via the use of cognitive behavioural therapy, helping individuals suffering from these conditions challenge their negative thoughts around physical appearance and find the triggers that initially start the negative view of their body as well as developed coping mechanisms and finally allowing them to gradually face situations that evoke anxiety that surrounds and feeds into the negative perceptions. This would prove to be beneficial to those suffering with negative body perceptions as it would enable them to feel comfortable and more confident in their own body and pave a path for new thought processes around their physical appearance towards themselves as well as others, the anxiousness of how other people perceive them would lessen and in turn the individuals would feel overall better with who they are and what they are going through rather than being stuck in on ongoing negative mental cycle that repeats itself every month on a continuum with all their symptoms. (body dysmorphic disorder, NHS, 2023)

*Reflection*

*My initial interest in endometriosis and adenomyosis came from my own experiences with the condition which led me to want to learn more about the condition in all aspects and help those going through the same thing along with helping to get these conditions recognized and make more people aware in the world due to the conditions affecting 1 in 10 women every day.*

*My own experiences with endometriosis and adenomyosis began when I was 11 years old, it showed in symptoms of debilitating pain and heavy menstruation, I was in and out of doctors offices which never took me seriously and told me I would get used to it, that this was just part of becoming a woman and sent me on my way with different forms of birth control. I believe having this experience aswell as a known presence within the community pages for endometriosis and adenomyosis, this allowed participants to feel more comfortable about opening up and sharing their own experiences in more detail than they would to someone else, knowing that I have a better understanding and more empathy because of my own experiences with endometriosis and adenomyosis.*

*By the time I was 13, my family, thought I was just dramatic and attention seeking often becoming the topic of conversation, they thought I was just trying to get out of going to school so on many occasions I was forced into going which lead to me a lot of the time crawling there and tears streaming down my face, the school thought the same thing as my family and just gave me heat pacts and told me to get on with it and suck it up otherwise I would be placed in isolation and have detention. I would say having this personal experience helped the participants when speaking about workplaces and education systems go into more detail and not feel like they would be judged about their complaints in the places they work or learn. Furthermore, it helped them open up in regards to friends and family along with other relationships due to the comfortability of having someone who listens and understands what they are implying or feeling.*

*Moreover, withing the advertising of this project I placed my recovery photograph from my laparoscopy the picture mostly consisted of the scarring that it leaves which I belive helped the participants be more open and comfortable knowing I was a part of the community group for some time and essentially looked the same as they do, I belive they viewed it as a relief that someone who is also living life the way they are helped them feel safer and finally listened to as someone just like them was the one conducting the study and would represent the population suffering from endometriosis and adenomyosis much more closely and more detailed instead of shying away from some aspects that come with the condition purley because it does not fit into the study the way I wanted it to.*

*Throughout my experiences with these gynecological conditions, I developed an interest and curiosity into the fact that no one seemed to know these conditions even existed and wondered how many more people out there where going through the same thing as me and how they were affected by it.*

*From these experiences I hit a bit of a low point mentally and found the endometriosis and adenomyosis social media groups, where these people helped me tremendously, just knowing I wasn’t alone and could seek advice and help lifted a huge weight off of my shoulders, through which lead to developing close relationships with a lot of the women in these groups.*

My personal experiences with these conditions and having close relationships with some of these people may have led me to interpret data differently than someone else would have. This could have led to me reading between the lines via the chosen language and being more sympathetic and understanding towards the participants and their stories and experiences with these conditions. On the other hand, I believe that this limitation was also a positive point of this research study because it allowed the participants to feel more comfortable talking to me and sharing their experiences with the condition, knowing that I would not be like most people they have encountered and “gaslit them about the conditions’. I believe that expressing my own experience and hardships with endometriosis and adenomyosis within the advertising of this study and having a known presence in the groups before this study enabled the participant’s comfortability in participating in the study themselves and being a lot more open, which in turn allowed for much more detailed data on the area.

REFERENCESE

Sayer-Jones, K., Sherman, K.A. (2023) “My body…tends to betray me sometimes”: a Qualitative Analysis of Affective and Perceptual Body Image in Individuals Living with Endometriosis.*Int.J. Behav. Med.* 30, 543–554 (2023). <https://doi.org/10.1007/s12529-022-10118-1>

Clarke, V. & Braun, V. (2013) Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning.The Psychologist, 26(2), 120-123

Mayoclinic.org (2023) Adenomyosis – symptoms & causes – mayo clinic. Retrieved October 3rd from

[https://www.mayoclinic.org/diseases-conditions/adenomyosis/symptoms-causes/syc-20369138#](https://www.mayoclinic.org/diseases-conditions/adenomyosis/symptoms-causes/syc-20369138)

DeCherney AH, et al.,(2020) eds. Benign disorders of the uterine corpus. In: Current Diagnosis & Treatment: Obstetrics & Gynecology. 12th ed. McGraw-Hill Education; 2019. https://accessmedicine.mhmedical.com. Accessed March 23,

Chapron C, et al. Diagnosing adenomyosis: An integrated clinical and imaging approach. Human Reproduction Update. 2020; doi:10.1093/humupd/dmz049.

Soave I, et al. Treatment options and reproductive outcome for adenomyosis-associated infertility. Current Medical Research and Opinion. 2017; doi:10.1080.03007995.2017.1393404.

Smith RP, et al. Dysmenorrhea in adult women: Treatment. https://www.uptodate.com/contents/search. Accessed March 23, 2020.

Pontis A, et al. Adenomyosis: A systematic review of medical treatment. Gynaecological Endocrinology. 2016; doi:10.1080/09513590.2016.1197200.

Endometriosis.org. (2011) about endometriosis. Retrieved October/2, 2024 from

<https://endometriosis.org/endometriosis/>

*Marjorie Hetch 2021, endometriosis vs. Adenomyosis: similarities and differences*

[*https://www.healthline.com/health/womens-health/adenomyosis-vs-endometriosis*](https://www.healthline.com/health/womens-health/adenomyosis-vs-endometriosis)

Gonzales, M., de Matos, L.A., da Costa Gonçalves, M.O. *et al.* Patients with adenomyosis are more likely to have deep endometriosis. *Gynecol Surg* 9, 259–264 (2012). https://doi.org/10.1007/s10397-012-0746-4

[*https://gynecolsurg.springeropen.com/articles/10.1007/s10397-012-0746-4*](https://gynecolsurg.springeropen.com/articles/10.1007/s10397-012-0746-4)

Giuseppe Benagiano, Ivo Brosens, Marwan Habiba, Structural and molecular features of the endomyometrium in endometriosis and adenomyosis, Human Reproduction Update, Volume 20, Issue 3, May/June 2014, Pages 386–402, <https://doi.org/10.1093/humupd/dmt052>

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*The endometriosis foundation 2025, internet source* [*https://www.theendometriosisfoundation.org/*](https://www.theendometriosisfoundation.org/)

*Van Niekerk, L., Steains, E., & Matthewson, M. (2022). Correlates of health-related quality of life: The influence of endometriosis, body image and psychological wellbeing. Journal of Psychosomatic Research, 161, 110993.* [*https://doi.org/10.1016/j.jpsychores.2022.110993*](https://doi.org/10.1016/j.jpsychores.2022.110993)

*Volker, C., & Mills, J. (2022). Endometriosis and body image: Comparing people with and without endometriosis and exploring the relationship with pelvic pain. Body Image, 43, 518-522.* [*https://doi.org/10.1016/j.bodyim.2022.10.014*](https://doi.org/10.1016/j.bodyim.2022.10.014)

*Pehlivan, M. J., Sherman, K. A., Wuthrich, V., Horn, M., Basson, M., & Duckworth, T. (2022). Body image and depression in endometriosis: Examining self-esteem and rumination as mediators. Body Image, 43, 463-473.* [*https://doi.org/10.1016/j.bodyim.2022.10.012*](https://doi.org/10.1016/j.bodyim.2022.10.012)

(body dysmorphic disorder, NHS, 2023)

<https://www.nhs.uk/mental-health/conditions/body-dysmorphia>

*uk parliament, Body Image Survey results-women and equalities-house of commons* [*https://publications.parliament.uk/pa/cm5801/cmselect/cmwomeq/805/80502.htm*](https://publications.parliament.uk/pa/cm5801/cmselect/cmwomeq/805/80502.htm)

*APPENDIX –*

1. ***INFORMATION SHEET : questionnaire***

INFORMATION SHEET

Experiences of Endometriosis And Adenomyosis: A Thematic Analysis:

Rebecca Machin:                                              M014285L@student.staffs.ac.uk
Alison Owen:                                                              Alison.Owen@staffs.ac.uk

INVITATION PARAGRAPH

 I would like to invite you to participate in this research project which forms part of my undergraduate psychology degree at the University of Staffordshire. The research will be conducted by Rebecca Machin. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve.

Please take time to read the following information carefully.

What is the purpose of the study?

I am conducting a study looking at how living with endometriosis and adenomyosis diagnosed or suspected has impacted your body image both physically and mentally, for example does you physical image change often or at all, do you have a positive mental view of your own physical image or is it more of a negative point of view. If its more on the negative side does this impact you mentality. How do you believe your partner if you have one or other people view your body image, And so on. the questions through the study may look similar to these ones.
This study is set on investigating the real experiences that surround body image and the impacts it can have on ones mental health that women with these gynaecological conditions face on a daily basis, along with giving them their voice on the subject. Who has given approval for this study? Approval for this study has been granted by University of Staffordshire, Department of Psychology, Ethics Committee.

 TAKING PART

Why have I been invited to take part?

I am recruiting participants over 18 years of age to take part in this study.
Participants should also meet the following criteria: have either a diagnosis for adenomyosis or endometriosis or have a suspected diagnosis either by a doctor or a self diagnosis with confidence for at least 3 years – this criteria is due to the long waiting list times to gain a diagnosis for these conditions therefore, self diagnoses will be accepted if you are upmost confident that these are what’s causing you pain and symptoms and nothing else has been proven to be the case. Both private and NHS will be accepted.

What will happen if I take part?

I am asking you to take part in a study that will take participants approximately 5 minutes to complete. This will involve the participants being asked to answer a range of questions regarding their diagnosis, about their physical body health and how these things can have an impact on mental state of mind. The participants do not have to answer all the questions they can refuse to answer any that they don’t feel comfortable with sharing, the participants will also be given the option to stop the questionnaire at any time.

 The study/experiment will take place online this will be carried out from the comfortability of your own home or a place you feel comfortable, this is due to the questionnaire being online so participants get the choice of when and where to complete the questionnaire.

 Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please feel free to ask any questions that will help you decide about taking part. If you decide to take part, we will ask you to sign a consent form. Incentives As a UG psychology student there are no incentives for taking part in the study.

What are the possible risks of taking part?

There may be some small risks to taking part, these could include discomfort or distress from sensitive topics within the subject area.

  What if I am upset by anything during the course of the study?

If this happens, you might like to take a break, or if you prefer, you can decide to end your participation and withdraw from the study at that point. If you decide to withdraw, I will provide you with a copy of the debriefing sheet, which contains information about sources of support you can access if there is anything you wish to talk about in confidence.

What are the possible benefits of taking part?

there are no direct benefits to you as a participant. However, the research may help us to better understand the experiences these women face every day with their body image and mental health within the modern society as times change. The researcher may also identify ways in which could improve these women’s treatment such as findings that positive body image therapy and various other cognitive therapies may be beneficial to those suffering.

What if I change my mind about taking part?

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You can also withdraw your data from the study after you have finished participating, up until 2 weeks after your participation has been completed, after which withdrawal of your data will no longer be possible as the data will already have been processed. To withdraw from the study, please email the researcher with the unique code you will have been given If you choose to withdraw from the study, we will not retain any information you have provided us.

  What if I don’t want to answer any particular questions?

If you do not wish to answer any of the questions that I ask you on the questionnaire you will be able to skip the question using the next question button at the bottom of your screen, you will be moved to the next question without having answered the previous question.

What if I don’t want you to include certain things I’ve said in the research?

 If during the questionnaire you say something which you decide you do not want me to include in my study, then please email myself with which parts of your participation you would like omitted from the analysis or the complete report.

DATA HANDLING AND CONFIDENTIALITY

 Will the information I give you be kept confidential?

 The information obtained will be treated with the strictest confidence throughout the study and the data will be stored safely in a secure location to which only the researcher has access. Your data will be processed in accordance with the data protection law and will comply with the General Data Protection Regulation 2018 (GDPR). Data Protection Statement The data controller for this project will be University of Staffordshire. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the data protection law is a ‘task in the public interest’ You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

  Who will have access to the recording /transcript of the recording?

 The researcher, academic staff from the Psychology department, and possibly an external examiner will have access to the transcribed questionnaires. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Staffordshire Data Protection Officer. If you wish to lodge a complaint with the Information Commissioner’s Office, please visit www.ico.org.uk

Who will see the finished report?

The final report will be seen by the researcher’s supervisor and a second marker from the Psychology department, and possibly by an external examiner. In addition, the completed report may also be made available to future University of Staffordshire students for teaching/reference purposes.

What will happen to my interview recording/transcript?

 questionnaire transcript will be destroyed after the transcription process. Transcript data will be kept in secure storage (to which only the researcher has access) for ten years, according to departmental policy, and it will be destroyed after that.

What will happen to the results of the study?

The results of the study will be disseminated in the final written report and in a student conference presentation. Sometimes there is a chance that results might be included in an article that is published in a peer-reviewed journal. If the research is written up for academic journal publication your anonymised transcript may be stored permanently in an online research data repository.

  FURTHER QUESTIONS

 Is there anyone I can talk to about the study before I take part?

 If you wish to talk to someone else about my study before taking part, then please feel free to contact my project supervisor Contact details located on the top of this form.

What if I have further questions, or if something goes wrong?

 If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the University of Staffordshire Ethics Committee for further advice and information: Ethics Committee Research, Innovation and Impact Services University of Staffordshire Cadman Building College Road Stoke-on-Trent ST4 2DE ethics@staffs.ac.uk

I know a friend who may be interested; can they participate in your study?

Yes, as long as your friend meets the criteria mentioned above. Your friend should contact me directly to discuss the study and make arrangements to take part. My contact details are given at the top of the page along with on the consent form.

If you have any further questions, please do not hesitate to contact me/ feel free to ask any questions . Thank you for your time.

Thank you for reading this information sheet and for considering taking part in this research.

***1a) INTERVIEW INFORMATION SHEET:***

INFORMATION SHEET
Experiences of Endometriosis And Adenomyosis: A Thematic Analysis:

Rebecca Machin:                                                    M014285L@student.staffs.ac.uk Alison Owen:                                                                   Alison.Owen@staffs.ac.uk

INVITATION PARAGRAPH:

 I would like to invite you to participate in this research project which forms part of my undergraduate psychology degree at the University of Staffordshire. The research will be conducted by Rebecca Machin. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve.

 Please take time to read the following information carefully.

 What is the purpose of the study?

 I am conducting a study looking at how living with endometriosis and adenomyosis diagnosed or suspected has impacted your body image both physically and mentally, for example does you physical image change often or at all, do you have a positive mental view of your own physical image or is it more of a negative point of view. If its more on the negative side does this impact you mentality. How do you believe your partner if you have one or other people view your body image, And so on. the questions through the study may look similar to these ones. This study is set on investigating the real experiences that surround body image and the impacts it can have on ones mental health that women with these gynaecological conditions face on a daily basis, along with giving them their voice on the subject.

 Who has given approval for this study?

Approval for this study has been granted by University of Staffordshire, Department of Psychology, Ethics Committee.

 TAKING PART

 Why have I been invited to take part?

 I am recruiting participants over 18 years of age to take part in this study. Participants should also meet the following criteria: have either a diagnosis for adenomyosis or endometriosis or have a suspected diagnosis either by a doctor or a self-diagnosis with confidence for at least 3 years – this criteria is due to the long waiting list times to gain a diagnosis for these conditions therefore, self-diagnoses will be accepted if you are upmost confident that these are what’s causing you pain and symptoms and nothing else has been proven to be the case. Both private and NHS will be accepted.

 What will happen if I take part?

 I am asking you to take part in a study that will take participants approximately 45 minutes to complete. This will involve the participants being asked to answer a range of questions regarding their diagnosis, about their physical body health and how these things can have an impact on mental state of mind. The participants do not have to answer all the questions they can refuse to answer any that they don’t feel comfortable with sharing, the participants will also be given the option to stop the interview at any time. The study/experiment will take place online via Microsoft teams this will be carried out from the comfortability of your own home or a place you feel comfortable, this is due to the interview being online so participants get the choice where to complete the interview.

 Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please feel free to ask any questions that will help you decide about taking part. If you decide to take part, we will ask you to sign a consent form. Incentives As a UG psychology student there are no incentives for taking part in the study.

 What are the possible risks of taking part?

 There may be some small risks to taking part, these could include discomfort or distress from sensitive topics within the subject area.

 What if I am upset by anything during the course of the study?

If this happens, you might like to take a break, or if you prefer, you can decide to end your participation and withdraw from the study at that point. If you decide to withdraw, I will provide you with a copy of the debriefing sheet, which contains information about sources of support you can access if there is anything you wish to talk about in confidence.

 What are the possible benefits of taking part?

 there are no direct benefits to you as a participant. However, the research may help us to better understand the experiences these women face every day with their body image and mental health within the modern society as times change. The researcher may also identify ways in which could improve these women’s treatment such as findings that positive body image therapy and various other cognitive therapies may be beneficial to those suffering.

 What if I change my mind about taking part?

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You can also withdraw your data from the study after you have finished participating, up until 2 weeks after your participation has been completed, after which withdrawal of your data will no longer be possible as the data will already have been processed. To withdraw from the study, please email the researcher with the unique code you will have been given If you choose to withdraw from the study, we will not retain any information you have provided us.

 What if I don’t want to answer any particular questions?

 If you do not wish to answer any of the questions that I ask you during the interview you will be able to skip the question by simply saying pass or next question please, and I will instantly offer for you to take a break or if you decide you do not need a brake I will move to the next question.

 What if I don’t want you to include certain things I’ve said in the research?

If during the interview you say something which you decide you do not want me to include in my study, then please email myself with which parts of your participation you would like omitted from the analysis or the complete report.

 DATA HANDLING AND CONFIDENTIALITY

 Will the information I give you be kept confidential?

The information obtained will be treated with the strictest confidence throughout the study and the data will be stored safely in a secure location to which only the researcher has access. Your data will be processed in accordance with the data protection law and will comply with the General Data Protection Regulation 2018 (GDPR). Data Protection Statement The data controller for this project will be University of Staffordshire. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the data protection law is a ‘task in the public interest’ You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

 Who will have access to the recording /transcript of the recording?

 The researcher, academic staff from the Psychology department, and possibly an external examiner will have access to the transcribed interviews. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Staffordshire Data Protection Officer. If you wish to lodge a complaint with the Information Commissioner’s Office, please visit www.ico.org.uk

 Who will see the finished report?

 The final report will be seen by the researcher’s supervisor and a second marker from the Psychology department, and possibly by an external examiner. In addition, the completed report may also be made available to future University of Staffordshire students for teaching/reference purposes. What will happen to my interview recording/transcript? Interview transcripts will be destroyed after the transcription process. Transcript data will be kept in secure storage (to which only the researcher has access) for ten years, according to departmental policy, and it will be destroyed after that. What will happen to the results of the study? The results of the study will be disseminated in the final written report and in a student conference presentation. Sometimes, there is a chance that results might be included in an article that is published in a peer-reviewed journal. If the research is written up for academic journal publication, your anonymised transcript may be stored permanently in an online research data repository.

 FURTHER QUESTIONS

 Is there anyone I can talk to about the study before I take part?

If you wish to talk to someone else about my study before taking part, then please feel free to contact my project supervisor Contact details located on the top of this form. What if I have further questions, or if something goes wrong? If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the University of Staffordshire Ethics Committee for further advice and information: Ethics Committee Research, Innovation and Impact Services University of Staffordshire Cadman Building College Road Stoke-on-Trent ST4 2DE ethics@staffs.ac.uk

 I know a friend who may be interested; can they participate in your study?

 Yes, as long as your friend meets the criteria mentioned above. Your friend should contact me directly to discuss the study and make arrangements to take part. My contact details are given at the top of the page along with on the consent form. If you have any further questions, please do not hesitate to contact me/ feel free to ask any questions . Thank you for your time.

 Thank you for reading this information sheet and for considering taking part in this research.

1. ***CONSENT FORM:***
2. ***Interview Consent form:***

I am over the age of 18 years of age, and I voluntarily agree to participate in a research project conducted by Rebecca Machin, an Undergraduate psychology student at the University of Staffordshire.

* Yes
* NO

I have read the information sheet and understand that this research is being conducted as part of a BSc Psychology undergraduate Degree.

* *YES*
* *NO*

I understand that I am being asked to participate in an online interview lasting approximately 45 minutes and respond to a series of open questions about endometriosis and adenomyosis in accordance with my body image both physically and mentally in the modern society.

* *YES*
* *NO*

I understand that I may withdraw from participating without penalty if I so wish and my data will be destroyed. I have been informed that withdrawal after 2 weeks of completing my interview will not be possible.

* YES
* NO

I understand I will be fully protected in accordance with the Data Protection Act of 2018, and in compliance with the British Psychological Society ethical guidelines, and that my data will be kept confidential and anonymous until they are securely destroyed.

* YES
* NO

I understand that if I so wish I may have a copy of the transcribed interview And to gain this I have to directly ask the researcher for this via email using my unique identifier.

* YES
* NO

I understand that my name and any personal details will be anonymised in any report based on this study. I agree that any of the data I provide may be used in the researcher’s report and possibly used for publication in academic journals.

* YES
* NO

I understand that in the case that a report is published based on this study, the fully anonymised data may be made available for the use of other researchers for an indefinite period of time and if the research is written up for academic journal publication my anonymised data may be stored permanently in an online research data repository. Otherwise, they will be kept until ten years after the article has been published, and then destroyed.

I am willing for the finished report to be used for teaching purposes at University of Staffordshire. Please note that is possible to consent and participate in the research even if you do not agree to this.

* YES
* NO

 Unique Identifier.

Please write a unique identifier, in the textbox below please put your initials with condition and a significant number to so that in the event of a withdrawal we can easily identify and remove your data collected from the study etc. I have provided some examples of a unique identifier in the box below :

RMENDO11
RMADENO23
RMBOTH24

DO you agree to willingly participate in this study?

* YES
* NO

If you have any further questions about this study, please contact the researcher, Rebecca Machin at M014285L@student.staffs.ac.uk or the Project Supervisor, Alison Owen at Alison.Owen@staffs.ac.uk

***2B) QUESTIONNAIRE CONSNT FORM:***

I am over the age of 18 years of age, and I voluntarily agree to participate in a research project conducted by Rebecca Machin, an Undergraduate psychology student at the University of Staffordshire.

* YES
* NO

I have read the information sheet and understand that this research is being conducted as part of a BSc Psychology undergraduate Degree.

* YES
* NO

I understand that I am being asked to participate in an online questionnaire lasting approximately 5 minutes and responding to a series of open questions about Endometriosis and Adenomyosis in accordance with my body image both physically and mentally in the modern society.

* *YES*
* *NO*

I understand that I may withdraw from participating without penalty if I so wish and my data will be destroyed. I have been informed that withdrawal after 2 weeks of submitting my questionnaire will no longer be possible.

* YES
* NO

I understand I will be fully protected in accordance with the Data Protection Act of 2018, and in compliance with the British Psychological Society ethical guidelines, and that my data will be kept confidential and anonymous until they are securely destroyed.

* YES
* NO

I understand that if I so wish I may have a copy of the questionnaire and or/transcript. And to gain this I have to directly ask the researcher for this via email.

* YES
* NO

I understand that my name and any personal details will be anonymised in any report based on this study. I agree that any of the data I provide may be used in the researcher’s report and possibly used for publication in academic journals.

* YES
* NO

I understand that in the case that a report is published based on this study, the fully anonymised data may be made available for the use of other researchers for an indefinite period of time and if the research is written up for academic journal publication my anonymised data may be stored permanently in an online research data repository. Otherwise, they will be kept until ten years after the article has been published, and then destroyed.

* YES
* NO

I am willing for the finished report to be used for teaching purposes at University of Staffordshire. Please note that is possible to consent and participate in the research even if you do not agree to this.

* *YES*
* *NO*

Unique Identifier. Please write a unique identifier, in the textbox below please put your initials with condition and a significant number to so that in the event of a withdrawal we can easily identify and remove your data collected from the study etc. I have provided some examples of a unique identifier in the box below:

RMENDO11
RMADENO23
RMBOTH24

do you agree to willingly participate in this study?

* *YES*
* *NO*

If you have any further questions about this study, please contact the researcher, Rebecca Machin at M014285L@student.staffs.ac.uk  or the Project Supervisor, Alison Owen at Alison.Owen@staffs.ac.uk

1. ***SURVEY QUESTIONS:***

Are you 18 or above?

* *YES*
* *No*

What is your current age?

What is your ethnicity?

What gender do you identify as?

Are you diagnosed or suspected of having Endometriosis or Adenomyosis?

At what age were you diagnosed or suspected of having one of these chronic conditions?

Do you feel like Endometriosis or Adenomyosis has impacted you psychologically in any way?

How have you been treated within the health care systems, before and during your diagnosis, along with after?

Does your condition have an impact on your body image physically or mentally in any way?

Do you think the body image aspect has impacted your relationships with partners, family or friends?

Has your condition ever made you feel different to other people?

Have you ever taken any steps to help eliminate symptoms of your condition? i.e. holistic treatment or normal treatments provided by the health care systems, and why?

What does "body image" mean to you?

Is there anything else you would like to add?

***4) Participants' nationality key***

The ethnicity key of the participants involved in this study is present in this way due to everyone using various names to each ethnicity despite the definition being the same, and it was important to use their descriptions as it can be a very sensitive subject to some people.

|  |  |
| --- | --- |
| ethnicity | Number of people |
| White British  | 97 |
| White | 89 |
| English | 3 |
| Scottish | 5 |
| Caucasian  | 33 |
| White Caucasian | 6 |
| Australian  | 9 |
| European  | 1 |
| NZ European  | 3 |
| Black  | 3 |
| Mixed | 14 |
| Anishinaabe | 1 |
| Other | 13 |
| Latin/o | 2 |
| Portuguese | 1 |
| Italian | 3 |
| Prefer not to say  | 37 |