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The Impact of Endometriosis-Associated Pelvic Pain on the Social and Academic Wellbeing of Women Enrolled in University

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THE IMPACT OF ENDOMETRIOSIS-ASSOCIATED PELVIC PAIN ON THE
SOCIAL AND ACADEMIC WELLBEING OF WOMEN ENROLLED IN
UNIVERSITY

by

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A thesis submitted in partial fulfillment of the requirements
for the Honors Undergraduate Thesis Program in Health Sciences
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Thesis Co-Chairs: Dr. Jeanette Garcia and Dr. Danielle Webster

ABSTRACT

Background: Endometriosis, a medical condition in which endometrial tissue lining grows outside of the uterus, affects approximately 10-15 percent of women of reproductive age. While research has shown that symptoms of endometriosis negatively affect quality of life in women, few studies have examined the impact of this condition specifically in college students who may be overwhelmed with the stress of school, living independently, and managing the symptoms of their endometriosis. **Purpose:** To examine the impact of endometriosis on academic and psychosocial factors in university students. **Methods:** Four college females completed the Pain Self-Efficacy Questionnaire (PSEQ), a 10-item survey used to measure participants' confidence in performing a range of activities despite their pain, and a modified version of the Endometriosis Impact Questionnaire (EIQ), a 21-item survey that examines the physical, psychological, and social impact of endometriosis. Participants also completed semi-structured Zoom interviews that focused on how their symptoms affected their academic performance, physical health, social interactions, and psychological well-being. All interviews were audio-recorded and transcribed verbatim. Content analysis was used to quantify and extract relevant themes. **Results:** Themes were identified for academic impact (negative impact, lack of awareness of academic accommodations, improvement in study habits), physical impact (pain, nausea, fatigue), social impact (avoidance of social events, impact on romantic relationships, importance of social support), and psychological impact (anxiety over symptoms, negative impact on self-esteem, increased compassion for others). **Conclusion:** Although endometriosis negatively impacted participants, positive impacts, such as improved study habits and greater feelings of compassion for others with chronic conditions, were reported as well. Future studies should further examine the impact of endometriosis in larger samples of college students.

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INTRODUCTION

Endometriosis is a medical condition in which endometrial tissue lining grows outside of the uterus. Approximately 10-15 percent of women of reproductive age and 70 percent of women with chronic pelvic pain have endometriosis (Parasar et al., 2017). Current treatments for endometriosis range from conservative measures such as taking non-steroidal anti-inflammatory drugs (NSAIDS) to more invasive treatments such as surgical removal of endometrial implants. Some women choose to undergo a complete hysterectomy (removal of the uterus) and bilateral oophorectomy (removal of the ovaries), but unfortunately, even this major surgery allows for a 5-15 percent chance of the endometriosis returning (Parasar et al., 2017).

Many women with endometriosis experience uncomfortable symptoms including dysmenorrhea (pain during menstruation), dyspareunia (pain during sexual intercourse), and dyschezia (painful and difficult defecation) (Della Corte et al., 2020). A study in California (Shliep et al., 2017) assessed the pelvic pain in women with no previous endometriosis diagnosis. Once pain levels were reported, women underwent a diagnostic surgery (laparoscopy or laparotomy) to determine if they had endometriosis. Women diagnosed with endometriosis had reported the highest level of cyclic or chronic pain along with higher levels of dyspareunia, dysmenorrhea, and dyschezia compared to women who were diagnosed with another uterine pathology or had a normal pelvis. Studies examining the relationship between endometriosis and mental health have shown that women with endometriosis are at a higher risk for experiencing psychiatric conditions. A retrospective matched-cohort study in 2021 examining the relationship between depression, anxiety, and self-directed violence in women with endometriosis found that women with endometriosis had an adjusted hazard ratio of 1.38 for anxiety, 1.48 for depression, and 2.03 for self-directed violence (95% CI) (Estes et al., 2021). A systematic review and meta-

analysis by Wang et al. (2021) studying if endometriosis disturbs mental health and quality of life found that endometriosis can decrease both the mental and physical health-related quality of life of patients.

Endometriosis care should address the social, emotional, and sexual issues caused by the condition in order to further improve comfort and quality of life for women with endometriosis (Bien et al., 2020). Thus, it is important to research the ways in which endometriosis impacts quality of life so that specific interventions can be developed to decrease the negative impact of the condition. While some research on the link between endometriosis and quality of life in general has been conducted, there is little to no research on how endometriosis affects the wellbeing of women in university specifically. Because such a large number of young adult women are enrolled in a university, it is important to gain an understanding of how the condition can impact their lives. Broadening the knowledge and research on how endometriosis affects quality of life can lead to better interventions and accommodations that may lessen the negative impact of the condition. This qualitative study explored themes related to the effects of endometriosis-associated pelvic pain on psychosocial factors in female college students diagnosed with endometriosis. It was hypothesized that female students who experienced endometriosis-associated pelvic pain would have difficulties related to their academic success, social life, and psychological health that would negatively impact their overall quality of life.

REVIEW OF THE LITEARTURE

Introduction

Endometriosis, a medical condition that affects approximately 10-15 percent of women of reproductive age, is the presence of functional endometrial glands and stroma in locations outside of the uterine cavity (Della Corte et al., 2020). Women with endometriosis often experience painful symptoms such as dysmenorrhea, dyspareunia, and dyschezia (Della Corte et al., 2020). A review of current literature has shown that these symptoms frequently interfere with the overall quality of life of women who experience them; however, it is clear that more research must be conducted in order to better understand the specific ways in which endometriosis impacts quality of life. The following sections of this literature review will examine: 1) An overview of endometriosis including theorized causes and current diagnostic processes; 2) An overview of the types of pain associated with endometriosis; 3) An overview of current interventions to improve endometriosis; 4) An overview of quality of life and factors that can influence it; and 5) The association between endometriosis and quality of life.

Endometriosis

Endometriosis is a serious, often painful condition affecting a significant portion of women of reproductive age. The exact cause of endometriosis is not currently known, but there are a few theories that may provide insight as to why the condition occurs. The leading theory is known as retrograde menstruation, which has been shown to occur in 76-90 percent of women with endometriosis that underwent a peritoneal dialysis and laparoscopy (Berkkanoglu et al., 2003). In retrograde menstruation, blood flows backward into the pelvis instead of leaving the body through the vagina. This may allow endometrial stromal cells to create lesions by

implanting and proliferating outside of the uterus (Koninckx et al., 2021). Proliferation of these endometrial cells is associated with angiogenesis, inflammation, immune reactions, and bleeding in the lesions, leading to fibrosis (Koninckx et al., 2021). Since evidence of retrograde menstruation is not seen in all women with endometriosis, it is suspected that there are multiple factors and causes that contribute to the development of the condition (Koninckx et al., 2021).

Receiving a diagnosis of endometriosis is often a long and arduous process involving multiple steps and procedures. Non-surgical approaches to diagnosing endometriosis involve analysis of symptoms, ultrasonography and magnetic resonance imaging to visualize endometriosis cysts and deep infiltrating endometriosis, and blood testing for serum markers (Ferrero et al., 2019). Unfortunately, while these tests can help rule out other potential diagnoses and indicate that a clinician should suspect endometriosis, a final diagnosis can only be made through laparoscopic examination of endometrial tissue growth outside of the uterus (Ferrero et al., 2019). Because of the lack of reliable, noninvasive procedures to detect the condition, endometriosis diagnosis is often delayed (Pasar et al., 2017). In fact, there is approximately a 7-year time interval between the first symptoms and a medical diagnosis of endometriosis (Alkatout et al., 2016). Because of the delay between the onset of symptoms and receiving a diagnosis, women often live for years without knowing the cause of their pain.

Endometriosis Symptoms

Pain is one of the most prominent symptoms of endometriosis. One major pain symptom associated with endometriosis is dysmenorrhea, or pain during the menstrual cycle (Ferries-Rowe et al., 2020). Dysmenorrhea is one of the most common causes of pelvic pain in women and can be categorized as primary (pain during the menstrual cycle without an identifiable cause)

or secondary (pain during the menstrual cycle due to an underlying cause) (Ferries-Rowe et al., 2020). Endometriosis is the most common cause of secondary dysmenorrhea (Osayande et al., 2014). A 2021 study examining the relationship between menstrual pain severity, menstrual symptoms, widespread pain, and functional pain disability in women in Australia found that women with endometriosis had significantly higher menstrual pain and symptom severity than women without endometriosis (Evans et al., 2021). Another type of pain frequently associated with endometriosis is dyspareunia, or pain during sexual intercourse (Facchin et al., 2017). Dyspareunia can cause significant disruptions in women's intimate relationships. A systematic review of the experience of dyspareunia in women with endometriosis found that dyspareunia impairs women's psychological health, "especially in terms of poor self-esteem and sense of femininity" (Facchin et al., 2017). Dyspareunia can cause women to develop a variety of coping mechanisms, from enduring the pain to avoiding intercourse altogether (Facchin et al., 2017).

Infertility or difficulty conceiving a child is another common symptom that women with endometriosis experience (de Ziegler et al., 2019). Approximately 40-50 percent of women diagnosed with infertility also have a diagnosis of endometriosis (de Ziegler et al., 2019). It is likely that inflammation, lesions in the ovaries, and endometrial receptivity altered by endometriosis contribute to problems with fertility in women (de Ziegler et al., 2019). Because of this, many women with endometriosis choose to undergo surgery or use assisted reproductive technology (ART) to become pregnant. Surgery has been shown to improve the chance of achieving natural conception; however, it is recommended that women wait 12-18 months to conceive after surgery and is not guaranteed to allow for natural conception (Ziegler et al., 2019). Thus, it is recommended that women over the age of 35 use ART as a first approach to becoming pregnant (Ziegler et al., 2019).

Current Medical and Surgical Interventions for Endometriosis

Current interventions for endometriosis range from more conservative measures such as medications like birth control or NSAIDs to more invasive measures such as surgical procedures to remove endometrial implants or even the entire uterus (Pasar et al., 2017). Unfortunately, medical therapy only provides symptomatic treatment and does not lead to a reduction of the endometriosis itself (Vercellini et al., 2014). When the medication is discontinued, symptoms will return. Additionally, medical interventions often cause uncomfortable or intolerable side effects such as erratic bleeding, weight gain, decreased libido, and headaches (Berlanda et al., 2017). Hormonal treatment is ineffective or not tolerated in approximately 30 percent of women with endometriosis (Berlanda et al., 2017). Because of the discomfort or ineffectiveness of medical therapy, many women opt for surgical procedures to relieve their symptoms. However, even invasive surgical procedures cannot guarantee relief of the condition, as they are associated with a high rate of recurrence. Up to 50 percent of women who receive surgical interventions experience a recurrence of pain at 5 years, causing the need for a repeat intervention (Singh et al., 2017).

Quality of Life and Wellbeing

Quality of life (QoL) and wellbeing are concepts that have many contributing factors and have only been vaguely defined. The World Health Organization defines QoL as an “individual’s perception of life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1995). The Center for Disease Control and Prevention states that well-being can be described as “judging life positively

and feeling good” (CDC). Though these concepts are not exactly the same, they intersect in many ways and are often used interchangeably.

There are multiple factors that contribute to an individual’s wellbeing and quality of life. The World Health Organization Quality of Life (WHOQOL), an assessment that can be used to examine quality of life, includes four domains: physical health, psychological health, social relationships, and environment. Questions from the WHOQOL ask about an individual’s satisfaction with their personal relationships, sex life, support from friends, ability to concentrate, financial situation, opportunities for leisure activities, and much more. Endometriosis has the ability to impact overall quality of life by affecting individual factors that contribute to quality of life and wellbeing.

Endometriosis and Quality of Life

Endometriosis can cause adverse psychological effects such as depression and anxiety, disrupt social and sexual relationships, and create economic burden due to decreased productivity at work and increased use of health resources (Della Corte et al., 2020). Current literature demonstrates that endometriosis is associated with an overall decreased quality of life. A systematic review examining the relationship between endometriosis and psychiatric disturbances showed that 14 out of 18 examined studies had found an association between endometriosis and poor psychological health (Pope et al., 2015). One study examining endometriosis and quality of life using a 30-item questionnaire called the Endometriosis Health Profile (EHP-30) found that 82 percent of participants reported being moderately severely anxious or depressed, and that participants gave the highest (worst) score to the domain of

control (Rush et al., 2017). Overall, this study found a negative association between endometriosis and subjective wellbeing (Rush et al., 2017).

The pain that women experience due to their endometriosis has been shown to have a significant correlation with decreased quality of life. A study by Facchin et al. (2015) comparing the impact of pelvic pain on quality of life and mental health for women with endometriosis demonstrated that women with symptomatic endometriosis had poorer quality of life and mental health when compared to those with asymptomatic endometriosis. A cohort study by Warzecha et al. (2020) found that chronic pelvic pain and painful defecation were associated with an increased risk of depression in women with endometriosis. Another study analyzing the improvement of quality of life and productivity in women enrolled in clinical trials for Elagolix, an oral, nonpeptide gonadotropin-releasing hormone, showed that women who experienced a decrease in their dysmenorrhea and non-menstrual pelvic pain experienced a significant improvement in their quality of life and productivity (Pokrzywinski et al., 2020).

Because of the impact that endometriosis can have on wellbeing and quality of life, care for the condition should not only address the physical symptoms, but also the social, emotional, and psychological issues that women with endometriosis often experience (Bien et al., 2020). A multidisciplinary approach involving medical and psychological management of endometriosis should be utilized to manage the condition (Lagana et al., 2017). A systematic review by Evans et al. (2019) studied evidence for psychological and mind-body interventions for endometriosis. This review found that all studies that included measurements of anxiety and/or depression reported a reduction in symptoms in conjunction with reduction of pain (Evans et al., 2019). This association emphasizes the importance of studying the relationship between endometriosis and wellbeing. Though current research demonstrates that endometriosis pain is associated with

decreased quality of life, there is no current research describing the impact of this condition on college women specifically.

Impact on Activities of Daily Living

Women with endometriosis often experience difficulties engaging in their normal daily routines. A cross-sectional study examining the impact of endometriosis symptoms on 230 patients' activities of daily living (ADLs) found that participants reported limitations most frequently in in bowel continence, housework, shopping, and meal preparation (Lozano-Lozano, 2021). Women with severe pelvic pain symptoms showed higher risk for ADL limitations (Lozano-Lozano, 2021). Endometriosis symptoms may also have the potential to decrease an individual's likelihood of participating in activities that are associated with improved health. A study by Gallagher et al. (2018) found that adolescents with endometriosis were more likely to avoid health-related activities, such as exercise, during menstruation compared to adolescents without endometriosis.

Impact on Social Interaction and Relationships

Endometriosis has been shown to have an impact on diagnosed women's sexual and intimate relationships. A review by Culley et al. (2013) reported that women diagnosed with endometriosis felt that it negatively affected their intimate relationships. One aspect of endometriosis that has the potential to negatively impact romantic relationships is infertility. Matasariu et al. (2017) found that approximately 60 percent of women with endometriosis reported that difficulties with conceiving caused higher infertility distress in their relationships. Endometriosis has also been shown to have an effect on social relationships. A study by Mellado et al. (2016) conducted focus groups among women with endometriosis and chronic pelvic pain

to assess the perceptions of these women regarding their social ties. This study found that social isolation, including components such as avoiding partner intimacy and isolation from family and friends, was the emerging theme. A prospective and multicenter cohort by Comptour et al. (2019) assessed the impact of surgical treatment of endometriosis on QoL and pain by having participants complete a survey analysis before the treatment, six months post-operative, and three years post-operative. This study found that women expressed improvement in multiple domains, including bodily pain and social functioning, in the survey completed six months post-operative, and that the improvements remained stable over time.

Impact on Productivity

Research demonstrates that women with endometriosis experience decreased work productivity compared to women without the condition. Hansen et al. (2013) compared work productivity in a sample of 610 women diagnosed with endometriosis and 751 women without endometriosis. This study found that women with endometriosis had more sick days, work disturbances due to symptoms, and lower work ability compared to women without endometriosis. Soliman et al. (2021) examined work fatigue in women with endometriosis compared to women without endometriosis, finding that women with endometriosis experienced significantly more fatigue than women without the condition. Additionally, it showed that women diagnosed with endometriosis that experienced moderate or severe symptoms experienced more fatigue than women diagnosed with endometriosis that experienced mild or no symptoms. A study by Facchin et al. (2019) examining the employment status of women with endometriosis found that women with endometriosis were less likely to be employed compared to women without endometriosis. Additionally, women with symptomatic endometriosis were

less likely to be employed than women without endometriosis or women with asymptomatic endometriosis. There was no significant difference among employment in women without endometriosis and women and women with asymptomatic endometriosis. Overall, the results from these studies indicate that endometriosis symptoms may have a negative impact on women's professional lives.

Impact on Psychological Health

Current literature suggests that women with endometriosis experienced decreased psychological health compared to women without endometriosis (Barneveld et al., 2022). A study by Gallagher et al. (2018) reported that adolescents with endometriosis were more likely to report mental health concerns compared to adolescents without endometriosis. It is possible that decreased psychological health in women with endometriosis may be attributed more to the pain associated with the disease than the disease itself. A review by Barneveld et al. (2022) found that endometriosis patients experienced significantly more symptoms of depression compared with healthy controls, but that there were no differences found when comparing endometriosis patients with participants that experienced chronic pelvic pain but did not have a diagnosis of endometriosis. Additionally, a study evaluating the impact of laparoscopic excision of endometriosis on QoL through pain reduction found that endometriosis patients who underwent the procedure experienced improvements in all QoL domains, including a reduction in pain (Comptour et al., 2019). It is unknown whether the improvement of QoL was associated with the removal of endometrial implants or with the reduction in pain that resulted from the removal of the endometriosis. One study using focus groups to examine the experiences of Latina women living with endometriosis found that the stigma associated with the condition had a negative

impact on participants' mental health (Matías-González et al., 2021). This study found that the emerging theme among the women was 'chagueria,' a cultural saying traditionally applied to a person who is perceived to be excessively whining or complaining without apparent reason. This study found that in family interactions, healthcare interactions, and social interactions, women felt that the people around them did not understand the severity of their pain, which had a negative impact on their overall health and wellbeing.

METHODS

Study Design and Sample

This qualitative, cross-sectional study recruited female students attending the University of Central Florida. Eligibility requirements included the following criteria: 1) Be at least 18 years of age; 2) Have a clinical diagnosis of endometriosis; 3) Experience dysmenorrhea or pelvic pain; and 4) Be enrolled part-time or full-time in classes at the University of Central Florida as an undergraduate, graduate, or non-degree-seeking student. All of the following procedures were approved by the University of Central Florida Institutional Review Board.

Recruitment

Students were recruited through email, social media, and flyers posted on campus. The study investigator also coordinated with faculty to present the study during various classes, and had flyers posted to course websites.

Study Procedures

Students who expressed interest in participating first completed a survey to determine their eligibility. Before accessing the survey, students were routed to a webpage where they were provided with relevant information describing the purpose of the study and their ability to withdraw from the study at any time without penalty. They then checked a box to consent to the study, and filled out the eligibility survey. Eligible students were contacted via email to set up an interview via Zoom. Following the interview, participants completed two short surveys on endometriosis-associated pelvic pain and the impact of endometriosis on quality of life. Students

that participated in the interview and completed the surveys were compensated with a \$15 Amazon gift card.

Measures

Semi-Structured Interview

Participants completed a semi-structured interview designed to investigate how endometriosis has impacted their academic and social life. The interview consisted of two parts: one part about how endometriosis has impacted participants' academic life in college, and one part about how it has impacted participants' social life in college. Each section consisted of follow-up questions to help guide the discussion. Follow-up questions about the impact of endometriosis on academic life asked about having to make accommodations for endometriosis symptoms, how symptoms have impacted class attendance or completion of assignments on time, and if symptoms have affected participants' ability to study for courses. Follow-up questions about the impact of endometriosis on social life asked about missing social events, if endometriosis has affected relationships with friends or peers, and if endometriosis has affected romantic relationships. Each interview lasted between 10 – 20 minutes and was audio-recorded and transcribed verbatim. A copy of the interview questions can be found in Appendix A.

Pain Self-Efficacy Questionnaire

The Pain Self-Efficacy Questionnaire (PSEQ) was used to measure participants' confidence in performing a range of activities despite their pain (Nicholas et al., 2007). The PSEQ is a 10-item survey that asks participants to score their responses on a numerical scale with numbers 0 through 5, where 0=Not Confident At All and 5=Completely Confident.

Participants were asked to rate statements such as: I can live normal lifestyle, despite the pain; I

can socialize with my friends or family members, despite the pain; and I can still accomplish most of my goals in life, despite the pain. A copy of the survey can be found in Appendix B. Raw scores were calculated by adding the score from each category to determine the sum of all responses. Raw scores could range from 0-50, with higher numbers correlating with a greater level of confidence to perform activities despite pain.

Endometriosis Impact Questionnaire (EIQ)

The Endometriosis Impact Questionnaire (EIQ) is a 63-question survey that examines the impact of endometriosis on a variety of aspects of life (Moradi et al. 2019). The original questionnaire includes questions about the physical, psychological, and social impact of endometriosis, as well as the impact of endometriosis on sexual relations and intimacy, fertility, employment, education, and substance use over the last 12 months, 1-5 years, and over 5 years. To align with the goals of the study and reduce participant burden, the survey was modified to include only 21 of the 63 items from the original survey. A copy of the modified survey can be found in Appendix B. These questions included 7 items related to physical factors, 7 items related to psychological factors, and 7 academic-related items. Participants were asked to consider how each of these factors were affected by their endometriosis during their time in university. A higher score indicated greater impact of endometriosis on their quality of life.

Data Analysis

Means and frequencies for the PSEQ and EIQ were calculated for each participant. Content analysis, with deductive reasoning, was used to analyze the interview data. Two investigators independently coded the interview transcriptions and extracted themes related to

academic performance, physical symptoms, and psychosocial factors impacted by endometriosis. The investigators then compared themes and discussed any discrepancies. The themes were then quantified and summarized into tables.

RESULTS

Participant Survey Results

A total of four participants completed the surveys and the semi-structured interview. All four participants were undergraduate females majoring in Health Sciences. Table 1 provides the summary of their scores for the PSEQ, the EIQ, and each of the subscales on the EIQ.

Table 1: Participant Survey Results (n=4)

Survey	Participant 1	Participant 2	Participant 3	Participant 4
PSEQ*	30	16	28	34
Overall EIQ*	32	53	56	53
EIQ - Physical	21	22	23	25
EIQ - Psychosocial	9	13	20	17
EIQ - Academic	2	18	13	11

*PSEQ: Pain Self-Efficacy Questionnaire; EIQ: Endometriosis Impact Questionnaire

Participant Interview Results

Themes were extracted for the following four categories: 1) Academic Impact; 2) Physical Impact; 3) Social Impact; and 4) Psychological Impact. Table 2 provides a summary of the main themes extracted for each category, and each theme is further described in the sections below.

Table 2: Summary of Themes

Category	Extracted Themes
Academic Impact	Negative impact on academic performance; Lack of awareness of academic accommodations; Improvement in study habits; Career influence
Physical Impact	Pain; Nausea; Bedridden; Fatigue
Social Impact	Frequent missing, avoidance, or cancellation of social plans due to pain; Planning social events around symptoms; Impact on- romantic relationships/sex life; Importance of social support
Psychological Impact	Mental exhaustion; Anxiety over symptoms;; Negative impact on self-esteem; More compassionate to others with chronic conditions

Academic Impact

All four participants reported that their endometriosis symptoms had a negative impact on their academic performance. All participants stated that their pain caused difficulty attending classes, concentrating, or completing assignments. Participant 3 reported missing an exam due to an endometriosis flare-up. Participants 3 and 4 reported improved study habits due to their endometriosis, stating that they procrastinate less and plan ahead more due to the unpredictable nature of their symptoms. Participant 3 stated that one positive outcome of her endometriosis is that it influenced her decision to go into the medical field. All four participants stated that they had not tried to ask for accommodations for their symptoms, and participants 1, 3, and 4 did not think they could potentially receive accommodations for endometriosis. Table 3 provides examples of participant quotes to support each theme extracted in this category.

Table 3: Notable Quotes for Academic Impact

Themes	Notable Quotes
Negative impact on academic performance	“Have I done bad on an exam because of it [endometriosis]? Absolutely. Because I’m not focused, I’m uncomfortable... you think you’re ready for the exam and you get there and you’re all inflamed.” (Participant #1) “I wake up in pain and my mind’s all flustered because of that and it definitely has impact my ability to complete an assignment or sit down for a long period of time for an exam.” (Participant #2) “I had an endo flare up and I did end up missing... a midterm for one of my science classes.” (Participant #3)
Lack of awareness of academic accommodations	“I king of just push through things and dealt with it in my own way because I didn’t know or even think that I could get accommodations for something like that.” (Participant #1)
Improvement in study habits	“I do a full month schedule to get ahead so I can take the two or three days of not doing anything without too much stress.” (Participant #4)

Career influence	“One of the reasons why I went in [the health field] was because I was diagnosed with endo.” (Participant #3)
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Physical Impact

All four participants reported significant pain due to their endometriosis. All participants expressed that their pain can be so intense that they struggle to get out of bed at times.

Participant 3 stated that she sometimes feels unsafe driving due to the severity of her symptoms.

Participant 1 experienced nausea and menopause-like symptoms that caused her to leave class.

All participants reported experiencing fatigue due to their symptoms, with participants 1, 2, and 3 stating that their pain and fatigue made it difficult for them to concentrate at times. Table 4 provides examples of participant quotes to support each theme extracted for this category.

Table 4: Notable Quotes for Physical Impact

Themes	Notable Quotes
Pain	“I find myself laying on the shower floor for literally an hour to two hours until the pain surpasses.” (Participant #1) “[Sometimes] I have really bad pelvic pain, really bad cramps, and... I feel unsafe driving.” (Participant #3)
Nausea	“During class I was really nauseous and I got up and I had to walk out because I just - I couldn’t sit there any longer.” (Participant #1)
Bedridden	“I have missed group things because of pain and being unable to move out of bed.” (Participant #4)
Fatigue	“I’m just, like, really exhausted, like I literally have no energy to even get off this couch right now.” (Participant #3)

Social Impact

All four participants reported frequently missing, avoiding, or cancelling social plans due to their pain. Participants 3 and 4 stated that they experience the most intense pain while they are menstruating, so they plan social activities around their menstrual cycle. Participant 1 expressed concerns regarding fertility and conception. Participants 1 and 3 stated that their endometriosis

creates stress in seeking and establishing romantic relationships, and that they experience anxiety when considering how they would talk to a potential partner about their condition. All four participants expressed the importance of the social support they received. All participants said that their family and/or friends have been supportive and understanding of their condition and their need to miss or cancel plans due to their symptoms. Participant 1 stated that she joined an endometriosis support group on Facebook and that connecting with a group of people with the same condition has helped her feel less isolated. Participant 4 expressed that her mother and sister also have endometriosis, and provide support for one another through shared experiences.

Table 5 provides examples of participant quotes to support each theme extracted in this category.

Table 5: Notable Quotes for Social Impact

Themes	Notable Quotes
Frequent avoidance or cancellation of social plans due to pain	<p>“I’ve missed more social events because it’s easier to say that you’re sick for a social event rather than academic settings.” (Participant #4)</p> <p>“They [friends] probably deem me as a homebody nowadays because I have avoided going out.” (Participant #1)</p>
Planning social events around symptoms	<p>“After so many years of having this pain I have revolved my whole entire schedule around, you know, when do I feel that pain.” (Participant #2)</p>
Impact on anxiety in romantic relationships and/or sex life	<p>“That’s a pretty heavy thing especially when you’re in a romantic relationship with someone... I’ve always wondered how I would deliver that [news about having endometriosis] to someone.” (Participant #2)</p> <p>“Romantic relationships can be pretty daunting... I definitely think it gives me a little bit of anxiety when it comes to romantic relationships.” (Participant #3)</p> <p>“I used to be very sexually active... as the endo has gotten worse and things like that I kind of just, like, stopped, and now longer... have a craving to have sex anymore.” (Participant #1)</p>

Importance of social support	<p>“If I needed a break... I explained to them my whole story so they [friends] were very understanding.” (Participant #2)</p> <p>“I’m very blessed to have people in my life who kind of see past it and understand.” (Participant #3)</p> <p>“The girls in my life absolutely understand... family is good. Friends are good.” (Participant #4)</p> <p>"I’m actually part of an endometriosis support group via Facebook so I get to hear all these stories um... you know just to- I’m not alone kind of thing” (Participant #1)</p>
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Psychological Impact

All four participants reported at least one incidence where endometriosis had a negative impact on their psychological health. Participant 1 expressed that her endometriosis had caused mental exhaustion when deciding if she wanted to go through another surgery. Participant 3 stated that her endometriosis had a negative impact on her self-esteem when it caused her to miss an exam. Participant 3 also described her experience with anxiety and endometriosis co-occurring and causing a more intense endometriosis flare-up. Participant 4 expressed feeling guilty because she is unable to run with her dog when her symptoms are particularly bad. Participant 3 expressed a positive impact of endometriosis on her psychological health; she stated that she felt more compassionate toward others with chronic conditions because of her own experience with endometriosis, and that she feels that her friends are also more compassionate toward others because of what they have seen her experience. Table 6 provides examples of participant quotes to support each extracted theme.

Table 6: Notable Quotes for Psychological Impact

Themes	Notable Quotes
Mental exhaustion	<p>“And it was kind of mentally exhausting because I’m like I don’t want to go through this again you know it’s like another surgery.” (Participant #1)</p> <p>“There’s been times that I’m so foggy or so drained that I am - I guess you could say that I am running behind [at work].” (Participant #1)</p>
Anxiety over symptoms	<p>“Now that I’m married... that infertility aspect is hitting really hard.” (Participant #1)</p> <p>“It definitely gives me a little bit of anxiety when it comes to romantic relationships” (Participant #2)</p>
Negative impact on self esteem	<p>“I had an endo flare-up and I did end up missing... a midterm for one of my science classes. That was a big blow to my grade and a big blow to my self-esteem. I felt like I couldn’t really do science and med and everything, like maybe I’m not healthy enough for this.” (Participant #3)</p>
More compassionate towards others with chronic conditions	<p>“When I knew people had certain conditions it’s not like sympathy it’s more like empathy like I understand to some extent what they’re going through.” (Participant #3)</p>

DISCUSSION

The purpose of this study was to explore the impact of endometriosis on academic and psychosocial factors in a sample of college women. It was hypothesized that participants would report the negative impact of endometriosis on academic and psychosocial aspects of their lives. In line with the hypothesis, all four participants reported that symptoms from their endometriosis negatively affected their academic performance, disrupted their plans, and caused anxiety regarding romantic relationships. In contrast to the hypothesis, however, some participants also reported positive impacts from their condition. Participants mentioned that their diagnosis motivated them to improve their study habits, become more compassionate towards others, and even influenced their decision to study medicine as a career choice. Therefore, based on the results of this study, it appears participants experienced both negative and positive impacts on various aspects of their lives due to their endometriosis.

Unsurprisingly, all four participants commented on the negative impact that symptoms of their condition had on academic performance. All participants reported that they had difficulties with concentrating on assignments and tests, suffered debilitating pain that caused them to miss class, and experienced discomfort that made sitting in class for prolonged periods of time difficult. Only a few studies have examined the impact of endometriosis on academic performance, but these studies found similar results, reporting that participants even admitted having to leave college before graduation due to the severity of their symptoms (Gilmour et al., 2008; Huntington and Gilmour, 2005; Faervold et al., 2009). A surprising finding from the interview data was that the majority of participants were unaware that they could seek out academic accommodations for endometriosis-related pain, despite acknowledging the negative effects of symptoms on academic performance.

While all participants reported the negative impact of their endometriosis on academic performance, some participants also reported positive impacts. For example, one of the participants reported that she had improved her study habits and was no longer procrastinating on assignments in case she would experience a flare-up of symptoms. Although the sample size in the current study was too small, larger studies should examine whether positive coping habits and attitudes in individuals with endometriosis are linked with better health outcomes, which has been reported with other chronic conditions (Hurt et al., 2013). This could lead to potential interventions that could focus on positive attitudes and coping skills, rather than just physical pain management.

Similar to prior research, participants reported feeling anxious regarding their romantic relationships and issues regarding infertility (Aerts et al., 2018). A review by Aerts et al. (2018) found that women with endometriosis felt anxiety, shame, and negative body image when discussing issues of sexual function and infertility with romantic partners. Although participants reported feelings of anxiety when discussing these potential issues with a partner, Aerts et al. (2018) found that having open communication with a romantic partner regarding these issues was associated with lower levels of distress and greater feelings of intimacy. Additionally, having supportive partners who did not minimize feelings of pain was linked with lower levels of anxiety and greater satisfaction in romantic relationships (Aerts et al., 2018; Rosen et al., 2012).

An interesting finding from the current study was the importance of social support and support groups. Participants reported that having friends who understood their struggles was key, and that the use of support groups for endometriosis was critical as well. In contrast to the studies by Mellado et al. (2016) and Matías-González et al. (2021), the four participants in the current study reported that their family and friends were very supportive and understanding, and a source

of comfort rather than feeling isolated from their social network. One participant in the current study reported not only having supportive family and friends, but that she had also joined an online endometriosis support group. Interestingly, this participant reported fewer negative impacts of her condition on her psychosocial health and academic performance. Although more research is necessary, strong social support may help to alleviate some of the negative impacts of endometriosis. This would align with previous research that indicates that strong social support may be one of the best protective factors for mental health for individuals with chronic conditions (Cockerham et al., 2017).

Limitations

The most notable limitation of this study is its small sample size. With only four participants interviewed, it is difficult to know if any results should be attributed to chance or confounding variables. In addition to this, participants were recruited from a single university, limiting any potential geographic or cultural variables that may have been controlled for in a larger sample size from diverse locations. Finally, the study did not collect information on additional health conditions that participants may be experiencing, which could have affected their results. For example, one participant mentioned the presence of an autoimmune condition that tends to cause fatigue, which may have exacerbated the fatigue the participant attributed to their endometriosis. Thus, further research is necessary with larger sample sizes that control for co-occurring health conditions.

Implications

Despite the small sample size, the current study has several important implications. First, although endometriosis tends to be diagnosed later in life, college-aged females still can suffer from severe pain and fatigue, making it difficult to focus on daily activities. All four participants in this study were unaware of the potential to receive university accommodations for their condition, which may have not only helped their academic performance, but also attenuate their level of stress and anxiety over their condition. University accommodation offices should reach out to students and inform them of their ability to apply for accommodations for chronic and potentially debilitating conditions, such as endometriosis. The current study also highlighted the lack of awareness of the condition at the university level.

Conclusion

Four college students with endometriosis reported that their symptoms had a negative impact on academic, physical, and psychosocial aspects of their lives. Interestingly, they also reported positive outcomes, such as improved study habits and increased compassion for others living with chronic conditions. The results from this study highlight the need for better awareness of this condition at universities so that accommodations can be offered for individuals with endometriosis. Additionally, further mixed-methods research with larger samples should be conducted to better determine any protective benefits of positive attitudes and strong social support on symptoms of endometriosis.

APPENDIX A: PAIN AND SELF EFFICACY QUESITONNARIE

Rank the following statements from 0-5

0 = Not confident at all

5 = Completely confident

1. I can enjoy things, despite the pain.
2. I can do most of the household chores (e.g. tidying-up, washing dishes, etc.) despite the pain.
3. I can socialize with my friends or family members, despite the pain.
4. I can cope with my pain in most situations.
5. I can do some form of work, despite the pain ('work' includes housework, paid and unpaid work).
6. I can still do many of the things I enjoy doing, such as hobbies or leisure activity, despite the pain.
7. I can cope with my pain without medication.
8. I can still accomplish most of my goals in life, despite the pain.
9. I can live a normal lifestyle, despite the pain.
10. I can still stay active, despite the pain.

Nicholas, M. K. (2007). The pain self-efficacy questionnaire: Taking pain into account. *European Journal of Pain*, 11(2), 153-163.

APPENDIX B: ENDOMETRIOSIS IMPACT QUESTIONNAIRE

The following questions have been selected from the Endometriosis Impact Questionnaire. Rank the following statements from 0-4. You will be asked to provide a ranking for how each statement has affected your life over two time periods (last 12 months and 1-5 years ago).

0 = Not at all

1 = A little

3 = Somewhat

4 = Quite a lot

4 = Very much

Because of my endometriosis:

1. I had severe pelvic pain.
2. I had pelvic pain between my periods.
3. I felt more tired than usual.
4. I spent time in bed or lying down due to period or pelvic pain.
5. I had trouble sleeping.
6. I felt that my energy levels have decreased.
7. I had difficulties carrying out normal daily activities (e.g. shopping, driving).
8. I felt depressed.
9. I felt uncertain because of the unpredictable nature of endometriosis and its symptoms.
10. I experienced mood swings due to my symptoms/pelvic pain.
11. I felt less self-confident.
12. I was worried about the effect of endometriosis on my future plans.
13. I reduced participation in social events like attending parties or going out with my friends.
14. I had problems with my relationships with other people because of my pain.
15. I had difficulty pursuing my preferred career.
16. I took time off school/studies.
17. I experienced difficulty concentrating or focusing on my studies.
18. I did not complete my study requirements on time.
19. I missed university exams.
20. I needed more time to complete schooling/studies (e.g. extensions, re-enrollment).
21. I felt that I was unable to reach my education goals.

Moradi, M., Parker, M., Sneddon, A. *et al.* The Endometriosis Impact Questionnaire (EIQ): a tool to measure the long-term impact of endometriosis on different aspects of women's lives. *BMC Women's Health* 19, 64 (2019). <https://doi.org/10.1186/s12905-019-0762-x>

APPENDIX C: INTERVIEW QUESTIONS

Academic Life

How has endometriosis impacted your academic life in college?

Follow-Up Prompts:

Have you ever had to ask for accommodations because of your endometriosis symptoms?

Have you ever missed class because of your endometriosis symptoms?

Have you ever fallen behind on assignments because of your endometriosis symptoms?

Have you ever had difficulty studying due to your endometriosis symptoms?

Social Life

How has endometriosis impacted your social life in college?

Follow-Up Prompts:

Have you ever had to miss a social event due to endometriosis symptoms?

Has your endometriosis ever affected relationships with friends or peers?

Has your endometriosis ever affected a romantic relationship?

APPENDIX D: IRB FORM AND APPROVAL



Date: Wednesday, November 16, 2022 8:11:25 PM

Print

Close

STUDY00004213

Basic Study Information

Basic Study Information

1. * Title of study:

The Impact of Endometriosis-Associated Pelvic Pain on the Social and Academic Wellbeing of University Students

2. * Short title:

The Impact of Endometriosis

3. * Brief description:

The purpose of this research is to examine the impact of endometriosis-associated pelvic pain on the social and academic well being of university students. Participants previously diagnosed with endometriosis will participate in this study via surveys and a semi-structured interview.

4. * What kind of study is this?

Single-site study

5. * Will an external IRB act as the IRB of record for this study?

Yes No

6. * Local principal investigator:

Danielle Webster

7. * Does the local principal investigator have a financial interest related to this research?

Yes No



UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board
FWA00000351
IRB00001138, IRB00012110
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

EXEMPTION DETERMINATION

May 12, 2022

Dear Danielle Webster:

On 5/11/2022, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Initial Study
Title:	The Impact of Endometriosis-Associated Pelvic Pain on the Social and Academic Wellbeing of University Students
Investigator:	Danielle Webster
IRB ID:	STUDY00004213
Funding:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • Interview Questions.docx, Category: Interview / Focus Questions; • Pain Questionnaire track changes(1).docx, Category: Survey / Questionnaire; • Recruitment and Eligibility Survey.docx, Category: Survey / Questionnaire; • Study 4213 Thesis HRP-254 (Explanation of Research) final.pdf, Category: Consent Form; • Study 4213 Thesis IRB HRP-255 track changes.docx, Category: IRB Protocol; • Study 4213 Thesis Recruitment Email track changes.docx, Category: Recruitment Materials;

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in are detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system. When you have completed your research, please

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