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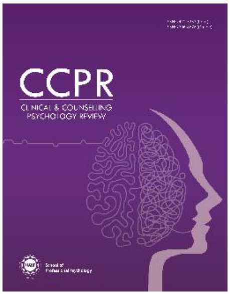

**Title:** **Perceived Effects of Endometriosis on Married Women: A Qualitative Study**

**Author (s):** Nuzhat-ul-Ain, Amna Khawar, and Amina Muazzam

**Affiliation (s):** Lahore College for Women University, Pakistan

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# Perceived Effects of Endometriosis on Married Women: A Qualitative Study

Nuzhat-ul-Ain*, Amna Khawar, and Amina Muazzam

Department of Applied Psychology, Lahore College for Women University, Pakistan

## Abstract

The current study aimed to explore the perceived effects of endometriosis on the lives of diagnosed married Muslim women residing in Lahore, Pakistan. Three semi-structured, in-depth interviews were conducted with gynecologists who had at least 10 years of experience. Moreover, six focus group discussions (FGDs) were conducted with women diagnosed with endometriosis, stratified into three distinct age groups: 18–24 years (Group 1), 25–34 years (Group 2), and 35 years and above (Group 3). For each age group, two FGDs were held, comprising four participants per session. Purposive sampling strategy was used to recruit participants for focus groups and interviews. Reflexive thematic analysis (Braun & Clarke, 2019) was conducted and four superordinate themes emerged. These included perceived physical effects, perceived psychological effects, perceived social effects, and perceived spiritual effects of endometriosis. Results were discussed in the light of previous literature and cultural background.

***Keywords:*** endometriosis, gynecologists, lived experiences, married women

## Introduction

Endometriosis is a gynecological condition in which the endometrium, a tissue which normally develops inside uterus in females, grows outside the uterus and involves ovaries, fallopian tubes, large intestines, and the tissue lining the pelvis area. Normally, endometrium in the uterus thickens, breaks down, and bleeds with each menstrual cycle. However, in women with endometriosis, it does not leave the body and gets trapped inside the pelvic region. This endometrium outside the uterus leads to cysts, scars, and adhesions (pelvic tissues and organs to stick to each other, hence, disturbing the anatomy of the organs) in pelvic region (Van Niekerk et al., 2019).

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*Corresponding Author: nuzhatulain4@gmail.com

Endometriosis is a painful condition. This, in addition to fertility, causes severe pain during periods, pain during sexual intercourse, and pain with bowel movements. Furthermore, it also causes pain with urination, excessive and clotted bleeding, fatigue, low energy, diarrhea, constipation, bloating, bleeding apart from menstrual days, or nausea during menstruation. It also increases the chances of developing ovarian cancer (Chiantera et al., 2017; Van Niekerk et al., 2019).

At present, endometriosis is thought to arise due to three factors, that is, retrograde menstruation, cellular metaplasia, and stem cells (Wen et al., 2019). Mills (2021) suggested that a lack of self-love and insecurity that may have originated in childhood, could result in rejecting one's femininity and an unresolved deep sadness and frustration. Conclusively, the probable cause of endometriosis could be a long-standing emotional problem not solved.

Endometriosis affects 10% of women of reproductive age worldwide (Gica et al., 2020). According to some other researches, the prevalence of endometriosis is estimated to be 5–15%; it is diagnosed in women with dysmenorrhea (40–60%), pelvic pain (71–87%), and subfertility (21–47%) (Falcone & Flyckt, 2018). In Pakistan, a nationwide study has not been conducted on this topic so far. However, some researches focusing on a few hospitals and cities were found during literature.

According to research, the incidence of endometriosis in one of the public hospitals of Multan City in Pakistan was 5.20 per 100 gynecological admissions with 24.88% prevalence of endometriosis in 201 women admitted for laparotomies/laparoscopies (Naseer-ud-Din & Illahi, 2000). Furthermore, Khawaja et al. (2009) reported that the frequency of endometriosis in women, at a public hospital in Karachi during 1999-2005, with primary compliant of infertility was found to be around 17%. Moreover, Naqvi et al. (2022) reported that out of a total of 800 women admitted to the gynecology ward in Kotri Pakistan, a total of 5% were diagnosed with endometriosis after performing laparoscopy or laparotomy. Similar to this study, Tahira et al. (2019) also reported that among 160 women who underwent laparoscopy, around 28% patient had findings suggestive of endometriosis. All the data for these prevalence researches was collected from women who were under some treatment and were approaching the health professionals for gynecological or reproductive health. Therefore, these estimates cannot be predictive of the general population. Till now, there is no research which could suggest a dependable prevalence estimate of the occurrence of endometriosis in Pakistan.

Effect of endometriosis is the negative influence of symptoms of endometriosis on different aspects of women's lives including physical, psychological, social, sexual, fertility, employment, educational, and lifestyle domains (Missmer et al., 2021; Moradi et al., 2019). Chaman-Ara et al. (2017) reported the prevalence rates of 86% for depression, 29% for moderate to severe anxiety, and 68% for mood problems among women diagnosed with endometriosis. Missmer et al. (2021) conclusively suggested that endometriosis may cause changes in temperament, such as mood swings, being short tempered, easily distressed, experiencing symptoms of depression, panic and other anxiety disorders, somatoform disorder, eating disorders, and low self-esteem (Vannuccini et al., 2018). Furthermore, literature has highlighted pain, bleeding, fatigue, body dissatisfaction, and psychological symptoms as the main causes of impaired social life (Forgeron et al., 2010).

Statistically speaking, 16–40% of women who have endometriosis find it difficult to conceive. Infertility itself is a significant factor which negatively affects the women's mental health, marital relationships, social interactions, and financial statuses (treatment costs) along with the stigmatization and hopelessness at the same time (Roomaney & Kagee, 2018). According to Facchin et al. (2021), dyspareunia increases the complications as it directly affects the sexual relationships. Due to this, Fecchin et al. stated that endometriosis is a "we-disease" in the context of a couple.

Research on endometriosis highlights the urgent need for better education, diagnosis, and holistic care. In Pakistan, Saad et al. (2023) demonstrated that a simple educational brochure significantly improved women's knowledge about endometriosis, emphasizing the importance of awareness to reduce diagnostic delays. Harder et al. (2024) reviewed literature showing wide disparities in endometriosis prevalence estimates—ranging from 1% (insurance data) to over 21% (symptomatic populations)—and attributed this to differences in methodology and reporting, pointing to widespread underdiagnoses. Netzl et al. (2023) found that over 40% of recently diagnosed women suffered from mental disorders, with many reporting childhood trauma and sexual dysfunction, supporting the need for a biopsychosocial approach. Similarly, Pontoppidan et al.

(2023) linked lower quality of life (QoL) in endometriosis patients to mental health problems and opioid use. On the other hand, patient-centered care improved QoL, underscoring the importance of integrating mental health and personalized care into treatment.

In considering the psychological aspect of the disease, Mills et al. (2023) undertook a qualitative study. He reported that women with endometriosis experience a sense of deficiency, societal and cultural shame of child bearing and pregnancy, as well as feelings of worthlessness as society members. Being at odds with the physicality, their bodies present 'unwanted signs and symptoms and unanticipated periods' all of which confirm their struggle with body image due to endometriosis.

Roudsari and Allan (2011) suggested that for people struggling with involuntary childlessness, spirituality may be experienced as a crisis as infertility may be thought of as a punishment of some wrongdoing. On the other hand, Roomaney and Kagee (2016) stated that evoking spirituality is one of the emotion-focused coping strategies used by women having endometriosis. Regarding spiritual coping with pain associated with endometriosis, decisive evidence does not exist. However, it has been reported that spirituality may reduce the feelings of pain via its impact through pain beliefs. Furthermore, it has been reported that women experiencing low spiritual coping or those struggling with their spirituality often catastrophize their symptoms. Moreover, they may consider their infertility and painful condition as a divine punishment of their sins (Ferreira-Valente et al., 2019). However, majority of the international researches focus on either biological aspect or biopsychosocial aspects of endometriosis.

In the Pakistani context, spirituality is deeply intertwined with how individuals perceive illness, cope with distress, and make healthcare decisions, particularly in relation to reproductive health conditions that carry significant social stigma and are rarely discussed openly. For women living with endometriosis, an often invisible and debilitating condition, spiritual beliefs may offer a culturally-acceptable framework for making sense of their symptoms, sustaining resilience, and preserving hope despite delayed diagnoses, scarce treatment options, and minimal psychosocial support. In a setting where specialized healthcare resources are limited and religious values hold strong cultural significance, examining the role of spirituality in endometriosis is crucial for informing holistic, culturallysensitive care approaches that address both the physical and psychosocial dimensions of the disease (Khan & Watson, 2006; Laganà et al., 2019). Spiritual component is missing in above mentioned researches. Moreover, Pakistani literature focusing on qualitative exploration of the effects of endometriosis is very scarce.

## Objectives

The current study aimed to address the following research objective: To explore perceived effects of endometriosis among surgically diagnosed married Muslim women.

# Method

The current study employed phenomenological research design, that focused on the participants' lived experiences. The current research explored the experiences of women living with endometriosis. Moreover, it also attempted to understand their perceptions pertaining to the effects of illness on various domains of life of the study participants, particularly in Pakistani culture. All the participants in the research were analyzed through an ideographic lens to understand the experiences of each participant living with endometriosis as a chronic health condition. Moreover, in-depth accounts from gynecologists were also analyzed in order to understand the perceived effects of illness, from a professional point of view.

## Participants

For focus group discussions (FGDs), a sample of 24 Muslim women being surgically diagnosed with endometriosis for at least one year, married for at last one year, and having minimum age of 18 years and onwards, was purposefully selected. Women with any other comorbid gynecological condition and severe physical and/or psychological illness were excluded. Permission was sought from government and private hospitals for the current research. Moreover, participants were also contacted through social media support groups created on Facebook, Instagram, and WhatsApp to increase generalizability of the results.

For semi-structured, in-depth interviews with gynecologists, the main recruitment criteria were 1) having at least 10 years of experience of working with women having endometriosis and 2) being currently involved in professional activity. Three gynecologists were contacted for the interviews.

## Procedure

Semi-structured, in-depth FGDs (Polit & Beck, 2017) were conducted after obtaining written informed consent. Participants filled a demographic questionnaire before the FGDs. The identity of the participants was kept anonymous and no names were used during the discussions. Ground rules to maintain dignity and confidentiality were discussed at the start of the FGDs. An interview guide was used during the FGDs which was developed after a through literature review.

- ‘How are your experiences while living with endometriosis?’ and
- ‘How does endometriosis impact your life?’ (Prompts about biological, social, psychological, and spiritual effects, and coping were used where needed).

Participants were divided into three distinctive age groups, that is, group 1 (18– 24 years), group 2 (25-34years), and group 3 (35 years and above). Two FGDs with each group were conducted and, hence, a total of six FGDs were conducted. These age groups were formed to explore detailed information covering various eras and socio-demographic specific effects of endometriosis on a married woman’s life. Each focus group included four participants. On average, each focus group lasted for 1.5 to 2 hours. Table 1 summarizes the demographic variables of the study participants.

**Table 1**

*Demographic Variables of the Study Participants (N = 24)*

| FGD no. | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| Mean Age (yrs) | 23.25 | 21. 5 | 31 | 31.25 | 39 | 38.25 |
| Having children | None | None | None | One participant had two children (natural conception) | None | One participant had a child (assisted reproduction) |
| Working status | 1-working<br>2-housewives<br>1-student | 3-students<br>1-houswife | 1-working<br>3-housewives | 1-working<br>3-housewives | 2-working<br>2-housewives | 2-working<br>2-housewives |

Moreover, three semi-structured, in-depth interviews were conducted with gynecologists. On average, each interview lasted for 1.5 hours.

Participants were included after taking informed consent and permission to record the interview. Interviews focusing on their experiences as gynecologists and an infertility expert while dealing with women diagnosed with endometriosis, conceptualization of the illness by these women, and impact on endometriosis on various domains of their life was conducted. Among the interviews, one of the gynecologists had 40 years of experience.

### Data Analysis

Reflexive thematic analysis (Braun & Clarke, 2019) was conducted. According to these guidelines, researchers need to acquaint themselves with the data by transcribing it and carefully reviewing it, making notes on their initial interpretations. Subsequently, they should create preliminary codes and organize data associated with each code in a structured manner. Following this, authors should aggregate codes into potential themes and assess these themes for logical coherence with both the extracts and the entire dataset. Finally, authors should articulate and define the themes.

Considering the above steps of reflexive thematic analysis, the research team met for the analysis. Themes were generated and discussed in the team meeting which enhanced the trustworthiness due to the remarkable similarity of the findings. Subsequent reviews of the data were conducted to ensure the identifiability of the researchers' interpretations. This process included the authors revisiting the transcripts after the establishment of themes to further validate the findings.

## Results

Based on the interpretation of the transcripts of focus group and interviews, four superordinate themes emerged:

- Physical effects of endometriosis
- Psychological effects of endometriosis
- Social effects of endometriosis
- Spiritual effects of endometriosis

Table 2 provides a brief overview of superordinate themes and sub-themes:

**Table 2**

*Superordinate Themes and Sub-themes*

| Superordinate Themes | | Sub-themes |
|---|---|---|
| 1 | Physical Effects of Endometriosis | Chronic pain,<br>Fatigue,<br>Difficulty maintaining straight body posture due to pain,<br>Difficulty in mobility,<br>Difficulty following routine,<br>Changes in sleep and diet patterns,<br>Poor sexual health,<br>Physical impact of treatment, poor body image |
| 2 | Psychological Effects of Endometriosis | Mood problems (feeling depressed, having mood swings, anger and irritability, hopelessness about cure),<br>Unable to avail life opportunities<br>Suicidal ideations,<br>Inability to perform as per one's potential,<br>Uncertainty due to illness symptoms,<br>Feeling lost to illness, loosing hope in recovery<br>Poor self-esteem (also associated with infertility),<br>Distorted identity as women,<br>Ruminating about illness all of the time,<br>Jealous of women who do not have endometriosis and infertility,<br>Financial stress,<br>Fear of second marriage or divorce, concerns of infertility<br>Shame |
| 3 | Social Effects of Endometriosis | Unable to participate in social and leisure activities,<br>feeling lonely,<br>Afraid of no social support in old age (due to childlessness),<br>Difficulty dealing with relationships in general and in laws,<br>Poor marital/sexual relationship.<br>Embarrassment |
| 4 | Spiritual Effects of Endometriosis | Strengthened faith (Acceptance, patience, religion as coping)<br>Weakened faith (detachment from Allah, feeling isolated in pain, hopeless about divine support) |

The following section includes verbatim of the participants and doctors related to each of the themes and sub-themes.

## Theme 1: Physical Effects of Endometriosis

One of the participants shared that the pelvic pain is so intense that she feels *fatigued and unable to maintain a healthy posture*: “I feel fatigued more than usual generally. My pain, especially during periods, makes it difficult for me to sit straight or stand straight. Whenever I walk during periods, my posture is usually bent forward.”

Another important issue is that endometriosis is highly linked with *mood swings* and *routine changes*, especially since dysmenorrhea is a very significant symptom experienced by all women. Due to painful days, women are unable to have a settled routine. Due to mood changes, *diet and sleep patterns* are also affected. These issues have been shared by one of the participants as follows (and has been discussed in detail in the theme of perceived psychological effects):

> I am unable to have a set routine. There are days when I don’t want to eat much and then there are days when I overeat. Due to periods and pain, I do not have a stable routine; and a normal sleep pattern as pain makes it difficult for me to sleep.

Dysmenorrhea affects *mobility* of the women as well as it has been highlighted in the following verbatim as: “Due to painful periods, it gets very difficult for me to go outside for work or grocery etc… plus I am fatigued more than usual.”

*Sexual health* is highly affected due to pain of dyspareunia. Moreover, ovulation pain, along with dyspareunia highly complicates the sexual performance and sexual satisfaction of these women. “My sexual life is a mess. I am not satisfied with my sexual life. Pain during sex is not only disturbing for me; but also, for my husband. I feel that he is not sexually satisfied with me.”

In addition to the patient’s experiences, doctors also endorsed these symptoms and highlighted *pain* as the major precursor of major effects of the illness. One of the doctors shared that:

> Excruciating and debilitating pain… especially during periods… is the first and foremost sign of endometriosis. Mostly, at initial stages, endometriosis is not diagnosed in ultrasounds. This is exactly the

> stage where medicines are helpful. We divide the first stage into two parts. First part of the first stage is treatable through medicines. Unfortunately, often girls do not get the diagnosis on time and miss this time period. It depends on the spread of the endometriosis and adhesions of organs; however, pain affects mostly the pelvic region of these women. This pain is so severe that they cannot sit or stand properly.

Another doctor also shared that the pain is not always limited to periods. She shared that:

> Endometriosis causes inflammation in pelvic region. Almost all women experience dysmenorrhea. In addition to dysmenorrhea, women can experience pain in other days of the cycle too. Most women experience painful ovulation. Married women also experience dyspareunia. Dysmenorrhea and dyspareunia, if present in the same case, are always number one indicator of endometriosis. Endometriosis also causes pelvic inflammation which further increases the intensity of pain.

### Theme 2: Psychological Effects of Endometriosis

*Mood swings* are very common shared by women with endometriosis as illustrated by following verbatim: “I feel that my mood also gets affected by my illness. I do not feel interested in my daily routine. I get angry or annoyed on petty issues.”

*Uncertainty about symptoms* is a very disabling situation. Women shared that they are mostly worried if they get symptoms and flare ups while they are not at their home. They consider it as a continuous struggle. Consider the following verbatim of a participant:

> I feel uncertain about my illness. I am always worried that my symptoms would get worse or I would get a flare-up. I am hopeless. I feel that I will never be cured of endometriosis. I have lost my battle with endometriosis. There are many times when I refused to go out due to this fear and there are many times that I decided to go out and then had a very painful flare-up which also made me feel embarrassed in public.

Since endometriosis is a non-stop struggle, participants stated that they are mostly inquired by people about their condition or reason for frequent visits to doctors. Some women shared that they sometimes faint at their homes due to uncontrollable bleeding and pain. Such issues create a scene and explanation of the situation makes them *feel ashamed*. It is obvious that people easily associate the condition with childlessness and it gets even more unbearable for them, making them *feel worthless.*

> I feel ashamed when I have to share the information about my illness with anyone. I am worthless as I am childless. I feel that I am not a woman or my identity is distorted due to a reproductive defect.

A participant considered endometriosis as a multi-faceted stressor and highlighted that the illness has many adverse effects. These include *stress about having intense pain, being unable to do daily chores, infertility, poor finances, fear of divorce or husband's second marriage* as shared in the following verbatim:

> There are many stressors or… you can say… multi-level of stressors. Stress about pain… stress about doing daily chores… mind that when you do not have a child you are considered as available to do all the house work since all other women or most of the other women have children and they are busy with them. Moreover, women experience stress about fertility and financial stressors are also there as the treatment is very expensive… stress that your husband will divorce you or go for second marriage for the sake of biological children. My mother-in-law pressurizes me to allow my husband for second marriage.

Women with endometriosis feel that they are *missing a lot of opportunities* as they cannot handle what they could have easily handled if they were not diagnosed with endometriosis. *Childcare becomes a struggle* as well. "Pain associated with endometriosis pain is so challenging that I am unable to take care of my child."

> I am not living up to my potential. I cannot do things that I could have if I were not diagnosed with endometriosis. I have missed many life opportunities, such as job etc. as I cannot commit to a job which demands regularity and mobility. My pain always comes in the way. It feels like endometriosis makes my life decisions… it's the Boss!

*Suicidal ideations* linked with pain were very common among the research participants. One of the participants shared that: "Once, the pain was so severe that I thought about tearing my belly apart with knife.”

Another participant shared that: “When me and my husband have a conflict due to infertility, I just want to end my life so that he can have his”. On the other hand, there are women who feel that the *psychological pain of not having children surpasses the physical pain* of dysmenorrhea as shared by a participant: “I can bear the pain but I cannot bear not having a child. I regret that I cannot have children.”

Doctors were also questioned about the psychological effects of endometriosis. Various responses were received in this regard. One of the doctors stated that *doctor shopping* is also very frequent among women with endometriosis.

> A very major psychological issue that I have seen is that when a woman is diagnosed with endometriosis, she, rather than moving on to treatment, changes her doctor…. obviously in hope of getting good news that she is not having such a severe fertility issue… but still, when you are not having a long-term relationship with your gynecologist, it gets difficult to properly educate, treat, and even support them psychologically.

*Stress, depressive symptoms, and sleep disturbances* among women with endometriosis, were highlighted by all three doctors. All of them shared that they had cases where these women have given birth as well. However, women who were easily stressed were the most difficult women. One doctor said that:

> Stress, depression, disturbed sleep… all are usually reported by women with endometriosis. As per my knowledge, what I believe is that… stressed women always find it difficult to conceive. Stress is a major factor. It can affect the hormones due to higher levels of cortisol. So, firstly, you have endometriosis, and then you have stress… it is not a good combination.

## Theme 3: Social Effects of Endometriosis

Most of the participants shared that they are *unable to attend social events* as they are uncertain of symptoms associated with their illness. This makes them *feel lonely and unsupported*. “I have reduced my participation in social gatherings. I usually do not go on weddings or parties as I am not usually sure about my pain and flare ups.”

> I feel lonely most of the times. I do not think that people who do not have endometriosis will ever be able to understand my pain and my feelings. I am also worried about my old age…I mean… I do not have children… so who will support me and my husband when we will get old.

Another important aspect of social effects is that women with endometriosis find it *difficult to maintain their social relationships*, especially with their spouses. Marital conflicts are very common among these women. The reasons of these marital conflicts are also explained by participants in the following verbatim:

> This illness has destroyed my social life. In general, I do not have good social relationships. I cannot tolerate other people's suggestions about fertility. My married life has been affected a lot. We live in separate rooms. We fight a lot. I feel under a lot of pressure due to not having children.

"Due to pain during intercourse, I am unable to satisfy my husband. This is the main cause of our marital conflict." "My in-laws are not happy with me and I live in joint family system. My mother-in-law wants my husband to either divorce me or go for second marriage for children."

Another important social effect is the *perception of not being heard by their healthcare providers*. This is quite significant for women who have been looking for answers since their menarche.

> The constant dismissal of my pain… firstly by my mother and then my doctors… is something that I would never forget. I repeatedly shared that I am NOT well! I would not have gotten married only if I knew. I wasted the life of my husband as well.

Mostly, doctors shared that *social judgements* and *fear of spousal mistrust* adversely affect the social life of these women. "Women feel embarrassed due to their pain and, in some cases, heavy periods."

One of the doctors also said that:

> I have noticed that there can be trust issues among spouses in cases where fertility is involved. Some women usually state that do not tell this to my husband or are worried about the reaction of the in-laws when they would find out that the patient has been suggested a surgery for endometriosis.

Regarding delay in diagnosis, one of the doctors said that:

> Societal reasons also come in the way. When a girl is diagnosed with such a condition that can lead to infertility, it gets very difficult for the her to survive. Many parents do not want their daughters to continue the treatment at all.

### Theme 4: Spiritual Effects of Endometriosis

According to participants, endometriosis also impacts their spiritual life. Some participants said that their faith *strengthens* and they apply *gratitude as coping strategy,* while others suggested that they have been questioning Allah's plans, especially during flare-ups, painful periods, and treatment phases.

One of the participants shared that: "This illness has taught me to have faith in Allah. I believe that He will never leave his believers hopeless. I am waiting for His miracle as I believe that children are a blessing from Allah."

Another participant added to the conversation by saying that there are people with more serious life problems than her. She shared that she feels that she was not tested beyond her limits.

> I feel gratitude when I see that other people have problems bigger than mine. I also gain patience when I read Quran and Hadith. Religion is my coping strategy. I feel that I have a different purpose than other women who have children. When Allah tests you, He also makes you emotionally strong so that you can pass the test.

On the other hand, one participant also said that she is *losing spiritual strength* as she questions Allah about her miseries.

> I am not that much spiritual anymore. I question Allah… Why me? There are women around me who are enjoying their life… giving birth… managing many things like home, job, children… and all of that without any pain… I am jealous of them. Why am I the only one with this illness? Why am I not getting a resolution or a way out? Why can't I move forward and enjoy my life? Why do I have to deal with this pain? I feel alone in all this!

Regarding spirituality, one of the doctors added in her interview that this illness requires a strong will and patience that has a lot to do with faith. She stated that:

> I have seen that, throughout my practice, women who were patients and had accepted endometriosis as Allah’s way to test them and reward them for every painful episode and flare up have lesser anxiety and are more focused on the treatment adherence. Once you educate them in a way that they get their answers and are satisfied with your skills and treatment, they will continue with you. On the other hand, the anxious ones are more oriented towards either having problem accepting the illness or blaming others for their illness rather than trying to be focused on the management of the condition. These are also more involved in doctor shopping.

## Discussion

The current study explored the perceived effects of endometriosis on the lives of diagnosed married Muslim women. Thematic analysis was conducted and four superordinate themes emerged, namely perceived physical effects, perceived psychological effects, perceived social effects, and perceived spiritual effects of endometriosis.

Literature also provided support for these domains. Missmer et al. (2021) concluded that endometriosis adversely affects daily and social activities, physical and sexual functioning, relationships, educational and work productivity, as well as mental health and well-being. Furthermore, Nnoaham et al. (2019) highlighted the adverse impacts of endometriosis on physical quality of life. Facchin (2015) focused on mental health and highlighted the prevalence of anxiety and depression in the diagnosed women. Moreover, Culley et al. (2013), Moradi et al. (2014), and Hudson et al. (2016) identified uncertainty about the nature of illness and recurrence, quality of life, disturbed intimate relationships, not being able to plan for and having children appropriately, impact on education and work, fertility, poor mental health, poor emotional well-being, and concerns regarding medical treatment were the main social and psychological issues of women diagnosed with endometriosis.

The results revealed that endometriosis has adverse effects on various aspects of daily life. Previous literature also suggested that psychological and psychosocial impact of endometriosis is very serious which reduces the quality of life of diagnosed women (De Graaff et al., 2013). Gao et al. (2006), in their systematic review, highlighted that endometriosis substantially affects the health-related quality of life, psychological, and social functioning and this detrimental effect stems from the intensity of pain experienced by these women. Moreover, the work done by Jones et al. (2004) also aligns with the current research. This is because they considered that the effect of the illness is multidimensional and complex.

Earlier qualitative studies identified common themes. These included pain, dyspareunia, diagnostic delays, and adverse effects on mental health, emotional well-being, education, work, social life, intimate and family relationships, as well as family planning and medical management (Culley et al., 2013). In the current study, pain emerged as the foremost and crucial issue discussed by the majority of women, consistent with previous researches. Pain was reported to negatively impact various life domains, including physical, psychological, social, sexual, and fertility aspects. Moreover, it also hindered in availing various life opportunities pertaining to education and employment. The prolonged diagnostic journey, disbelief from doctors, family, friends, and colleagues, as well as inappropriate labels added to the frustration and anger of the women in this study. This aligns with reported difficulties in diagnosis and limited treatment effectiveness in the literature (Manderson et al., 2008).

Some participants believed that endometriosis-induced pain, stress, anger, and mood swings significantly strained their relationships, especially due to dyspareunia, leading to conflicting relationships for some. Dyspareunia emerged as a serious problem for women as it affected their sexual performance. It is important to add here that the impact on sexual relations, including painful intercourse, was recognized as a neglected aspect of endometriosis by the World Endometriosis Society (Vercellini et al., 2011).

The lack of understanding of the disease by the public and the lack of support from the medical service providers also exacerbated the impact of endometriosis, as reported by many participants. Suggestions to alleviate the negative impact included enhancing practitioners' knowledge, providing more information to women, enhancing awareness in society, and treating endometriosis with seriousness accorded to other chronic diseases. Participants expressed a desire for more support groups, networks, and better understanding without criticism or stigma. Most women added that dismissal of pelvic pain in early puberty years is very disheartening. Doctors should respect patient’s reporting of symptoms and examine the problem thoroughly instead of just dismissing the issue and giving general guidelines.

In Pakistan, cultural and societal factors significantly contribute to the poor biopsychosocial-spiritual health of women with endometriosis. A study by Saad et al. (2023) highlighted those misconceptions about fertility and societal pressures to prioritize marriage and motherhood often delay diagnosis and treatment of endometriosis. These cultural norms discourage open discussions about reproductive health, leading to a lack of awareness and understanding among women and healthcare providers. Also, the taboo around menstruation and other reproductive health issues worsens the medical attention they seek to get regarding endometriosis due to the embarrassment they feel as a result of this stigma. Women experiencing these problems due to cultural stigma have a deeper challenge ahead. Women suffering from endometriosis face a public and professional ignorance which causes them to go through wrong or delayed diagnoses. This, in turn, affects them for a longer time and decreases their standard of living. Added to these physical concerns, the lack of societal support due to stigma around reproductive healthcare issues has positive correlation with poor mental health, such as anxiety and depression. This is because women tend to feel alone and unaided without societal support.

In Pakistan, endometriosis remains underdiagnosed and poorly-understood, with cultural stigma around menstruation and reproductive health often delaying diagnosis and treatment. Women may avoid seeking medical help due to fear of judgment or societal pressure to prioritize fertility, leading to prolonged untreated symptoms ("Lack of awareness blamed", 2025; Shah, 2023). Beyond stigma, diagnostic delays are compounded by low awareness among patients and healthcare providers, absence of noninvasive diagnostic tools, and limited specialist access. Diagnosis often depends on laparoscopy, which is costly and not widely available, resulting in delays comparable to the global average of 7–12 years (Kainat et al., 2024).

Lifestyle, dietary, and environmental factors also influence the onset and severity of endometriosis. Diets high in red and processed meats and saturated fats are associated with increased risk, while greater intake of fruits, vegetables, omega-3 fatty acids, and antioxidants may reduce disease risk and symptom severity (Arab et al., 2022; Rashidian et al., 2025). Exposure to endocrine-disrupting chemicals, early menarche, short cycles, low BMI, and genetic predisposition are also implicated in disease development (Abulughod et al., 2024). In Pakistan, spiritual and religious beliefs can shape illness perceptions some women may view their suffering as a test of faith, delaying medical engagement, whereas others draw emotional resilience and social support from faith practices, potentially aiding coping.

The findings of this research and above discussion points out to the fact that women with endometriosis are experiencing poor quality of life. This outcome has been highly reported by the literature in recent past. Pontoppidan et al. (2023) reported that, in Sweden, women generally had a low quality of life mainly related to age of onset, more than ten consultations to general physicians prior to gynecologist referral, mental health, self-centeredness, and the use of opioids. The study concluded that quality of life was adversely affected by the use of opioids and by mental health issues but it was positively affected by the extent of patient-centered care. The linkage between the quality of life and use of opioids may not only be explained by the use of drugs, however, also by the severity of symptoms and their psychological illnesses. The studies concluded that attending to broadening scope of mental health as well as patient emotional contact could be additional strategies to improve lives of women who experience endometriosis. While Flores et al. (2021) supported the conclusion of poor quality of life of women diagnosed with endometriosis, their study highlighted the importance of assessing pain catastrophizing and incorporating psychological interventions into pain management plans in order to improve therapeutic outcomes and quality of life for women with endometriosis.

Considering the similarity of the problem, the work of Benidir et al. (2023) can be studied to understand the influence of religious beliefs and practices on the health and therapeutic course of breast cancer patients. The results showed that the older patients showed greater commitment to prayer, regardless of the time since diagnosis. Patients with lower levels of education exhibited a higher degree of religious faith, and religion had a more significant impact on their therapeutic decisions. Not much work has been done on the impact of religion or spirituality on endometriosis.

This research has been inspired by the third sustainable developmental goal (SDG) of good health and well-being. This goal ensures that health and well-being are promoted across all ages and for all genders. This research would empower psychologists with practical knowledge to assess and manage mental health issues of women having endometriosis. Knowing the perceived effects of endometriosis is important to gain insights about the struggles as well as effective coping mechanisms of these women. It is highly recommended that healthcare providers should integrate spiritual and cultural compassion into their services which is mainly possible when the patients are referred to health psychologists. Endometriosis is a very painful condition which tests patient's resilience and faith. Ensuring the spiritual steadfastness can lead to better treatment outcomes for Muslim women.

## Strengths

This study delved into a new area, exploring the impact of endometriosis on spiritual health. Limited studies have focused on the spirituality of women with endometriosis. This highlights infertility more rather than endometriosis as a distinct condition with its own diverse symptomatology. Although limited evidence exists regarding the impact of endometriosis on spirituality, Roomaney and Kagee (2016) identified that spirituality is one of the major coping strategies used by women with endometriosis. However, the expression of spirituality varies from culture to culture and religion to religion. This research focused on the Islamic beliefs and representations of spirituality which are prevalent in Pakistan. It is also evident from the women and doctors' responses about spirituality. Doctors stated that women who have spiritual coping mechanisms are more oriented towards problem-solving and treatment adherence. Moreover, they also have less anxiety as compared to women with poor spiritual coping mechanisms. Additionally, being connected with the divine being, rather than isolating yourself, also came out to be a strong and helpful theme during the thematic analysis. The study concluded that the body, mind, and spirit are the three basic components of healing. Hence, this research also endorsed the biopsychosocial-spiritual approach to well-being.

A strength of the current study is that it also involved experienced doctors who have experience in dealing with women having endometriosis along with highlighting the lived experiences of women diagnosed with endometriosis. During the FGDs, the stressors and problems of women in Pakistan came into light.

## Limitations

Several challenges were faced during the study. There exists a very strong cultural stigma and sensitivity related to illnesses that cause infertility. This might affect the willingness to participate in the research and participants may hold certain information. Moreover, the awareness and knowledge about endometriosis and its effects is quite limited. Another factor was that there are no specified endometriosis centers in Pakistan. So, the women were recruited from various hospitals and fertility clinics where women and couples having other medical concerns were also being provided services at the same time. Hence, in the current healthcare system, it was difficult to identify the women who had endometriosis. Focusing more on healthcare system, accessibility to healthcare is a serious problem in Pakistan due to which the researcher had a limited access to women belonging from low socio-economic background.

## Implications

On the basis of the findings of the current study, following research-based implications can be drawn:

- It is important to develop and validate a psychometric scale measuring perceived effects of endometriosis among married Muslim women so that their cultural-specific effects can be highlighted.
- Future researches should develop a multifaceted approach in order to improve data quality and ensure an in-depth qualitative information. This should also include procedures to improve participant recruitment and retention.
- Since financial stress has been highlighted by the participants in the current study, it is suggested that future research should focus on the financial burden of the disease on each socio-economic division and also explore possible solutions which may reduce financial stress.
- It is also implied that researchers should work on the efficacy of a therapeutic protocol, based on biopsychosocial-spiritual model, to reduce the perceived effects of endometriosis on the lived of diagnosed married Muslim women.

## Conclusion

Focusing on the overall results, it can be concluded that the effects of endometriosis are of biopsychosocial and spiritual in nature. A biopsychosocial and spiritual model is a holistic approach that acknowledges the interaction between physical, psychological, social, and spiritual aspects to patient well-being, which helps to reduce the perceived effects of endometriosis on the lives of the affected individuals (Gatchel, 2007; Hatala, 2012).

## Conflict of Interest

The authors of the manuscript have no financial or non-financial conflict of interest in the subject matter or materials discussed in this manuscript.

## Data Availability Statement

The data associated with this study will be provided by the corresponding author upon request.

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