

Dimensions of Sexual Self-Concept in Women with Endometriosis: A Qualitative Exploration

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ABSTRACT

This study aimed to explore and interpret the dimensions of sexual self-concept among women living with endometriosis, focusing on how chronic pelvic pain, emotional distress, and relational factors shape their perceptions of sexuality and identity. A qualitative exploratory design was employed using semi-structured, in-depth interviews with 20 women diagnosed with endometriosis residing in Canada. Participants were selected through purposive sampling, ensuring variation in age, marital status, and duration since diagnosis. Interviews continued until theoretical saturation was achieved. Data were analyzed using thematic analysis following Braun and Clarke's six-phase framework, supported by NVivo 14 software for coding and data organization. Trustworthiness was ensured through member checking, peer debriefing, and maintaining an audit trail. Analysis revealed three overarching themes: (1) Altered Body and Self-Perception, describing loss of femininity, body shame, and internalized guilt; (2) Emotional and Relational Challenges in Sexual Intimacy, highlighting fear of pain, avoidance of intercourse, communication barriers, and relational insecurity; and (3) Coping, Adaptation, and Sexual Empowerment, encompassing self-acceptance, meaning-making, spiritual coping, and redefinition of sexual identity. Participants demonstrated both vulnerability and resilience, reconstructing their sexual self-concept through self-compassion, supportive relationships, and advocacy. The findings indicate that endometriosis affects not only physical sexuality but also emotional identity and relational dynamics. Sexual self-concept in women with endometriosis is a multidimensional construct shaped by pain, body image, partner understanding, and personal meaning-making. The study underscores the importance of integrating psychosocial and relational support into endometriosis care to promote sexual well-being and identity reconstruction.

Keywords: Endometriosis; Sexual self-concept; Dyspareunia; Qualitative research; Women's health; Psychological adaptation.

1. Introduction

Endometriosis is a chronic, estrogen-dependent inflammatory disease that affects approximately 10% of reproductive-aged women worldwide, often leading to pain, infertility, and significant psychosocial consequences (Zhu et al., 2023). Among its various manifestations, sexual dysfunction—particularly dyspareunia, or pain during intercourse—has emerged as one of the most distressing symptoms, deeply influencing women's quality of life and intimate relationships (Agarwal et al., 2020; Wahl et al., 2020). The recurrent and unpredictable nature of endometriosis-associated pain can disrupt a woman's sense of bodily control and identity, resulting in feelings of inadequacy, shame, and altered self-perception (Chaman-Ara et al., 2017; Mazalin et al., 2024). Despite growing biomedical attention to the physical and reproductive aspects of endometriosis, less emphasis has been placed on the subjective, psychological, and relational dimensions—particularly how women conceptualize their sexual selves within the context of chronic pain and relational strain.

Sexual self-concept refers to an individual's perception, beliefs, and emotional responses concerning their sexuality, encompassing aspects such as sexual confidence, body image, desire, and perceived attractiveness (Farhoudi Manesh, 2025). For women with endometriosis, sexual self-concept becomes an arena of complex negotiation between physical limitation and emotional resilience. Studies have consistently shown that sexual pain is not only a physiological symptom but also a psychological and relational phenomenon shaped by social meanings and interpersonal dynamics (Facchin et al., 2022; Wahl et al., 2020). The presence of chronic pelvic pain can gradually erode a woman's sense of femininity, sexual agency, and relational satisfaction (Bieñ et al., 2020; Rao et al., 2023). Consequently, understanding how women construct, experience, and reconstruct their sexual self-concept under these conditions is essential for developing more holistic and person-centered approaches to sexual health and chronic illness management.

Existing quantitative and clinical research has primarily focused on measuring sexual function outcomes, such as frequency of intercourse, satisfaction scores, and levels of pain during sex. However, these indicators often fail to capture the deeper experiential and emotional meanings attached to sexuality among women living with endometriosis (Oppenheimer et al., 2024). The development of standardized sexual function assessment tools has indeed

improved comparability across studies, but the subjective dimensions—such as internalized shame, identity reconstruction, and relational negotiation—remain underexplored (Privitera et al., 2023). A recent systematic review of psychometric instruments highlighted that while several tools effectively assess physical pain and arousal difficulties, they inadequately reflect the psychological components of sexual self-perception (Oppenheimer et al., 2024). This gap underscores the importance of qualitative inquiry to complement biomedical data with the nuanced, narrative perspectives of women themselves.

Research suggests that the experience of dyspareunia in endometriosis extends beyond physical discomfort to influence self-esteem, emotional intimacy, and perceived partner acceptance (Facchin et al., 2022; Halıcı et al., 2022). In particular, women often describe feeling “trapped” in a painful body that no longer aligns with their internalized image of femininity or sexual desirability (Mazalin et al., 2024; Wahl et al., 2020). This dissonance can manifest in self-blame, fear of rejection, and avoidance of intimacy, further reinforcing a negative cycle of pain, tension, and emotional distance (Niekerk et al., 2024). Qualitative evidence demonstrates that women frequently reinterpret sexual encounters through a lens of guilt and inadequacy, perceiving their bodies as unreliable and even “hostile” in sexual contexts (Helfenstein et al., 2023). Such narratives reveal that the sexual impact of endometriosis cannot be fully understood without considering women's internal dialogues, identity struggles, and meaning-making processes.

Furthermore, the relational consequences of endometriosis are significant, as sexual difficulties often intersect with emotional intimacy and communication challenges between partners (Pereira et al., 2021). Partners may experience frustration, helplessness, or misinterpret pain-related avoidance as rejection, which can create emotional distance and mutual misunderstanding (Helfenstein et al., 2023; Rao et al., 2023). Some studies have shown that couple-based interventions and empathy-driven communication can mitigate relational distress, leading to improved sexual satisfaction and overall well-being (Farhoudi Manesh, 2025; Karimi et al., 2025). The dyadic perspective is therefore critical, as both partners' interpretations of pain and intimacy co-construct the sexual experience (Pereira et al., 2021). Yet, much of the literature continues to focus on women in isolation, neglecting the interplay between individual self-concept and relational context. This limitation calls for more comprehensive

explorations that integrate psychological, emotional, and relational dimensions of sexuality in endometriosis.

Cultural and contextual factors also play a crucial role in shaping women's sexual self-concept and willingness to discuss sexual issues. In many societies, including those with conservative sexual norms, women's experiences of sexual pain and dysfunction are often silenced or trivialized, contributing to delayed diagnosis and internalized stigma (Chaman-Ara et al., 2017; Malekmalesi et al., 2022). The taboo surrounding female sexuality can inhibit open dialogue with healthcare providers and partners, exacerbating feelings of isolation and shame (Privitera et al., 2023). Research from various cultural contexts has revealed that women may perceive sexual difficulties as moral failings rather than medical or psychological conditions, reinforcing patterns of self-silencing (Sayed & Samia Abdel Hakeem Hanseen, 2018). This tendency underscores the need to contextualize sexual self-concept within sociocultural frameworks that influence how women interpret and communicate their pain, desires, and identities. Moreover, differences in cultural scripts about femininity, motherhood, and body autonomy can profoundly affect how women navigate their sexual lives after diagnosis (Halici et al., 2022; Niekerk et al., 2024).

The chronic and often invisible nature of endometriosis further complicates women's psychological adjustment. Many participants in previous studies have described the illness as "a hidden enemy" that disrupts not only sexual relationships but also social roles, work life, and emotional well-being (Bieñ et al., 2020; Mazalin et al., 2024). As endometriosis lacks a definitive cure, coping becomes an ongoing process that requires continuous adaptation and resilience. Recent qualitative work has shown that women engage in diverse strategies to manage their sexual identities—from avoidance and emotional withdrawal to self-affirmation and empowerment (Niekerk et al., 2024; Privitera et al., 2023). Such processes align with broader theories of identity reconstruction in chronic illness, where individuals strive to reconcile their pre-illness selves with altered bodies and new limitations (Mazalin et al., 2024). In this context, sexual self-concept functions as both a site of vulnerability and a source of potential growth.

Empirical evidence also indicates that surgical and medical interventions, while improving physical symptoms, do not necessarily restore sexual confidence or relational satisfaction (Halici et al., 2022; Niekerk et al., 2024). For instance, postoperative studies have found improvements in sexual functioning scores but persistent emotional distress

and diminished self-esteem among women who continue to fear recurrence or pain during intercourse (Malekmalesi et al., 2022). Similarly, pharmacological treatments that alleviate dyspareunia can enhance sexual quality of life but may fail to address the psychological sequelae of chronic illness (Agarwal et al., 2020). As a result, researchers have emphasized the importance of integrating psychosocial components into medical care, advocating for multidisciplinary models that encompass emotional and relational well-being (Oppenheimer et al., 2024; Pereira et al., 2021). Interventions such as sexual counseling, emotion-focused therapy, and educational programs have demonstrated promising outcomes in improving sexual function and reducing distress (Farhoudi Manesh, 2025; Karimi et al., 2025). These findings suggest that a comprehensive understanding of sexuality in endometriosis must extend beyond symptom management to include the subjective experiences that define sexual identity and self-concept.

Recent studies have also highlighted the transformative potential of self-compassion and self-acceptance in fostering positive adjustment among women with endometriosis (Mazalin et al., 2024; Niekerk et al., 2024). Through processes of meaning-making and identity redefinition, many women develop new ways of relating to their bodies and partners, moving from self-blame toward empowerment (Helfenstein et al., 2023). The emergence of online support communities has further facilitated this transformation by providing spaces where women can share their stories, validate each other's experiences, and reconstruct narratives of resilience and sexual worth (Privitera et al., 2023). These collective exchanges contribute to a sense of belonging and normalization, countering isolation and enhancing psychological coping (Bieñ et al., 2020). At the same time, the diversity of women's experiences underscores that sexual self-concept in endometriosis is not static but evolves dynamically through the interplay of physical, emotional, and relational factors (Zhu et al., 2023). Understanding these dimensions requires a qualitative lens capable of capturing the subtle shifts in meaning, identity, and self-perception over time.

Given this background, the present study aims to explore the dimensions of sexual self-concept in women with endometriosis using a qualitative approach.

2. Methods and Materials

2.1. Study Design and Participants

This study employed a qualitative design with an exploratory approach to understand the dimensions of sexual self-concept among women living with endometriosis. The qualitative paradigm was selected due to its capacity to capture the subjective, emotional, and contextual experiences of participants in depth. The study was conducted in Canada, where endometriosis is increasingly recognized as a chronic and multidimensional condition that affects not only physical health but also psychosocial and sexual functioning.

A total of 20 participants were recruited using purposive sampling to ensure diversity in age, marital status, educational background, and duration since diagnosis. The inclusion criteria consisted of women aged between 20 and 45 years who had received a confirmed medical diagnosis of endometriosis from a gynecologist, had been in a heterosexual relationship for at least one year, and were willing to discuss issues related to their sexual self-perceptions and experiences. Exclusion criteria included current pregnancy, diagnosis of a severe psychiatric condition, or recent participation in psychotherapy focused on sexual functioning. The sample size was determined based on the principle of theoretical saturation, achieved after the twentieth interview when no new themes or concepts emerged from the data.

2.2. Measures

Data were collected through semi-structured, in-depth interviews designed to elicit participants' personal narratives and reflections on their sexual self-concept in the context of endometriosis. The interview guide included open-ended questions such as "How has endometriosis affected the way you view yourself as a sexual partner?" and "What changes have you noticed in your sense of femininity and sexual confidence?" Interviews were conducted in a private and comfortable setting, either face-to-face or via secure online platforms for participants who preferred remote participation. Each interview lasted between 50 and 80 minutes and was audio-recorded with the participants' consent.

2.3. Data Analysis

The study included 20 women diagnosed with endometriosis who participated in in-depth semi-structured interviews. The participants were aged between 22 and 44 years ($M = 33.6$, $SD = 5.8$), representing a range of educational and socioeconomic backgrounds. In terms of marital status, 15 participants (75%) were married, 3 (15%) were in long-term cohabiting relationships, and 2 (10%) were single but previously partnered. The majority of participants ($n = 12$, 60%) had completed higher education, while 5 (25%) held secondary-level qualifications, and 3 (15%) were postgraduate students or degree holders. Regarding employment status, 9 participants (45%) were employed full-time, 5 (25%) worked part-time, 4 (20%) were homemakers, and 2 (10%) were unemployed due to health complications. The duration since medical diagnosis of endometriosis ranged from 2 to 14 years, with an average of 7.3 years. Approximately 13 participants (65%) reported having at least one child, while 7 (35%) had no children. All participants resided in various regions of Canada, representing both urban ($n = 14$, 70%) and rural ($n = 6$, 30%) areas.

3. Findings and Results

A total of 23 healthcare workers from various hospitals and clinics across the United States participated in this study. The sample consisted of 14 women (60.9%) and 9 men (39.1%), with ages ranging from 26 to 58 years (mean age = 39.4 years). In terms of professional roles, 10 participants (43.5%) were registered nurses, 5 (21.7%) were physicians, 4 (17.4%) were laboratory or radiology technicians, and 4 (17.4%) were administrative and support staff. The majority of participants (17 individuals, 73.9%) worked in hospital settings, while 6 (26.1%) were employed in private clinics or outpatient centers. Regarding work experience, 7 participants (30.4%) had between 2 and 5 years of experience, 9 (39.1%) had 6–10 years, and 7 (30.4%) had more than 10 years in healthcare practice. Marital status data showed that 15 participants (65.2%) were married, 6 (26.1%) were single, and 2 (8.7%) were divorced. The educational background ranged from associate degrees (4 participants, 17.4%) to bachelor's degrees (11 participants, 47.8%) and master's or doctoral degrees (8 participants, 34.8%).

Table 1

Themes, Subthemes, and Concepts (Open Codes)

Main Themes (Categories)	Subthemes (Subcategories)	Concepts (Open Codes)
1. Altered Body and Self-Perception	1.1. Disrupted Body Image	Feeling unattractive; Avoiding mirrors; Comparing body to others; Loss of confidence in appearance; Hiding scars or bloating
	1.2. Sense of Femininity Loss	Feeling less feminine; Questioning womanhood; Associating pain with loss of beauty; Disconnect between body and identity
	1.3. Shame and Stigma about the Body	Embarrassment about pelvic pain; Fear of judgment by partner; Internalized stigma; Concealing illness symptoms
	1.4. Self-Blame and Guilt	Feeling guilty for avoiding intimacy; Believing pain is personal weakness; Self-criticism about sexual performance
	1.5. Emotional Withdrawal	Emotional detachment; Low self-esteem; Avoiding emotional closeness due to body image issues
	1.6. Reclaiming Positive Self-Image	Engaging in self-care; Affirming physical strength; Reinterpreting scars as survival marks; Finding empowerment through body acceptance
2. Emotional and Relational Challenges in Sexual Intimacy	2.1. Pain-Related Fear and Avoidance	Anticipating pain before intercourse; Avoiding sexual contact; Anxiety during intimacy; Linking pain to rejection
	2.2. Communication Barriers with Partner	Avoiding conversations about sex; Fear of being misunderstood; Minimizing symptoms; Partner's lack of awareness
	2.3. Partner's Emotional Reactions	Partner frustration; Sympathy mixed with distance; Feeling emotionally unsupported; Misinterpretation of disinterest
	2.4. Role of Empathy and Understanding	Supportive partner behavior; Emotional reassurance; Encouraging nonsexual closeness; Validating pain experiences
	2.5. Relational Redefinition	Developing nonpenetrative intimacy; Emphasizing emotional connection; Redefining sexual satisfaction; Prioritizing affection over performance
	2.6. Fear of Rejection and Relationship Instability	Fear of abandonment; Insecurity about partner's fidelity; Feeling undeserving of love; Hypervigilance about intimacy cues
	2.7. Negotiating Intimacy Boundaries	Setting limits during intercourse; Communicating comfort levels; Seeking mutual consent; Establishing safe intimacy routines
3. Coping, Adaptation, and Sexual Empowerment	3.1. Coping Strategies for Sexual Pain	Using relaxation techniques; Pain management before intercourse; Seeking medical or therapeutic help; Adopting flexible positions
	3.2. Emotional Resilience and Acceptance	Accepting chronic condition; Viewing pain as part of life; Reframing self-worth beyond sexuality; Emotional growth through struggle
	3.3. Seeking Knowledge and Support	Consulting specialists; Joining endometriosis groups; Sharing experiences online; Learning from peers' coping methods
	3.4. Spiritual or Existential Meaning-Making	Viewing suffering as transformative; Seeking meaning in illness; Connecting spirituality to healing; Faith as source of comfort
	3.5. Redefinition of Sexual Identity	Exploring alternative expressions of sexuality; Shifting from performance to connection; Reclaiming pleasure on own terms
	3.6. Empowerment through Advocacy	Educating others about endometriosis; Breaking sexual taboos; Engaging in public awareness; Transforming pain into purpose

Participants consistently described endometriosis as a condition that deeply disrupted their sense of bodily integrity and sexual self-image. Many women expressed a profound disconnection between their physical appearance and their perceived femininity, often linking chronic pain and physical changes to diminished attractiveness. The subthemes of disrupted body image, loss of femininity, shame, and self-blame emerged as central to this experience. Several participants reported that bloating, scars from laparoscopic surgeries, and persistent pelvic pain altered how they viewed themselves as sexual partners. One woman remarked, *"When I look in the mirror, I don't see a woman who is desirable anymore. I just see the pain written all over my body."* Feelings of guilt for avoiding intimacy and internalized stigma were also common, with participants describing embarrassment about their symptoms and fear of

being perceived as "broken" or "cold." Another participant reflected, *"I feel guilty for saying no to my husband. It's not that I don't want to; it's that the pain scares me, but I can't help feeling like I'm failing him."* Despite these struggles, some women reported gradual acceptance and reclamation of their self-image, often through self-care and self-affirmation. As one participant stated, *"After years of hating my body, I've started to see it as a survivor's body. It has carried me through so much."* Collectively, these narratives demonstrate a transition from self-devaluation to self-compassion, as women began to reinterpret their bodily experiences not as deficits but as evidence of endurance and strength.

The emotional and interpersonal consequences of endometriosis were among the most frequently discussed issues. Sexual relationships were often marked by anxiety,

fear of pain, and miscommunication, leading to emotional distance between partners. Participants explained that anticipating pain during intercourse created a pattern of avoidance and heightened relational tension. One woman explained, *"Before he even touches me, my body tenses up because I know what's coming. It's not about pleasure anymore—it's about fear."* Communication barriers also emerged as a significant subtheme; many women avoided discussing sexual difficulties with their partners due to shame or fear of misunderstanding. As one participant shared, *"He thinks I don't love him anymore, but it's not that. I just can't explain the pain in words that make sense."* While some partners responded with frustration or emotional withdrawal, others showed empathy and flexibility by focusing on nonsexual intimacy. A participant noted, *"My husband started holding me more and stopped insisting on sex. That simple act made me feel loved again."* Over time, several women described redefining intimacy beyond physical intercourse, emphasizing mutual understanding and emotional closeness. However, fear of rejection persisted for many. *"I keep worrying that one day he'll find someone who isn't broken,"* said one participant tearfully. These accounts reflect how endometriosis reshapes the emotional fabric of relationships, forcing couples to negotiate intimacy boundaries, reestablish trust, and redefine what sexual satisfaction means in the context of chronic pain.

Despite the difficulties imposed by endometriosis, participants demonstrated notable resilience and agency in reconstructing their sexual self-concept. Many developed individualized coping strategies to manage pain, maintain intimacy, and restore emotional well-being. These included practical techniques such as pre-intercourse relaxation, adapting sexual positions, or incorporating medical and psychological support. One participant explained, *"I've learned what works for my body. It's about finding comfort first, then connection."* Emotional resilience and acceptance were also pivotal; several women described a gradual shift from despair to self-acceptance as they learned to integrate endometriosis into their identity. *"It doesn't define me anymore. I live with it, but it's not who I am,"* expressed one participant. Seeking knowledge and community support, particularly through online forums and endometriosis advocacy groups, emerged as an empowering resource that provided validation and practical guidance. Others turned to spirituality and existential reflection to make sense of their suffering, with one woman describing, *"Pain brought me closer to my faith. It taught me compassion for myself and others."* For some, empowerment extended beyond personal

coping to public advocacy, as they began educating others about endometriosis and breaking cultural taboos around female sexuality. *"Talking openly about my condition gave me power,"* noted a participant. Collectively, these findings reveal a transformative process in which women move from vulnerability to empowerment, redefining sexual identity through self-knowledge, acceptance, and resilience.

4. Discussion and Conclusion

The present study explored the multifaceted dimensions of sexual self-concept in women with endometriosis through qualitative analysis of their lived experiences. The findings revealed three central themes: (1) altered body and self-perception, (2) emotional and relational challenges in sexual intimacy, and (3) coping, adaptation, and sexual empowerment. Together, these themes illustrate how women construct and reconstruct their sexual identities within the interplay of chronic pain, emotional distress, and relational negotiation. The narratives in this study underscore that sexual self-concept is not merely a reflection of sexual functioning but an evolving psychosocial process influenced by physical symptoms, partner dynamics, and personal meaning-making. These findings align closely with previous research emphasizing the psychological complexity of sexuality among women with endometriosis (Chaman-Ara et al., 2017; Mazalin et al., 2024; Privitera et al., 2023).

Participants described profound disruptions in their relationship with their bodies, often characterized by feelings of unattractiveness, loss of femininity, and self-blame. Chronic pelvic pain, surgical scars, and visible symptoms such as bloating contributed to a fragmented body image and diminished sense of desirability. This finding echoes the argument that endometriosis undermines bodily integrity and evokes shame and alienation from one's own body (Bień et al., 2020; Chaman-Ara et al., 2017). Women's narratives demonstrated a recurring tension between their internal sense of womanhood and their embodied experiences of pain. Similar results were observed by (Mazalin et al., 2024), who found that individuals with endometriosis often experience self-disgust, embarrassment, and struggles with self-compassion.

This diminished self-image is also linked to the symbolic meaning of femininity and fertility. For many women, infertility or sexual pain was interpreted as a challenge to their sense of womanhood, consistent with findings by (Rao et al., 2023), who reported that endometriosis-related sexual

dysfunction often evokes a perception of personal deficiency and failure within intimate partnerships. Likewise, (Malekmaleki et al., 2022) demonstrated that even after surgical intervention, sexual self-efficacy and sexual quality of life remain significantly lower compared to pain-free women, suggesting that physical recovery alone does not restore sexual self-concept. Participants in this study described emotional withdrawal and avoidance of intimacy as self-protective behaviors, reinforcing prior observations that women internalize feelings of guilt and failure when they cannot meet perceived relational or sexual expectations (Wahl et al., 2020).

However, the study also identified moments of resistance and transformation. Some participants reported reclaiming their sense of bodily worth through acts of self-care, self-affirmation, and reinterpretation of their physical changes. This process of positive reframing aligns with the findings of (Mazalin et al., 2024), who observed that self-compassion can facilitate the reintegration of self-image by reducing shame and fostering emotional acceptance. In this way, the altered body can become a site of empowerment rather than limitation—a notion that resonates with broader feminist perspectives on chronic illness and embodied resilience (Farhodi Manesh, 2025; Niekerk et al., 2024).

The second major theme revealed that endometriosis disrupts emotional closeness and sexual communication within intimate relationships. Participants described fear of pain and anxiety during sexual encounters, often anticipating discomfort even before physical contact occurred. This fear-based avoidance mirrors the anticipatory anxiety patterns identified in clinical studies, where dyspareunia is linked not only to physical factors but to conditioned emotional responses and relational stress (Agarwal et al., 2020; Facchin et al., 2022). The findings reinforce that dyspareunia should be understood as a biopsychosocial phenomenon, as it simultaneously affects emotional intimacy, partner empathy, and sexual spontaneity (Wahl et al., 2020; Zhu et al., 2023).

Communication barriers between partners were a salient issue. Many participants expressed difficulty articulating their sexual pain or emotional needs, fearing misunderstanding or rejection. This aligns with (Helfenstein et al., 2023), who found that couples affected by endometriosis often experience asymmetrical communication patterns, where male partners underestimate the emotional and sexual impact of the disease. Likewise, (Pereira et al., 2021) highlighted that unexpressed frustration and avoidance behaviors can lead to emotional detachment,

underscoring the importance of mutual empathy and dialogue in maintaining relationship stability.

Interestingly, the present study revealed that supportive partner behavior and emotional reassurance could mitigate the psychological burden of sexual dysfunction. Participants who reported open communication and emotional intimacy described a greater sense of safety and self-acceptance during sexual interactions. This finding aligns with (Rao et al., 2023), who demonstrated that perceived partner understanding and compassion are key predictors of marital satisfaction among women with endometriosis. Furthermore, couple-based interventions such as emotion-focused therapy have been shown to improve relational satisfaction and sexual functioning by fostering emotional attunement (Farhodi Manesh, 2025).

Nonetheless, the fear of rejection and relational instability remained pervasive. Women reported concerns about being abandoned or replaced due to their reduced sexual activity, a theme echoed in multiple studies where endometriosis is associated with relational insecurity and decreased sexual confidence (Halıcı et al., 2022; Privitera et al., 2023). In this context, intimacy becomes a negotiated space shaped by both partners' expectations, empathy, and willingness to adapt. Redefining intimacy beyond penetrative intercourse emerged as an adaptive strategy for many participants, reflecting the growing recognition that emotional closeness and nonsexual expressions of affection play critical roles in preserving relationship satisfaction (Niekerk et al., 2024).

The third major theme emphasized women's active coping strategies and their journey toward sexual empowerment. Despite experiencing significant emotional and physical distress, participants demonstrated agency in reconstructing their sexual selves. Strategies such as using relaxation techniques, modifying sexual positions, and integrating medical or therapeutic support were commonly reported. These findings resonate with studies that underscore the effectiveness of pain-management interventions and behavioral adjustments in restoring sexual function (Agarwal et al., 2020; Halıcı et al., 2022). However, beyond behavioral adaptation, participants in this study described deeper psychological shifts—moving from self-pity to acceptance, and from silence to self-expression.

This process mirrors the identity reconstruction model described by (Mazalin et al., 2024), who argued that self-compassion and acceptance play pivotal roles in rebuilding a coherent sense of self after chronic illness. The women in this study exhibited similar trajectories, where acceptance of pain became a foundation for emotional healing and renewed

sexual identity. Likewise, (Niekerk et al., 2024) found that postoperative improvements in physical symptoms often coincided with psychological growth, including increased self-awareness and self-worth. For many participants, empowerment involved seeking knowledge, joining online support communities, and advocating for awareness of endometriosis—behaviors that transformed their private suffering into collective resilience (Bień et al., 2020; Privitera et al., 2023).

Spirituality and existential meaning-making also emerged as unique subthemes in this study. Several participants described interpreting their pain as a source of personal growth or spiritual strength, echoing the findings of (Chaman-Ara et al., 2017), who noted that meaning-making processes can buffer the emotional toll of chronic reproductive conditions. The concept of “redefining sexuality” also appeared prominently, reflecting a shift from viewing sexual activity as performance-based toward valuing emotional connection and self-awareness. Similar transformations were observed in (Helfenstein et al., 2023), where women reported enhanced relational quality when they detached self-worth from physical functioning. Ultimately, empowerment was characterized by reclaiming sexual agency, asserting boundaries, and using personal narratives to challenge stigma—outcomes consistent with feminist health frameworks that emphasize self-determination and voice in chronic illness management (Farhodi Manesh, 2025; Niekerk et al., 2024).

The overall findings of this study confirm that sexual self-concept among women with endometriosis is dynamic and multifactorial, influenced by physical, emotional, and social dimensions. Similar to the meta-analytic conclusions of (Zhu et al., 2023), the results highlight that biomedical approaches alone cannot fully address the complex sexual sequelae of endometriosis. Psychological constructs such as body image, self-esteem, and relational trust must be integrated into assessment and intervention frameworks. Studies focusing solely on symptom reduction risk neglecting the identity-level disruptions and self-conceptual shifts that accompany chronic illness (Malekmaleki et al., 2022; Oppenheimer et al., 2024).

Moreover, the findings contribute to growing calls for patient-centered, interdisciplinary care. Evidence indicates that psychosexual counseling, mindfulness, and couple-based therapies yield significant benefits in improving sexual well-being and relationship satisfaction (Karimi et al., 2025; Pereira et al., 2021). In this sense, addressing sexual self-concept extends beyond symptom management to

encompass empowerment and narrative healing. Importantly, the study also aligns with (Niekerk et al., 2024) and (Mazalin et al., 2024), who emphasized the value of qualitative research in revealing the lived realities that quantitative data often obscure.

This qualitative exploration from Canada adds a sociocultural layer to the global understanding of endometriosis, where traditional norms about sexuality and womanhood may intensify self-silencing and shame. Consistent with findings from Middle Eastern and European contexts (Chaman-Ara et al., 2017; Halıcı et al., 2022), the participants in this study described cultural discomfort in discussing sexual issues, highlighting the need for culturally sensitive communication in clinical care. Taken together, the findings illustrate that sexual self-concept is a vital but often overlooked determinant of quality of life, deserving equal attention to physical pain and fertility outcomes in endometriosis research and practice (Agarwal et al., 2020; Bień et al., 2020).

While this study offers deep insights into the psychological and relational experiences of women with endometriosis, several limitations must be acknowledged. First, the qualitative design and small sample size limit the generalizability of findings to broader populations. Participants were drawn exclusively from Canada, where cultural factors and healthcare access may differ from other contexts. Second, data were based on self-reported narratives, which might be influenced by memory bias or social desirability, especially regarding sensitive sexual topics. Third, only women’s perspectives were included; incorporating partners’ viewpoints could have provided a more comprehensive understanding of dyadic interactions. Finally, although thematic analysis was conducted rigorously, the interpretation of meaning is inherently subjective and shaped by the researchers’ positionality.

Future research should adopt mixed-methods or longitudinal designs to explore how sexual self-concept evolves over time following medical or psychological interventions. Including partners in dyadic or family-based studies would provide deeper insights into relational coping mechanisms and communication patterns. Comparative studies across cultural settings could also elucidate how sociocultural expectations and stigma influence sexual identity reconstruction. Additionally, intervention-based qualitative studies could assess how therapeutic modalities—such as emotion-focused therapy, mindfulness, or self-compassion training—affect both sexual satisfaction and self-concept. Expanding the sample to diverse age

groups, sexual orientations, and relationship statuses would further enrich understanding of intersectional experiences.

Clinicians should approach sexuality in endometriosis care with sensitivity, openness, and holistic awareness. Routine screening for sexual and psychological concerns should accompany medical treatment to ensure that emotional distress is addressed early. Interdisciplinary collaboration among gynecologists, psychologists, and sex therapists can promote integrated care pathways that validate both physical and emotional pain. Educational programs aimed at couples can enhance empathy, communication, and shared coping strategies, reducing isolation and relational strain. Finally, healthcare professionals should normalize conversations about sexuality, empowering women to articulate their needs, redefine intimacy, and cultivate a positive sexual self-concept despite chronic illness.

Authors' Contributions

Authors contributed equally to this article.

Declaration

In order to correct and improve the academic writing of our paper, we have used the language model ChatGPT.

Transparency Statement

Data are available for research purposes upon reasonable request to the corresponding author.

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Declaration of Interest

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Ethics Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants.

References

- Agarwal, S. K., Soliman, A. M., Pokrzywinski, R., Snabes, M. C., & Coyne, K. S. (2020). Clinically Meaningful Reduction in Dyspareunia Is Associated With Significant Improvements in Health-Related Quality of Life Among Women With Moderate to Severe Pain Associated With Endometriosis: A Pooled Analysis of Two Phase III Trials of Elagolix. *Journal of Sexual Medicine*, 17(12), 2427-2433. <https://doi.org/10.1016/j.jsxm.2020.08.002>
- Bień, A., Rzońca, E., Zarajczyk, M., Wilkosz, K., Wdowiak, A., & Iwanowicz-Palus, G. (2020). Quality of Life in Women With Endometriosis: A Cross-Sectional Survey. *Quality of Life Research*, 29(10), 2669-2677. <https://doi.org/10.1007/s11136-020-02515-4>
- Chaman-Ara, K., Bahrami, M. A., & Bahrami, E. (2017). Endometriosis Psychological Aspects: A Literature Review. *Journal of Endometriosis and Pelvic Pain Disorders*, 9(2), 105-111. <https://doi.org/10.5301/jepdpd.5000276>
- Facchin, F., Barbàra, G., Buggio, L., Drudi, D., Frassinetti, A., & Vercellini, P. (2022). Assessing the Experience of Dyspareunia in the Endometriosis Population: The Subjective Impact of Dyspareunia Inventory (SIDI). *Human Reproduction*, 37(9), 2032-2041. <https://doi.org/10.1093/humrep/deac141>
- Farhodi Manesh, A. A.-S. (2025). *The impact of emotion-focused couples therapy on sexual function and frustration tolerance in working women*
- Halıcı, B. N. A., Aktoz, F., Kabakcı, M., Kiran, G., & Özcan, P. (2022). Analysis of Preoperative and Postoperative Quality of Life, Sexual Function, and Sleep in Patients With Endometriosis: A Prospective Cohort Study. *Archives of gynecology and obstetrics*, 307(1), 113-120. <https://doi.org/10.1007/s00404-022-06562-9>
- Helfenstein, F., Schwartz, A. K., Imesch, P., Rauchfuß, M., Wölfler, M., Haeblerlin, F., Orelli, S. v., & Leeners, B. (2023). Comparison of Male and Female Perspective in Couples Involved in Sexual Relationships and Facing Endometriosis. *Sexual Medicine*, 11(2). <https://doi.org/10.1093/sexmed/qfad013>
- Karimi, M., Heshmatnia, F., Azima, S., Akbarzadeh, M., & Thapa, S. (2025). Effectiveness of Low-Cost, Virtual Sexual Health Education and Educational Leaflets on Reducing Anxiety and Enhancing Sexual Function Among Infertile Women: A Pilot Randomized Controlled Trial. <https://doi.org/10.21203/rs.3.rs-5831384/v1>
- Malekmaleki, S., Shahali, S., & Moini, A. (2022). Sexual Self-Efficacy and Sexual Quality of Life Before and After Laparoscopic Surgery in Women With Endometriosis Lesions: A Cross-Sectional Study. *International Journal of Reproductive Biomedicine (Ijrm)*, 20(6), 469-476. <https://doi.org/10.18502/ijrm.v20i6.11442>
- Mazalin, K., Evans, S., & Niekerk, L. V. (2024). A Template Thematic Analysis of Self-Concept and Self-Compassion in People Living With Endometriosis: Analysis of Qualitative Survey Responses. *Journal of Advanced Nursing*, 81(7), 4216-4227. <https://doi.org/10.1111/jan.16645>
- Niekerk, L. V., Pugh, S., Mikocka-Walus, A., Ng, C., O'Hara, R., Armour, M., Leonardi, M., & Evans, S. (2024). An Evaluation of Sexual Function and Health-Related Quality of Life Following Laparoscopic Surgery in Individuals Living With Endometriosis. *Human Reproduction*, 39(5), 992-1002. <https://doi.org/10.1093/humrep/deae063>
- Oppenheimer, A., Boitrelle, F., Nicolás-Boluda, A., & Fauconnier, A. (2024). Measurement Properties of Sexual Function Assessment Questionnaires in Women With Endometriosis: A Systematic Review Following <sc>COSMIN</Sc>

- Guidelines. *Acta Obstetrica et Gynecologica Scandinavica*, 103(5), 799-823. <https://doi.org/10.1111/aogs.14768>
- Pereira, M. G., Ribeiro, I., Ferreira, H., Osório, F., Nogueira-Silva, C., & Almeida, A. C. (2021). Psychological Morbidity in Endometriosis: A Couple's Study. *International journal of environmental research and public health*, 18(20), 10598. <https://doi.org/10.3390/ijerph182010598>
- Privitera, G., O'Brien, K., Misajon, R., & Lin, C. Y. (2023). Endometriosis Symptomatology, Dyspareunia, and Sexual Distress Are Related to Avoidance of Sex and Negative Impacts on the Sex Lives of Women With Endometriosis. *International journal of environmental research and public health*, 20(4), 3362. <https://doi.org/10.3390/ijerph20043362>
- Rao, S. R., Sy-Cherng, L. W., Abdul Muzhill Hannaan Abdul, H., Yusof, M. N. M., & Shafiee, M. N. (2023). Sexual Functioning and Marital Satisfaction Among Endometriosis Patients in Malaysia: A Cross-Sectional Study. *Frontiers in psychology*, 14. <https://doi.org/10.3389/fpsyg.2023.1224995>
- Sayed, H. A. E., & Samia Abdel Hakeem Hanseen, A. (2018). Effect of an Educational Intervention on Quality of Life and Sexual Function in Women With Endometriosis. *International Journal of Studies in Nursing*, 3(2), 127. <https://doi.org/10.20849/ijsn.v3i2.452>
- Wahl, K., Imtiaz, S., Lisonek, M., Joseph, K. S., Smith, K. B., Yong, P. J., & Cox, S. (2020). Dyspareunia in Their Own Words: A Qualitative Description of Endometriosis-Associated Sexual Pain. *Sexual Medicine*, 9(1), 100274-100274. <https://doi.org/10.1016/j.esxm.2020.10.002>
- Zhu, X., Wu, Y., Jia, J., Zhao, X., & Zhao, X. (2023). Impact of Endometriosis on Female Sexual Function: An Updated Systematic Review and Meta-Analysis. *Sexual Medicine*, 11(2). <https://doi.org/10.1093/sexmed/qfad026>