

Secondary Publication



Helgerth, Katharina A C; Schütz, Astrid

Medical and psychosocial influences on quality of life in endometriosis : A holistic narrative review

Date of secondary publication: 18.09.2026

Version of Record (Published Version), Article

Persistent identifier: urn:nbn:de:bvb:473-irb-117256x

Primary publication

Helgerth, Katharina A C; Schütz, Astrid (2026): Medical and psychosocial influences on quality of life in endometriosis : A holistic narrative review, in: Journal of endometriosis and pelvic pain disorders : JEPPD, Thousand Oaks, CA: Sage Publishing, Vol. 18, No. 3, pp. 175–185, doi: 10.1177/22840265251411717.

Legal Notice

This work is protected by copyright and/or the indication of a licence. You are free to use this work in any way permitted by the copyright and/or the licence that applies to your usage. For other uses, you must obtain permission from the rights-holders.

This document is made available under a Creative Commons license.



The license information is available online:

<https://creativecommons.org/licenses/by-nc/4.0/legalcode>

Medical and psychosocial influences on quality of life in endometriosis: A holistic narrative review

Katharina A C Helgerth and Astrid Schütz

Journal of Endometriosis and
Pelvic Pain Disorders
2026, Vol. 18(3) 175–185
© The Author(s) 2026



Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/22840265251411717

journals.sagepub.com/home/pev

MaryAnnLiebert

A Part of Sage

Abstract

Endometriosis is a chronic gynecological condition with profound consequences. Despite increasing research, studies on health-related quality of life (HRQoL) in endometriosis remain fragmented, often neglecting the interplay between medical and psychosocial aspects. This narrative review aims to provide an integrated perspective on the medical and psychosocial factors influencing HRQoL in individuals with endometriosis. A comprehensive literature search identified peer-reviewed studies examining both qualitative and quantitative research. Medical aspects such as chronic pain, dysmenorrhea, infertility, dyspareunia, fatigue, and treatment side effects were strongly associated with reduced HRQoL. Psychosocial aspects included depression, anxiety, self-esteem, body-image, coping strategies, illness perceptions, and social and work-related challenges. Treatment-related aspects, including diagnostic delay and patient-centered care, emerged as important factors associated with HRQoL. The findings highlight the necessity of a holistic approach to improve patients' HRQoL. However, research on the implementation and effectiveness of such approaches remains scarce. Future research should prioritize adolescents, longitudinal designs, and integrative analytic frameworks to better capture both short and long-term effects of the complex interactions between medical and psychosocial factors relevant to HRQoL in those affected.

Keywords

Endometriosis, health-related quality of life, psychosocial, medical, mental health, coping strategies, chronic pain

Date received: 9 April 2025; accepted: 11 December 2025

Introduction

Endometriosis is a prevalent gynecological condition in women of reproductive age,¹ marked by ectopic endometrial lesions,² causing chronic inflammation,³ scarring, and adhesions that may distort pelvic anatomy.⁴ Symptoms include chronic pelvic pain, dysmenorrhea, infertility, back pain, dyspareunia, cyclical micturition or defecation problems, and fatigue.^{5,6} Chronic pain is the leading symptom,⁷ initially cycle-dependent, but eventually persistent.⁸ Up to 50% of patients face fertility issues.^{9,10} The cause-and-effect relationship remains controversial,⁹ but endocrine abnormalities and altered pelvic anatomy may impact fertility.¹¹

Despite a prevalence of 10%–15% among women of reproductive age,¹² awareness of its clinical presentation remains low,⁶ with many cases unreported.¹ Research is

scarce, and consensus on definition, classification, and treatment is lacking.² The multifactorial etiology involves genetic, immunological, hormonal and environmental interactions.¹³ This uncertainty hinders causal therapy development, shifting focus to symptom management^{11,12} through pain medications, hormonal treatments, and surgery.¹³ Recurrence and symptom exacerbation remain major concerns.⁷ Diagnostic delay averages 10 years¹² due to factors such as reliance on laparoscopy for diagnosis.^{1,6}

University of Bamberg, Bamberg, Germany

Corresponding author:

Astrid Schütz, University of Bamberg, Kapuzinerstr. 16, Bamberg 96047, Germany.

Email: astrid.schuetz@uni-bamberg.de

Beyond physical burden, endometriosis affects psychological health and social participation, though underexplored. Research indicates psychological distress,¹⁴ impaired mental health, and reduced health-related quality of life (HRQoL¹⁵). HRQoL, a multidimensional construct, encompasses physical, psychological, social, and environmental domains.¹⁶ In chronic illnesses like endometriosis, these domains are commonly assessed through subdomains such as physical functioning, emotional well-being, control or powerlessness, self-image, and social aspects.¹⁷ Overall HRQoL in endometriosis is reduced across all domains.¹⁸ Patients are at risk of developing depression and anxiety,¹⁹ and disruption in academic, professional, and economic potential.¹² We want to acknowledge that in this review, the term “patients” refers to all individuals affected by endometriosis, including those with diverse gender identities.

Given the complexity of endometriosis, both psychosocial and medical factors affect HRQoL, with psychosocial factors influencing symptom severity and coping.²⁰ Understanding and managing endometriosis must include both medical and psychosocial dimensions to improve overall HRQoL for those affected. However, previous reviews have neglected this issue and a holistic approach is needed.

This narrative review addresses these gaps by asking: What medical and psychosocial factors influence HRQoL of women with endometriosis? How do they affect HRQoL? What are methodological limitations in existing research? To answer these questions, it synthesizes existing findings, critically evaluates methodological limitations, and identifies research gaps. Both qualitative and quantitative research are included to capture the complexity of patient experiences and clinical outcomes. By advocating for a holistic framework, it contributes to a comprehensive understanding of the disease’s multidimensional impact. In this review, the term “holistic approach” refers to an interdisciplinary and biopsychosocial perspective that considers medical, psychological, and social factors in conceptualization and clinical management. The insights gained may support the development of practical interventions that address both medical and psychosocial needs and thereby enhance HRQoL of those affected.

Methods

To ensure scientific rigor, the Scale for the Assessment of Narrative Review Articles²¹ was used to select high-quality studies, following Baumeister and Leary’s²² criteria for a structured and comprehensive synthesis. Each eligible study was critically evaluated to ensure methodological rigor and relevance before inclusion. The search terms were intentionally kept broad to allow psychosocial constructs (e.g., self-perception, self-concept) to emerge from

the literature rather than being predefined. Figure 1 provides a visual overview of the review process, outlining the steps of literature search, screening, and eligibility assessment.

Table 1 outlines the methodological characteristics of selected studies.

Results

Medical factors

HRQoL in endometriosis patients is associated with various medical factors, encompassing somatic features and menstrual cycle characteristics. Chronic pain negatively correlates with HRQoL.^{23,24} However, the pain-HRQoL association varies across dimensions. Some studies show stronger correlations with the psychological domain,²⁵ while others find stronger ones with the physical domain.²⁶ De Graaff et al.²⁷ found negative effects of pain on both physical and psychological components. Specifically, pelvic pain severity correlates negatively with HRQoL,^{28–31} particularly within the psychological (emotional well-being, control³²) and physical domains (pain experience;^{32,33} physical functioning³⁴). In adolescents, intensity significantly affects both psychological and physical HRQoL.³⁵ The negative impact is likely due to reduced physical functioning, including mobility and daily activities, and its recurrent nature.²⁴

Menstrual irregularities, such as dysmenorrhea, irregular cycles, and heavy bleeding, also reduce HRQoL.^{24,29,36,37} Dysmenorrhea correlates with lower physical^{33,38} and psychological HRQoL domains,²⁴ while heavy bleeding affects the physical (pain), psychological (control, emotional well-being, self-image) and social domain (social support³⁹). The relative impact of dysmenorrhea versus heavy bleeding on HRQoL remains unclear, as comparative studies are limited.

Dyspareunia also affects HRQoL,^{28,40} impacting psychological, social,²⁴ and physical domains.²⁷ Using the same scales, Facchin et al.³⁸ found no significant effects of dyspareunia on HRQoL in another sample, suggesting moderating factors. Moreover, fatigue reduces HRQoL,^{36,41} not only predicting HRQoL impairment,²⁴ but also mediating the pain-HRQoL association.⁴¹ Additional symptoms such as nausea, bloating, anemia,³⁶ skin problems,²⁴ and dysuria further diminish HRQoL.^{24,32} Physical changes such as surgical scarring, abdominal bloating, or weight-gain negatively impact the subdomains within the psychological domain self-image and body-related perceptions,^{24,34,42} yet research on these factors remains limited. The impact of any endometriosis symptom on HRQoL is profound, particularly in terms of the psychological subdomain powerlessness.³⁶ Severity and number of symptoms impair the physical subdomains physical functioning and self-care, including standing

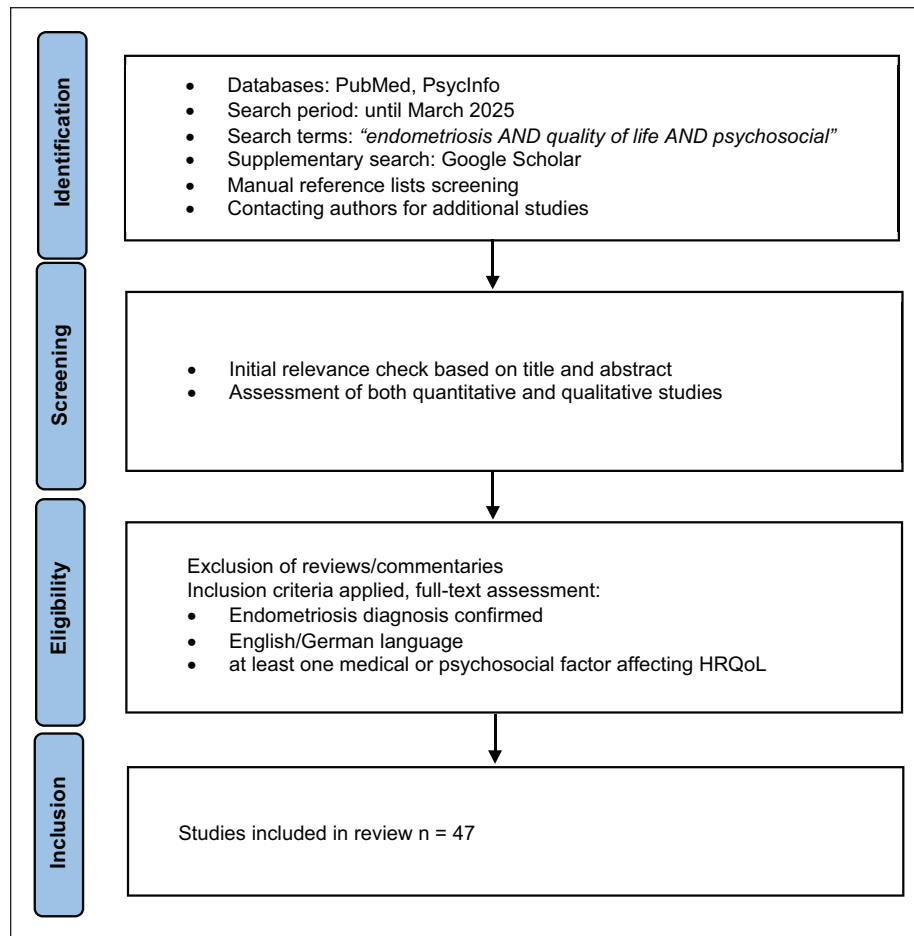


Figure 1. Flowchart of the narrative review process.

and walking.²⁹ Comorbidities independently affect physical and psychological HRQoL.²⁷ Infertility further negatively impacts HRQoL,⁴³ despite its emotional burdens manifesting as anxiety, depression, and feelings of inadequacy.²⁴

Van Niekerk et al.⁴⁴ report negative associations between disease severity and psychological HRQoL, while Pessoa de Farias Rodrigues et al.²⁸ found no significant effects. Symptom duration negatively correlates with HRQoL,⁴⁰ particularly in the physical (pain), psychological (control, powerlessness), and social domains (social support³²).

Patient age also influences HRQoL, with younger women reporting more severe symptoms and lower overall HRQoL.^{45,46} Age predicts impairments in the social domain of HRQoL.³⁴ Adolescents with an early menarche report poorer physical HRQoL.³⁵ However, physical HRQoL declines with age, while psychological HRQoL tends to improve,²⁶ suggesting adaptation and changes in expectations.

In summary, while chronic pain and menstrual irregularities have well-established impact on HRQoL, dyspareunia, fatigue, physical changes, and infertility require further exploration. Long-term effects of symptom

duration and age require more investigation to improve understanding of the medical factors affecting HRQoL in endometriosis.

Treatment-related aspects

A significant treatment-related factor negatively associated with HRQoL in endometriosis is the delay in diagnosis and treatment.^{35,46} Impairments on psychological HRQoL (frustration, disillusionment, and psychological distress) often result from unclear explanations or dismissal by healthcare providers.²⁴ Contributing factors include misdiagnosis, multiple consultations before specialist referral, and inadequate knowledge among healthcare professionals.²⁴ More visits to general practitioners before referral are negatively associated with the psychological subdomain self-image.⁴⁶ The effect of early diagnosis on HRQoL remains unclear, as studies mainly focus on negative consequences of delays.

Pharmacological treatments play a central role in endometriosis but have a complex and sometimes contradictory impact on HRQoL. Prescription medications are negatively associated with physical HRQoL,²⁶ and opioid use

Table 1. Methodological characteristics of studies on medical and psychosocial factors related to health-related quality of life in endometriosis.

Authors (year)	Study design	Sample	Main variables	Analytical methods
Ahmad et al. (2024)	Cross-sectional study	354 endometriosis patients	Quality of life, pain intensity, patient health engagement	Correlation analysis, structural equation modeling
Barberis et al. (2023)	Cross-sectional study	364 endometriosis patients	Quality of life, emotional intelligence, illness perceptions, psychological distress	Structural equation modeling, mediator analysis
Bień et al. (2020)	Cross-sectional study	309 endometriosis patients	Quality of life, acceptance of illness, pain intensity	Regression analysis
Bień et al. (2024)	Cross-sectional study	425 endometriosis patients	Quality of life	Regression analysis
de Barros Meneguetti et al. (2022)	Cross-sectional study	102 endometriosis patients	Quality of life, anxiety, depression, pain intensity	Comparative analysis
De Graaff et al. (2013)	Cross-sectional study	931 endometriosis patients	Quality of life	Regression analysis
Del Forno et al. (2024)	Cross-sectional study	334 endometriosis patients	Quality of life, sexual function	Comparative analysis
Facchin et al. (2015)	Cross-sectional study	110 endometriosis patients, 61 healthy controls	Quality of life, anxiety, depression, pain intensity	Comparative analysis, regression analysis
Gallagher et al. (2018)	Cross-sectional study	360 endometriosis patients, 207 controls, 10–24 years	Quality of life	Comparative analysis, correlation analysis
González-Echevarría et al. (2019)	Cross-sectional study	24 endometriosis patients (13–25 years)	Quality of life, coping styles, anxiety, depression	Correlation analysis
Grinberg et al. (2024)	Cross-sectional study	89 endometriosis patients, 81 healthy controls	Quality of life, psychological well-being, catastrophizing	Comparative analysis, correlation analysis
Güvenç and Bozo (2023)	Cross-sectional study	174 endometriosis patients	Quality of life, attachment style, pain catastrophizing, coping strategies	Path analysis, mediation analysis
Guillemot et al. (2024)	Cross-sectional study	1039 endometriosis patients	Quality of life, pain severity, body-image, self-esteem, anxiety, depression	Regression analysis
Jaeger et al. (2024)	Cross-sectional study	627 endometriosis patients	Quality of life, relationship quality	Correlation analysis, mediation analysis
Jones et al. (2004)	Qualitative study	24 endometriosis patients	Quality of life	Text analysis, coding
Kupec et al. (2025)	Cross-sectional study	175 endometriosis patients	Quality of life, pain severity	Regression analysis
Lövkvist et al. (2016)	Cross-sectional study	431 endometriosis patients	Quality of life	Comparative analysis
Márki et al. (2017)	Cross-sectional study	193 endometriosis patients	Quality of life, perceived stress, anxiety, depression, emotional regulation	Correlation analysis, structural equation modeling, mediator analysis
Matías-González et al. (2022)	Cross-sectional study	169 endometriosis patients	Quality of life, social support, self-esteem	structural equation modeling
McPeak et al. (2018)	Cross-sectional study	236 endometriosis patients	Quality of life, pain catastrophizing	Regression analysis
Melis et al. (2015)	Cross-sectional study	41 endometriosis patients, 40 healthy controls	Quality of life, depression, anxiety, body image, pain intensity, sexual functioning	Correlation analysis, comparative analysis
Moore et al. (2023)	Qualitative study	30 endometriosis patients	Quality of life, illness perceptions	Reflexive thematic analysis

(continued)

Table 1. (continued)

Authors (year)	Study design	Sample	Main variables	Analytical methods
Mundo-López et al. (2020)	Cross-sectional study	230 endometriosis patients	Quality of life, fatigue, psychosocial status	Regression analysis
Nielsen et al. (2023)	Qualitative study	7 endometriosis patients	Quality of life	Structure analysis
Nnoaham et al. (2011)	Cross-sectional study	745 endometriosis patients, 673 controls	Diagnostic delay, HRQoL, work productivity	Comparative analysis, regression analysis
Nogueira Neto et al. (2023)	Longitudinal study (3–6 months)	102 endometriosis patients	Quality of life	Comparative analysis
O'Hara et al. (2021)	Cross-sectional study	620 endometriosis patients	Quality of life, self-management factors	Regression analysis
Pehlivan et al. (2022)	Longitudinal study (2 months)	996 participants at T0, 451 participants at T1 and T2	Quality of life, body image, depression, self-esteem, rumination	Regression analysis, mediation analysis
Pessoa de Farias Rodrigues et al. (2020)	Cross-sectional study	106 endometriosis patients	Quality of life, endometriosis stage	Correlational analysis, comparative analysis
Pontoppidan et al. (2023)	Cross-sectional study	476 endometriosis patients	Quality of life	Regression analysis
Rees et al. (2022)	Cross-sectional study	230 endometriosis patients	Quality of life, pain self-efficacy, health locus of control, coping style, illness uncertainty	Regression analysis
Ribeiro et al. (2014)	Longitudinal, prospective study (1 year)	40 endometriosis patients	Quality of life	Comparative analysis
Roomaney and Kagee (2018)	Qualitative study	25 endometriosis patients	Quality of life	Coding
Skinner and Kuijer (2024)	Cross-sectional study	603 endometriosis patients	Quality of life, self-compassion, resilience	Correlation analysis, mediator analysis
Soliman et al. (2017)	Cross-sectional study	1269 endometriosis patients	Quality of life	Regression analysis
Souza et al. (2011)	Cross-sectional study	32 endometriosis patients, 25 controls	Quality of life, pain intensity	Comparative analysis, correlation analysis
Spinoni et al. (2024)	Cross-sectional study	273 endometriosis patients	Quality of life, pain severity, illness perceptions, coping strategies	Structural equation modeling, mediator analysis
Sullivan-Myers et al. (2021)	Cross-sectional study	584 endometriosis patients	Quality of life, psychological distress	Regression analysis
Tiringer et al. (2022)	Retrospective and longitudinal study (6–10 weeks)	115 endometriosis patients	Quality of life	Comparative analysis
Valentin et al. (2017)	Prospective and longitudinal study (1 year)	167 endometriosis patients	Quality of life	Comparative analysis
Van Niekerk Steains, et al. (2022)	Cross-sectional study	318 endometriosis patients, 420 controls	Quality of life, body image, depression, anxiety	Regression analysis, comparative analysis
Van Niekerk, Johnstone, and Matthewson (2022)	Cross-sectional study	318 endometriosis patients	Quality of life, pain, distress	Correlation analysis
Van Niekerk et al. (2023)	Cross-sectional study	318 endometriosis patients	Quality of life, self-compassion, body compassion	Correlation analysis, regression analysis
Van Poll et al. (2020)	Cross-sectional study	224 endometriosis patients	Quality of life, sexual function	Univariate analysis, regression analysis
Wu et al. (2024)	Cross-sectional study	216 endometriosis patients	Quality of life, self-management strategies, distress	Regression analysis

reduces pain (physical domain) but also affects psychological (control), and social subdomains (social support⁴⁶), raising question on long-term well-being. Hormonal treatments reduce pain and improve HRQoL⁴⁶ but may cause side effects side like mood disturbances and weight gain. Despite its widespread use, comparative research on hormonal treatments' HRQoL outcomes remains limited.

The relationship between surgery and HRQoL also is complex, with both positive and negative effects. Some studies show surgery reduces physical (pain) and psychological domains (control³⁹), while others report improvements in HRQoL,^{47–49} for example, physical (pain), and psychological (control, emotional well-being, and self-image³²). However, improvement may depend on the stage of endometriosis, with minimal cases showing low success rates,⁵⁰ highlighting the need for careful patient selection and alternative treatment considerations.

Beyond medical treatments, care delivery significantly impacts HRQoL. Patient-centered care improves all HRQoL domains,⁴⁶ with effective communication, education, and emotional support being key.⁵¹ Providing detailed information about disease mechanisms, treatment options, and self-management strategies improves HRQoL.²⁹ Conversely, feeling neglected or not taken seriously reduces HRQoL.⁵² Barriers such as limited access to specialists, inconsistent medical advice, and incorrect diagnoses lower HRQoL and trust in healthcare.²⁹ Despite growing recognition of patient-centered care's importance, research evaluating its long-term effects on HRQoL remains limited.

In summary, diagnosis delays are consistently associated with lower HRQoL, yet long-term benefits of early detection remain unclear. Medical and surgical treatments affect HRQoL differently, but interpersonal aspects of healthcare are crucial for endometriosis patients.

Mental-health aspects

Psychological distress symptoms reduce HRQoL in endometriosis patients.^{44,46} Psychological distress correlates with psychological subdomains such as self-image⁵³ and predicts lower scores in the psychological subdomains emotional well-being and self-image as well as in the social subdomain social support.⁴⁶ Specifically, higher levels of depressive and anxiety symptoms impair HRQoL.^{18,24,53,54}

Beyond symptoms of depression and anxiety, stress,³⁶ isolation and hopelessness further impair HRQoL, particularly within the psychological domain.²⁹ Patients describe constant somatic concerns, fear, and unpredictability, particularly regarding pain—factors affecting both the psychological and physical domains of HRQoL.^{40,52} Emotional distress may manifest as irritability and mood swings, exacerbating overall psychological burden.²⁴ However, conceptual overlap between stress, uncertainty, and emotional distress complicates measurement.

Body-image is an important, yet understudied aspect in psychological subdomain of HRQoL in endometriosis.^{18,44}

Some women report a sense of incompleteness due to infertility, impacting the psychological subdomain self-perception and overall HRQoL.²⁴ Evidence further suggests that body-image concerns are not only associated with psychological but also physical HRQoL.⁵⁵ Despite its importance, existing research on body image in endometriosis primarily examines the concept in relation to psychological distress, such as depression or anxiety. Broader aspects of self-perception, such as identity, embodiment, and self-concept, are less frequently explored.

Endometriosis symptoms contribute to reduced self-esteem, negatively impacting HRQoL.²⁹ Recent findings further suggest that higher self-esteem is associated with better psychological and physical HRQoL, indicating that self-esteem may serve as a protective factor across multiple domains.⁵⁵ Self-esteem also mediates the relationship between body-image and depression, with negative body-image leading to reduced self-worth and greater depressive symptoms.⁴² However, its role in resilience and coping is understudied.

In summary, mental health aspects of endometriosis are complex and impact HRQoL. Research on body-image and self-esteem remains scarce, highlighting the need for further investigation. Additionally, it should be noted that most studies assessed symptoms of psychological distress rather than clinically diagnosed mental health disorders. Therefore, the findings refer to reported symptoms rather than diagnostic prevalence.

Aspects of coping

Coping strategies significantly shape HRQoL in endometriosis patients.²⁹ Adaptive strategies improving HRQoL include problem-focused coping (self-management, knowledge-seeking, symptom-focused living, social support) and emotion-focused coping (acceptance, positive attitude, self-talk, spirituality²⁹). Problem-focused coping mediates the relationship between attachment anxiety and HRQoL, with lower use leading to poorer outcomes.⁵⁶ Engagement in health management also mitigates negative impacts of chronic pain on HRQoL.²² However, coping preferences vary; some gain control through information-seeking, while others rely on supportive communities.⁵²

In young patients, self-criticism correlates with work impairment (social domain), mood disturbances (psychological domain), and physical distress (physical domain), while social withdrawal exacerbates the psychological domain and the social subdomain academic career.⁵⁷ Conversely, emotional expression, social support, and cognitive restructuring reduce the psychological subdomain mood stability.⁵⁷ Maladaptive coping strategies, particularly catastrophizing, are associated with lower HRQoL.^{33,56,58} and mediate the negative link between pelvic pain and HRQoL.⁴¹

Self-compassion buffers against HRQoL impairment, with resilience mediating its effects on the psychological

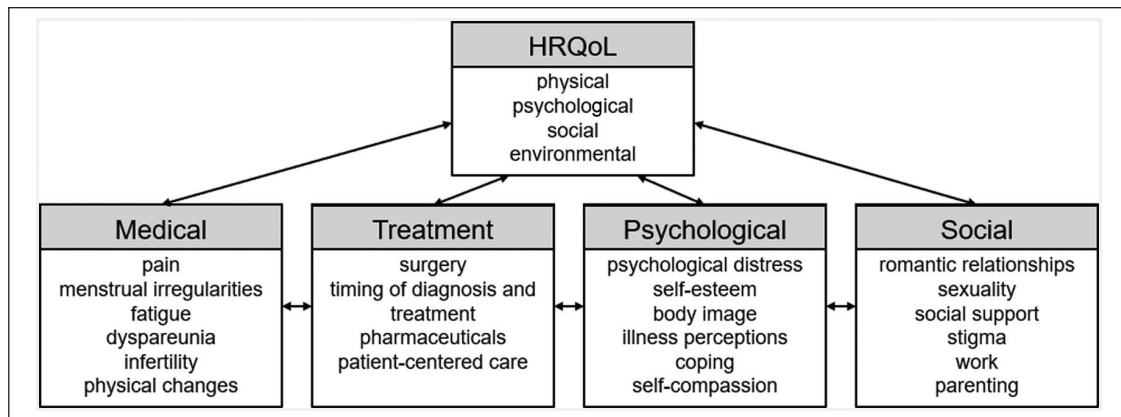


Figure 2. Holistic model of HRQoL in endometriosis.

subdomains emotional well-being and control.⁵⁹ Body compassion predicts improvements in the physical and social domains, and overall HRQoL.⁶⁰ Self-management behaviors (medication adherence, rest, dietary modifications) improve HRQoL,³⁷ and self-efficacy predicts HRQoL.^{26,61} However, causal pathways between self-compassion, self-efficacy, and HRQoL remain underexplored.

Illness perceptions profoundly influence HRQoL. Illness uncertainty impairs physical, psychological, social, and environmental HRQoL.⁶¹ Negative illness perceptions (endometriosis limiting career, relationships, or fertility) further impair HRQoL.^{62–64} Patients feeling controlled by the disease report fear and identity loss, and reduced levels on the psychological domain.⁶³ Maladaptive coping mediates these effects, leading to greater HRQoL impairment.⁶⁴ Conversely, adaptive coping fosters control and resilience, improving HRQoL.⁶³ These findings highlight the need for interventions targeting illness perceptions and promoting adaptive coping strategies.

Acceptance of illness is associated with higher physical, psychological, and social HRQoL.³⁴ Conversely, pain unpredictability induces helplessness and frustration, further reducing HRQoL.²⁴ Emotional regulation difficulties negatively impact psychological HRQoL,⁵⁴ while higher emotional intelligence improves it.⁶² Interventions targeting emotional regulation may improve HRQoL outcomes.

In summary, coping strategies, self-compassion, self-management, emotional intelligence, and illness acceptance influence HRQoL. However, research on individual differences remains limited.

Social life and work-related aspects

Endometriosis significantly impacts the social domain of HRQoL, causing isolation, misunderstanding, and loneliness.²⁴ Unpredictable pain and fatigue lead to missed social gatherings, exacerbating social withdrawal and reducing overall HRQoL.²⁴ Additionally, endo-stigma stress, defined as social labeling and rejection of differences, negatively

correlates with HRQoL.⁶⁵ However, social support buffers these effects, highlighting the role of strong interpersonal networks.⁶⁵ Yet, research on long-term effects of stigma stress and social support remains limited.

Dyspareunia and infertility frequently impair romantic relationships and sexual well-being, reducing HRQoL.^{24,29,34} Specifically, reduced sexual functioning is directly associated with poorer overall HRQoL,⁶⁶ and the strength of this relationship varies according to severity and type of dyspareunia.⁶⁷ Reduced libido and lower relationship quality correlate with poorer outcomes in the social and psychological domains.^{18,68} Interestingly, being in a relationship is associated with higher psychological HRQoL,²⁶ suggesting that emotional support mitigates distress. However, most studies rely on cross-sectional data, limiting causal conclusions.

Endometriosis profoundly affects the social subdomain professional life. Many women experience guilt when taking leave from professional responsibilities due to symptoms.^{24,29} In male-dominated workplaces, shame and the need to justify absences further impair HRQoL.²⁴ Chronic pain and fatigue interfere with career progression and workplace engagement,³⁹ yet research on workplace adaptations and employer support remains scarce. Additionally, many patients struggle with childcare²⁹ and worry about transmitting endometriosis to their daughters, increasing psychological distress.²⁴

In summary, endometriosis reduces HRQoL by affecting social life, relationships, work, and parenting, with social isolation, stigma, and relationship strain adding to its psychological burden.

Based on the findings of this review, Figure 2 illustrates a holistic model of HRQoL in endometriosis.

Discussion

This review underscores the substantial impact of endometriosis on HRQoL, spanning physical, psychological, social, and, although less frequently examined, environmental domains. Chronic pain, menstrual irregularities, fatigue, and

infertility significantly impair HRQoL, with pain as the primary factor. Diagnostic delays and inconsistent healthcare further diminish HRQoL. Mental health issues, self-esteem, coping strategies, self-compassion, and patient engagement emerged as crucial factors. Social support and interpersonal relationships also influence HRQoL, as patients frequently experience social isolation, stigma, and challenges in relationships and professional settings. The review demonstrates the fundamental influence of medical and psychosocial factors on HRQoL in endometriosis.

However, the predominance of cross-sectional studies limits causal interpretations, as these designs capture only a single time point and cannot determine the temporal direction of associations between psychosocial factors and disease outcomes. Consequently, it is not clear whether factors such as depression, anxiety, and social support contribute to changes in disease progression and quality of life or are a consequence of disease burden. Longitudinal research is necessary to evaluate these dynamics over time, especially across significant life stages such as adolescence, pregnancy, and menopause. Such research would provide a more comprehensive understanding of the relationship between psychological and medical factors. Additionally, this review only included English- and German-language studies, which limits the generalizability of the findings to other cultures. Recognizing these limitations is important because both the reliance on cross-sectional designs and the language restrictions constrain the conclusions. This fact highlights the need for future studies with different cultures and longitudinal designs. A common methodological feature across reviewed studies is the use of standardized self-report instruments, which may introduce bias.⁶⁹ However, self-report remains the most appropriate method for assessing psychosocial constructs in endometriosis. Many of these experiences, such as pain and HRQoL, are inherently subjective and cannot be meaningfully captured through objective indicators alone. Although self-report measures can introduce biases, this fact is mitigated if well-validated instruments are used and if self-report data is supplemented with other methods such as objective data where possible. Further, psychosocial variables (e.g., social support and coping strategies) are frequently examined separately rather than within an integrative analytical framework. In this review, “integrative models” refers to multi-layered statistical approaches that can examine medical, psychological, and social determinants of HRQoL simultaneously. Advanced techniques, such as mediation and moderation analyses, multivariate path models, and structural equation modeling, remain underutilized. These techniques would enable researchers to map indirect effects, reciprocal pathways, and the joint contribution of biological and psychosocial stressors. These models could clarify how factors interact over time, moving the field beyond simple bivariate associations. Additionally, further research on psychosocial experiences

of adolescents is warranted, as symptoms often emerge at puberty, a period associated with educational disruptions and body-image concerns. Also, patient-centered approaches remain underutilized despite evidence that shared decision-making, disease education, and psychological support enhance well-being. Many healthcare systems fail to implement these practices, leaving patients feeling disregarded. Greater mental health service integration is essential to optimize patient care.

A comparison with previous reviews reveals both converging and diverging findings regarding medical and psychosocial aspects of HRQoL in endometriosis. Prior research underscores the impact of chronic pain, dysmenorrhea, dyspareunia,^{70–72} infertility,⁷³ and mental health disorders on HRQoL.^{70,74–76} Social and occupational consequences on HRQoL are equally well-documented.^{70,72,75,77} Consistent with prior literature, delayed diagnosis and inadequate healthcare interactions reduce HRQoL.⁷⁵

Unlike reviews that focus solely on medical or psychosocial factors (e.g., Della Corte et al.,⁷⁰ Heng and Shorey⁷³), this review integrates both dimensions within a holistic framework, addressing underexplored areas such as self-perception, body dissatisfaction, and identity-related concerns. It broadens perspectives on coping, considering maladaptive (e.g., catastrophizing) and adaptive strategies (e.g., self-compassion, cognitive restructuring, social engagement). Moreover, it extends the literature by highlighting the psychological impact of infertility on identity, relationships, and HRQoL, aspects rarely addressed in past reviews. While prior reviews acknowledge diagnostic delays, this review also explores how patient-provider interactions, shared decision-making, and emotional support influence HRQoL. Unlike most reviews relying solely on quantitative HRQoL scales, this review incorporates qualitative and quantitative research, offering a comprehensive exploration of subjective experiences. Still, this review, like all of the previous ones, is limited by language restrictions, potentially introducing language bias by excluding relevant non-English studies, and by publication-bias, as non-significant findings are less frequently published.

The findings of this review have several practical implications for improving the HRQoL of individuals with endometriosis. Due to the multidimensional nature of the condition, clinical management should take a biopsychosocial and patient-centered approach. First, integrating mental health professionals into endometriosis care through embedded psychotherapy, psychoeducation, or depression and anxiety screening pathways could reduce the psychological burden on patients and improve their emotional and social functioning. Interventions that target maladaptive illness perceptions and enhance adaptive coping strategies, such as cognitive restructuring, self-compassion, and resilience training, may further mitigate the negative effects of chronic pain and uncertainty. Routine assessment of psychosocial factors, such as psychological

distress, illness perceptions, coping strategies, and social support, could complement medical evaluations. These psychosocial factors substantially shape HRQoL outcomes and often interact with symptom severity. Second, multidisciplinary care models combining gynecology, pain medicine, psychology, and physiotherapy may be beneficial to endometriosis patients, especially those with complex symptom profiles. These models support individualized treatment planning, strengthen self-management skills, and reduce care fragmentation. Third, patient-centered communication has been shown to build trust in the therapeutic relationship, improve treatment adherence, and positively impact HRQoL. As diagnostic delays and negative healthcare experiences contribute to psychological distress and reduced HRQoL, integrating patient-centered communication with early symptom recognition in primary care and establishing standardized referral pathways and systematic provider training are essential strategies for mitigating distress and supporting patients. Finally, given the substantial impact of endometriosis on social participation, work functioning, and intimate relationships, supportive workplace policies, couple-based interventions, and peer support programs may reduce isolation and stigma while strengthening social HRQoL. Together, the findings of the present review underscore the importance of integrated, multidisciplinary, psychosocially informed care models that address the intricate interplay between medical and psychosocial factors which influence HRQoL in endometriosis.

Conclusion

In sum, significant advancements have been made in understanding the medical (e.g., pain, infertility) and psychosocial (e.g., depression, relationships) impact of endometriosis on HRQoL across its physical, psychological, social, and environmental domains, yet key gaps remain. Endometriosis is a complex condition that extends beyond physical symptoms.

This review contributes to the field by synthesizing existing research, highlighting methodological limitations (e.g., lack of longitudinal, integrative designs) and underexplored factors (e.g., illness perceptions, coping strategies). By incorporating qualitative and quantitative research, it provides a broad perspective on HRQoL impairments. This review emphasizes medical and psychosocial aspects of endometriosis, contributing to a holistic understanding of the multidimensional impact. Importantly, our findings highlight that the interplay between medical and psychosocial factors is crucial in shaping HRQoL outcomes and developing effective support strategies. Future research should prioritize longitudinal designs, adopt holistic frameworks, and expand beyond adult populations to fully capture patients' experiences.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

ORCID iDs

Katharina A C Helgerth  <https://orcid.org/0009-0003-9679-8263>

Astrid Schütz  <https://orcid.org/0000-0002-6358-167X>

Data availability statement

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

References

1. Kohring C, Holstiege J, Heuer J, et al. Endometriose in der vertragsärztlichen Versorgung – Regionale und zeitliche Trends im Zeitraum 2012 bis 2022. *Zentralinstitut für die kassenärztliche Versorgung in Deutschland* 2022; 24(1): 1–25.
2. Johnson P, Hummelshoj L, Adamson GD, et al. World Endometriosis Society consensus on the classification of endometriosis. *Hum Reprod* 2017; 32(2): 315–324.
3. Calvi C, Sherman KA and Pham D. Loneliness and perceived social support in endometriosis: the roles of body image disturbance and anticipated stigma. *Int J Behav Med* 2024; 31: 433–444.
4. Kennedy S, Bergqvist A, Chapron C, et al. ESHRE guideline for the diagnosis and treatment of endometriosis. *Hum Reprod* 2005; 20(10): 2698–2704.
5. Chiantera V, Abesadze E and Mechsner S. How to understand the complexity of endometriosis-related pain. *J Endometr Pelvic Pain Disord* 2017; 9(1): 30–38.
6. Willer D, Peters G, Tesch K, et al. Endometriose – mehr als “nur” Dysmenorrhö! *Gynäkologie* 2023; 56: 445–453.
7. Maulitz L, Stickeler E, Stickel S, et al. Endometriosis, psychiatric comorbidities and neuroimaging: estimating the odds of an endometriosis brain. *Front Neuroendocrinol* 2022; 65: 100988.
8. Renner S, Burghaus S, Hackl J, et al. Endometriose. *Gynäkolog Endokrinol* 2013; 11: 115–128.
9. Macer ML and Taylor HS. Endometriosis and infertility: a review of the pathogenesis and treatment of endometriosis-associated infertility. *Obstet Gynecol Clin North Am* 2012; 39(4): 535–549.
10. La Marca A, Semprini M, Mastellari E, et al. Fertility preservation in women with endometriosis. *Hum Reprod Open* 2025; 2: hoaf012.
11. Bulletti C, Coccia ME, Battistoni S, et al. Endometriosis and infertility. *J Assist Reprod Genet* 2010; 27: 441–447.
12. Beyer S, Trillsch F, Kost B, et al. Langer Leidensweg bei Endometriose. *MMW Fortschr Med* 2022; 164(21–22): 64–66.
13. Zondervan KT, Becker CM and Missmer SA. Endometriosis. *N Engl J Med* 2020; 382(13): 1244–1256.

14. Rowlands IJ, Teede H, Lucke J, et al. Young women's psychological distress after a diagnosis of polycystic ovary syndrome or endometriosis. *Hum Reprod* 2016; 31(9): 2072–2081.
15. Friedl F, Riedl D, Fessler S, et al. Impact of endometriosis on quality of life, anxiety, and depression: an Austrian perspective. *Arch Gynecol Obstet* 2015; 292(6): 1393–1399.
16. World Health Organization. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* 1995; 41(10): 1403–1409.
17. Jones G, Kennedy S, Barnard A, et al. Development of an endometriosis quality-of-life instrument: the endometriosis health profile-30. *Obstet Gynecol* 2001; 98(2): 258–264.
18. Melis I, Litta P, Nappi L, et al. Sexual function in women with deep endometriosis: correlation with quality of life, intensity of pain, depression, anxiety, and body image. *Int J Sex Health* 2015; 27(2): 175–185.
19. Chen LC, Hsu JW, Huang KL, et al. Risk of developing major depression and anxiety disorders among women with endometriosis: a longitudinal follow-up study. *J Affect Disord* 2016; 190: 282–285.
20. Gatchel RJ, Peng YB, Peters ML, et al. The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychol Bull* 2007; 133(4): 581–624.
21. Baethge C, Goldbeck-Wood S and Mertens S. SANRA-a scale for the quality assessment of narrative review articles. *Res Integr Peer Rev* 2019; 4: 5.
22. Baumeister RF and Leary MR. Writing narrative literature reviews. *Rev Gen Psychol* 1997; 1(3): 311–320.
23. Ahmad M, Sechi C, Guerriero S, et al. Patient engagement, quality of life and chronic pain: a cross-sectional study on endometriosis. *J Health Psychol* 2024; 30(8): 1990–2000.
24. Jones G, Jenkinson C and Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obstet Gynaecol* 2004; 25(2): 123–133.
25. Souza CA, Oliveira LM, Scheffel C, et al. Quality of life associated to chronic pelvic pain is independent of endometriosis diagnosis - a cross-sectional survey. *Health Qual Life Outcomes* 2011; 9: 41.
26. O'Hara R, Rowe H and Fisher J. Self-management factors associated with quality of life among women with endometriosis: a cross-sectional Australian survey. *Hum Reprod* 2021; 36(3): 647–655.
27. De Graaff AA, D'Hooghe TM, Dunselman GA; WERF EndoCost Consortium. The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Hum Reprod* 2013; 28(10): 2677–2685.
28. Pessoa de Farias Rodrigues M, Lima Vilarino F, de Souza Barbeiro Munhoz A, et al. Clinical aspects and the quality of life among women with endometriosis and infertility: a cross-sectional study. *BMC Womens Health* 2020; 20(1): 124.
29. Roomaney R and Kagee A. Salient aspects of quality of life among women diagnosed with endometriosis: a qualitative study. *J Health Psychol* 2018; 23(7): 905–916.
30. de Barros Meneguetti M, Silva FP, Dias GN, et al. Assessment of quality of life and psychological repercussions in women with endometriosis according to pain intensity. *Psychol Health Med* 2022; 28(3): 660–669.
31. Nnoaham KE, Hummelshoj L, Webster P, et al. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011; 96(2): 366–373.
32. Kupec T, Kennes LN, Senger R, et al. The multifactorial burden of endometriosis: predictors of quality of life. *J Clin Med* 2025; 14(2): 323.
33. McPeak AE, Allaire C, Williams C, et al. Pain catastrophizing and pain health-related quality-of-life in endometriosis. *Clin J Pain* 2018; 34(4): 349–356.
34. Bieñ A, Rzońca E, Zarajczyk M, et al. Quality of life in women with endometriosis: a cross-sectional survey. *Qual Life Res* 2020; 29(10): 2669–2677.
35. Gallagher JS, DiVasta AD, Vitonis AF, et al. The impact of endometriosis on quality of life in adolescents. *J Adolesc Health* 2018; 63(6): 766–772.
36. Soliman AM, Coyne KS, Zaiser E, et al. The burden of endometriosis symptoms on health-related quality of life in women in the United States: a cross-sectional study. *J Psychosom Obstet Gynaecol* 2017; 38(4): 238–248.
37. Wu YH, Lu YY and Liu KF. Factors influencing health-related quality of life in women with endometriosis: a cross-sectional study. *Nurs Health Sci* 2024; 26(1): e13100.
38. Facchin F, Barbara G, Saita E, et al. Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. *J Psychosom Obstet Gynaecol* 2015; 36(4): 135–141.
39. Bieñ A, Pokropska A, Grzesik-Gąsior J, et al. Clinical factors affecting the quality of life of women with endometriosis. *J Adv Nurs* 2024; 81(8): 4667–4680.
40. Van Niekerk L, Johnstone L and Matthewson M. Health-related quality of life in endometriosis: the influence of endometriosis-related symptom presence and distress. *J Health Psychol* 2022; 27(14): 3121–3135.
41. Mundo-López A, Ocón-Hernández O, San-Sebastián AP, et al. Contribution of chronic fatigue to psychosocial status and quality of life in Spanish women diagnosed with endometriosis. *Int J Environ Res Public Health* 2020; 17(11): 3831.
42. Pehlivan MJ, Sherman KA, Wuthrich V, et al. Body image and depression in endometriosis: examining self-esteem and rumination as mediators. *Body Image* 2022; 43: 463–473.
43. Zarbo C, Compare A, Frigerio L, et al. Going beyond the surface: a mixed-method exploration of infertility-related quality of life of women with endometriosis. *Psychol Health Med* 2022; 28(10): 2832–2847.
44. Van Niekerk L, Steains E and Matthewson M. Correlates of health-related quality of life: the influence of endometriosis, body image and psychological wellbeing. *J Psychosom Res* 2022; 161: 110993.
45. Lökvist L, Boström P, Edlund M, et al. Age-related differences in quality of life in Swedish women with endometriosis. *J Womens Health* 2016; 25(6): 646–653.
46. Pontoppidan K, Olovsson M and Grundström H. Clinical factors associated with quality of life among women with endometriosis: a cross-sectional study. *BMC Womens Health* 2023; 23(1): 551.

47. Nogueira Neto J, Melo VG, Lima LCS, et al. Improved quality of life (EHP-30) in patients with endometriosis after surgical treatment. *Rev Assoc Med Bras* 2023; 69(8): e20230316.
48. Ribeiro PA, Sekula VG, Abdalla-Ribeiro HS, et al. Impact of laparoscopic colorectal segment resection on quality of life in women with deep endometriosis: one year follow-up. *Qual Life Res* 2014; 23(2): 639–643.
49. Tiringier D, Pedrini AS, Gstoettner M, et al. Evaluation of quality of life in endometriosis patients before and after surgical treatment using the EHP30 questionnaire. *BMC Womens Health* 2022; 22(1): 538.
50. Valentin L, Canis M, Pouly JL, et al. SF-36 preoperative interest of predicting improvement of quality of life after laparoscopic management of minimal endometriosis. *J Gynecol Obstet Hum Reprod* 2017; 46(2): 137–142.
51. Geukens EI, Apers S, Meuleman C, et al. Patient-centeredness and endometriosis: definition, measurement, and current status. *Best Pract Res Clin Obstet Gynaecol* 2018; 50: 11–17.
52. Nielsen LJ, Poulsen K, Funch AL, et al. The lived experiences of endometriosis in adolescence—a critical hermeneutic perspective. *Scand J Caring Sci* 2023; 37(4): 1038–1047.
53. Sullivan-Myers C, Sherman KA, Beath AP, et al. Delineating sociodemographic, medical and quality of life factors associated with psychological distress in individuals with endometriosis. *Hum Reprod* 2021; 36(8): 2170–2180.
54. Márki G, Bokor A, Rigó J, et al. Physical pain and emotion regulation as the main predictive factors of health-related quality of life in women living with endometriosis. *Hum Reprod* 2017; 32(7): 1432–1438.
55. Guillemot C, Klinkenberg J and Sordes F. The psychopathological repercussions on patients faced with pain: a focus on endometriosis. *L'Encephale* 2024; 50(3): 289–295.
56. Güvenç İB and Bozo Ö. Health-related quality of life of women with endometriosis: an attachment-diathesis model of chronic pain perspective. *Health Care Women Int* 2023; 45(4): 412–429.
57. González-Echevarría AM, Rosario E, Acevedo S, et al. Impact of coping strategies on quality of life of adolescents and young women with endometriosis. *J Psychosom Obstet Gynaecol* 2019; 40(2): 138–145.
58. Grinberg K, Sela Y and Nissim S. The psychological well-being, catastrophizing, and quality of life among women diagnosed with endometriosis. *Womens Health Rep* 2024; 5(1): 860–866.
59. Skinner CM and Kuijter RG. Self-compassion and health-related quality of life in individuals with endometriosis. *Psychol Health* 2024; 40(9): 1479–1496.
60. Van Niekerk LM, Dell B, Johnstone L, et al. Examining the associations between self and body compassion and health-related quality of life in people diagnosed with endometriosis. *J Psychosom Res* 2023; 167: 111202.
61. Rees M, Kiemle G and Slade P. Psychological variables and quality of life in women with endometriosis. *J Psychosom Obstet Gynaecol* 2022; 43(1): 58–65.
62. Barberis N, Cannavò M, Cuzzocrea F, et al. Illness perceptions and factors of distress as mediators between trait emotional intelligence and quality of life in endometriosis. *Psychol Health Med* 2023; 28(7): 1818–1830.
63. Moore C, Cogan N and Williams L. A qualitative investigation into the role of illness perceptions in endometriosis-related quality of life. *J Health Psychol* 2023; 28(12): 1157–1171.
64. Spinoni M, Capano AU, Porpora MG, et al. Understanding the psychological factors linking pelvic pain and health-related quality of life in endometriosis: the influence of illness representations and coping strategies. *Am J Obstet Gynecol* 2024; 233(1): 54e1–54e10.
65. Matías-González Y, Sánchez-Galarza A, Rosario-Hernández E, et al. Stigma and social support and their impact on quality of life and self-esteem among women with endometriosis in Latin-America and the Caribbean. *PLoS Glob Public Health* 2022; 2(12): e0001329.
66. van Poll M, van Barneveld E, Aerts L, et al. Endometriosis and sexual quality of life. *Sex Med* 2020; 8(3): 532–544.
67. Del Forno S, Raspollini A, Doglioli M, et al. Painful sexual intercourse, quality of life and sexual function in patients with endometriosis: not just deep dyspareunia. *Arch Gynecol Obstet* 2024; 310(6): 2091–2100.
68. Jaeger M, Niederkrotenthaler T, Till B, et al. Associations between health-related quality of life, infertility-related psychological well-being, and relationship quality in individuals with endometriosis: a cross-sectional study. *BMC Womens Health* 2024; 24(1): 657.
69. Röhner J, Thoss PJ and Schütz A. Lying on the dissection table: anatomizing faked responses. *Behav Res Methods* 2022; 54(6): 2878–2904.
70. Della Corte L, Di Filippo C, Gabrielli O, et al. The burden of endometriosis on women's lifespan: a narrative overview on quality of life and psychosocial wellbeing. *Int J Environ Res Public Health* 2020; 17(13): 4683.
71. Marinho MCP, Magalhaes TF, Fernandes LFC, et al. Quality of life in women with endometriosis: an integrative review. *J Womens Health* 2018; 27(3): 399–408.
72. Missmer SA, Tu FF, Agarwal SK, et al. Impact of endometriosis on life-course potential: a narrative review. *Int J Gen Med* 2021; 14: 9–25.
73. Heng FW and Shorey S. Experiences of endometriosis-associated infertility among women and their partners: a qualitative systematic review. *J Clin Nurs* 2022; 31(19–20): 2706–2715.
74. Colombo GE, Vijayanathan S, Breton Z, et al. Health-related quality of life in individuals with endometriosis and mental health symptoms: a scoping review. *J Endometriosis Uterine Disord* 2025; 9: 100105.
75. Culley L, Law C, Hudson N, et al. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update* 2013; 19(6): 625–639.
76. Kalfas M, Chisari C and Windgassen S. Psychosocial factors associated with pain and health-related quality of life in endometriosis: a systematic review. *Eur J Pain* 2022; 26(9): 1827–1848.
77. Aerts L, Grangier L, Streuli I, et al. Psychosocial impact of endometriosis: from co-morbidity to intervention. *Best Pract Res Clin Obstet Gynaecol* 2018; 50: 2–10.