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Understanding the impact of endometriosis on women's life: an integrative review of systematic reviews

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Abstract

Background Endometriosis is a challenging chronic condition with a significant impact on women's well-being. This systematic review of systematic reviews aims to assess the evidence investigating the intricate interplay between endometriosis and quality of life (QoL).

Methods A systematic review was performed for English-language studies up to January 2022 to identify systematic reviews with and without meta-analysis analyzing quantitative or qualitative data The following databases were searched: Scopus, PubMed, Embase, Web of Science and Cochrane Central Register of Controlled Trials. Participants/population were women with endometriosis, and the outcomes included were all reported outcomes evaluating the impact of endometriosis on women's QoL (PROSPERO 2021 CRD42021289347).

Results 15 systematic reviews were identified. 8 included meta-analysis: 4 explored the prevalence of mental health problems, and 1 analyzed, respectively, the overall impact of endometriosis, headache migraine, and sexual function. 7 articles reported on the mental consequences, and three sexual functioning. One was a qualitative review. The impact of the relationships with the healthcare system was analyzed in 3 reviews. Pain is a hallmark of endometriosis. Infertility and sexual problems are also frequent. Depression, anxiety, and stress represent significant contributors to lessening women's QoL. Women have frustrating relationships with the healthcare system: the complex and long diagnostic process, lack of treatment effectiveness, and persistence of symptoms contribute to emotional challenges. Negative cognitive patterns developed by women with emotional distress, such as catastrophizing and fear-avoidance behaviors, amplify the experience of pain.

Conclusion The limitations of this review are the high degree of heterogeneity of papers that include many factors, including comorbidities, and use of medical care that may impact QoL, and that most of them were cross-sectional. Endometriosis is a chronic disease that significantly impacts all domains of women's lifes. Pain, infertility, and stress linked with depression, and anxiety significantly influence QoL. Women are dissatisfied with the care they receive.

Keywords Endometriosis, Quality of life, Pelvic pain, Social wellbeing, Mental health, Sexual life, Infertility

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Background

Endometriosis is a challenging chronic condition affecting millions of women of reproductive age worldwide [1]. It is manifested by the presence of functionally active endometrial stroma and glands outside the uterine cavity [2]. Women with this condition experience chronic pelvic pain, dyspareunia, dysmenorrhea, dysuria, and dyschezia [3]. Infertility is also frequently associated with endometriosis [4]. Symptoms tend to worsen with advanced stages, especially in case of deep infiltrating endometriosis. Several theories have been proposed to explain its pathogenesis, but the complex processes behind the development of endometriosis remain unclear [5–7]. Increasingly, endometriosis is considered not only as a pelvic localized process but a systemic condition, as it features chronic neuro-inflammation and hormone changes leading to multidimensional effects of the disease with a higher prevalence of other conditions [8, 9] including mental health problems [10].

Diagnosis of endometriosis is challenging, because of the absence of specific biomarkers, while imaging may not be definitive. There is no specific symptom either that could be solely attributed to endometriosis [11]. Delayed diagnosis and ineffective treatments stemming from a lack of understanding of endometriosis etiology and its variability in progression pose significant challenges in disease management [12]. The diversity in clinical course and diagnostic complexities also contributes to the variability in estimates of its prevalence and incidence [13], which are dependent on the type of data and the design used for those analyses [14].

Overall, endometriosis has detrimental effects on women's functional status and physical, mental, social, and sexual well-being [15–19]. All listed disruptive physical and psychosocial symptoms can be disabling.

Given that endometriosis mostly affects women of reproductive age, which is also active work age, imposes a considerable social and economic burden, both for women as well as for society's economy at large [20, 21]. Although presenting with debilitating symptoms that sometimes remain invisible to the clinician's eye, endometriosis continues to be experienced and lived by the patient.

QoL is a broad concept that has been defined by the World Health Organization as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards, and concerns, that incorporate physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment [22]. The QoL of women with endometriosis has been investigated from different perspectives and methods. However, these analyses focus on specific aspects or domains, limiting to providing a comprehensive perspective of such a diverse and heterogeneous health condition. This review aims to systematize the available evidence investigating the intricate interplay between endometriosis and QoL, considered from a broad perspective, including physical and mental well being, and to provide an integrated understanding of the challenges faced by women living with endometriosis.

Methods and materials

A systematic review of systematic reviews was performed following the recommendations of the Centre for Reviews and Dissemination and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [23] and AMSTAR [24]. This review was registered at the International Prospective Register of Systematic Reviews PROSPERO (Prospero ID: PROSPERO 2021 CRD42021289347).

A systematic review of the literature search was performed for English-language studies up to January 2022 using the terms "life", "quality of life", "health related quality of life", "social well-being", "mental wellbeing", "sexual life", "relationships", "depression", "anxiety" in combination with "endometriosis". Only systematic reviews with and without meta-analysis analyzing quantitative or qualitative data with full-text availability were included. Additional articles were identified by manual searching of the references of the retrieved reviews.

The following databases were searched for the potentially eligible studies: Scopus (1), PubMed (2), Embase (3), Web of Science (4), and Cochrane Central Register of Controlled Trials (CENTRAL) (5). Grey literature (6) also was searched. The search strategy included terms refer to the two key domains of interest: (1), endometriosis and systematic review (2).

The search terms within each domain included:

1) "endometriosis" OR "pelvic pain" OR "endometriosis health profile" AND.
2) "systematic review".

Studies were eligible if they evaluated the impact of endometriosis on women's QoL using systematic review and(or) meta-analysis methodology. Studies were excluded if they meet one of the following conditions: (1) focus specifically on the properties of the different available instruments to measure QoL, (2) non-research-based articles, such as conference abstracts, commentaries, opinion pieces, book chapters, and editorials; (3) narrative, descriptive, scoping and realist literature reviews; (4) are not written using the Latin alphabet, Russian or Kazakh; (3) abstract was not available; (5) or full text was not available. The condition or domain being used was the impact of endometriosis on women's QoL.

Participants/population were women diagnosed with endometriosis, and the outcomes were all reported outcomes evaluating the impact of endometriosis on women's QoL.

Data extraction (selection and coding)

Titles and abstracts were screened following inclusion criteria by a first reviewer (AK). A random sub-sample of 20% of titles and abstracts were screened by a second reviewer (TM, DM) to ensure the accuracy of selection. All included papers were read in full and assessed again for relevance to the research question and inclusion criteria (AK, TM, DM). During the full-text review, articles were independently assessed for eligibility by the primary reviewer (AK) and review team members (TM, DM). In case of discrepancies, the topic of disagreement was resolved through discussion with a third reviewer (ASS). A data extraction form was developed and piloted with a random selection of 10% of the included papers. Extracted data was collated in a table produced in MS Excel. The following elements were extracted from each review: Authors, Search period, Quality assessment, Number of articles reviewed, Meta-analysis, Fndings, Implications for research, and Implications for clinical practice.

AMSTAR [24] critical appraisal tool for systematic reviews was used to assess the quality of included studies. A narrative synthesis approach [25] was applied to explain and integrate our findings. This process included the following steps:

1) Preliminary synthesis, which aims to describe patterns across the included studies in terms of the differences in QoL. Textual descriptions of studies and tabulation were used as specific tools.
2) Exploring relationships in the included data, which aims to take into consideration the experiences of women diagnosed with endometriosis.
3) Generalising conclusions on the outcomes of interest.

Results

The PRISMA flow diagram (Fig. 1) shows the exclusion of studies after a rigorous check on screening and full-text assessment at each of the stages. After eliminating duplicates, a total of 919 articles were screened, and 100 papers were checked for suitability according to the predefined inclusion criteria, of which 13 systematic reviews were selected; additionally, 2 reviews were included from the references of papers found in the initial stages.

15 papers were subjected to data extraction (for details, see Table 1) and for generating the main themes analyzed in this paper [3, 10, 26–38]. 8 papers included

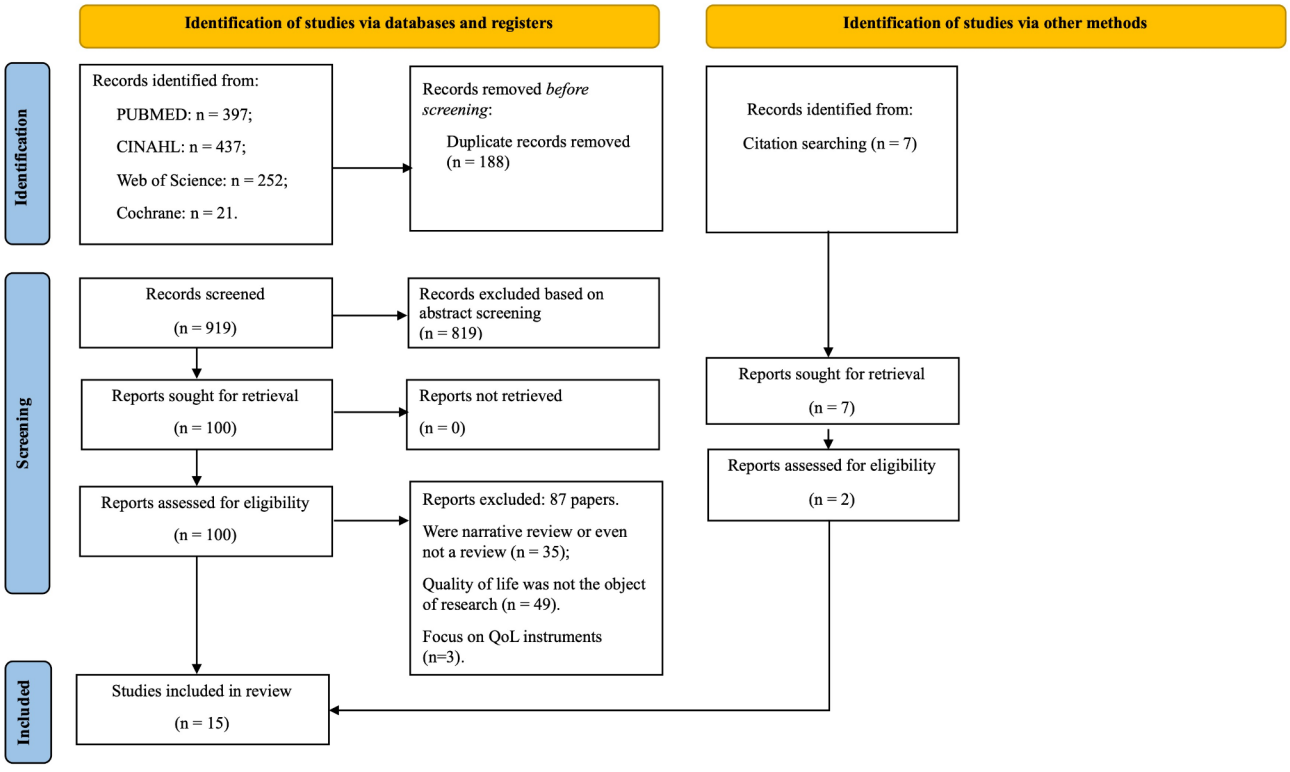

Fig. 1 PRISMA flow diagram

Table 1 Endometriosis SR QoL evidence table

	Authors	Search period	Quality assessment	Number of articles reviewed	Meta-analysis	Findings	Implications for research	Implications for clinical practice
1	**van Barneveld et al., 2022** [3]	Until June 2020	Newcastle-Ottawa	47 for SR, 17 for MA	Yes	Anxiety and depression are frequent in endometriosis and interrelated with pain perception. Other intercorrelated factors included age, QoL, quality of sleep, fatigue, sexual function, gastrointestinal symptoms, comorbidity, self-esteem, emotional self-efficacy, coping style, social adjustment, pain imagery, and pain sensitization.	Investigate the process that may link endemotriosis, depression, anxiety and pain	Integrated patient-centred approach to medical, psychological and sexual issues.
2	**Brasil et al., 2020** [8]		Newcastle-Ottawa	15	Yes	Stress has a high prevalence in endometriosis and may have an important role in enhancing inflammatory and pain mechanisms, which is also linked with sexual function and infertility, although the ethipatogenic mechanisms are unclear.	Better understanding of the underlying mechanisms linking endometriosis, pain and psychological stress.	Interdisciplinary team providing psychological care beyond pain management, aiming to emotion regulation strategies adapted to women's needs.
3	**Barbara et al., 2017** [26]	January 2000 - September 2016	not mentioned	9	No	Women with endometriosis have frequent sexual dysfunctions not limited to deep dyspareunia suggesting the effect of psychosocial factors, including emotional distress associated with the disease and quality of intimate relationships.	Investigate the global sexual impact of endometriosis, focusing not only on pain during intercourse but also on psychological and relational dimensions, including the partner's sexual functioning.	Personalized management program, cooperation between different professional figures, routine "screening" on sexual health, training in sexual health for medical students
4	**Chaman-Ara and Bahrami, 2017** [27]	Until November, 19, 2016	Checklist designed based on STROBE	7	Yes	Endometriosis affects all aspects of women's QoL and has the most negative effect on control and powerlessness and infertility. Also, it has the least negative effect on the self-image as well as in the relationship with medical profession.		Early diagnosis and developing effective treatment protocols are very important to prevent the reduction of QoL due to endometriosis.

Table 1 (continued)

	Authors	Search period	Quality assessment	Number of articles reviewed	Meta-analysis	Findings	Implications for research	Implications for clinical practice
5	**Delanerolle et al., 2021** [28]	November 1995–30 November 2020		34 papers and 15 in the meta-analysis.	Yes	Depression and anxiety are frequently reported in endometriosis. Studies investigating mental health problems in endometriosis present significant limitations, preventing to provide a valid estimates of the impact of those problems. Pain and dyspareunia are also recurring themes in endometriosis.	Good designed and powered enough studies to analyze the complex relationships and directionality between endometriosis, pain and mental health problems.	Holistic management requires understanding the applicability of existing instruments to assess QoL and whether these could be harmonized. Finally, the mental burden and its associated pain disorders should be determined to improve clinical practices.
6	**Gambadauro et al., 2019** [29]	September 2017	Modified Newcastle-Ottawa Scale	27	Yes	The association between endometriosis and depressive symptoms is largely determined by chronic pain but may also be modulated by psycho-social individual and context vulnerabilities. Self-esteem and self-efficacy are associated with psychological well-being, independently of pelvic pain.	Investigate the clinical and social burden associated with early diagnosis and treatment of depression as well as the interaction in infertile women.	Awareness of the complex relationship between endometriosis and depressive symptoms has to inform tailored patient-centered care. New paradigm of care has to be directed toward improving the mental health of all women with pelvic pain and depression, shifting care from a clinical focus on lesions and their removal, to more pragmatic on treating symptoms.
7	**Jenabi et al., 2021** [30]	all existing publications until May 2020	Newcastle Ottawa Statement Manual	9	Yes	There is a significant association between endometriosis and migraine headaches. Endometriosis and migraine share some symptoms and risk factors, having many similarities regarding epidemiology, pathogenesis, and physical or psychiatric comorbidities.	Investigate the molecular physiopathology of these two conditions, exploring the possible effect of biochemical mediators, like prostaglandins or up-regulation or dis-regulation of nitric oxide synthesis.	Consider migraine as a differential diagnosis in headaches in women with endometriosis.

Table 1 (continued)

	Authors	Search period	Quality assessment	Number of articles reviewed	Meta-analysis	Findings	Implications for research	Implications for clinical practice
8	**Jia et al., 2012** [31]	Until May 2012	standardized checklist with small modifications	39	No	Women with endometriosis reported significant impairments in QoL, since pelvic pain intensity was negatively associated with QoL.	Investigate the directionality and independent effect on QoL of pain, infertility and features as extension, duration of endometriosis.	Endometriosis management from the woman's point of view has to address the associated emotional, sexual, and social problems. Thus, a multidisciplinary strategy involving a pain clinic and counseling is recommended.
9	**Kalfas et al., 2022** [32]	Until April 2021	Quality assessment criteria developed by the authors	27	No	Catastrophising and anxiety were the factors most consistently associated with greater pain, whilst depression, anxiety, and stress were related to worse QoL. Findings regarding depression and pain were mixed, and research on social factors was limited.	Investigate psychosocial approaches that may improve emotional functioning, reduce pain impact, and enhance women's QoL: how social factors influence the perception of women of their health and disease: and the role that protective factors for pain and QoL (e.g., cognitive flexibility, acceptance) may have.	Care for women with endometriosis has to focus on their individual needs, exploring the whole socio-psychological dimenions. Pain has to be properly estimated and addressed in clinical care which has to focus on what is important for women, potentially reducing distress and impact.

Table 1 (continued)

	Authors	Search period	Quality assessment	Number of articles reviewed	Meta-analysis	Findings	Implications for research	Implications for clinical practice
10	**Leite Ferreira et al., 2016** [33]	January 2010 - October 10th 2015	not mentioned	18	No	Endometriosis affects the everyday lives of women, hindering their daily activities, in personal relationships, and interfering with their reproductive capacity. Endometriosis has a physical, mental, and adverse impact on social well-being and thus negative effect on QoL. The impact of endometriosis is related to the complex interactions between pain, fertility, sexuality, and ability to work and maintain personal relationships.	Investigate the development and implementation of biopsychological model of care that consider the multidimensionality of endometriosis including that includes emotional support, stress reduction, social support, coping strategies, psychosexual treatment and focus on sex and relationships, control of pain and career counseling	To improve QoL, it is necessary to understand patients according to their clinical condition. Women have to be informed of the treatment options and decide on how best to adapt to their needs. Treatment should not only aim to eradicate the underlying condition but improve QoL and also the emotional, sexual and social problems that come with the disease. Patients heve to learn how to deal with chronic pain, to explore ways to have sexual intercourse without pain and to strengthen relations with its partners and friends so that they are in solidarity in dealing with the disease.

Table 1 (continued)

	Authors	Search period	Quality assessment	Number of articles reviewed	Meta-analysis	Findings	Implications for research	Implications for clinical practice
11	**Norinho et al., 2020** [34]	January 2000 - December 2020	not mentioned	10	No	Dyspareunia is a frequent complaint, but lack of communication about sexuality, sexual problems or dysfunction, and avoidance of sexual intercourse have an impact on sexual function and relationships. Catastrophising pain and depression and anxiety symptoms may have, indirectly, also an impact. Endometriosis has a profound impact on partners, affecting many life domains including sex, intimacy, and the relationship in general.	Future research is needed to investigate ways to address the male partner and the relationship as a whole. Data suggests that male partners should not be overlooked in the treatment of endometriosis and that psychosocial support including sexual and couple therapy might be beneficial.	Partners should not be overlooked in the treatment of endometriosis and that psychosocial support including sexual and couple therapy might be beneficial
12	**Perez Lopez et al., 2020** [35]	Until March 9 2020	Newcastle–Otawa	4	Yes	Women with endometriosis have an increased risk of sexual dysfunction and dyspareunia. There is no association between anatomical or clinical symptoms, dyspareunia, chronic pain, and sexual distress. Metacognitive beliefs may have more influence on sexual distress than pain. Alterations of sexual function in women with endometriosis are related to anxiety, depression, sleep problems, excessive body weight, and less physical activity.	Investigate dyspareunia along with the use of tools that evaluate depressive/anxiety symptoms, and emotional and sexual function.	Consider the impact on sexual function in women with endometriosis, and severity of dyspareunia and chronic pelvic pain

Table 1 (continued)

	Authors	Search period	Quality assessment	Number of articles reviewed	Meta-analysis	Findings	Implications for research	Implications for clinical practice
13	**Pope et al., 2020** [36]	Until December 2014	not mentioned	18	No	Women with endometriosis are at risk for psychosocial disturbances and psychiatric distress. Pain is not associated with the stage of the condition and did not dissipate with treatment, but has a has a multifactorial etiology, including central sensitization. Chronic pain is associated with negative psychological, physical, and social consequences, depression and anxiety. Long delays in diagnosis and hard-to-manage symptoms increase stress, sexual dissatisfaction, and decreased self-esteem, and increase the risk for psychiatric complications.	Investigate the directionality of the associations between psychosocial disruptions, pain, sexual dysfunction and the effect that fertility has as well as the role that systemic inflammatory conditons may play.	Women with endometriosis should be be screened for potential social, relationship, and psychiatric disturbances.
14	**Wang et al., 2021** [37]	Until May 2020	Newcastle-Ottawa	44 (31 related to depression, 22 related to anxiety, and 17 using the SF-36.	Yes	Endometriosis is associated with depression, anxiety and reduced QoL, probably due to pain. The psychological effects of endometriosis extend beyond mental health, as patients display somatization, sensitivity, fatigue and insomnia. Endometriosis has persistant long time effects on economic pressure, career development, sexual relations, marital status.	Investigate the directionality of the association between endometriosis and mental health and their effect on QoL, and study psychosocial interventions for endometriosis	The purpose of treatment for endometriosis should be pain control, improvement of quality of life, prevention of disease recurrence, fertility preservation, and the reduction of anatomical damage. Consider psychological factors for managing the disease and selecting the most appropriate therapy.

Table 1 (continued)

	Authors	Search period	Quality assessment	Number of articles reviewed	Meta-analysis	Findings	Implications for research	Implications for clinical practice
15	**Young et al., 2015** [38]	not mentioned	Quality assessment criteria developed by the authors	18	No	Endometriosis affects all areas of a woman's life, most notably sex life, social life and work life. Despite the many symptoms associated with endometriosis (such as nausea, diarrhoea and fatigue), pain (including during intercourse) and infertility are mostly investigated. Women report frustration in their relationship with care they receive. Painful sexual intercourse, work productivity losses because of the lack of flexibility to accommodate the needs of women with endometriosis; emotional difficulties to the ramification of living with a complex condition; pain and delays in diagnosis are factors that affect women's QoL.	Investigate women's experience with infertility taking also into account fertility goals; and how endometriosis inhibits social participation. Ensure diversity ensure diversity among participants in terms of age, socioeconomic status, cultural and linguistic background, and sexual identity.	Given the chronic nature of endometriosis, long-term management plans are necessary, with a focus on supporting women and enhancing their experience with healthcare: diagnostic process, impact of symptoms on women's life: explore the impact on sex life.

quantitative synthesis performing meta-analysis: 4 explored the prevalence of mental health problems, and 1 analyzed, respectively, the overall impact of endometriosis [27], headache migraine [30], and sexual function [34]. Seven articles reported on the mental consequences [3, 10, 30, 32, 36, 37]. Three articles explored sexual functioning and relationships [23, 34, 35]. One qualitative review was on patients' experiences living with endometriosis [38]. The impact on QoL of the relationships with the healthcare system and professionals was specifically investigated in 3 reviews [27, 36, 38], however, all 15 indicated recommendations to improve clinical care for women with endometriosis, as well as 14 of them included recommendations for further research.

Results from the reviews confirm the significant impact on QoL of endometriosis, and how their diverse and interrelated symptoms and impairments influence numerous aspects of women's lives at specific points of time but also over the years, from adolescence through menopause, affecting physical, mental, and emotional health, family, social life and leisure time, work productivity [39], hampers educational attainment [40], alters career choices and success [41] and impairs sexual and couple's life [42].

Table 2 shows the risk assessment of the selected studies based on the AMSTAR criteria. Most of the studies had a quality. The main problem is that several of these reviews did not have clear inclusion and exclusion criteria in their respective methods section, as indicated by explicit PICO questions.

The most relevant findings of this review address the following major themes are reflected in Fig. 2.

Pain

Chronic pain is the most prominent symptom of endometriosis [43] as well as the major stressor and most relevant contributor to lower scores in QoL [37, 44]. Women describe pain as a controller of their life; they are concerned by pain's duration and quality not just site and duration as screened by health professionals [38]. Leite Ferreira et al. mentioned the disabling effect of pain on the daily routines of women as it disturbs

Table 2 Quality of included systematic reviews and meta-analysis based on AMSTAR criteria

	Author	PICO	Review methods	Selection of study designs	Comprehensive search	Duplicate selection	Duplicate extraction	Justify exclusions	Detail description of included studies	Risk of bias
1	Barbara	Partial	Yes	Yes	No	Yes	Yes	Yes	Yes	No
2	Barnevald	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3	Bourdel	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4	Brasil	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5	Chaman-Ara	Partial	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6	Delanerolle	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
7	Denny	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Partial	Yes
8	Gambadauro	Partial	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
9	Jenabi	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
10	Jia	Partial	Yes	Yes	Yes	Yes	Yes	Yes	Partial	No
11	Jones	Yes	Yes	Yes	Yes	No	No	Yes	Partial	Yes
12	Leite Ferreira	Partial	Yes	Yes	Yes	No	No	Yes	Yes	No
13	Norinho	Partial	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
14	Perez Lopez	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
15	Pope	Partial	Yes	Yes	Yes	No	No	No	Yes	No
16	Wang	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
17	Young	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No
18	Kalfas	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

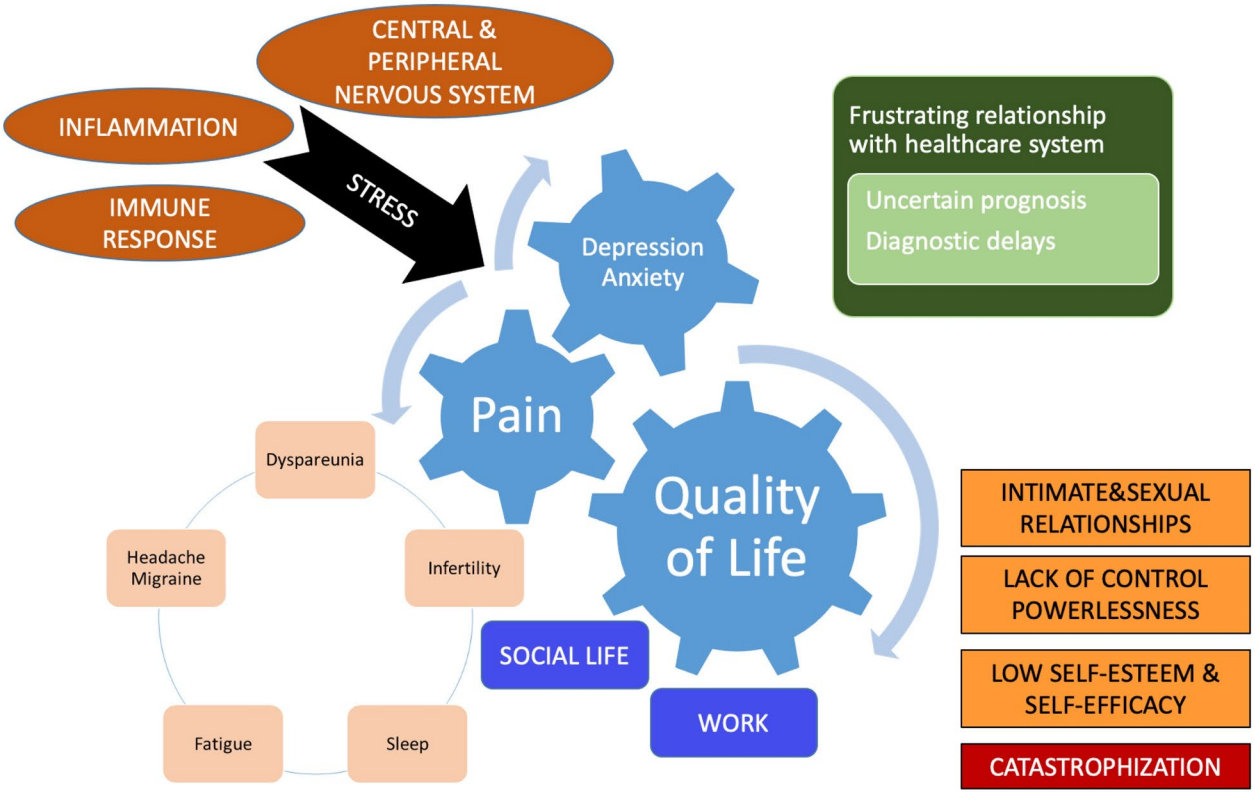

Fig. 2 Interconnections of factors associated with lowered Quality Life of Women with Endometriosis

sleeping, eating, and moving but also during sexual intercourse, bladder expansion, and bowel movements [33]. Jia et al. explored differences in QoL comparing patients with chronic pelvic pain with and without endometriosis, finding no differences between those having or not having endometriosis [31]. Of note, pain is not directly correlated with the extent of the endometriosis stage or extension [45] but is found to be greater in the presence of concurrent depression, anxiety, and catastrophizing disorders [32].

Social impact of endometriosis

The symptoms and effects of endometriosis have a significant influence on women in all domains of their lives [33, 38]. Young et.al's qualitative review described women's experiences of endometriosis in public when they had to plan their life around the symptoms and the feeling of losing their life to the condition [38]. Significant losses of productivity due to absenteeism and presenteeism have been reported [33]. Avoidance of disease reporting to employers and discussion with colleagues - especially men - are measures taken by women so as not to be blamed for making a disease an excuse for missing work and duties [38]. Some women are forced to reduce their workload or leave the job due to severe symptoms [38] or may feel guilty for not being able to work [46].

Physical impact of endometriosis

Women with endometriosis suffer from diverse physical health ailments. This could be related to somatization, but also to systemic syndrome mediated by neuro-endocrine-inflammatory mechanisms associated with endometriosis, which currently is being considered not a localized pelvic but a systemic conditon [10]. Thus, the association between migraine and endometriosis was reported in several studies [30]. The findings were attributed to the biochemical changes in chronic inflammation accompanying endometriosis with raised levels of prostaglandins also contributing to migraine pathogenesis [47].

Mental health impact of endometriosis

Women with endometriosis also show consistently higher intensity and severity of depression and anxiety [29, 37]. While the Global burden of mental health in women of reproductive age is estimated at 4.5-7% for depressive and 5.5-6% for anxiety disorders [48], the prevalence of depression and anxiety among women with endometriosis ranges from 20 to 85% [3, 28, 36]. And, remarkably, in women with endometriosis, the presence and severity of pain are a key determinant of higher scores of depressive symptoms [28, 29].

Brasil et al. demonstrated high rates of psychological stress levels in nearly 70% of women with endometriosis [10], suggesting that stress-induced central sensitization and neuro-immunological pathways activated by high levels of cortisol could be contributing factors in endometriosis [10]. Psychological distress that represents living with chronic pain is lined with the severity of depression or anxiety which are better predictors of QoL than the severity or extension of endometriosis lesions [48, 49, 50].

Sexual life and couple relationships impact of endometriosis

Up to 60–70% of women complain of some form of sexual dysfunction affecting QoL. Conditioned experience of painful intercourse led to a disturbed sexual life characterized by partial or complete avoidance of it [26, 34]. Dyspareunia brings other detrimental effects that further aggravate the sexual life of a woman such as diminished sexual desire, arousal, lubrication, and orgasm. The meta-analysis of Perez-Lopez et al. reported that women with endometriosis score lower in each domain of the Female Sexual Function Index (desire, arousal, lubrication, orgasm, satisfaction, pain) and showed higher levels of pain scores for dyspareunia and chronic pain compared to those without endometriosis [35]. Emotional distress and the quality of sexual relationships also affect couples' lives, as found by Norinho et al., who explored the topic by examining couples' perceptions of relationships and sexual life. A significant finding is the correlations between sexual problems and dyspareunia and worse sexual performance with mental anguish and the subsequent detrimental effect on relationships, which alters the reproductive goals of couples, and also generates negative emotions in women's partners [34].

Infertility

Infertility is a problem commonly associated with endometriosis however its impact on women's QoL is not consistent. Chaman-Ara, Wang, and Leite Ferreira found this association in their meta-analysis [27, 33, 37], suggesting that the inability to have a child causes depression and feelings of inadequacy among women, uncertainty about future fertility, and affects sexual and intimate relationships. This, in turn, can negatively influence patients' self-esteem and even cause problems in marital relationships, exerting persistent psychological pressure on patients. Over time, this can lead to further deterioration in the QoL of endometriosis patients. However, the results of other reviews [3, 31] did not confirm this effect.

Relationship with healthcare

There are frequent complaints from women with endometriosis of dissatisfaction and frustration with the care they receive. The complexities and uncertainties of the disease (related to pathophysiology, staging, severity, and treatment responses) and its clinical management

[27], generate a feeling of lack of control, loss of vitality and energy, decreased self-esteem, difficulties regulating emotions, and low sleep quality, contributing to a vicious cycle of catastrophizing that further deteriorate their QoL [51]. The long time required to diagnose endometriosis leads to frustration and isolation and increases psychological distress, shame, anxiety, and depressive symptoms. Delayed diagnosis may contribute to the exacerbation of symptoms, prolonged pain, increased stress, and sexual dissatisfaction [12–14, 32], and may impact initiating treatment, and hence the QoL. The disease may also progress, and worsen every cycle; meanwhile, the woman will suffer from the consequences of the progression of the disease in their routines. Patients heve to learn how cope with the daily impact of endometriosis, manage pain, and explore ways to maintain their sexuality, couples and social life [32].

Women with endometriosis express that often they experience stigma, invalidation, and dismissal from health professionals, especially primary care professionals. In the opinion of women, doctors' attitudes and courses of action further delayed diagnosis. Some women had to persuade their primary care providers to refer them to a gynecologist, and they felt vindicated when they were finally diagnosed after having their symptoms dismissed or disbelieved by relatives, friends, colleagues but also health professionals. Diagnosis validated women's experiences and provided a medical term with which they could explain their symptoms to others.

Discussion

The purpose of this review of systematic reviews was to provide a comprehensive overview of the literature assessing the burden that endometriosis represents on women's lives and how it impacts their QoL and wellbeing. In total, this review incorporates the findings of 15 systematic studies, including 6 meta-analyses, that have explored the impact of endometriosis on QoL of women. Findings reflect the complex interaction between different factors, which span from biomedical through psycho-social and medical care. This review may help to emphasize the need for develop integrative research projects as well as to develop comprehensive support and empathy for those affected by the condition. QoL is critical in chronic health problems like endometriosis, as it represents the most important predictor of total direct and indirect costs [52].

Findings from this review provides support for the need to consider the interconnected and multifactorial effects (physical, mental, and emotional) that extend across women's lifespan, together with the complex relationship with the healthcare system [53]. Throughout a lifetime, these difficulties make it harder for women to reach certain milestones, including completing school or continuing education, deciding on a career path, establishing stable, fulfilling relationships, or starting a family [41].

Chronic pelvic pain, of variable type, duration, and intensity, is a hallmark symptom of endometriosis. Pain may be associated with menstruation, sexual activity, or other activities [54]. However, there is no connection between the severity of the extension of the endometrial lesion or the progression of the disease and pain [55]. The exact mechanisms causing pain in endometriosis are not fully understood but mutual influences between central and peripheral nervous sensitizations play a key role in pain modulation [19]. Chronic systemic inflammation, prostaglandins, and cytokines [56] as well as circulating immune cells, and hormonal changes may contribute to both peripheral – through heightened responsiveness of sensory nerves to pain signals – and central sensitization – involving changes in the central nervous system that amplify the perception of pain reducing pain thresholds [57]. Psychological factors, such as anxiety and depression, may activate the sympathetic nervous system leading to increased release of stress hormones and exacerbate central sensitization by influencing the perception and processing of pain signals. Pain may also be exacerbated by possible interactions with the emotional distress generated by frequent problems occurring in endometriosis, like deteriorated sexual relationships [58] or infertility [59], and ultimately worsening QoL [60].

Migraine is also frequent in endometriosis, and may also increase excitability of the central nociceptive system resulting in hypersensitivity to sensory inputs [61]. Fatigue and sleep disturbances further impact daily functioning [62]. Fatigue may be related to systemic inflammatory or endocrinology disturbances of endometriosis. However, chronic pain and sleep disturbances can also lead to fatigue.

Negative cognitive patterns developed by women with emotional distress, such as catastrophizing and fear-avoidance behaviors, can amplify the experience of pain [63]. Women with positive coping strategies adapted to stress better report less depression [64], and enjoy a better QoL despite pain or infertility, while women experiencing negative self-image, feelings of loss, hopelessness, alexithymia, worthlessness, frustration, isolation, low self-esteem, and self-efficacy are common emotional responses generating emotional distress, anxiety, and depression that significantly deteriorate their QoL.

To fully understand endometriosis and to improve the effectiveness of medical care, studies that analyze longitudinal quantitative and qualitative data from a systems perspective are needed: a comprehensive and integrative perspective, considering the entire network of biological and psychological interactions, including genetic, epigenetic, and gene expression, immune responses, hormone

regulation, and tissue remodeling, toward supporting women in achieving their full life potential.

A critical transformation would also be necessary in the care that women receive. Chronic diseases, like endometriosis, impact and change patients' lives. Endometriosis become part of women's lives, who have to find new ways to cope with their changed situation and develop coping strategies [65]. Women with endometriosis report important deficiencies and frustration with healthcare reflecting a generalized and global deficit in "patient-centered care" in endometriosis [66]. Identifying valid biomarkers for early diagnosis and developing new pharmacological alternatives could prevent the reduction of women's QoL, but would probably not be enough to overcome the negative experience of women with healthcare [41, 67]. Current guidelines include pain treatment as a major component of endometriosis management [1], however, they usually provide an assessment of the efficacy of the diverse therapeutic options to control pain but do not consider the diverse implications that endometriosis has for women. Patients with long-term conditions value that health professionals provide with clear and tailored information, build a trust context, support changes, and take into account their perspectives and living circumstances [69].

The chronic nature, long-term burden, substantial recurrence of symptoms, and the impact that the disease has on various aspects of women's lives and the concurrent impact on QoL and consequent direct and indirect costs, suggest the need to redefine endometriosis care [20]. Patient-centered care based on a proactive multidisciplinary coordinated healthcare delivery system, and activation of patients could be appropriate for endometriosis care [68, 70].

Endometriosis care should be based on a fundamental principle: maintaining and improving women's QoL. This requires considering the clinical process from two dimensions: early diagnosis and initiation of effective treatment protocols to prevent emotional distress associated with delayed diagnosis and its impact on QoL; and patient-centered long-term management plans focused on supporting women and improving their healthcare experience [71].

Limitations

Although almost all included reviews and meta-analysis had a very good quality, some have some limitations in the definition of patients with endometriosis. The papers included in the reviews had a high degree of heterogeneity concerning study design, patients' demographics, disease extension, stage, specific location, severity and duration, diagnostic methods, treatments received measures of QoL, and data presentation. These factors may influence the impact of endometriosis on QoL but this review has not considered the possible influence that may have on QoL. Typical studies included in the reviews were cross-sectional limiting the possibility of determining the directionality of the complex interactions in endometriosis. Endometriosis has also been linked with diverse comorbidities: this review has not considered either the possible effects of these conditions on endometriosis QoL. This work has not investigated how any healthcare, medical, pharmaceutical or surgical intervention may influence women's QoL. The search strategy included both quality of life and mental and physical well-being, so some of the included reviews focus more on symptom burden and life circumstances among women with endometriosis.

Finally, this review does not attempt to investigate the complex interactions of the diverse factors identified, but just to describe them. In this sense, it may provide with a relevant source for research aimed at investigating the multidirectional influences among them, as well as to develop new models of care better suited to women's needs.

Conclusion

The strength of the review is the broad scope it had to assess how endometriosis affects women's lives. Pain and infertility are significant symptoms in women with endometriosis. Stress, linked with the presence of depression, anxiety, and co-occurring catastrophic disorders appear to significantly influence QoL. Women with endometriosis are dissatisfied with the care they receive, which needs to be reoriented to address the complex interactions between physical and mental health as well as sexual life. Focusing on biomarkers and early detection is essential, but the implementation of new models of care that offer effective, women-centered, comprehensive clinical, psychological, and sexual management and long-term goals empowering women to develop positive coping strategies are necessary to reduce the harmful consequences of endometriosis [42]. For patients with endometriosis, healthcare providers are of particular importance. While on many occasions they are perceived as barriers, they should be facilitators for improving their QoL, changing the course of the care trajectory, and significantly impacting a patient's care experience [72].

Abbreviations

QoL Quality of life

Author contributions

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