



THESIS

IMPACT OF ENDOMETRIOSIS ON QUALITY OF LIFE IN WOMEN

A Descriptive Literature Review

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Endometriosis is a chronic, oestrogen-dependent inflammatory condition affecting about 10% of women globally. It primarily affects pelvic tissues, including the ovaries, and significantly reduces quality of life by causing chronic pelvic pain, menstrual irregularities, and psychological distress.

The purpose of this thesis was to examine impact of endometriosis on the quality of life in women. The aim was to identify the impact of endometriosis and its symptoms on a woman's quality of life and thereby help healthcare personnel better understand and guide patients suffering from endometriosis.

The thesis was carried out as a descriptive literature review, the material of which was sought to respond to the theme: endometriosis and quality of Life. The research articles were retrieved from electronic databases. The report consisted of twelve articles in English. The selected data were analyzed using deductive content analysis.

The results of the thesis show that the impact of endometriosis on quality of life in women is multifaceted, and these impacts are interrelated. Endometriosis negatively affects physical, psychosocial, emotional, social, educational and work life aspects of women's perceived quality of life. For women living with endometriosis, chronic pain is central limiting factor to their physical and psychological well-being.

The results of this thesis could serve as a valuable source of information for healthcare professionals and nursing students, providing a deeper understanding of the effects of endometriosis on women's quality of life. Thereby contributing to a better understanding of the disease and its treatment.

Keywords Endometriosis, quality of life, Pain, Health.

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Endometrioosi on krooninen, estrogeeniriippuvainen tulehdustila, joka vaikuttaa noin 10 prosenttiin naisista maailmanlaajuisesti. Se vaikuttaa ensisijaisesti lantion kudoksiin, mukaan lukien munasarjat, ja heikentää merkittävästi elämänlaatua aiheuttamalla kroonista lantion kipua, kuukautisten epäsäännöllisyyttä ja psykologista ahdistusta.

Opinnäytetyön tarkoituksena oli tutkia endometrioosin vaikutusta naisten elämänlaatuun. Tavoitteena oli selvittää endometrioosin ja sen oireiden vaikutus naisen elämänlaatuun ja siten auttaa terveydenhuollon henkilöstöä ymmärtämään paremmin ja ohjaamaan endometrioosista kärsiviä potilaita. Tutkielma toteutettiin kuvailevana kirjallisuuskatsauksena, ja aineisto hankittiin vastaamaan teemaa: Endometrioosi ja elämänlaatu. Tutkimusartikkelit haettiin sähköisistä tietokannoista. Raportti koostui kahdentoista englanninkielisestä artikkelista.

Tutkimuksen tulokset osoittavat, että endometrioosin vaikutus naisten elämänlaatuun on monitahoinen ja vaikutukset liittyvät toisiinsa. Endometrioosi vaikuttaa kielteisesti naisten fyysiseen, psykososiaaliseen, emotionaaliseen, sosiaaliseen, koulutukselliseen ja työelämän laatuun. Naisilla, jotka elävät endometrioosin kanssa, krooninen kipu on keskeinen rajoittava tekijä heidän fyysiselle ja psyykkiselle hyvinvoinnilleen.

Tämän opinnäytetyön tulokset voivat toimia arvokkaana tietolähteenä terveydenhuollon ammattilaisille ja hoitotyön opiskelijoille ja tarjota syvempää ymmärrystä endometrioosin vaikutuksista naisten elämänlaatuun. Näin edistetään sairauden ja sen hoidon parempaa ymmärtämistä.

Avainsanat Endometrioosi, Elämänlaatu, Kipu, Terveys

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FOREWORD

This thesis would not have been possible without the invaluable support, guidance, and encouragement of numerous individuals and institutions, to whom we owe our deepest gratitude.

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To all who have walked alongside us on this journey, we extend our heartfelt thanks. This thesis is not only a reflection of our efforts but also a testament to your invaluable contributions.

Thank you.

SYMBOLS AND ABBREVIATIONS USED

MRI	Magnetic Resonance Imaging
STDs	Sexually Transmitted Diseases
DIE	Deep Infiltrating Endometriosis
PCOS	polycystic ovarian syndrome
WHO	World Health Organization
QOL	Quality of Life
HRQoL	Health-Related Quality of Life
HIV	Human Immunodeficiency Virus
NMPP	Non-Menstrual Pelvic Pain
EAPP	Endometriosis-Associated Pelvic Pain
WHOQOL-BREF	World Health Organization Quality of Life-BREF
AYA	Adolescent and Young Adults
CPP	Chronic Pelvic Pain
CBT	Cognitive Behavioral Therapy

1 INTRODUCTION

Endometriosis is a chronic, systemic disorder that occurs when endometrial-like cells grow abnormally outside the uterus. Endometriosis affects approximately 190 million people globally and is found to be prevalent amongst approximately 10% of women of reproductive age (Shafrir et al. 2018).

Several risk factors are robustly associated with endometriosis, including an early age at menarche, shorter menstrual cycle lengths, and a lean body size. Conversely, factors such as greater parity appear to be protective. However, associations with other quality of life factors such as physical activity, dietary influences, and lactation remain inconsistent, largely due to methodological challenges requiring rigorous longitudinal data collection (Shafrir et al. 2018).

Accurately measuring the prevalence and incidence of endometriosis presents significant challenges, primarily because the condition requires surgical visualization for definitive diagnosis. This reliance on surgery introduces a diagnostic bias, as those who undergo surgical evaluation often represent a subset of patients with severe symptoms. Reported prevalence estimates vary widely, from as low as 2% to as high as 43% in asymptomatic women undergoing elective tubal ligation, and between 5% and 50% in women experiencing infertility. Among women hospitalized for pelvic pain, prevalence ranges from 5% to 21%. These estimates highlight that endometriosis is both underdiagnosed in some populations and overrepresented in clinical settings focused on infertility or chronic pain (Shafrir et al. 2018).

Endometriosis, a chronic inflammatory condition characterized by the presence of endometrium-like tissue outside the uterine cavity, is a global health concern affecting approximately 10% of women of reproductive age (Wang et al. 2022). This condition is associated with a range of debilitating symptoms, including chronic pelvic pain, dysmenorrhea, dyspareunia, and infertility, significantly impairing reproductive performance and quality of life. The socio-economic burden of endometriosis is substantial, as the disease frequently disrupts daily living and presents long-term health challenges, such as fibrosis, adhesions, and a potential risk of malignant transformation (Wang et al. 2022).

Endometriosis manifests in various subtypes based on its location, including ovarian endometrioma, adenomyosis, deep infiltrating endometriosis, and superficial endometriosis, which may occur alone or in combination. Among these, ovarian endometrioma is one of the most common phenotypes, with a prevalence ranging from 17% to 55%. The primary goals of endometriosis management include alleviating pain, restoring reproductive functionality, and preventing or delaying long-term sequelae. However, achieving these objectives is often complicated by the challenges associated with accurate diagnosis and effective treatment strategies (Wang et al. 2022).

Endometriosis is a complex and multifaceted disorder characterized by the growth of endometrial-like cells outside the uterus. It presents a wide range of manifestations, associated clinical problems, and therapeutic challenges. Among its various forms, deep endometriosis, which infiltrates multiple pelvic organs, is considered the most severe. This form poses significant uncertainties in the management of infertility and pelvic pain, both of which severely impact the quality of life of affected individuals (Vercellini, 2015).

Recent evidence challenges the traditional understanding of endometriosis as a purely gynecological condition. Contrary to earlier beliefs, its effects extend beyond reproductive health, influencing pregnancy, delivery, and the postpartum period. The longstanding notion that pregnancy serves as a cure for endometriosis has been discredited, emphasizing the need for updated clinical approaches. For instance, safe and effective treatments to minimize symptom recurrence and lesion regrowth after conservative surgery are now available and should be offered to patients not immediately pursuing conception (Vercellini, 2015).

While endometriosis is associated with a moderate increase in ovarian cancer risk, current evidence does not support its classification as a pre-neoplastic condition. Consequently, routine screening for undiagnosed endometriosis in asymptomatic women is not recommended. As endometriosis is not malignancy, shift from lesion-focused treatment to symptom-focused management is essential. This patient-centered approach should address the primary clinical problems, align with the patient's preferences and priorities, and incorporate transparent

counseling about the potential benefits, risks, and costs of each therapeutic option. Gynecologists play a crucial role in supporting patients during the shared decision-making process by providing detailed explanations of all available treatments, rather than limiting discussions to their personal preferences or expertise (Vercellini, 2015).

Endometriosis in women causes recurring strong pains presenting in the lower abdomen and pelvic area according to the menstrual cycle. Furthermore, there may be long-term continuous pain, exacerbations of pain independent of the menstrual cycle, and pain related to intercourse, defecation, or urination (Hamunen, Sipilä, Jernfors & Härkki 2022) and onset of symptoms frequently occurs in adolescence, with two-thirds of adult diagnoses having their roots before the age of 20. Despite this early manifestation, the diagnosis in young women is often delayed, with an average delay of 12 years reported in adolescents (Wüest et al.2023).

Endometriosis tissue, believed to stem from retrograde menstruation implanting endometriotic tissue, remains incompletely understood. Despite symptom onset often occurring in adolescence and young adulthood, studies on this demographic are limited (Naoko et al. 2020) The condition profoundly affects the quality of life, contributing to school absenteeism and hindering daily activities. Recognizing and addressing endometriosis in its early stages, especially in the young population, holds potential for preventing chronic pain and mitigating its adverse effects on the quality of life in this demographic (Wüest et al. 2023).

The purpose of the thesis is to review literatures that examines the physical and psychological impact of endometriosis on the quality of life in women. The aim is to identify the unique challenges faced by endometriosis patients and understand how these challenges affect their daily lives.

2 AIM AND RESEARCH QUESTIONS

2.1 PURPOSE AND AIM

The purpose of the thesis is to examine impact of endometriosis on the quality of life in women. The aim is to identify the impact of endometriosis and its symptoms on a woman's quality of life and thereby help healthcare personnel better understand and guide patients suffering from endometriosis.

2.2 RESEARCH QUESTIONS

How does endometriosis affect the quality of life of women, and in what ways does it impact their overall physical, emotional, and psychological well-being? To what extent can the symptoms and challenges associated with endometriosis interfere with daily activities, relationships, work, and mental health, and how do these effects vary across different individuals?

3 ENDOMETRIOSIS AND QUALITY OF LIFE

3.1 Etiology of Endometriosis

Endometriosis is a complex clinical syndrome that has undergone significant advancements in our understanding over the past two decades. Characterized by an estrogen-dependent chronic inflammatory process, it primarily affects pelvic tissues, including the ovaries. This condition stands as the leading cause of chronic pelvic pain in women of reproductive age, intricately linked to persistent episodes of ovulation, menstruation, and cycling steroid hormones. Its multifactorial origin and high prevalence align it with other chronic inflammatory disorders associated with pain, such as inflammatory bowel disease and gastroesophageal reflux disorder. However, what sets endometriosis apart is its unique dependence on estrogen as the primary biological driver of inflammation (Bulun et al. 2019.)

Endometrioses occur when endometrial cells that reach the peritoneal cavity through the retrograde menstruation (this process occur in almost all women) are not broken down and cleared. This is postulated to occur due to cellular adhesion and proliferation, inflammation, localized steroidogenesis, neurogenesis, somatic mutations and immune dysregulation. This endometrial-like cells implant outside the uterus and respond to estrogenic stimulation from the ovaries and the cells themselves, leading to inflammation and subsequent scarring and adhesions (Al-laire, Bedaiwy & Yong 2023.)

3.2 Risk Factors of Endometriosis

Endometriosis can be chronic and progressive in a subset of patients. The exact cause of endometriosis remains unknown. However, the most widely accepted theory is Sampson's theory (1927) that during menstruation endometrial cells regurgitate through the fallopian tubes and implant on the surrounding pelvic viscera. Other hypotheses suggest a multi-factorial etiology with immunological, anatomical, and genetic mechanisms leading to dysfunction in the ectopic endometrium and/or immune system. However various individual features (family history of endometriosis, early menarche, and exposure to circulating steroid hormones,

body mass index during late childhood and early adolescence), lifestyle characteristics and environmental factors are likely related to the development of endometriosis (Janssen, Rijkers, Hoppenbrouwers, Meuleman, & D'Hooghe 2013.)

Early life exposures, such as mode of delivery, parental smoking, and exposure to breastfeeding, may modify the hormonal and immune status of the newborn, which could influence disease risk later in life. Among adolescents and young adults, data suggest exposures to breastfeeding in early life and secondhand smoke during childhood may be associated with endometriosis risk, specifically, maternal exposure to diethylstilbestrol, smoking during pregnancy, and lower birthweight have been reported to be associated with greater risk of endometriosis diagnosed in adulthood. (Naoko et al. 2020.)

3.3 Classification of Endometriosis

Pelvic endometriosis can be categorized into three distinct subtypes each with different symptom presentation and method of diagnosis (Figure 1). Endometriomas are cysts that develop in the ovary and contain dark, blood-stained fluid often referred to as “chocolate cysts”. Deep endometriosis (formerly known as deep infiltrating endometriosis) involves lesions that extend beyond the peritoneum. These lesions are typically nodular and fibrotic and could invade nearby pelvic organs such as the rectosigmoid colon, ureter or bladder. Superficial Peritoneal Endometriosis is the most common form, characterized by lesions of varying colors on the peritoneal surface. These lesions are typically small and located on the peritoneum. (Allaire et al. 2023.)

Subtypes can overlap with some patients having more than one manifestation of the disease at the same time. For example, endometriomas often co-occur with deep endometriosis, and the discovery of an endometrioma on ultrasonography should prompt further investigation, particularly if the patient reports severe pain. Deep endometriosis can lead to serious complications, including organ damage such as kidney failure (due to ureter obstruction) or bowel obstruction, making early diagnosis and management critical. Extra-pelvic endometriosis, which occurs less frequently, can involve areas outside the pelvis, such as the diaphragm, thoracic cavity, or surgical scars (Allaire et al. 2023.) (Figure 1) shows imaging and laparoscopic appearance of endometriosis subtypes (Allaire et al. 2023).

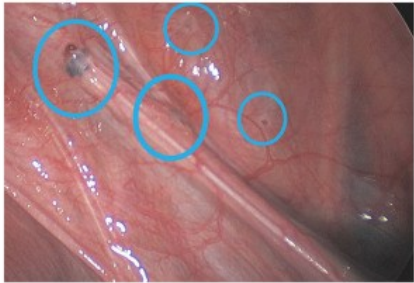
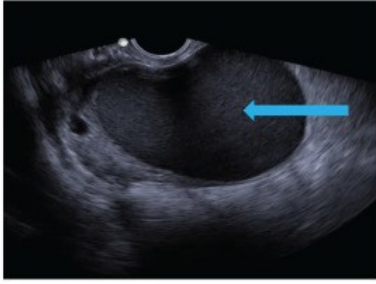
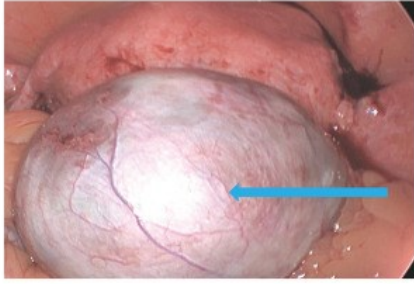


Endometriosis subtype	Transvaginal ultrasonography	Laparoscopy
Superficial peritoneal endometriosis	Not visible on imaging	
Ovarian endometrioma		
Deep endometriosis of sigmoid colon		

Figure 1. Imaging and laparoscopic appearance of endometriosis subtypes (Allaire et al. 2023).

3.4 Diagnosis of Endometriosis

There are multiple pathways through which a person with endometriosis may be diagnosed or mis/undiagnosed, some women are diagnosed due to pelvic pain, whereas others are diagnosed at the time of an infertility evaluation or diagnosed incidentally for unrelated pelvic surgical procedures (such as appendectomy or tubal ligation). The wide variation in symptoms, surgically visualized presentation, and pathologic findings makes selection of an appropriate case definition for endometriosis both critical and challenging. Laparoscopy remains the gold standard for diagnosing endometriosis. However, making a case definition for endometriosis especially in adolescents is challenging, as only those with the most severe symptoms will undergo surgery hence surgical diagnosis. (Shafrir et al. 2018.)

The diagnostic process for endometriosis remains controversial, with laparoscopy long regarded as the gold standard. Despite its utility in direct visualization and histological confirmation, laparoscopy poses certain risks, including vascular and visceral injuries and post-operative complications. Additionally, the absence of histological confirmation in some cases further complicates the diagnostic process. Non-invasive diagnostic tools, such as high-resolution vaginal ultrasound and magnetic resonance imaging, have advanced significantly, but limitations in their reproducibility and validation hinder their widespread application. (Wang et al. 2022.)

The pathophysiology of endometriosis also remains incompletely understood, despite the existence of various hypotheses and theories exploring genetic, epigenetic, immunological, hormonal, and environmental factors. This uncertainty contributes to ongoing debates about the optimal timing, duration, and type of treatment. For instance, there is no consensus on whether laparoscopy should precede medical therapy, nor is there agreement on the best strategies for integrating surgical and medical treatments. These uncertainties often lead to delays in both diagnosis and therapeutic intervention, posing significant challenges to clinicians and patients alike. Advances in minimally invasive technologies and therapeutic approaches have provided improved options for managing this complex condition, but controversies in routine clinical practice persist. Addressing these challenges is essential for developing patient-centered strategies that enhance the quality of life for women affected by endometriosis (Wang et al. 2022).

Ultrasound examinations are most frequently used as the initial imaging technique for endometriosis. This allows for a detailed exploration of the pelvis with the ability to exclude pelvic masses or structural anomalies, although easily visualized endometriomas are less common in adolescents compared to adults hence magnetic resonance imaging (MRI) provides a better understanding of endometriosis compared to ultrasounds as this gives a more detailed imaging of the pelvic compartment. Laparoscopy, however, compared to MRI give more endometriosis finding and is more cost effective as an initial screening tool. Laboratory studies such as complete blood count or erythrocyte sedimentation rate which

reflects underlying inflammation process have low effectiveness in the identification of endometriosis. Currently there are no standardized blood tests or serum markers for the diagnosis of endometriosis however, pregnancy tests, urine analysis and sexually transmitted disease tests (STDs) should be used to rule out other potential causes. (Liakopoulou et al. 2022.) Therefore, many endometriosis case definitions can be considered, including diagnosis based on symptoms, laparoscopic confirmation due to pelvic pain, infertility or unrelated surgery, or visualization by using imaging techniques (Shafrir et al. 2018).

Endometriosis is classified into various types, including ovarian endometriosis, deep infiltrating endometriosis (DIE), and involvement of adjacent pelvic structures, highlighting its diverse clinical presentations. Each type presents a unique set of characteristics, contributing to the complexity of effectively managing this condition. (Dunselman et al. 2014).

3.5 Quality of Life

The World Health Organization (WHO) defines Quality of Life (QoL) as an individual's perception of their position in life, considering the cultural and value systems in which they live and relative to their goals, expectations, standards, and concerns (WHO, 2024.) QoL is a complex collection of interacting objective and subjective domains and expresses the individual's perspective and experiences which is likely to be mediated by cognitive factors. Other components of a person's perceived quality of life include their functional capacity in physical activities, the level and quality of social interaction, psychological well-being, somatic sensations, happiness, life situations, life satisfaction and need for satisfaction (Megari ,2013).

Chronic diseases are characterized by their slow progression, long duration and need for medical treatment. They hold the potential to worsen the overall health of patients by limiting their ability to live a healthy life, limit the functional status, productivity and health related quality of life (HRQoL) and make significant contributions to the overall costs of healthcare. Among these diseases are cancer, heart diseases, stroke, diabetes, human immunodeficiency virus (HIV), bowel diseases, renal diseases and diseases of the central nervous system. There's a notable rise in the rate of chronic diseases and the need for more studies on the impact of the disease symptoms and their treatment on the HRQoL of patients to improve patient centered care. (Megari, 2013.)

3.5.1 Physical Quality of Life

The presence of one or more chronic disorders in women has been established to impact on perceived physical quality of life, decreased quality of life from weight gain, acne vulgaris, alopecia, mood disturbances and decreased sexual satisfaction because of polycystic ovarian syndrome (PCOS) a chronic endocrine disorder has been well documented. PCOS affects 5%–10% of women in the developed world and is the most common endocrine disorder of women in their reproductive years. Women with PCOS often feel less sexually attractive and less satisfied with their sex life. (Brady, Mousa, & Mousa, 2009.)

One of the most significant impacts of PCOS on women's physical quality of life as reported in a study is Hirsutism, defined as the excessive hair growth in women that follows a male distribution pattern. The presence of facial hair causes distress in women giving a “unfeminine”, “freakish”, “weird” and “different” feeling. This is also accompanied with other troubling problems as expressed by 30 interviewed women who described excess hair growth, irregular menses and infertility as their worst troubles from PCOS. (Brady, Mousa, & Mousa, 2009.)

3.5.2 Psychological and Emotional Quality of Life

Presence of a chronic illness has significant impact on the self-assessed quality of life among women as seen in women with polycystic ovarian syndrome (PCOS), the disease showed a multifaceted impact on their well-being, particularly in the sexual, psychological, and social spheres. While most women rate their overall quality of life as good or very good, a significant proportion report challenges, with PCOS predominantly affecting their sexual relationships (79.2%), family life (61.9%), and social interactions (50.6%). Emotional burdens are pronounced, with 79% experiencing sadness and 75% feeling out of control due to the condition. Body image issues are prevalent, as only 40.5% accept their appearance, and 67.5% report low self-esteem. Although family support is generally rated as moderate to good, the variability in support levels underscores the need for stronger social and emotional backing. These findings align with broader chronic illness trends, where physical symptoms, mental health struggles, and social impacts collectively diminish quality of life. (Ligocka et al. 2024.)

3.5.3 Social Quality of Life

The social impact of chronic PCOS is significant in the patient's family life and social life. More than half, 61.9% (family life) and 50.6% (social life), with fewer women noting an effect on their occupational life (24.4%). The condition appears to have a more significant impact on intimate relationships and social interactions compared to work-related activities, possibly due to the emotional and psychological consequences of managing PCOS symptoms. (Ligocka et al. 2024).

3.5.4 Nursing Care for Endometriosis Patients in Finland

The Finnish healthcare system, known for its patient-centered approach, offers a unique context for understanding nursing care for endometriosis patients (Finnish Ministry of Health and Social Affairs, 2022). Finnish nursing professionals are at the forefront of patient care, providing essential support, education, and advocacy. Their role in managing the physical, emotional, and social aspects of endometriosis is indispensable (Nursing Association of Finland, 2021.)

4 METHODOLOGICAL IMPLEMENTATION

This research methodology involves a descriptive literature review to explore the impact of endometriosis on quality of life in women, descriptive literature review employs a phenomenological method to comprehensively collect, describe, and systematically examine previous information regarding a chosen research topic. This method of literature review was chosen as it aligns with the purpose of the studies to collect and analyze data from previous research on the impact of endometriosis using previously defined domains and present the process in stages to describe the special features as well as ethical and reliability issues. The descriptive literature review is based on a research question and produces a descriptive, qualitative answer based on the selected material. Its steps are defined as 1) creating a research question, 2) choosing the material. 3) building the description and examining the desired result. (Kangasniemi & Utriainen & Ahonen & Pietilä & Jääskeläinen 2013: 291–301.)

4.1 Creating Research Questions and Data Collection

The descriptive literature review is based on research questions, and they are followed throughout the process, which is why it is important that the research questions are sufficiently limited and precise. If the research questions are broad, the matter being described can be examined from many different perspectives. (Kangasniemi et al., 2013: 291-301). On this basis the research question which guided this work was: How does endometriosis affect the quality of life of women, and in what ways does it impact their overall physical, emotional, and psychological well-being? To what extent can the symptoms and challenges associated with endometriosis interfere with daily activities, relationships, work, and mental health, and how do these effects vary across different individuals?

After the research questions have been formed, a selection of data was made with the aim of finding the studies that answer the research questions as well as possible. The descriptive literature review includes a description of how the material was selected. The material selected for the review is retrieved from various scientific databases and scientific publications. Data selection is described as two different processes: implicit and explicit data selection. In implicit data selection,

it is not separately stated how the data was searched, and which databases were used, but the report highlights the reliability and source criticality of the data and that the choice is justified in relation to the research question. In explicit data selection, the selection process is described in detail, indicating which keywords and databases have been used, as well as exclusion and inclusion criteria. The selection method may, however, deviate from precise search terms, as well as time and language restrictions, if this is relevant to the research questions. For this research an explicit data selection process was employed (Kangasniemi et al. 2013: 291–301.)

This thesis was implemented as a descriptive literature review and the search for original research and articles was carried out systematically. In the initial phase of getting to know the topic, information was searched extensively from various reference databases in the health sector. The final information searches were conducted from international health sector reference databases EBSCOhost CINAHL with full text, EBSCOhost Medline, PubMed, ScienceDirect and Wiley online Library.

The keyword terms used in the article search were “endometriosis AND quality of life” on the database ScienceDirect and Wiley Online Library while in certain databases more specific terms were used to enhance the search result deliberately. Information retrieval from PubMed was done using the search terms “(endometriosis [Title]) AND (quality of life [Title])”, while from EBSCOhost CINAHL and Medline the keywords were searched at the Title: endometriosis AND (quality of life or wellbeing or well-being or health-related quality of life)

Automated filters for Full text articles, English language articles and articles from 2014 till date was further applied. The purpose was to find relevant, recent and international studies on the topic. For the original studies selected for the literature review, admission criteria were defined before the selection, with the help of which an effort was made to narrow down the most relevant studies to be processed in the literature review. Inclusion and exclusion criteria are described in Table 1.

Table 1. Inclusion and exclusion criterion table.

Inclusion Criteria	Exclusion Criteria
Available articles to the search engine.	Article in languages other than English.
Free access articles	Articles published prior to 2014
PDF articles with full texts	Articles unrelated to endometriosis
Presence of the keywords	Articles that focus on medical aspect of endometriosis (e.g. laparoscopy)
Articles published 2014-till date	Articles unrelated to the research questions
Peer reviewed articles	Duplicate articles
Articles in English language	

The selection of included and excluded studies for the literature review was done step by step at the title, abstract and full text level, so that the studies found in the searches are mirrored in the inclusion criteria.

The selection of the original studies selected for this literature review was determined by the following inclusion criteria: the subject of the study is endometriosis, the study has discussed the effects of endometriosis on a woman's life and quality of life (Keywords: Endometriosis AND Quality Of Life), the study is an original study, or an article written about it, peer reviewed articles, and the study can be read entirely electronically, free access and PDF articles with full texts. In addition, the research is in English and published between 2014–till date.

In the PubMed database search, the search term returned a total of 251 publications, these were limited based on language (English language), Full text articles and year of publication (2014-2024), 106 articles remained, these were then examined based on Title from which 31 articles were selected. From the EBSCOhost-CINAHL with Full Text database using the search terms (Title: endometriosis AND (quality of life or wellbeing or well-being or health-related quality of life) gave

a total of 163 publications, these were limited based on language (English language), Full text articles and year of publication (Past ten years), 45 articles remained from which 9 articles were selected based on Title.

A search was also conducted on EBSCOhost Medline database using the search terms (Title: endometriosis AND (quality of life or wellbeing or well-being or health-related quality of life) which returned a total of 264 results these were limited by language (English language), Full text articles and publication year (Past 10 years), a total of 36 articles were remaining from which 6 articles were selected based on Title.

ScienceDirect database search using the search terms (Endometriosis AND Quality of life) returned 11,141 results limited based on Year of publication: 2015–2025, Title: endometriosis AND Quality of life Open Access and Open archive, 25 articles remained from which 4 articles were selected based on Title.

Also, from the database Wiley online library a search was conducted using the search terms (Endometriosis AND quality of life) which returned 10,738 publications, application of the filters Publication year 2014–2024 (Title: Endometriosis AND quality of life), Open Access content returned 1 article which was a duplicate of another article from previous database search result. The information retrieval process from electronic databases is presented in Table 2.

Table 2. Information Retrieved from Database search results.

Database search terms	Results(and n=)	Filters	Chosen after filter	In-cluded in re-view based on title
PubMed (endometriosis [Title]) AND (quality of life [Title])	n=251	English language, Full text articles, 2014 till date	n=106	n=31
EBSCOhost- CI-NAHL with Full Text: Title: endometriosis AND (quality of life or	n=163	English language, Full text articles, Past 10 years.	n=45	n=9

Database search terms	and	Results(n=)	Filters	Chosen after filter	In-cluded in re-view based on title
wellbeing or well-being or health-related quality of life)					
ScienceDirect: endometriosis AND Quality of life		n=11,141	Year: 2015-2025 Title: endometriosis AND Quality of life Open Access and Open archive	n=25	n=4
EBSCOhost Medline: Title: endometriosis AND (quality of life or wellbeing or well-being or health-related quality of life)		n=264	English language, Full text articles, Past 10 years.	n=36	n=6
Wiley online library: Endometriosis AND quality of life		n=10,738	Year 2014-2024 Title: Endometriosis AND quality of life Open Access content	n=1	n=0

The studies found in the information search were further reviewed at the keyword and abstract level, and full text level for eligibility. For this literature review, research that focus on Endometriosis risk factors, diagnosis and prevention of endometriosis, endometriosis associated diseases/symptoms and show no clear association with quality of life in endometriosis were excluded from the search result. In the selected articles, the effects of endometriosis on a woman's quality of life were discussed at a more general level. In addition, the studies had to meet

the inclusion criteria mentioned above. In the end a total of 12 articles were included for the literature review. The final selected articles are shown in Appendix 1. The research articles selection process is shown in Figure 2.

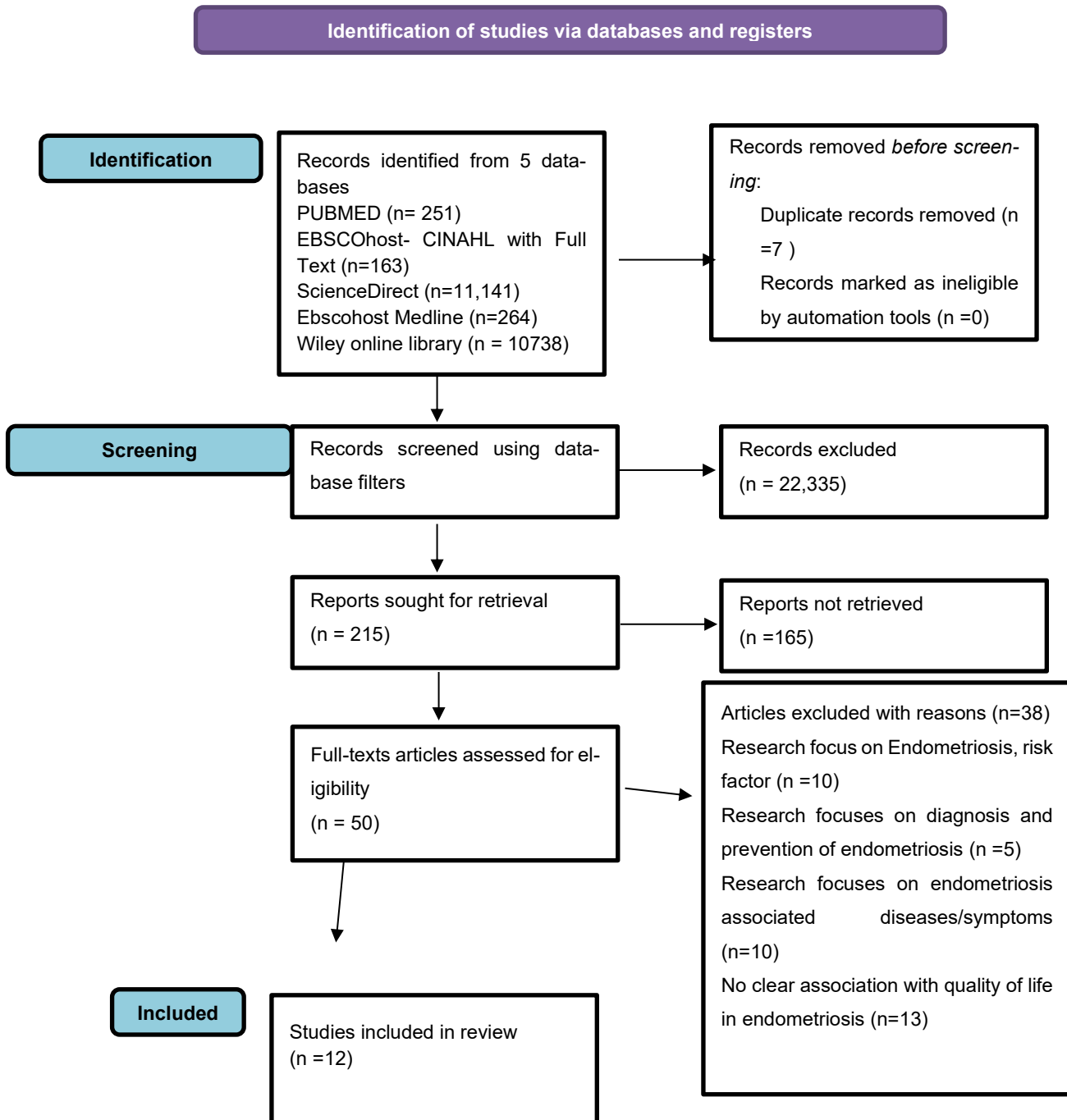


Figure 2. Research articles selection process.

4.2 Content Analysis

Content analysis is a systematic and objective research method used to describe and quantify phenomena, in content analysis words are grouped into a smaller set of categories that are relevant to the content. The assumption is that words, phrases, and other elements within the same category convey similar meanings. content analysis serves to make valid and replicable inferences from data to its broader context, with the aim of generating new knowledge, offering fresh insights, presenting facts, and providing practical guidance for action. (Elo & Kyngäs, 2008. 107-115.) This analysis can be Inductive or Deductive. Inductive analysis process includes open coding, creating categories and abstraction. Open coding means that notes and headings are written in the text while reading it. Deductive content analysis is used to retest existing data in a new context, to do this a categorization matrix is developed from previous literature, after this, all the data are reviewed and coded for correspondence with or without exemplification of the identified categories. The results are therefore a described content of the categories, i.e. the meanings of the categories. The content of the categories is described through subcategories. (Elo & Kyngäs, 2008. 107-115.)

Deductive content analysis is appropriate for this study as we seek to apply the World Health Organization's (WHO) definition of Quality of Life (QoL) and its dimensions namely physical (this includes chronic pain, physical functionality, and the impact of symptoms like fatigue or infertility on daily activities), psychological (this addresses emotional burdens, mental health challenges such as anxiety and depression, and issues related to self-esteem and body image) and social domains(which examines the impact of endometriosis on social relationships, family dynamics, and professional life) to the data collected from the literature on endometriosis. The categorization matrix was developed using these predefined dimensions to ensure a structured and comprehensive analysis. The focus on deductive analysis allows the study to explore how existing theoretical frameworks on QoL intersect with the lived experiences of women diagnosed with endometriosis. This approach not only facilitates a deeper understanding of the phenomenon but also ensures that findings are aligned with established QoL constructs (WHO, 2024; Elo & Kyngäs, 2008).

During the organizing phase the data was reviewed systematically and coded based on its correspondence to the categories in the matrix. The pre-existing structure allowed the analysis to focus on identifying patterns and variations in how endometriosis affects each domain of QoL. For instance, statements or findings about pain interfering with daily tasks were categorized under Physical QoL, while references to feelings of sadness or isolation were classified under Psychological QoL (Elo & Kyngäs, 2008). Example of categorization process is shown in Figure 3. In the reporting phase, the results are presented in alignment with the predefined categories. This structured approach ensures clarity and coherence in the findings, linking the data to the broader theoretical framework of QoL. (Elo & Kyngäs, 2008.) Table detailing the categorization process is shown in Appendix 2.

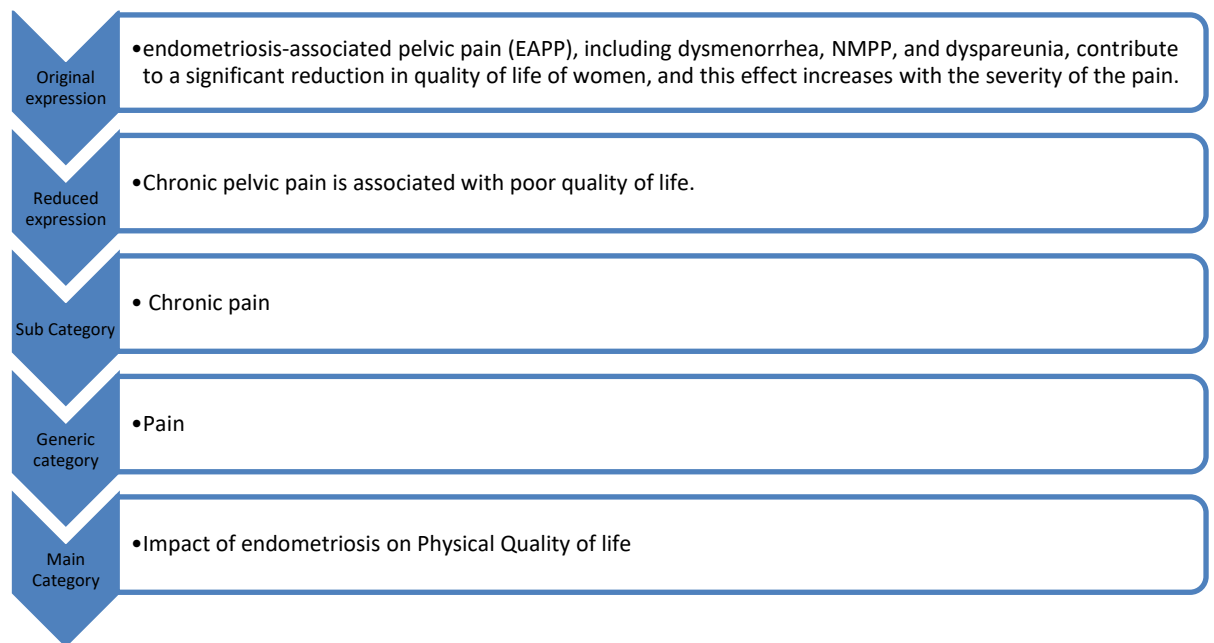


Figure 3. Example of categorization process.

5 RESULTS

The aim of this research was to identify the impact of endometriosis and its symptoms on a woman's quality of life and thereby help healthcare personnel better understand and guide patients suffering from endometriosis. This led to the research question, how does endometriosis affect the quality of life of women, and in what ways does it impact their overall physical, emotional, and psychological well-being? To what extent can the symptoms and challenges associated with endometriosis interfere with daily activities, relationships, work, and mental health, and how do these effects vary across different individuals? The result of the research shows no doubt that endometriosis impacts the overall quality of life of women (this includes physical, mental wellbeing, social and sexual life and work life) and these effects impact on the overall wellbeing and life course of women with endometriosis. (Missmer et al. 2021.)

5.1 Endometriosis and Its Impact on Overall Quality of Life

Endometriosis affects the overall wellbeing of a person living with endometriosis, including social participation, physical and sexual functioning, and mental wellbeing, which collectively affect individuals' educational, professional, and relational fulfillment. Over time, these disruptions can lead to significant life course limitations, restricting educational achievements, career progression, and stable relationships. These limitations may manifest most acutely during formative periods from adolescence to middle age, when significant, trajectory-defining decisions are made. Consequently, the effect of endometriosis induced symptoms and impairments is seen across the life-course of women and these effects are interrelated. (Missmer et al., 2021). (Figure 4) shows the interrelation between endometriosis-associated symptoms and quality of life impacts.

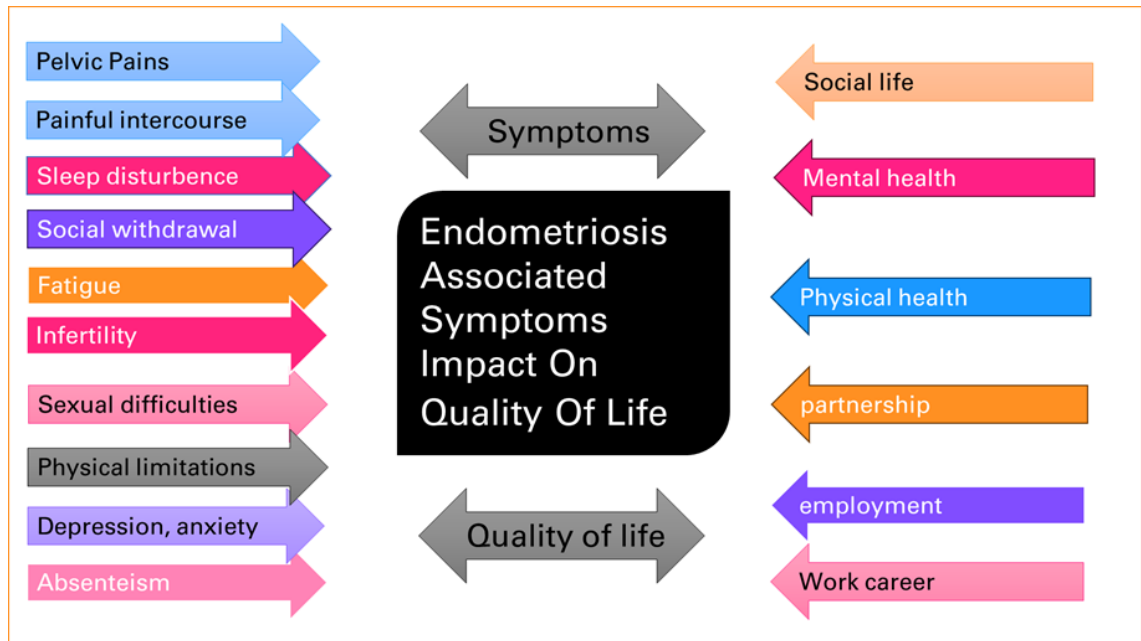


Figure 4. Interrelation between endometriosis-associated symptoms and quality of life impacts.

5.2 Impact of Endometriosis on Physical Quality of life in Women

To explain the main category (impact of endometriosis on physical quality of life), Original expressions were reduced from the selected articles and (n=3) generic categories were derived from (n=7) Subcategories. (Figure 5) shows the categorization process for Impact of endometriosis on Physical quality of life of women.

Endometriosis as a chronic inflammatory condition characterized by the presence of endometrial-like tissues outside the uterus is strongly associated to and can impose significant personal, societal, and economic burdens, including poor health-related quality of life (HRQoL), loss of productivity, and direct healthcare costs on women. In women, endometriosis is often accompanied by pelvic pain, this includes a variety of chronic pelvic pain of which painful menstrual periods (Dysmenorrhea) are reported to be the most common, other pains include, non-menstrual pelvic pain (NMPP) and painful intercourse (Dyspareunia). (As-Sanie, Shafir, Halvorson, Chawla, Hughes, & Merz, 2024.)

According to As-Sanie et al. (2024) endometriosis-associated pelvic pain (EAPP), including dysmenorrhea, NMPP, and dyspareunia, contribute to a significant reduction in quality of life of women, and this effect increases with the severity of the pain. In several studies that investigated the impact of EAPP on the HRQOL of women using indices such as the World Health Organization Quality of Life-BREF (WHOQOL-BREF), adolescents and young adults (AYA) with endometriosis and dyspareunia showed significant fatigue, poor sleep quality, physical, mental, and bodily pain when compared to other AYA without endometriosis.

Women diagnosed with endometriosis have painful periods and pains that adversely affect their day-to-day functioning. In research by Kalfas, Chisari, & Windgassen, (2022) there were positive associations between endometriosis associated pain and depression, anxiety, stress, generalized worry and somatization (defined as the tendency to experience psychological distress in the form of somatic symptoms). Consequently, there is critical need for heightened awareness among healthcare providers and patients, advocating for early intervention to mitigate dysmenorrhea's long-term impacts on life trajectory and overall quality of life (MacGregor, Allaire, Bedaiwy, Yong, & Bougie, 2023).

Muscle strength is vital for managing daily physical demands, but women with endometriosis show notable impairments according to a study by Álvarez-Salvago et al. (2020) where physical health domain between patients diagnosed with endometriosis in Spain were compared with women with no reported endometriosis. Low back muscle strength in the endometriosis group studied was lower than controls, accompanied by reduced spinal flexibility likely due to adhesions, pain, and lumbar fascia thickening. These factors, along with diminished postural balance and proprioception, hinder static and dynamic balance, affecting daily activities. Functional capacity was also reduced in these women with higher endometriosis-related fatigue correlating with declines in strength, flexibility, balance, and overall fitness, alongside poorer sleep and quality of life. (Álvarez-Salvago et al., 2020.)

Endometriosis has a profound impact on the overall well-being and quality of life of affected women. Research has demonstrated a significant negative association between endometriosis and sleep quality, as assessed through measures

such as sleep quality indices, sleep latency, and sleep disturbance scales. Among women engaged in night-shift work, particularly those who perform night shifts for most of their work schedule, notable alterations in sleep patterns on non-working days have been identified. These changes have been associated with an increased risk of endometriosis. Furthermore, endometriosis has been linked to heightened levels of daytime sleepiness, subthreshold insomnia, and moderate clinical insomnia, underscoring the condition's pervasive impact on sleep health. (Youseflu, Sadatmahalleh, Roshanzadeh, Mottaghi, Kazemnejad, & Moini, 2020.)

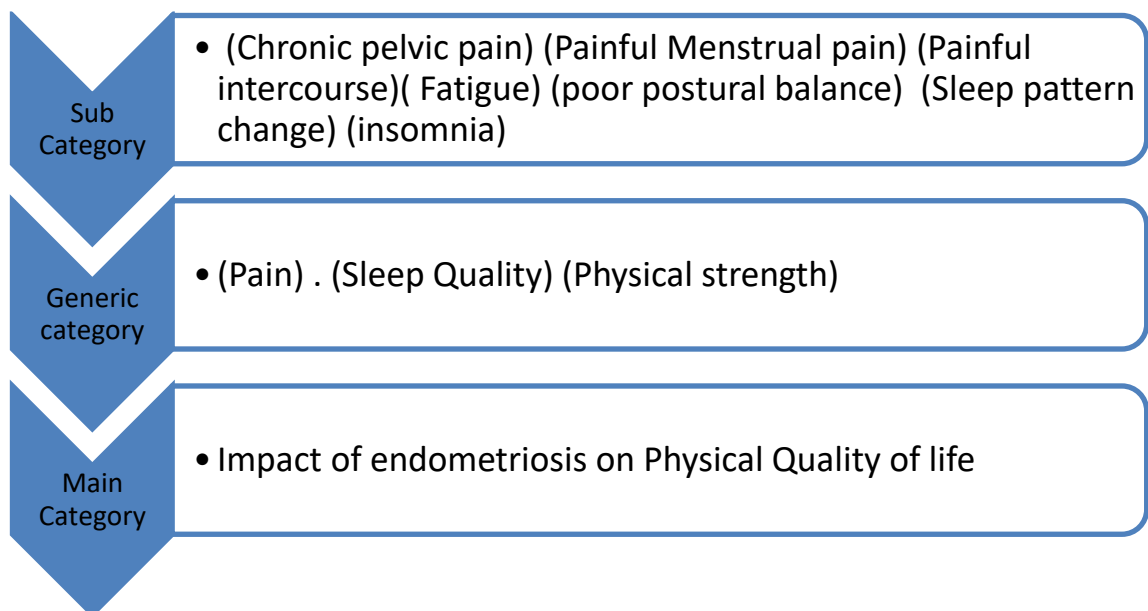


Figure 5. Categorization Process for Impact of Endometriosis on Physical quality of life in women.

5.3 Impact of Endometriosis on Psychological and Emotional Quality of Life in Women

To explain the main category (impact of endometriosis on psychological and emotional quality of life), original expressions were reduced from the selected articles and (n=2) generic categories were derived from (n=6) Subcategories. (Figure 6) shows the categorization process for Impact of endometriosis on psychological and emotional quality of life of women.

The psychological toll of endometriosis is profound, as emotional dysregulation and psychological distress are often reported among patients. With severe pain symptoms, patients experience higher rates of anxiety and depression, suggesting a bidirectional relationship between pain and psychological health. (Rodríguez-Lozano et al. 2022) Emotional dysregulation is a phenomenon marked by difficulties in managing emotions, heightened sensitivity, and impaired stress response, which in turn exacerbates the overall impact on quality of life. The study by Rodríguez-Lozano et al. (2022) explores the complex relationship between endometriosis and emotional dysregulation, offering insight into how the condition impacts mental health and emotional well-being. This study indicates that chronic pain and physical limitations imposed by endometriosis can lead to elevated anxiety, depression, and emotional instability, particularly among women who experience severe symptoms. Emotional dysregulation, according to this study, often manifests as irritability, mood swings, and difficulty in emotional control, adding another layer of challenge to daily life. Women with endometriosis may also face social and interpersonal issues, stemming from both the physical pain and the emotional turmoil caused by the condition. This emotional impact not only affects their mental health but also strains their relationships and social interactions, leading to potential isolation and reduced quality of life. (Rodríguez-Lozano et al., 2022.)

In a study by Muharam et al. (2022) exploring the association between chronic pelvic pain of endometriosis and psychiatric disorder in women, it was revealed that pain and "control and powerlessness" were the most significant components among women with endometriosis, with pain scores indicating severe levels and suggesting life control impairment due to the experienced pain. Emotional well-being also scored high, reflecting notable emotional disturbances and psychiatric perceptions. Depression and anxiety disorders were the most prevalent psychiatric conditions, with more than a quarter of participants experiencing depression. Hormonal changes in women are known to increase susceptibility to depression, and women with endometriosis face an elevated risk of generalized anxiety disorder, depression, alcohol addiction, and ADHD. Previous research indicates a slight hazard ratio for depression in women with endometriosis. (Muharam et al. 2022.)

One of the causes of infertility is endometriosis, this relationship between endometriosis and infertility is significant, with around 40% of women with endometriosis are infertile, and between 25% and 50% of infertile women have endometriosis. Women dealing with infertility sometimes because of endometriosis lose control over reproductive decisions and experience feelings of guilt, sadness, shame, and social isolation which has shown to reduce quality of life and negatively affect their mental wellbeing. In addition to infertility clinical symptoms of endometriosis such as menstrual irregularity, chronic pelvic pain (CPP), dysmenorrhea, and dyspareunia also emotionally affect patients. (Mori, Zaia, Montagna, Vilarino, & Barbosa, 2024.)

Integrative therapeutic interventions aimed at addressing both physical symptoms and emotional dysregulation, with approaches like cognitive behavioral therapy (CBT) and stress management techniques can help patients better navigate the psychological challenges of endometriosis. This approach may foster emotional resilience, allowing women to manage their symptoms more effectively and improve their overall quality of life. (Rodríguez-Lozano et al., 2022.)

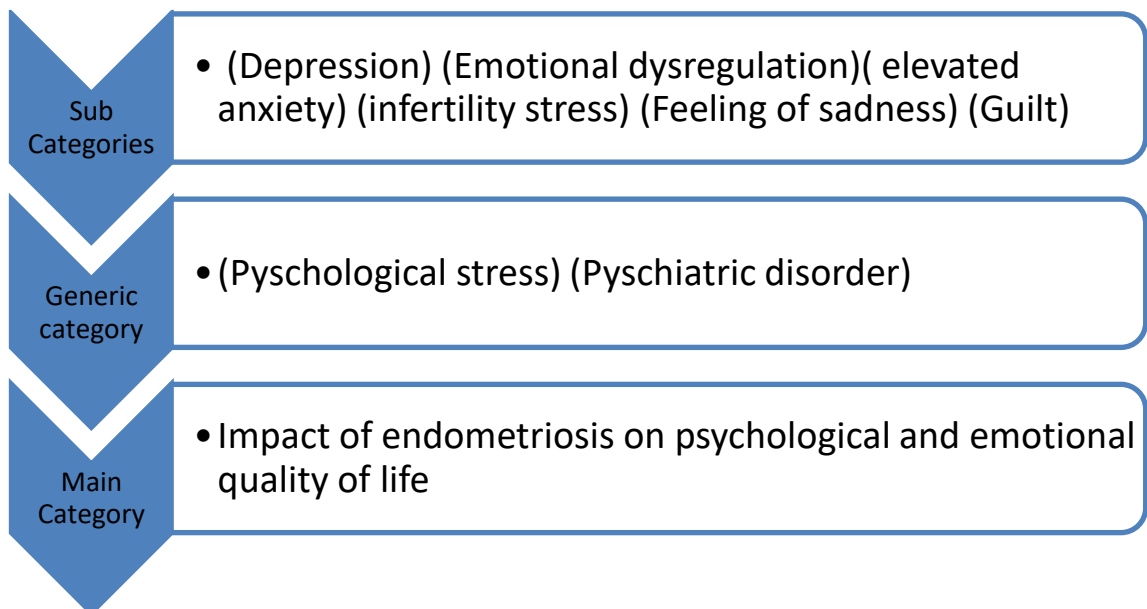


Figure 6. Categorization process for Impact of endometriosis on psychological and emotional quality of life in women.

5.4 Impact of Endometriosis on Social Quality of Life and Sexual Health of Women.

To explain the main category (impact of endometriosis on social quality of life and sexual health), Original expressions were reduced from the selected articles and (n=3) generic categories were derived from (n=8) Subcategories. (Figure 7) shows the categorization process for Impact of endometriosis on social quality of life and sexual health of women.

Endometriosis significantly impacts social lives, with many women reporting restricted participation in social activities due to pain, dyspareunia, fatigue, and depression. Nearly half of women in a long-term registry cited physical limitations as a direct cause of reduced social engagement, often leading to isolation. Symptoms like dysmenorrhea further exacerbate social withdrawal, as seen in a Swedish study where 60% of adolescents avoided social activities due to menstrual pain. (Missmer et al.2021.)

Negative impact of endometriosis symptoms on daily activities amongst adolescents with endometriosis and dysmenorrhea have also been reported. This can include missing out on social events, school, or work, which contributes to social isolation and difficulties in maintaining social commitments. social relationships, including friendships, family dynamics, and romantic relationships. The condition's chronic pain and unpredictability often make it difficult to engage in normal social activities, leading to social isolation, withdrawal from social networks, diminish in coping abilities and an increase in feelings of loneliness. (Liakopoulou et al. 2022.) In addition, Women with endometriosis often experience fatigue linked to pain, reduced emotional well-being, and inadequate social support. Delayed diagnosis and treatment due to insufficient healthcare support worsen the social and emotional burden, resembling challenges seen in adolescents with other chronic pain conditions like fibromyalgia or migraines. (Missmer et al. 2021.)

Endometriosis profoundly affects women's sexual health, emotional well-being, and relationships. Dyspareunia, chronic pelvic pain, and depression contribute to reduced sexual activity, satisfaction, and self-esteem, lowering overall quality of life. Women with endometriosis face increased risks of depression and anxiety,

which, along with poor sleep quality, exacerbate pelvic pain and impair daily functioning, creating a vicious cycle. Social isolation and feelings of shame further strain relationships, with many women reporting a lack of understanding and support. While chronic pain is a key factor, the complex interplay between physical and psychological distress remains under investigation. Women with endometriosis face significant reductions in both mental and physical quality of life (QoL), surpassing those seen in conditions that primarily affect physical health. Emotional and sexual challenges, alongside feelings of frustration, anger, guilt, and shame, further compound these effects. Promoting open communication about relational and sexual issues can aid in coping and improving overall well-being. (Della Corte et al., 2020.)

Endometriosis significantly affects personal relationships, including social, family, and intimate connections, due to their physical and emotional burdens. Sexual health is particularly impacted, with studies showing high rates of sexual distress and dysfunction. In Austria and Germany, 78% of women with endometriosis reported sexual distress, and 32% experienced sexual dysfunction, often linked to pain during intercourse. A Dutch study found women with endometriosis had more dyspareunia and lower sexual functioning scores. Dyspareunia and depression were strong predictors of sexual difficulties, with many fearing it would affect their relationships. (Missmer et al., 2021.)

Endometriosis profoundly impacts sexual and relational dynamics. Women often experience reduced sexual frequency, satisfaction, and self-esteem, leading to feelings of inadequacy, guilt, and difficulty engaging with their partner. Fear of pain further diminishes intimacy and affection, while male partners report frustration, decreased libido, and relational challenges, including infidelity or reliance on digital media. These issues exacerbate the emotional burden for women, worsening their quality of life and fuelling guilt and shame tied to the condition. (Farenga et al., 2024.)

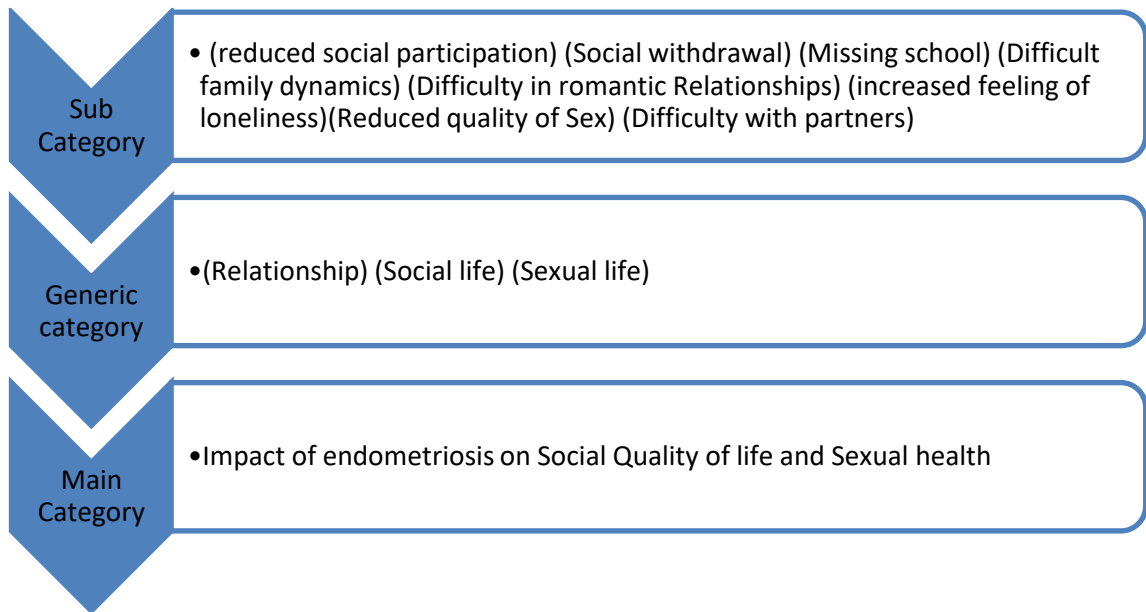


Figure 7. Categorization Process for Impact of Endometriosis on Social Quality of Life and Sexual Health in Women

5.5 Impact of Endometriosis on Work Life and Education of women

To explain the main category (impact of endometriosis on work life and education of women), Original expressions were reduced from the selected articles and (n=2) generic categories were derived from (n=4) Subcategories. (Figure 8) shows the categorization process for Impact of endometriosis on work life and education of women.

The educational impacts of endometriosis on women, highlighting the challenges that symptoms, especially pain, impose on academic progression has been widely. For instance, a qualitative study from Sweden involving women diagnosed with endometriosis reported that the condition had led to missed educational and career opportunities, as cited by women receiving chronic pain treatment in a clinical setting. Another study using self-reported questionnaires found that about 23.2 % of 431 women with endometriosis indicated they had refrained from pursuing further education due to their condition. Notably, participants in this study generally had a higher education level than comparable populations, potentially due to care access bias where women with diagnosed endometriosis

may have more educational resources. Pain emerged as a critical factor in limiting educational opportunities. (Missmer et al., 2021.)

A cross-sectional study involving both adolescents and adults with confirmed endometriosis found that around 60% reported moderate-to-extreme interference with work or school from endometriosis-related pain. Similarly, a large web-based survey of Swedish adolescent girls linked dysmenorrhea with school absences, suggesting that even without an official endometriosis diagnosis, pain may significantly disrupt schooling. Additionally, a French study on the adolescent history of women undergoing surgery for endometriosis (2021) found that those with deep endometriosis experienced more frequent absenteeism during menstruation than those with other types. These findings align with impacts observed in other chronic pain conditions, like adolescent fibromyalgia, which also correlates with reduced educational attainment in young women. (Missmer et al., 2021.)

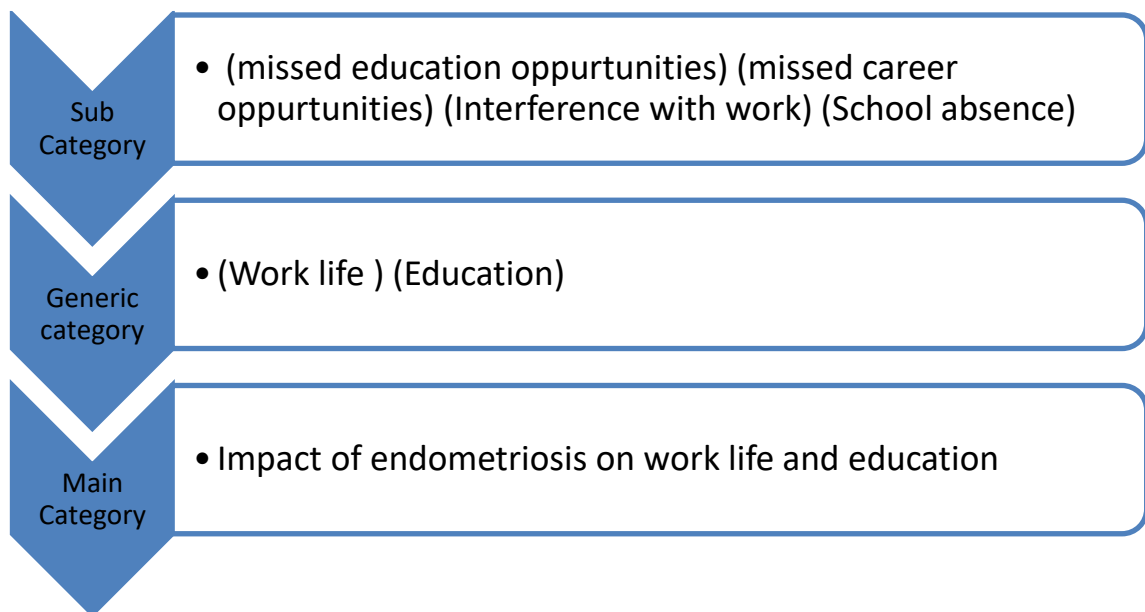


Figure 8. Categorization process for the Impact of Endometriosis on work life and education

6 THESIS ETHICS AND RELIABILITY

As a descriptive literature review, ethicality in every phase of the thesis is emphasized due to methodological looseness. To do this, a clear description and transparency of the method is done to ensure the reliability and sufficiency of the review (Kangasniemi et al., 2013 291–301.) In the formulation of the research question, selection and processing of the data, ethics compliance is ensured by recognizing the bias caused by possible subjectivity, fairness, equality, and honesty of the data report. (Kangasniemi et al. 2013: 291–301.)

To ensure reliability of the research, the research question is presented clearly and detailed theoretical justification for the questions are done. Also, the basis for the materials selected is detailed to improve the reliability of the thesis. (Kangasniemi et al. 2013: 291–301.) Proper citation and referencing were diligently employed to ensure due credit to the original authors and prevent plagiarism. To ensure trustworthiness, reliability and validity of the analysis, the study employed transparent documentation of the coding process, consistent application of the categorization matrix, and cross-referencing with source material. Authentic citations were used to enhance trustworthiness, and care was taken to present findings that reflect the nuances of the data while maintaining alignment with the pre-defined framework (Elo & Kyngäs, 2008.)

This study delved into the experiences and perspectives of adolescents in the care of endometriosis patients. It comprehensively explores the impact of endometriosis on various facets of patients' lives, encompassing physical health, emotional well-being, social interactions, and daily activities. The research methodology includes a meticulous review of existing literature on the topic. The methodology for this literature review-based research thesis emphasizes descriptive literature review approach to identifying, evaluating, and synthesizing existing research on the impact of endometriosis-associated symptoms on the quality of life of women. By employing this methodology, the research aims to contribute to a comprehensive understanding of the topic and its implications for women's awareness and healthcare globally. (Kangasniemi et al. 2013: 291–301.)

While descriptive literature review is a helpful methodological approach to review scientific information in nursing and other health sciences, we acknowledge its reliability may be limited by 1) the fact that the studies analyzed may be too thinly connected to the theoretical background 2) selective review of the analyzed result 3) limitation to current situations and possible future. (Kangasniemi et al. 2013: 291–301.)

7 DISCUSSION

The purpose of our thesis was to find out how the physical and psychological quality of life of women living with endometriosis was affected by the symptoms of the disease and what extent can these symptoms and challenges associated with endometriosis interfere with daily activities, relationships, work, and mental health, and how do these effects vary across different individuals. The findings demonstrate the multifaceted impact of endometriosis on women's quality of life, significantly influencing physical, psychosocial, emotional, social, educational, and occupational domains. These interconnected effects substantially disrupt day-to-day functioning (Kalfas et al., 2022).

From the results, endometriosis is associated with pain, variety of chronic pelvic pain of which painful menstrual periods (Dysmenorrhea) are reported to be the most common, other pains include, non-menstrual pelvic pain (NMPP) and painful intercourse (Dyspareunia). Pain directly affected the living conditions of women living with endometriosis, this effect increases in tandem with the severity of pain experienced, according to Bien et al. (2020) daily functioning of most women living with endometriosis is significantly reduced due to pain. Furthermore, endometriosis associated pain (EAP) is positively associated with the presence of psychological stress symptoms such as depression, anxiety, stress, worry and somatization. (Kalfas et al. 2022.)

The findings underscore that the physical symptoms of endometriosis, such as dysmenorrhea, chronic pelvic pain (CPP), and dyspareunia, severely impair daily functioning and health-related quality of life (HRQoL). The chronic inflammatory nature of endometriosis contributes to muscle fatigue, reduced strength, and diminished flexibility, as noted by Álvarez-Salvago et al. (2020) According to As-Sanie et al (2024) pain is a central symptom of endometriosis; individualized pain management strategies must be implemented. This includes pharmacological treatments (e.g., NSAIDs, hormonal therapy) and non-pharmacological methods (e.g., heat therapy, exercise) to provide holistic relief. Limiting physical capacity

and further exacerbating fatigue and pain. Pain severity, particularly endometriosis-associated pelvic pain (EAPP), is strongly correlated with poorer physical health outcomes and increased healthcare costs (As-Sanie et al. 2024.)

Additionally, the significant impact on sleep quality—manifesting in insomnia, sleep disturbances, and fatigue—further amplifies these physical limitations. Research by Youseflu et al. (2020) highlights the correlation between disrupted sleep patterns and heightened endometriosis risk, adding another dimension to its pervasive influence. Early interventions targeting pain and sleep quality may be critical in mitigating these compounding effects on physical well-being (Youseflu et al. 2020). Tailoring the treatment approach to the specific needs of each patient can help mitigate pain's disruptive effects on daily activities and work productivity (Macgregor et al. 2023.)

Endometriosis exerts profound psychological and emotional tolls on affected women, as evidenced by heightened rates of anxiety, depression, and emotional dysregulation. Chronic pain and hormonal changes appear to exacerbate these mental health challenges, creating a bidirectional relationship where psychological distress worsens physical symptoms. This cycle can further manifest in social withdrawal, irritability, and mood swings, as women struggle to manage their symptoms alongside daily life demands (Rodríguez-Lozano et al. 2022.)

Given the multidimensional impact of endometriosis on both physical and psychosocial well-being as highlighted by Rodríguez-Lozano et al., (2022) treatment plans should integrate medical, psychological, and social support. Along with traditional pharmacological therapies for pain management, healthcare providers should also consider psychosocial interventions, such as cognitive behavioural therapy and stress management techniques, to improve the mental health and overall well-being of patients (Rodríguez-Lozano et al. 2022)

The emotional burden is particularly pronounced among women facing infertility due to endometriosis, which can lead to feelings of guilt, shame, and loss of control over reproductive decisions. The findings reinforce the need for integrative

therapeutic approaches, such as cognitive-behavioral therapy (CBT), that address both physical symptoms and psychological distress to foster resilience and improve mental well-being (Mori et al. 2024.)

Social isolation is a pervasive consequence of endometriosis, driven by physical limitations, pain, and psychological distress. Women with endometriosis often experience restricted participation in social activities, leading to feelings of loneliness and diminished coping abilities (Liakopoulou et al., 2022.) The condition also profoundly impacts sexual health, with dyspareunia and reduced sexual satisfaction contributing to lower self-esteem and relational challenges. As Farenga et al. (2024) noted, the interplay between chronic pain, psychological distress, and fear of intimacy creates a vicious cycle that negatively affects women and their partners, underscoring the need for open communication and tailored support (Farenga et al. 2024.) There is a variation in the factors that affect QoL in women with endometriosis, showing the need for a multidisciplinary, patient-centered care approach. Patient-oriented care, characterized by continuity, respect, and provision of information, may improve HRQoL in women with endometriosis (Bień et al. 2020.)

Educational interventions focusing on positive coping mechanisms, such as cognitive restructuring, can be beneficial in helping patients manage the emotional toll of the disease. Healthcare professionals should encourage psychosocial support and coping skills training as part of standard care for endometriosis patients. Adolescents with endometriosis are particularly vulnerable to emotional distress, social isolation, and missed educational opportunities as reported by Missmer et al. (2020) Specialized care pathways for young women should incorporate age-appropriate counselling and peer support networks to address the unique challenges they face, including difficulties in school and social settings. Collaboration with schools, families, and community organizations can further help reduce stigma and provide holistic support for affected individuals (Missmer et al. 2020)

Empowering patients with knowledge about their condition and equipping them with coping strategies can drastically improve their experience with endometriosis. Educating both patients and healthcare providers about the psychological and social dimensions of the disease will help reduce stigma and improve the holistic care provided. This is particularly significant for young women, who may feel isolated due to the nature of their symptoms and the delayed diagnosis. Women with endometriosis often undergo unnecessary tests and treatments, raising healthcare costs and risks of adverse effects. Including HRQoL measures in clinical assessments can enhance diagnostic accuracy, improve outcomes, and foster self-efficacy while promoting public health. Early diagnosis and effective management can help prevent or mitigate the negative outcomes on these critical aspects of life. Additionally improving diagnostic accuracy and treatment efficacy could have substantial benefits not only for patient well-being but also for the wider economy. By addressing work productivity loss and minimizing disability, healthcare systems could reduce the overall economic impact of the disease (Missmer et al. 2020.)

One of the most notable findings is the impact of psychosocial interventions on quality of life. According to Rodríguez-Lozano et al. (2022.) integrating psychological care, such as counselling, stress management, and coping skills training, into the treatment plan, healthcare providers can significantly improve the psychological well-being and overall QoL of endometriosis patients. These interventions can also prevent the escalation of emotional dysregulation and mental health disorders like anxiety and depression, which are commonly associated with chronic illness (Rodríguez-Lozano et al. 2022.)

As Nursing students, working on this thesis provided us with insights into the right process of systematic literature review, the data collection, analysis and reporting stages were all significant learning points, we also deepened our knowledge of the effect of endometriosis as a chronic disease on women's wellbeing, and factors that contribute to these effects. This body of work highlights the life-long impact of endometriosis, as it affects crucial areas such as education, career development, relationships, and family formation, also provides information on the effects of endometriosis on the quality of life and overall wellbeing of women.

Recognizing the long-term implications of this disease can guide healthcare providers in not only addressing the current symptoms but also in helping patients navigate life decisions that are influenced by their condition.

There are plenty of medical studies and articles about endometriosis that focus on surgical and medical treatments and their importance for quality of life cannot be underestimated. These studies focused mainly on medical and surgical treatments and aspects, with little emphasis on women's quality of life factors. In the future, there should be even more research into the effects of the disease on women's quality of life and how endometriosis patients could be better supported in both physical and psychosocial matters. Studies on the role of nursing care in improving quality of life would also be useful for professionals. Future research should focus on understanding the long-term psychological effects of endometriosis, particularly its impact on life-course potential. Studies should explore how different coping strategies and psychosocial interventions influence the trajectory of the disease and the long-term outcomes in terms of career, relationships, and family building. Moreover, research into pain mechanisms and how they relate to disease severity could improve the clinical understanding of endometriosis and inform more effective treatments.

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APPENDICES

Appendix 1.	Table of articles chosen for the review
Appendix 2.	Categorization Table

Number	Article Author,year and title
1	<p>Bień A, Rzońca E, Zarajczyk M, Wilkosz K, Wdowiak A, Iwanowicz-Palus G. 2020</p> <p>Quality of life in women with endometriosis: a cross-sectional survey. Qual Life Res.</p>
2	<p>Mori, L. P., Zaia, V., Montagna, E., Vilarino, F. L., & Barbosa, C. P. (2024).</p> <p>Endometriosis in infertile women: An observational and comparative study of quality of life, anxiety, and depression.</p> <p>This study assessed and compared the levels of depression, anxiety, and quality of life in infertile women with and without endometriosis.</p>
3	<p>Liakopoulou, M.-K., Tsarna, E., Eleftheriades, A., Arapaki, A., Toutoudaki, K., & Christopoulos, P. (2022).</p> <p>Medical and Behavioral Aspects of Adolescent Endometriosis: A Review of Literature.</p> <p>Study aims to work on Medical and Behavioral Aspects of Adolescent Endometriosis</p>

4	Missmer, S. A., Tu, F. F., Agarwal, S. K., Chapron, C., Soliman, A. M., Chiuve, S., Eichner, S., Flores-Caldera, I., Horne, A. W., Kimball, A. B., Laufer, M. R., Leyland, N., Singh, S. S., Taylor, H. S., & As-Sanie, S. (2021).
5	<p>Kalfas, M., Chisari, C., & Windgassen, S. (2022). Psychosocial factors associated with pain and health-related quality of life in Endometriosis.</p> <p>The systematic review aims to explore the association of psychosocial factors with pain intensity/severity and HRQoL in women with Endometriosis.</p>
6	<p>Youseflu, S., Jahanian Sadatmahalleh, S., Roshanzadeh, G., Mottaghi, A., Kazemnejad, A., & Moini, A. (2020).</p> <p>Effects of endometriosis on sleep quality of women: Does lifestyle factor make a difference?</p> <p>Study aimed to compare the lifestyle factors and SQ between women with and without endometriosis.</p>
7	<p>MacGregor, B., Allaire, C., Bedaiwy, M. A., Yong, P. J., & Bougie, O. (2023).</p> <p>Disease Burden of Dysmenorrhea: Impact on Life Course Potential</p> <p>Study aimed to check disease Burden of Dysmenorrhea: Impact on Life Course Potential</p>
8	<p>Álvarez-Salvago, F., Lara-Ramos, A., Cantarero-Villanueva, I., Mazheika, M., Mundo-López, A., Galiano-Castillo, N., Fernández-Lao, C., Arroyo-Morales, M., Ocón-Hernández, O., & Artacho-Cordón, F. (2020).</p> <p>Chronic Fatigue, Physical Impairments and Quality of Life in Women with Endometriosis,</p> <p>The aim of the study was to examine Chronic Fatigue, Physical Impairments and Quality of Life in Women with Endometriosis</p>

9	<p>Mińko, A., Turoń-Skrzypińska, A., Rył, A., Bargiel, P., Hilicka, Z., Michalczyk, K., Łukowska, P., Rotter, I., & Cymbaluk-Płaska, A. (2021).</p> <p>Endometriosis-A Multifaceted Problem of a Modern Woman.</p> <p>Examine Endometriosis as a multifaceted problem of a modern woman</p>
10	<p>Muharam, R., Amalia, T., Pratama, G., Harzif, A. K., Agiananda, F., Maidarti, M., Azyati, M., Sumapraja, K., Winarto, H., Wiweko, B., Hestiantoro, A., Suarthana, E., & Tulandi, T. (2022).</p> <p>Chronic Pelvic Pain in Women with Endometriosis is Associated with Psychiatric Disorder and Quality of Life Deterioration To examine the association of Chronic Pelvic Pain in Women with Endometriosis with Psychiatric Disorder and Quality of Life Deterioration</p>
11	<p>Della Corte, L., Di Filippo, C., Gabrielli, O., Reppuccia, S., La Rosa, V. L., Ragusa, R., Fichera, M., Commodari, E., Bifulco, G., & Giampaolino, P. (2020).</p> <p>The Burden of Endometriosis on Women's Lifespan: A Narrative Overview on Quality of Life and Psychosocial Wellbeing.</p> <p>The aim is to summarize impact of endometriosis on quality of life in all its aspects including sexual life, work, and social relationships</p>
12	<p>Farenga, E., Bulfon, M., Dalla Zonca, C., Tersar, C., Ricci, G., Di Lorenzo, G., & Clarici, A. (2024).</p> <p>A Psychological Point of View on Endometriosis and Quality of Life: A Narrative Review.</p> <p>The publication explores the pathology of endometriosis, review its impact on quality of life and psycho-social effects, and discuss the experience of pain within the mind-brain-body relationship.</p>

Appendix 2. Categorization process table

MainCategory	Generic Category	Sub Category	Reduced Expression	Original Expression
Impact on Quality of Life	Life Course Effects	Overall Well-being	Disrupts education, career, and relationships.	Endometriosis affects social participation, physical and sexual functioning, and mental well-being, influencing education, career, and relationships across the life course, particularly during formative years.

		Life Course Limitations	Long-term life limitations due to symptoms.	Symptoms restrict key decisions and achievements, with compounded effects across social and professional domains, manifesting strongly during adolescence to middle age.
Impact on Physical Quality of life	Pain, sleep quality and physical strength	Chronic pelvic pain) (Painful Menstrual pain) (Painful intercourse) (Fatigue) (poor postural balance) (Sleep pattern change) (insomnia)	Chronic pelvic pain reduces quality of life.	Endometriosis-associated pelvic pain (EAPP), including dysmenorrhea, non-menstrual pelvic pain (NMPP), and dyspareunia, significantly reduces quality of life, with severity increasing impacts.

			Endometriosis disrupts sleep patterns and quality.	Poor sleep quality, sub-threshold insomnia, and changes in sleep patterns, especially for night-shift workers, are linked to endometriosis.
		Comorbid Psychological Distress	Pain linked to mental health challenges.	Pain is associated with increased rates of depression, anxiety, and stress, necessitating early intervention to mitigate long-term impacts on quality of life.
. Impact of endometriosis on psychological and emotional quality of life of wom-en.	<ul style="list-style-type: none"> • Psychological stress) • (Psychiatric disorder) 	<ul style="list-style-type: none"> • Depression) (Emotional dysregulation)(elevated anxiety) (infertility 	Pain heightens emotional instability.	Chronic pain exacerbates emotional instability, leading to irritability, mood swings, and difficulties in emotional control,

		stress) (Feeling of sadness) (Guilt		which compound the challenges of endometriosis.
		Anxiety and Depression	Severe symptoms linked to anxiety and depression.	Women with severe symptoms face higher rates of anxiety and depression, impacting both mental health and interpersonal relationships.
		Infertility-Related Distress	Infertility impacts mental health and quality of life.	Endometriosis-associated infertility causes guilt, sadness, and isolation, reducing quality of life and mental well-being.
		Integrated Therapies	CBT and stress management aid emotional well-being.	Approaches like CBT and stress management foster

				resilience and help manage the psychological toll of endometriosis.
Impact of endometriosis on Social Quality of life and Sexual health	<ul style="list-style-type: none"> (Relationship) (Social life) (Sexual life) 	<ul style="list-style-type: none"> reduced social participation) (Social withdrawal) (Missing school) (Difficult family dynamics) (Difficulty in romantic Relationships) (increased feeling of loneliness) (Reduced quality of Sex) (Difficulty with partners) 	Symptoms lead to reduced social interactions.	Pain, fatigue, and emotional turmoil often lead to withdrawal from social interactions, diminished coping abilities, and loneliness.

		Relationship Challenges	Strains personal and romantic relationships.	Physical pain and emotional distress strain personal and intimate relationships, with many fearing its impact on maintaining partnerships.
		Sexual Dysfunction	Dyspareunia affects sexual health and relationships.	High rates of dyspareunia and sexual distress significantly impact sexual health, with pain predicting sexual difficulties.
Impact on Work and Education	Productivity and Education	Educational Challenges	Pain disrupts education and schooling.	Pain and fatigue cause school absences, reduced academic performance, and missed educational opportunities, especially for adolescents.

		Career Limitations	Pain restricts career opportunities.	Symptoms, particularly during menstruation, lead to absenteeism and restricted career progression, impacting long-term professional fulfillment.
		Societal and Economic Burdens	Productivity and economic losses due to symptoms.	Loss of productivity and high healthcare costs contribute to the broader burden of endometriosis.