

Health Seeking Behaviors and Healthcare Utilization in Women Diagnosed with Endometriosis: A Systematic Review

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Abstract: Introduction: Endometriosis is a chronic inflammatory condition affecting women of childbearing age worldwide. There are limited roles of medical or surgical treatments. Endometriosis not only affects quality of life but also results in significantly increased healthcare service utilization. The review aims to examine the existing literature to gain a comprehensive understanding of healthcare resource utilization in endometriosis patients across different countries. Methods: The systematic review was conducted to include studies on healthcare utilization among endometriosis patients from January 2000 to 2023. The search was conducted in Medline and Embase databases. Search terms related to endometriosis and healthcare resource utilization were used. Studies published in English with data on healthcare utilization across inpatient, outpatient, emergency care, and other services (such as specialist and primary care physician) were included. The studies only examined the cost- or cost-effective analysis were excluded. Results: Women with endometriosis experience a higher prevalence of gynecological and abdominal pain-related conditions, along with a greater burden of comorbidities and infertility issues. They also exhibit significantly higher healthcare utilization across various healthcare settings, including emergency care, inpatient visits, outpatient visits, and specialist care. These utilization differences remain significant up to one year before the diagnosis and persist for at least five years following the diagnosis, with the highest disparity observed in the first year after diagnosis. Conclusion: The systematic review examines the health-seeking behavior and healthcare utilization patterns among women diagnosed with endometriosis across different countries. The findings indicate that women with endometriosis experience a higher burden of medical comorbidities and exhibit increased rates of emergency care visits, inpatient visits, and outpatient visits.

Keywords: Endometriosis; Infertility; Pelvic Pain; Medical Burden; Seek Medical Care; Healthcare; Chronic Inflammatory Diseases

Introduction

Endometriosis is a systemic gynecological condition characterized by the presence of endometrial glands and stroma tissue in ectopic sites outside the uterus. Despite being a common disease affecting approximately 10% of women of reproductive age worldwide, endometriosis has historically been under-recognized and often overlooked ^[1]. Endometriosis affects both quality of life and productivity of individuals, it also results in significant impact on

healthcare service utilization and cost ^[11]. Women with endometriosis have a higher burden of comorbidities, including upper respiratory infection, ovarian cysts, uterine fibroids, fatigue, vaginitis and depression, leading to a significantly higher number of outpatient and emergency visits ^[2]. Healthcare expenditures and health-related productivity loss are notably

higher among patients with severe stages of the disease, longer diagnostic delay and concurrent symptoms of pelvic pain and infertility [4].

Understanding the health seeking behavior among affected individuals provides valuable insight into the disease burden, direct health-care related costs, and informs the future decision-making and resource allocation. This review aims to assess and synthesize existing literature on endometriosis-related healthcare resource utilization.

Methods

Literature search

The systemic review follows the PRISMA guideline (Supplementary Figure 1). Medline and Embase search were performed in May 2023, with search terms relating to endometriosis and healthcare resource utilization (Supplementary Table 1). The search was limited to human studies published in English between January 2000 to May 2023. No restrictions were imposed to subject age or study type.

Inclusion criteria and study selection

The studies of interest were limited to those that evaluates the healthcare utilization and/or costs among different healthcare settings including emergency services, inpatient hospitalization, and outpatient specialist services. Search results were screened by two independent reviewers (JC 100%, YL 20%), remaining articles were assessed for eligibility by reviewing methods or full text.

Data extraction

Data extraction was performed by author JC, the following parameters were recorded: Study, study period, setting, country, subjects, types of study and types of health care utilized. A narrative synthesis of extracted data was used to present findings as a meta-analysis was not feasible due to heterogeneity of the study design and outcomes.

Result

Summary of included studies

study (year)	study design and data source	study period	Setting	Data	country/sector	subjects	Types of study	Aim of the study
Solman et al(2018)	Truven Health MarketScan Commercial Claims and Encounters and Market Scan HPM databases	Jan 1 2018- June 30 2014	Inpatient admission, ER, physician offices visit, OB/GYN specialist	Significant higher rate of healthcare utilization. (More ER, physician, OB/GYN pre and post-index periods), higher all-cause hospital admission, increased utilization 12 month prior to index date and post-index	USA	113, 506 women with endometriosis	Retrospective cohort study	Compare HRU during the 12-month pre- and post- index period
Eisenberg et al(2022)	nationwide healthcare plan database	1998 to 2015	Inpatient, ER, family physician, gynaecologist	Endometriosis group showed significant higher SES and lower BMI, reside in the central region. endometriosis was significantly associated with higher burden of infertility, chronic comorbidities, utilization of healthcare services, pain medications, and antidepressants, and overall, 1.75-fold higher direct medical costs	Israel	6146 women with endometriosis aged 15-55years	Retrospective case-control study	Evaluate burden-healthcare resource utilization, total direct medical costs, infertility and comorbidity rates
Fuldeore et al(2015)	Truven Health MarketScan Commercial Claims and Encounters and Market Scan HPM databases	2000-2010	Inpatient, ER, Outpatient	Endometriosis patients had a higher utilization of outpatient and emergency room services during each pre- and postindex year, and a higher utilization of inpatient services during the last preindex year and all 5 postindex years.		37,570 endometriosis 18-45 years	Retrospective case-control study	Assess HCRU during the 5 years before and after diagnosis
Soliman et al(2019)	Truven Health MarketScan Commercial Claims and Encounters and Market Scan HPM databases	Jan 2008-sept 2014	Inpatient admission, ER, physician offices visit, OB/GYN specialist	HCRU were significant higher among endometriosis cases, largely driven by hospitalization and highest in the first year after endometriosis diagnosis. HCRU were significant higher than pre-index. Endometriosis patient has higher pre-index comorbidity score and high pre-index HCRU.	USA	15,615 endometriosis patients 18-69 years	Retrospective cohort study	Evaluate direct healthcare utilization and costs among women newly diagnosed with endometriosis

Patient characteristics

Women diagnosed with endometriosis tend to have a higher socioeconomic status, lower body mass index (BMI), and reside in urban areas (1). They also experience a greater medical burden, as evidenced by significantly higher mean Charlson Comorbidity Index (CCI) scores (2). There are elevated rates of pain-related abdominal conditions, including irritable bowel syndrome and appendicitis, among women with endometriosis. In addition, women with endometriosis have a higher prevalence of other gynecological conditions including ovarian cysts and uterine fibroids, and chronic comorbidities, such as cardiovascular disease, hypertension, diabetes, cancer, depression, and chronic kidney disease.

Emergency care utilization

Endometriosis patients have significantly higher rates of emergency department visits, with 12.5% of patients having visited the emergency department at least once in one year (5). Compared to their matched control group, they are 1.7 times more likely to visit the emergency department at least once and 1.9 times more likely to attend the emergency department at

least five times (5).

A US study showed all-cause related emergency department visits occurred in 71.5% cases in endometriosis patients compared to 42.2% in the control group (8). A woman with endometriosis has an average of 3.24 visits to emergency each year, with 0.15 visits attributable to endometriosis-related causes. In contrast, the control group averages 1.24 visits to the emergency department for various health related reasons (8). These differences in emergency care utilization persist over a ten-year period, with the most significant difference observed in the year before and after diagnosis, as well as in the mean annual number of emergency department visits (8).

Inpatient utilization

Hospital admissions are significantly more frequent among endometriosis patients, with 12.5% of patients being admitted to the hospital at least once during a one-year period, which is twice the rate observed in control patients (5). A 10-year study showed that endometriosis patients had a higher proportion of hospital admissions and longer lengths of stay (LOS), with 8.6% of endometriosis patients being admitted and an average LOS of 0.44 days per patient, compared to 8.2% and an average LOS of 0.38 days per patient in the control group (5).

In the first year after the index date, the utilization difference between endometriosis patients and control patients was the highest. A study found that 39.7% of endometriosis patients had at least one inpatient visit, with an average of 0.45 visits per patient and a mean LOS of 1.63 days per patient. In comparison to 7.7% in the control patients with an average of 0.09 visits per patient and a mean LOS of 0.38 days per patient (7). This difference in utilization between the two groups remained significant for four years.

Another study found that during the 12-month post-index period, 29% of patients in the endometriosis cohort were admitted to the hospital for various reasons. This percentage was significantly higher compared to the control cohort, where the hospital admission rate was only 6% (6). Additionally, a separate study reported that 33.1% of the case group had all-cause healthcare-related hospital admissions, with an average length of stay (LOS) of 1.30, which was significantly higher compared to 7.2% in the control group with an average LOS of 0.39. The utilization of inpatient services related to endometriosis in this cohort was estimated to be 14.5% with an average LOS of 0.52 (7).

Specialist Utilization

Women diagnosed with endometriosis have significantly higher likelihood of seeking care from a gynecologist compared to individuals without the condition. Around 68% of women with endometriosis consult a gynecologist, while the proportion is lower at 55.5% among the control group. Approximately 20% of patients with endometriosis have at least five visits to a gynecologist within a one-year period. The higher prevalence of infertility in women with endometriosis, accounting for 36.9% of the study group, also contributes to increased utilization of specialized healthcare services (5).

Outpatient utilization

Endometriosis patients consistently have a higher percentage of outpatient visits. Throughout each year of the study period, a statistically significant higher percentage of endometriosis patients (ranging from 91.9% to 98.2%) had outpatient visits compared to the control group (ranging from 85.4% to 90.2%). Furthermore, the mean annual number of outpatient visits for endometriosis patients is persistently higher than that of control patients in every year of the 10-year study period. The disparity between endometriosis patients and controls ranged from 2.15 to 6.33 visits per year per patient, with the highest difference observed in the first year following the index date (7).

Primary care physicians

Endometriosis women, particularly those in the younger age group (under 20 years old) are significantly more likely to see a primary care physician. It is estimated 955 of endometriosis patients visit their family physician at least once, 1.9 times higher than their paired control. In an US study, it is estimated that nearly 97% of patients visited a physician compared to

87% in the control group (5).

Discussion

The findings of this study provide valuable insights into the healthcare utilization patterns of women with endometriosis compared to control patients. It is evident that women diagnosed with endometriosis exhibit distinct characteristics and face a higher medical burden. These individuals tend to have higher socioeconomic status, lower body mass index, and are more likely to reside in urban areas. Additionally, they experience a higher prevalence of comorbidities, such as cardiovascular disease, hypertension, diabetes, cancer, depression, and chronic kidney disease.

Emergency care utilization is notably higher among women with endometriosis, with a greater propensity for emergency department visits compared to control groups. The rates of emergency department visits in the endometriosis cohort are notably higher, with a substantial proportion of patients attending the emergency department at least once annually. This increased utilization is primarily driven by pain-related conditions, potentially influenced by the use of opioid analgesics, which could contribute to the increased rate of emergency care utilization.

Inpatient utilization is also considerably higher among women with endometriosis. The proportion of hospital admissions among endometriosis patients is double that of the control group, maintaining a significant difference over a 10 year study period. Particularly, the mean length of hospital stay is prolonged for endometriosis patients, especially in the year preceding the index date. This suggests that women with endometriosis require more frequent and prolonged inpatient care, potentially due to the severity of symptoms and the necessity for surgical interventions or other specialized treatments.

Specialist utilization, particularly gynecological care, is more prevalent among women with endometriosis as evidenced by a higher proportion of these patients seeking care from gynecologists compared to the control group. This is expected given the nature of endometriosis, which primarily affects the reproductive system. The higher prevalence of infertility among women with endometriosis further contributes to increased utilization of specialized healthcare services.

Outpatient utilization consistently demonstrates higher rates among women with endometriosis, as indicated by the higher proportion of outpatient visits and the greater number of annual visits compared to control patients. This pattern highlights the ongoing need for symptom management and treatment monitoring. The greatest disparity in outpatient visits is observed in the first year following the index date, highlighting the initial impact of diagnosis and treatment initiation on healthcare utilization.

Primary care physician utilization is also increased among women with endometriosis, particularly in the younger age group. These individuals are more likely to visit their primary care physicians compared to control patients.

This underscores the necessity for comprehensive and coordinated care across various healthcare providers to address the multifaceted needs of these patients.

Conclusion

In conclusion, women with endometriosis experience higher rates of emergency care utilization, inpatient admissions, specialist utilization (specifically gynecological care), and outpatient visits compared to control patients. These findings emphasize the substantial healthcare burden associated with endometriosis and highlight the importance of comprehensive and specialized care to address the complex needs of these patients. Further research and healthcare initiatives are needed to improve the management, accessibility, and coordination of care for women with endometriosis.

References

- [1] Rowlands JJ, et al. "Prevalence and incidence of endometriosis in Australian women: a data linkage cohort study." *BJOG: An International Journal of Obstetrics & Gynaecology* 128.4 (2021): 657-665.

- [2] Cea Soriano, Lucia, et al. "Incidence, treatment and recurrence of endometriosis in a UK-based population analysis using data from The Health Improvement Network and the Hospital Episode Statistics database." *The European Journal of Contraception & Reproductive Health Care* 22.5 (2017): 334-343.
- [3] Grundström, Hanna, et al. "Healthcare consumption and cost estimates concerning Swedish women with endometriosis." *Gynecologic and obstetric investigation* 85.3 (2020): 237-244.
- [4] Simoens, Steven, et al. "The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres." *Human Reproduction* 27.5 (2012): 1292-1299.
- [5] Eisenberg, Vered H., et al. "Burden of endometriosis: infertility, comorbidities, and healthcare resource utilization." *Journal of Clinical Medicine* 11.4 (2022): 1133.
- [6] Soliman, Ahmed M., et al. "Real-world evaluation of direct and indirect economic burden among endometriosis patients in the United States." *Advances in therapy* 35 (2018): 408-423.
- [7] Fuldeore, Mahesh, et al. "Healthcare utilization and costs in women diagnosed with endometriosis before and after diagnosis: a longitudinal analysis of claims databases." *Fertility and sterility* 103.1 (2015): 163-171.
- [8] Soliman, Ahmed M., et al. "Health care utilization and costs associated with endometriosis among women with medicaid insurance." *Journal of managed care & specialty pharmacy* 25.5 (2019): 566-572.
- [9] Surrey, Eric, et al. "Impact of endometriosis diagnostic delays on healthcare resource utilization and costs." *Advances in Therapy* 37 (2020): 1087-1099.
- [10] Selcuk, İ. and Bozdag, G. (2013) 'Recurrence of endometriosis; risk factors, mechanisms and biomarkers; review of the literature', *Journal of the Turkish German Gynecological Association*, 14(2), pp. 98–103.
- [11] Buquet, R. and Rolla, E. (2012) 'Faculty opinions recommendation of the burden of endometriosis: Costs and quality of life of women with endometriosis and treated in referral centres.', *Faculty Opinions – Post-Publication Peer Review of the Biomedical Literature* [Preprint].