



Endometriosis in outpatient care – regional and temporal trends in the period 2012 to 2022

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Abstract

Background

Endometriosis is one of the most common gynecological diseases in girls and women in the reproductive phase of life, characterized by a broad spectrum of symptoms and varying degrees of intensity. The diagnosis is characterized by a considerable delay, which can be attributed to various societal and care-specific factors. The aim of this study was to determine the prevalence of diagnosed endometriosis in Germany, to investigate regional clusters and the development of patient numbers undergoing outpatient surgery.

Methods

This study is based on nationwide claims data of statutory health insurance (SHI)-accredited physicians and psychotherapists according to §295 Social Code Book 5 (SGB V) from the first quarter of the year 2012 until the first quarter 2023. The annual study populations consisted of statutory health insured girls and women aged 10 years and older with at least one billable contact in the respective reporting year. Insured females were defined as having a prevalent disease if a diagnosis of endometriosis (ICD-10-GM: N80) in combination with the mandatory suffix “assured” was documented in the reporting year, which was either confirmed again in the patient-specific three subsequent quarters, was initially coded by a gynecologist, or for which a specific diagnostic or surgical service was billed. The prevalence was calculated as the proportion of those with a validated endometriosis diagnosis in the study population in the respective reporting year per 1,000 girls and women aged 10 and over, both crude and age-standardized (reference: German population as of December 31st, 2022). *Local Moran’s I* analysis was used to identify spatially autocorrelated regions. In addition to the description of coded endometriosis localizations, there was also a descriptive evaluation of the outpatient operations performed.

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Results

In 2022, 339,718 out of 35,602,313 SHI-insured females aged 10 and older had a documented diagnosis of endometriosis according to the case definition; these patients had a median age of 40 years. The nationwide crude prevalence of diagnosed endometriosis rose from 5.7 per 1,000 females in 2012 to 9.5/1,000 in 2022; corresponding to a relative increase of +65%. The most common specific localizations were the myometrium (adenomyosis), the pelvic peritoneum and the ovaries. At the level of the Associations of Statutory Health Insurance Physicians, the prevalence varied by a factor of 1.7 and by a factor of 12.2 at district level. A large cluster of neighboring districts with high prevalence was identified in the northern part of Lower Saxony and a second smaller one in the Mittelbaden region (Baden-Wuerttemberg). The proportion of patients undergoing ambulatory surgery was constant during the study period. The most common procedure overall was diagnostic hysteroscopy and the most common surgical procedure was laparoscopic adhesiolysis of the bowel.

Conclusion

Despite the rise in diagnoses of endometriosis by SHI-accredited physicians in outpatient care during the study period, the prevalence remains markedly lower than estimated, suggesting a high level of underdiagnosis. Possible explanations for this could be delayed utilization of medical care by patients on the one hand, insufficient billing options with simultaneously high anamnesis costs in the statutory health insurance sector, but also a partial lack of persistence of endometriosis diagnoses once they have been confirmed.

Keywords

Adenomyosis, claims data, cluster analysis, endometriosis, outpatient surgery, prevalence

Citation

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