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From suspected to assured endometriosis diagnosis: The meaning of diagnostic certainty in German outpatient care

Claudia Kohring[1,2] • Evelyn Matthäus[3] • Doreen Hannemann[4] • Jennifer Bundesmann-Grap[5,6] • Manas K. Akmatov[1] • Jakob Holstiege[1] • Nina Kirsch[1] • Iris Brandes[7] • Sylvia Mechsner[8] • Doreen Müller[1]

[1] Department of Epidemiology and Health Care Atlas, Central Research Institute of Ambulatory Health Care in Germany
[2] Charité – University Medical Center Berlin
[3] Gynecology and Obstetrics Practice 1, Medical Care Center, Bad Salzungen Hospital
[4] Department of Medicine, Central Research Institute of Ambulatory Health Care in Germany
[5] Billing Management, FAM – Gynecological Group Practice, Berlin
[6] Master's Program Management and Quality Development in the Health Care Sector, Alice Salomon University of Applied Sciences Berlin
[7] Institute of Epidemiology, Social Medicine and Health System Research, Hannover Medical School
[8] Endometriosis Center, Department of Gynecology, Charité – University Medical Center Berlin

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Abstract

Background

In the outpatient care sector, diagnosis coding is pivotal not only for documenting but also for plausibly justifying billing of provided medical services. Furthermore, there are sector-specific particularities as well as individual coding practices. Using endometriosis and adenomyosis – complex and chronically recurrent diseases – underscores differences between the required assigning of mandatory markers that express the current status of diagnostic certainty by office-based physicians and the process of diagnostics itself, but also misconceptions that result from these different aspects. We aimed to examine how mandatory markers for diagnostic certainty are used and investigated how endometriosis diagnoses persist in the German outpatient care sector.

Methods

This study was based on nationwide outpatient claims data from the 1st calendar quarter of 2015 through the 3rd quarter of 2025. The study population comprised girls and women aged 10 years and above who are covered by statutory health insurance (SHI). We assessed the frequency of different markers for diagnostic certainty (suspected, assured, excluded, status post) following an initial suspected endometriosis diagnosis (ICD-10-GM: N80) in the index years 2017 and 2022. Additionally, we explored the persistence of an endometriosis diagnosis that was marked "assured" for the first time and met at least one applied validation criterion (coded repeatedly, by a gynecological specialist, along with a specific fee schedule item, or along with a code of the German Procedure Classification) over the following up to 7 years after the index diagnosis in 2017.

Corresponding author: Claudia Kohring
Central Research Institute of Ambulatory Health Care in Germany (Zi)
Salzufer 8 – 10587 Berlin – Tel. +49 2200 56133 – E-Mail: CKohring@zi.de

Results

In 2017, a total of 42,752 patients received a new suspected endometriosis diagnosis after two years without such a diagnosis. Of these, 31% were later diagnosed with assured endometriosis diagnosis within the index quarter and the two subsequent years, 25% had another suspected diagnosis, 5% were coded with a status post diagnosis, and 3% had an excluded diagnosis. For 70,463 patients in 2022 who had an initial suspected endometriosis diagnosis following seven diagnosis-free preceding years, the figures were 33% assured, 27% suspected, 3% status post, and 4% excluded.

The diagnostic persistence among the 65,566 patients whose endometriosis diagnosis was documented as assured and validated for the first time in 2017 was 48% in the following year, 2018, and declined to 13% by 2024. In age-specific analyses, there were notable differences: in the first follow-up year, persistence was highest among women aged 20–29 at 55% and lowest among those aged 50–59 at 36%.

Conclusion

Office-based, SHI-accredited physicians use all mandatory markers of diagnostic certainty in connection with an endometriosis diagnosis. Due to a lack of comparative data, these findings cannot be definitively interpreted, though they at least suggest a nuanced utilization. The results concerning diagnostic persistence may initially appear contradictory under the assumption of lasting treatment needs. However, there are several plausible explanations related to the specific nature of the disease, available treatment options, and documentation and billing requirements, which interact in complex ways. For example, subsequent visits may focus on current complaints or other reasons for contact that could be related to the underlying endometriosis condition, but it was not the primary reason for the visit. In such cases, endometriosis probably appears as an accompanying (anamnesis-based) diagnosis, which under billing rules may not need to be reported. Comprehensive studies of disease progression and treatment trajectories are thus necessary both for accurately reflecting the current state of care and for the evidence-based development of especially outpatient care options and the underlying reimbursement structures.

Keywords

Adenomyosis, assured diagnosis, confirmed diagnosis, diagnostic certainty, endometriosis, excluded diagnosis, persistence, status post, suspected diagnosis

Citation

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