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Mini Commentary on 2016-OG-18785R1: Epidemiology of endometriosis: a large population-based database study in a 2-million-member health care provider

Efforts to redefine endometriosis prevalence in low risk patients

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Endometriosis has significant implications on patient health and well-being, particularly when it comes to pelvic pain and infertility. However, the true epidemiologic state of the disease has remained elusive. Many of the foundational studies characterize surgically confirmed endometriosis in highly selected patient populations. It has been hypothesized that the prevalence of endometriosis is approximately 10% (Vigano et al, *Best Practices and Research in Clinical OB/GYN*, 2004, 18(2):177-200) of reproductive aged women and may reach rates of 30-50% in symptomatic women.

However, other investigators have sought to determine the prevalence in unselected populations finding rates around 1.5% (Ballard et al, *BJOG*, 2008, 115(11):1382-91). In this edition of *BJOG*, Eisenberg et al report on a large population-based database study which sought to describe the “real world” disease burden. They found a point prevalence of endometriosis of 1% in women age 15-55 and 2% in the highest prevalence age group. Interestingly, a small but significant increase in incidence was noted over time, although it is unclear if this relates to a true increase in disease or simply to an increased awareness of the disease and thus increase in diagnosis.

While the overall 10-fold decrease in prevalence of endometriosis found in this study is striking, it is important to take some precautions when translating this to clinical practice. The identification of endometriosis was based solely upon International Classification of Disease (ICD) coding from primary care physicians, gynecologists, or other specialists. Some had records of ultrasounds being performed prior to the diagnosis code being given, but, as one might expect in a low risk population,

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very few had any record of a surgical procedure preceding the diagnosis. Further, the diagnosis was unable to be validated. The possibility of differential coding bias can be illustrated with the high prevalence in the infertility population where providers may be more likely to take detailed histories geared towards identification of endometriosis.

These findings must be placed into context given the incidence of endometriosis varies by diagnostic method with surgical visualization greatly increasing the rates (Buck Louis et al, *Fertility and Sterility*, 2011 96(2):360-5). Thus, one must think about the meaning of clinically diagnosed endometriosis versus surgically diagnosed endometriosis and what patient populations may have been included in those groups historically. There are studies which show that symptoms such as dysmenorrhea and history of infertility greatly increase the odds of findings surgically confirmed endometriosis (Peterson et al *American Journal of OB/GYN*, 103 (208(6):451), but these findings are often studied in cohorts with much higher rates of endometriosis than is reported by Eisenberg et al. Further, this study does not take into account cases of asymptomatic endometriosis as they would have no record or knowledge of the diagnosis.

Beyond the issue of reliable detection, the clinical questions remain: does the clinical identification in the low-risk population lead to interventions which promote overall better quality of life and maybe even prevent progression of disease? These questions are not answered here but must be considered as we determine how best to identify patients in the community setting with endometriosis and determine effective interventions.

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