

HIGH INCIDENCE OF DIAGNOSTIC ERROR OF ENDOMETRIOSIS IN THE U.S.

Allyson C. Bontempo, Katherine Ognyanova, & Lisa Mikesell
Rutgers University

BACKGROUND

- Endometriosis is an estrogen-dependent reproductive disease resulting in pain, infertility, and considerable physical and psychosocial dysfunction^{1,2}
- Endometriosis occurs when tissue similar to that which lines the uterus forms *outside* the uterus (e.g., pelvic cavity, fallopian tubes, bladder)¹
- Endometriosis affects roughly 10% of females of reproductive age, yet its etiology is unknown and there is no known cure^{3,4}
- The profound diagnostic delay of endometriosis ($M = 10$ years)⁴ warrants study into the diagnostic error (DE) rates of this disease



Objectives

- Establish the incidence of self-reported DE in women with endometriosis
- Determine by which type of healthcare providers DE is reportedly being made

METHOD

Participants

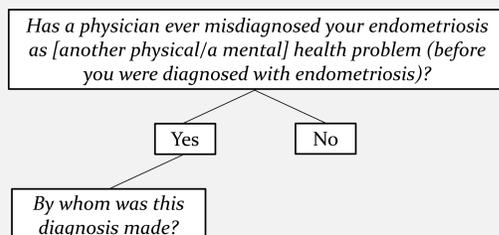
- 727 U.S. women with a self-reported, surgically-confirmed diagnosis of endometriosis

Procedure

- Consented to and completed a larger, one-time cross-sectional online research study between April 15 and August 31, 2017

Measurement

- Data were obtained from single-item survey questions



RESULTS

Participant Characteristics

- Age:** Age ranged from 18 to 56 ($M = 33.1$, $SD = 7.0$)
- Race/Ethnicity:** White (93.5%), black (3%), mixed race (1.6%), American Indian/Alaska Native (1.2%), Asian (0.6%), and Native Hawaiian/other Pacific Islander (0.2%), and 4.8% identified as Hispanic/Latina/o
- Marital status:** Married (55.3%), single/never married (19.6%), in a relationship (10.9%), separated/divorced (7.4%), cohabitating (6.2%), and widowed (0.6%)
- Education:** college degree (52.8%); some college/2-year degree (32.8%); high school diploma or equivalent (7.9%); business, trade, or technical school (5.8%), and some high school (0.8%)

Incidence of Diagnostic Error

- 75.6% of women reported having had their endometriosis initially misdiagnosed as a mental and/or other physical health problem
 - 71.9% of all women reported having had it misdiagnosed as another physical health problem
 - 36.8% of all women reported having had it misdiagnosed as a mental health problem

Type of provider	Misdiagnosed as another physical health problem (% of N)	Misdiagnosed as a mental health problem (% of N)
General practitioner	23.8	19.8
OB/GYN, Gynecologist	49.2	19.4
Endometriosis Specialist	2.8	0.8
Other type of provider	9.1	4.2

- Mean diagnostic delay was 8.64 years ($SD = 6.48$)
- Misdiagnosis predicted diagnostic delay after controlling for demographics ($\beta = .162$, $p < .001$)

DISCUSSION

Discussion

- Self-reported DE incidence in this online endometriosis sample is considerably higher than the estimated incidence of DE in medicine in general (10-15%)⁵
- In previous work, Graber (2013)⁶ noted that retrospective case reviews yielded DE incidences for a range of diseases that are “unacceptably high”; however, none of which had approached the unacceptable rates of misdiagnosis, missed diagnosis, and delayed diagnosis readily documented in the endometriosis literature
- The long diagnostic delay of endometriosis cited in prior research supports this increased incidence

Implications and applications

- Results provide the necessary motivation to provide more extensive training to health care providers—especially gynecologists—in the recognition of endometriosis
 - Behavioral medicine researchers could play a pivotal role, with their focus on health services and implementation research
- Results highlight the need for interdisciplinary medicine
 - Clinical psychologists may play a pivotal role in ruling out the high number of incorrect mental health diagnosis prescribed to these women during their search for a diagnosis

In a current medical climate that has placed patient safety at its forefront⁷, one must ask: *what efforts are currently in place for addressing this diagnostic challenge?*

REFERENCES

- Eskenazi, B., & Warner, M. L. (1997). Epidemiology of endometriosis. *Obstetrics and Gynecology Clinics of North America*, 24, 235-238.
- Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgarten, M., & Raine-Fenning, N. (2013). The social and psychological impact of endometriosis on women's lives: A critical narrative review. *Human Reproduction Update*, 19, 625-639.
- Endometriosis Foundation of America. (nd). *What is endometriosis?* Retrieved March 25, 2018, from https://www.endofound.org/member_files/editor_files/resource_materials/new/EFA_TEEN_OUTPUT.pdf
- Rogers, P. A., D'Hooghe, T. M., Fazleabas, A., Gargett, C. E., Giudice, L. C., Montgomery, G. W., . . . Zondervan, K. T. (2009). Priorities for endometriosis research: Recommendations from an international consensus workshop. *Reproductive Sciences*, 16, 335-346.
- Elstein, A. (1995). Clinical reasoning in medicine. In J. Higgs (Ed.), *Clinical reasoning in the health professions* (pp. 49-59). Oxford, England: Butterworth-Heinemann Ltd.
- Graber, M. L. (2013). The incidence of diagnostic error in medicine. *BMJ Quality & Safety*.
- Institute of Medicine; Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academies Press.

ACKNOWLEDGEMENTS