Absence of evidence is not evidence of absence: Symptom misattributions stemming from null nondiscriminatory testing for endometriosis

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Learning objective: To understand common misattributions of endometriosis and the bias that may result from negative test results.

BACKGROUND

Endometriosis is an estrogen-dependent inflammatory disease in which endometrial-like tissue grows outside the uterus, causing bleeding, scarring, adhesions, and anatomical distortion.1

According to extant work, clinicians, when they communicate their diagnostic impression to patients presenting with endometriosis, reportedly make certain misattributions regarding the origin of these symptoms.2

Extant work has also demonstrated that one factor leading to diagnostic delay for endometriosis is clinicians' inappropriate use of nondiscriminatory diagnostic testing.3

This research thus sought to catalogue these misattributions as reported by patients and assess whether such misattributions reportedly followed nondiscriminatory diagnostic testing.

METHODS

An anonymous online survey for which self-identified endometriosis patients were recruited via endometriosis organizations' social media

Participants (N = 822) from across the globe were asked to describe an interaction that occurred prior to diagnosis during which they felt they or their symptoms had been dismissed by a clinician.

SELECTED REFERENCES

1 Eskenazi B, Warner ML. Epidemiology of endometriosis. Obstet Gynecol Clin North Am 1997;24:235–38.

2 Culley L, Law C, Hudson N, et al. The social and psychological impact of endometriosis on women's lives: a critical narrative review. Hum Reprod Update 2013;19:625–39.

3 Ballard KD, Lowton K, Wright JT. What's the delay? a qualitative study of women's experiences of reaching a diagnosis of endometriosis. Fert Steril 2006;86:1296-1301.

4 American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. Washington, DC: American Psychiatric Association; 2013.

RESULTS

Patients commented that clinicians made misattributions following null test results of nondiscriminatory diagnostic tests (blood tests, ultrasound, CT, MRI) **(Table 1)**

Misattribution types:

1. **Symptoms were physically normal:** symptoms were misattributed to features of normal physiology (menses, PMS, ovulation, perimenopause, menopause, gas, constipation, high BMI; IBS, cysts, and fibroids, though abnormal, were considered normal)
2. **Symptoms were psychological but real:** symptoms were believed as real but misattributed to physical manifestations of or sequelae to psychological factors (conversion disorder, repressed trauma from sexual abuse)
3. **Symptoms were psychological and not real:** symptoms were not believed as real and were therefore misattributed to specific explanatory psychological factors (hypochondriasis, "all in the head" or imaginary, misinterpretation of symptoms due to anxiety/depression, attention-seeking/faking, drug-seeking)
4. **Symptoms were physically abnormal:** symptoms were misattributed to other physical health diagnoses (STIs/STDs/PID, UTIs) or other pre-existing health diagnoses (PCOS, celiac disease)

CONCLUSION

The only definitive testing is laparoscopy with biopsy, yet a wide range of nondiscriminatory testing methods are reportedly being used to diagnose endometriosis and/or other sources of pelvic pain.

- If true, this points to a lack of education and training among clinicians – especially OB/GYNs – on the appropriate guidelines for diagnosing endometriosis.
- If true, OB/GYNs and other clinicians may ne overhasty in attributing patients' symptoms to normal physiology and/or largely psychological factors following these negative test results.

It is critical to ensure OB/GYNs and other clinicians are trained in appropriate testing for endometriosis, especially due to its modest prevalence rate (10%).

It is also critical to ensure OB/GYNs and other clinicians are appropriately trained to diagnose/rule out psychosomatic disorders and/or refer patients to trained mental health specialists to rule out psychopathology, as the absence of physical evidence alone is not sufficient for a psychosomatic diagnosis.4

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"'Pain with your period is normal. Blood in your urine is concerning, but we already did blood tests, ct scan w contrast and nothing comes up. So let's not worry about it for now.'"

"'It is clearly seen in ultrasounds and in your last ultrasound I saw no signs of endometriosis.'"

"Once I was writhing in pain and the doctor said 'well, maybe it's appendicitis' but when the scans cane back normal I was simply sent home because I must be exaggerating."

"Most memorable [interaction] was when I went to [hospital] and the doctor said he thought it was a mental health issue and that maybe I was drug-seeking because they did not see anything on any of the many scans done."

"Went to the ER in excrutiating pelvic pain, ran all the tests, nothing was immediately conclusive. ER doc told me it's an STD and sent me home."

"When tests came back inconclusive, I was told I likely had IBS."

"I had back and leg pain for years prior to having any pelvic pain. I had a male doctor look at my MRI and tell me I shouldn't have any pain because my MRI is normal."

"'...all your test results are normal (blood tests, ultrasounds, physical exams) so there's nothing wrong with you, it could all be in your mind.'"

"They did x rays and blood tests, said it was normal and then told my mom and I that I was making it up.."

"'I think you don't have to worry about this. Your labs all came back fine. It might be that your white blood cell count is just a little higher because it is a natural set point for you. I'd like to refer you to our nutritionist to get your weight under control. Do you have a goal weight?'"