

A lifetime quest to be believed – stigmatization and bias in the prolonged diagnostic delay of endometriosis

Introduction

Endometriosis is a medical condition where tissue that is similar to endometrial glands and stroma grows outside of the uterine cavity (1, 2). It is an inflammatory disease which results in significant morbidity and is characterized by symptoms such as chronic pain, dysmenorrhea, dyspareunia, heavy menstrual bleeding, pelvic inflammatory disease, and infertility (2-5). An estimated one in ten women suffer from endometriosis and it is the second most common gynaecological condition in the UK (6-8). Despite the prevalence of endometriosis, there is a significant diagnostic delay worldwide. A cross-sectional study across 10 countries found that the average delay was 6.7 years (9). Studies across the globe reveal the time to diagnosis to be between 5-12 years in the United States, Germany, Austria, United Kingdom, Netherlands, Norway, Italy, Ireland, Belgium, and Brazil (5, 9-15). Diagnostic delay is seen to be the primary factor for improving care by both patients and doctors alike (16).

The diagnostic delay associated with endometriosis creates numerous issues. A study looking at compliance to ESHRE guidelines found obstacles exist at the individual, societal, and clinical level (17). At the individual level, women suffer unnecessarily for years, if not decades. Left undiagnosed and untreated, endometriosis can significantly impair a woman's quality of life as well as lead to disease progression (8). Many women find difficulty with navigating social and work absences and determining how to explain symptoms. Discrimination in the workplace, marital problems, loss of friendships, and judgement by others of hypochondrium leaves women feeling alone, depressed, and worthless (18-21). One study quantified that 67% of the participants experienced relationship problems, 48% had to work less, and 19% considered it to be the reason for their divorce (22). In contrast, there is indication that a diagnosis alone is therapeutic, as it relieves women of the mystery of their pain and provides a language to discuss their symptoms and experiences (23). Furthermore, having a medical label legitimizes the illness and opens doors for treatment as well as social support (18).

On a societal level, endometriosis creates a massive burden due to loss of productivity and economic cost. A national survey of American women found that 49.6% of women with endometriosis reported they had an average of 18 "bed days" per year where they could not get out of bed due to their condition (24). In Switzerland, Austria, and Germany, endometriosis has been found to limit career choice, increase sick leave and create productivity loss for women (25). Nnoaham et al.'s global study found that endometriosis patients lost 10.8 hours of work weekly, due to reduced effectiveness (9). Another survey found that women lost 7.41 hours of work time, with presenteeism at 65%, activity impairment at 60% and work productivity loss at 64% (26). When one quantifies these symptoms to represent economic cost, the numbers are quite staggering. In 2002, the estimated annual cost of endometriosis in the United States was \$22 billion (27). The largest study, conducted in 2012, found that if one assumes a 7% rate of endometriosis worldwide (lower than the 10% rate that is well supported by research) there is an annual societal burden of 1.3 billion in Switzerland, 1.7 billion in Belgium, 2.6 billion in the Netherlands, 9.3 billion in Italy, 9.5 billion in France, 9.9 billion in the UK, 12.5 billion in Germany, and 49.6 billion in the United States (28).

This is not only an issue of lost work productivity, but healthcare costs as well. The U.S. Army revealed that surgical hospitalizations alone cost 2.6 million dollars in just a six-year time span (29). D’Hooge found the total cost to be €9872 per patient per year in Belgium and an analysis of 900 women across 10 countries supported this number, determining €9579 euros to be the average cost per patient (29, 31). A systematic review of healthcare costs suggests this is perhaps higher, with a cost per patient of \$11,688-12,941 per year (30). Thus, the financial burden of this illness is highly significant.

The diagnostic delay associated with endometriosis undoubtedly creates a burden on society. This paper will address how stigmatization and bias impact diagnostic delay at the societal, individual and clinical level. Endometriosis has the disadvantage of being a woman’s disease, a pain problem, and involves “lady problems”. These factors lead to issues such as menstrual stigmatization, clinical gender bias, and general sexism, all of which play considerable roles in increasing diagnostic delay. While almost all papers mention stigma and bias in some form, few articles primarily focus on the impact of societal constructs on diagnostic delay. Acknowledging these issues is an essential step towards shifting perspective and decision-making around endometriosis care in order to decrease the diagnostic delay.

Analysis

Societal

At the most fundamental level, diagnostic delay in endometriosis stems from a larger societal norm around the global “taboo” of menstruation (32). “Taboo” is often used to describe menstruation, but Laws observes that even the word taboo perpetuates the idea of menstruation being supernatural, rather than a natural physiological function that has been shamed by society. This societal stigmatization leads women to maintain a “menstrual etiquette” where menstruation is equated with shame. When women see menstruation as a discrediting attribute, they implement “strategic informational management” behaviours such as concealing bodily functions, avoiding the subject, hiding sanitary items, and not drawing attention to menstruation (33).

When menstrual etiquette deprives women of information, space, and encouragement to discuss reproductive health, it disadvantages half the population and can be viewed as a form of social poverty (34). While this stigmatization is a global issue in its own right, one relevant consequence of menstrual etiquette is that it both masks and exasperates the diagnostic delay of endometriosis. Across society, menstrual etiquette creates a wall of silence between women and medical care. Reminiscent of the personal being political, for endometriosis patients, the personal is pathological. For example, while endometriosis is as common as diabetes, issues such as heavy bleeding, painful sex, or severe premenstrual symptoms are seen as private matters, rather than openly discussed as medical symptoms such as insulin resistance or weight gain (35). As the idea of keeping endometriosis symptoms discreet prevails, the prevalence and severity of this issue is understated worldwide.

The effects of stigmatizing menstrual health present at both the individual level and within healthcare. One can differentiate between the two by assessing the time discrepancy from onset

of symptoms to first appointment, which demonstrates a delay at the individual level, and the delay from first appointment to diagnosis, which reveals a delay at the clinical level. Research provides examples of patient delays at 2.1, 2.3, or 4.6 years, and delays with physicians at 3.4, 2.7, and 4.7 years, demonstrating that these societal norms are pervasive throughout both groups (5, 15, 22).

Individual

The stigmatization of menstrual health affects endometriosis diagnosis at the individual level through normalisation of symptoms, influence of others, embarrassment, and fear. This is exemplified in an article of adolescent girls in the UK that found 79% have experienced concerning, period-related symptoms but have not seen a health professional. Of those women, 54% thought that their symptoms were normal, 13% said people told them they were exaggerating, and 27% felt embarrassed (36). These themes are consistently prevalent across the literature.

Normalisation/Influence

Many women are taught to normalize medical symptoms as simply “a part of womanhood”, rather than identifying them as pathology. There is a clear pattern of women internalizing their experience as “unlucky” or “lady problems” rather than identifying medical symptoms that point to illness (37). Familial normalisation, when a mother has a similar experience, further contributes to delay in diagnosis (18, 33, 37). Among patients who were studied in Germany, a mother’s negative perception led to a five-year extension of diagnostic delay (15). Similarly, research suggests that the influence of other women who convince endometriosis patients that their periods are normal further deters individuals from seeking medical care (20).

Embarrassment/Fear

Shame and embarrassment are two other factors that exacerbate the problem of diagnostic delay (18). Many women commonly associate menstruation with embarrassment. A survey of women in the UK demonstrated that 71% of women are embarrassed about buying sanitary products and 48% are embarrassed by their periods in general (38). This perspective influences how women engage with healthcare, as many women do not disclose a full medical history due to fear or stigma (39). Considering that endometriosis commonly includes symptoms such as painful sex or heavy bleeding, patients are particularly affected by this social construct (20). Furthermore, there is a striking pattern of hiding symptoms out of fear of being perceived as weak (18). Women do not feel comfortable taking ownership of “the sick role” because they anticipate ostracism, criticism, and trivialization in response (33, 41). Rather than disclosing symptoms, women demonstrate turning to coping strategies, bed days, withdrawing from social events, and taking potentially harmful amounts of analgesics (18). In sum, women who suffer from endometriosis are silenced by social cues and resist coming forward, leading to diagnostic delays as well as the underreporting of endometriosis overall.

Healthcare

Dismissal of Symptoms

Women are logical to have fears of being ignored or judged, because that is frequently what happens. Societal views towards women, women's pain, and menstruation often lead clinicians to dismiss symptoms. Dismissal of symptoms is the most prevalent aspect of diagnostic delay at the medical level (41). There is a common theme across the literature of patients feeling like they were not taken seriously and that their pain was trivialized by doctors (21,42). In a study that looked at over 4,5000 women with surgically confirmed endometriosis, 59% of participants reported that their physicians did not take them seriously and 63% of them were told by at least one physician that nothing was wrong (39). In a study by Denny, more than half of participants were told nothing was wrong with them (21). The majority of women cited the doctor's perception of their symptoms as the least helpful aspect of their experience (15,18). A systematic review that appraised research on clinical care revealed that being respected and believed by medical staff was the largest concern among patients (16). This dismissal can be broken down into three parts; general gender bias, pain bias, and menstruation bias.

Clinical gender bias

The belittling of this disease stems in part from the systemic, centuries-old narrative of perceiving women's health concerns as psychological, rather than medical. This was further popularized by Freud's definition of "hysteria" and is still pervasive within healthcare (43). Endometriosis is no exception, as somatization of endometriosis remains persistent in modern medicine (20). A study that observed 145 general practitioners found that many of them assumed anxiety and depression symptoms were a cause rather than a result of chronic illness among women. Their perceptions of the patient were highly influenced by psychological characteristics, the thickness of their medical records, sexual dysfunction, and the lack of identifiable pathology (44). This is highly reminiscent of Freud's outdated perspective that women's illnesses were either "all in their head" or related to sexual issues (43). For example, while depression is a common misdiagnosis, many women perceive their depression to be a result of having clinicians negate their experience and view them as neurotic, rather than as a cause (41, 42).

Pain gender bias

This problem is further exacerbated when it comes to the subjective experience of pain and particularly with pain that lacks physical presentation (45). The existence of pain bias is demonstrated by the discrepancy between endometriosis patients whose primary symptom is pelvic pain versus those whose primary symptom is infertility. Studies in the United States, Brazil, and the Netherlands reveal examples of 3-6 years of further delay for pelvic pain sufferers (12, 14, 46). This supports the idea that women who experience pain have a harder time obtaining treatment, suggesting the presence of bias.

Menstruation bias

Lastly, when symptoms are related to menstruation, they are often not taken seriously as legitimate medical issues deserving of attention (21). Similar to the "personal is pathological" issue at the societal level and the normalisation of one's individual symptoms, doctors are equally influenced by the societal norm of perceiving menstrual difficulties as "bad luck" rather than illness. This is evident in comparison studies of endometriosis and migraines. While both of these issues are female-dominant, complex, and "invisible" medical conditions, physicians doubt the pain of endometriosis patients far more frequently than with migraine patients (37). This normalisation of symptoms has been shown to increase diagnostic delay by up to three years

(15). Thus, women's "bad luck" is not because they must tolerate menstruation, but because they must tolerate clinical bias surrounding menstruation. Generally, it appears that medical practitioners often do not perceive women as being capable, competent, and credible to relay their experience or symptoms effectively (47).

Lack of Medical Education

Bias in healthcare is not only found in the doctor-patient relationship but also in how much the doctor prioritizes staying up to date about the disease overall. Endometriosis has been widely neglected by healthcare at a macro level and knowledge about endometriosis is disappointingly limited. In a study by van de Zaden, GPs scored 59% on an endometriosis knowledge test and 87% said they needed further education (48). Another study demonstrated that gynaecologists are unaware of the severity of this problem and underestimate the diagnostic delay by 33% (17). The lack of fundamental knowledge about the illness becomes a diagnostic barrier when a clinician's decision-making process relies on outdated or inaccurate advice.

Adolescence issue

One antiquated idea that is still common in a clinical setting is that endometriosis develops later into one's reproductive years and therefore is not possible in adolescence (42, 49). This has been entirely debunked by science as endometriosis is found in girls as young as eight (39, 50-52). This specific medical oversight is a particularly significant element of diagnostic delay. Those who present with endometriosis in adolescence are far more likely to be told nothing is wrong than adults (69.6% vs 49.8%) and to be taken less seriously (65.2% vs 48.9%) (46). In a survey of 3,680 surgically confirmed endometriosis patients, 70% had symptoms before 20, 38% had symptoms before 15, but only 7% were diagnosed by age 20 (53). A comparable study in Brazil showed 44% had symptoms before age 20, but only 3.5% were diagnosed by 20. The outcome was an increase in diagnostic delay from 7 years to 12 years for women under 19 (14). A threefold increase is also found in the United States' younger patient population (54).

Ultrasound issue

Another major roadblock due to medical ignorance is the use of ultrasound technology as a diagnostic tool. While ultrasound can confirm endometriomas, it cannot confirm adhesions (55). The only way to confirm the presence of endometriosis is via a diagnostic surgical procedure known as a laparoscopy (56). The NICE guidelines state that endometriosis shall not be excluded based on a normal ultrasound (57). However, patients continue to be diagnosed by ultrasound, or even multiple ultrasounds (18). This is not only a blatant misuse of healthcare resources, but false negative test results further perpetuate doctors and peers to question the credibility of patients (18). Overall, the lack of understanding of these basic endometriosis facts about this disease leads to grave outcomes for women worldwide.

Recommendations

In order to shorten the diagnostic delay, it is necessary to create awareness that endometriosis is incredibly prevalent, has significant personal and global impact, and is largely affected by stigmatization and bias. In order to do this, the societal view of menstruation has to be rid of its "taboo" label. Physicians, families, employers, and peers should work to create a safe environment for women to discuss these topics openly. Increasing knowledge among all

stakeholders is also vital. An improved understanding of “normal” menstrual health is especially necessary, both for women and doctors. Therefore, sex education and medical training are two evident places for educational interventions. Furthermore, rather than normalising or trivialising endometriosis symptoms, doctors also should be able to recognise pathological issues as warranting medical attention. Bias training, regarding overall gender bias, pain bias, and period bias, is highly recommended to improve diagnostic skills. While not the topic of this essay, further funding for research and advocacy is needed, and more research is required to create necessary diagnostic advancements. Considering how social determinants of health play a role would be an important part of increased awareness and bias training as well.

Conclusion

The prevalence and severity of endometriosis leads to decreased quality of life, massive economic costs, and a large burden on healthcare. The impact of this disease is largely due to the prolonged diagnostic delay, which greatly stems from the disease being highly stigmatized, both openly and implicitly, around the world. This stigmatization leads to the normalisation of symptoms by individuals, medical staff, and peers, resulting in women feeling embarrassed, ashamed, or scared to seek care. Women who do come forward are dismissed by medical professionals as having mental health issues, exaggerating about their pain, or being hypochondriacs. Often, this illness is so underprioritized that medical professionals do not even know basic facts about the disease. The issue of delayed diagnosis of endometriosis provides a particularly compelling example of how stigmatizing the female body and discrediting women’s experiences of illness can lead to detrimental outcomes. Hopefully, bringing awareness to these issues and suggesting places for improvement can help shorten diagnostic delay of endometriosis.

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